

Reimagining Psychiatric Hospitalization by Using Narrative Analyses and Co-design to
Center People's Experiences

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Abstract

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Psychiatric hospitalization is a significant and often traumatic event for the person who is hospitalized. Negative experiences of psychiatric hospitalization can erode individuals' trust in the healthcare system and impact their willingness to seek any care in the future. This distrust in and avoidance of services can, in turn, lead to negative outcomes like worsening mental health and increased likelihood of rehospitalization. In this dissertation, I investigate how a patient-centered informatics approach can be used to address these particular challenges. Although health informatics researchers have used patient-centered care as a model for researching and designing interventions to support increased collaboration between patients and providers, as well as peer support among patients, much of this work is around non-psychiatric care. Work that is related to mental

health or psychiatry is often focused on outpatient care, personal health informatics (e.g., self-management), or online communities and peer support, rather than psychiatric hospitalization.

To address these critical gaps, my work aims to understand and support the underrepresented population of people with (past, present, and potentially future) experiences of psychiatric hospitalization and aims to validate the embodied knowledge and expertise of this community and their right to be active decisionmakers in their own care. To achieve these goals, I first investigated how people in this community made positive connections with each other on TikTok and provided insights for social media developers and designers to support them. Secondly, I performed an inductive analysis of personal stories of psychiatric hospitalization published in the organization Mad in America's online Personal Stories section and presented a framework for understanding how information flows in psychiatric facilities, as well as design provocations for health informatics interventions. Finally, I conducted an interview and co-design study with this population, using utopian thinking and speculative design to envision ideal, patient-centered care futures related to psychiatric hospitalization.

Together, the findings across all three studies contribute to a further understanding of people's experiences with psychiatric hospitalization. My research makes several contributions, including:

1. Analyses of rich accounts of people's experiences with psychiatric hospitalization across multiple mediums, in which I found corroborative

themes as well as diverse insights afforded by different mediums of communication.

2. A framework of information flows and pathways based on people's psychiatric hospitalization narratives, which I used to identify barriers and missed opportunities that hospitalized people and their clinicians encountered when seeking and sharing information in the psychiatric hospital setting.
3. Provocations for patient-centered informatics interventions co-designed with people with experiences of psychiatric hospitalization, who envisioned ideal care futures that included information access inside and outside of psychiatric facilities, patient-defined and -controlled collaborative care, and interventions that may be implemented with traditional institutions or outside of them.

This dissertation underscores the need for deeper engagement by the health informatics community in this domain, and demonstrates the necessity of centering the diverse voices, experiences, and expertise of people with experiences of psychiatric hospitalization in the creation of patient-centered futures for mental health care.

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Dedication

To my mom, dad, and, of course, Jeannette.

Chapter 1: Introduction

*Much Madness is divinest Sense –
To a discerning Eye –
Much Sense – the starkest Madness –
'Tis the Majority
In this, as all, prevail –
Assent – and you are sane –
Demur – you're straightway dangerous –
And handled with a Chain –*
– Emily Dickinson

Psychiatric hospitalization¹ is acute psychiatric care in which the patient resides in a psychiatric facility to undergo treatment. Unlike other types of inpatient admittance, a patient can be admitted into psychiatric hospitalization involuntarily as well as voluntarily, and admittance can be based on referral from the patient's personal psychiatrist, therapist, or law enforcement. Hospitalization is a significant and often

¹ Also referred to as inpatient/acute psychiatric/mental health care/treatment/services, etc.; standalone facilities may be referred to as psychiatric/mental (health)/behavioral health hospitals or psychiatric wards/units when located within a general hospital. These terms also apply to forensic patients, i.e., those receiving psychiatric inpatient treatment in the criminal justice system. For the purposes of this dissertation, I will primarily refer to the treatment as “psychiatric hospitalization,” and psychiatric wards or hospitals as “psychiatric facilities.”

traumatic event for the patient (Bartl et al., 2024; Cohen, 1994) and many people are hospitalized multiple times over the course of their lives. Negative experiences during psychiatric hospitalization can cause or exacerbate trauma and decrease individuals' trust in healthcare professionals and the healthcare system, leading to avoidance or refusal of healthcare services and, consequently, negative clinical outcomes, such as worsening symptoms and increased likelihood of rehospitalization (Hennessy et al., 2023).

In the field of health informatics, researchers have adopted the principles of patient-centered care, shifting the focus to inclusive processes and holistic approaches, through the use of user-, human-, and value-centered design. Patient-centered care is a broad care model that emphasizes the role and experience of individual patients in their own care, rather than exclusively or primarily focusing on disease or other biomedical data (Jayadevappa & Chhatre, 2011). I use this approach as a motivating framework in my research, and in particular the concept of *patient expertise*, defined by Hartzler & Pratt (2011) as “experiential knowledge gained from personally managing the day-to-day experience of illness,” in contrast to clinician expertise, which takes the form of “knowledge gained from professional training and practice.” Although health informatics researchers have used patient-centered care as a model for researching and designing interventions to support increased collaboration between patients and providers, as well as peer support among patients, much of this work is around non-psychiatric care. Work that is related to mental health or psychiatry is often focused on outpatient care, personal health informatics (e.g., self-management), or online communities and peer support, rather than psychiatric hospitalization.

In my work, I aim to locate and validate the expertise of people with experiences of psychiatric hospitalization. Implementing patient-centered care in clinical practice has been an uphill battle due to a variety of factors, and doing so in the context of psychiatry, and psychiatric hospitalization in particular, faces additional barriers due to stigma and institutional biases that position this population as inherently untrustworthy and lacking rights usually afforded to non-psychiatric patients.

Many researchers have approached mental health research from a clinical perspective, using diagnostic terminology (e.g., Balani & De Choudhury, 2015; Chancellor, Pater, et al., 2016; Sowles et al., 2018), for example, to identify or characterize the target population. How we frame the population of people with experiences of psychiatric hospitalization matters in how we conceive of these challenges—do the people impacted by this research consider themselves “mentally ill”? Do they identify as “patients”? Some would say yes to one or both of these questions; some would vehemently disagree. People with these experiences have and continue to use a multitude of terms to describe themselves, from “mental health service users” to “psychiatric survivors” to “ex-patients/inmates” (Penney & Prescott, 2016).

Researchers have approached the question of terminology following a framework similar to that used by the psychiatric consumers/survivors/ex-patient (c/s/x) movement.² For example, O’Leary et al. (2017), citing the prevalence of “comorbidities with different mental health conditions, multiple diagnoses, and struggles with misdiagnoses” in

² https://en.wikipedia.org/wiki/Psychiatric_survivors_movement

addition to “social challenges such as stigma, withdrawal, and loneliness,” identified their target population as any person over 21 who used “technologies for mental health peer support” and chose not to measure participants’ diagnoses or severity of mental health conditions. Similarly, I identify my target population as “people with experiences related to psychiatric hospitalization,” which includes people with multiple mis/diagnoses, those without diagnoses, and those with other marginalized identities,³ in order to focus on their lived experience with the psychiatric healthcare system.

We can iterate on endless categorizations of this heterogenous population of people with experiences of psychiatric hospitalization. Or, we can assume that we can never provide a full encapsulation of “what it means to be someone who has experienced psychiatric hospitalization” and identify every possible value or need they may have, even in a lifetime of papers. By emphasizing the role of an individual in their own care, patient-centered care addresses this problem—as it is not isolated to this particular population, but is true of any group of human beings we can devise. Identifying the breadth of experiences and needs of people with experiences of psychiatric hospitalization is crucial for identifying certain commonalities and frictions that require more attention, and to thoughtfully develop provocations for designers that can help to

³ There are a number of correlates between many population variables and psychiatric hospitalization rates, including age, gender, race/ethnicity, homelessness, and employment status (APA, 2022; Unick et al., 2011).

frame their work in the context of supporting care work that attends to the whole person, not merely a diagnosis.

1.1 Research Objectives

This dissertation will answer the following research questions:

- **RQ1:** What can we learn about people's experiences with psychiatric hospitalization through narrative accounts across different mediums? (**Chapters 3, 4, and 5**)
- **RQ2:** How do people who have experienced psychiatric hospitalization perceive information flows in the hospital environment? (**Chapter 4**)
- **RQ3:** How do people with experiences of psychiatric hospitalization envision ideal, patient-centered informatics interventions related to psychiatric hospitalization? (**Chapter 5**)

1.2 Dissertation Overview and Contributions

In this section, I provide an overview of this dissertation and its contributions.

In **Chapter 2**, I provide a non-exhaustive review of related work from fields including Mad Studies, psychiatry, healthcare, health informatics, and human-computer interaction. From these sometimes-distinct, sometimes-overlapping areas of research, I focus on research exploring experiences of psychiatric hospitalization and its historical background, patient-centered care, and ethical considerations for conducting research work with marginalized populations.

In **Chapters 3-5**, I present three studies that collectively answer my four research questions.

Chapter 3 describes the first of these studies. In a qualitative content analysis, I investigated how TikTok creators and commenters connect around the topic and lived experience of psychiatric hospitalization and provided design provocations based on my findings. The chapter's findings contribute to **RQ1** by revealing the ways that TikTok serves as a community-building platform for people to connect around psychiatric hospitalization, share their experiences and humor, celebrate their recovery, identify with others with similar experiences, and to provide and receive peer support. These findings suggest that this population needs creative, hopeful, and humorous ways to connect with each other, and that these goals should be supported by digital platforms.

In **Chapter 4**, I continue my analysis of unsolicited, online narrative artifacts in an inductive thematic analysis of personal stories of psychiatric hospitalization sourced from, and in partnership with, Mad in America,⁴ a non-profit organization centered around rethinking the current system of psychiatric care. The chapter contributes to **RQ1** by providing analysis of rich, written narratives published through the organization Mad in America, and contributes to **RQ2** by providing a framework of information flows and pathways based on people's psychiatric hospitalization narratives. The chapter's findings show that people in psychiatric facilities (both those hospitalized and their clinicians) encounter different barriers to effective information seeking and sharing, and illustrate

⁴ <https://www.madinamerica.com>

how missed opportunities for collaborative care can happen for multiple reasons, from negative clinician attitudes to rigid institutional processes, which should be considered in future work and design.

In **Chapter 5**, I present findings on interviews and co-design sessions with people with experiences of psychiatric hospitalization. This chapter's findings contribute to **RQ1** by providing further descriptions and analysis of people's experiences with psychiatric hospitalization through narratives elicited in interviews. This chapter also contributes to **RQ3** by providing patient-centered informatics interventions co-designed with people with experiences of psychiatric hospitalization, which include 1) improving access to information both inside and outside psychiatric facilities to improve continuity of care, 2) supporting patient-defined and -controlled collaborative care networks, and 3) considering whether interventions are collaboratively implemented with institutions or outside of them.

1.3 Research Approach and Positionality

1.3.1 Approach

During the course of my work, I familiarized myself with 290 narrative accounts and artifacts, from 5-second TikTok videos to 90-minute interview and co-design sessions. However, I emphasize that, as qualitative research, this dissertation does not pretend to provide “generalizability” but rather a deep and highly contextual

understanding of a necessarily limited number of people's experiences with psychiatric hospitalization.

People with experiences of psychiatric hospitalization tend to be highly familiar with quantitative measures in the form of questionnaires (e.g., the PHQ-9⁵), lab work, and so on. They have also critiqued the limitations of these measures, especially when given more credibility by clinicians over their own accounts of their experiences. The people included in this dissertation are used to being “numbers”; but, to quote W59 in Chapter 4, “*why is what really matters.*”

My methods necessarily could not capture a full representation of this population of people with experiences of (primarily US) psychiatric hospitalization. I did not collect demographic information for creators in **Chapter 3** and writers in **Chapter 4** and I collected limited information for participants in **Chapter 5**.

As a researcher in health informatics, I naturally look at a problem through the lens of my own field and the tools available in its toolbox, so to speak. I am wary of assuming that informatics approaches are the “right” tools to use when it comes to the issues I have found in my research. I balance this by identifying how the problems surfaced in this dissertation are the result of broader cultural and systemic factors, and that interventions can mitigate certain problems, but not necessarily force systemic change. Through my

⁵ A standard questionnaire for depression screening: <https://www.apa.org/depression-guideline/patient-health-questionnaire.pdf>

experiences in advocacy and citizen lobbying, I know that research is a useful tool for education and providing institutionally-backed “evidence” for policymakers.

1.3.2 Positionality

Positionality statements can be beneficial as tools for self-reflection on the part of the researchers, and also serve to make visible the subjectivity of the researchers themselves, which has historically been avoided in scientific research in order to position researchers as coming from an “objective” standpoint. There are certain disclosures, such as researcher privilege, values, and cultural context, that can critically contextualize the “we” or “I” permeating a publication. However, concerns have been raised over whether it is appropriate to request or require positionality or reflexive statements on the part of researchers, because possible negative repercussions of self-disclosure disproportionately affect marginalized researchers (Liang et al., 2021; Schlesinger et al., 2017).

One approach that some have taken to mitigate this is to include a positionality statement that discloses the makeup of the research team without singling out particular authors, although this is only effective with large research teams or ones in which the disclosures cannot be reasonably matched to individual. Another approach is to make the disclosure itself only as specific as necessary to indicate the researcher relationship to participants, which I and my collaborators chose to do in the publications that comprise **Chapter 3** and **Chapter 4**. For example, in **Chapter 3**, we disclosed that “all authors ... have at least one close connection to someone who has been hospitalized in a psychiatric

unit,” which indicated our general level of relationship to the participant population without subjecting each person to unnecessary academic voyeurism.

I struggle with the vulnerability and violation of privacy that positionality statements can force, but in qualitative research, “the researcher *is* the instrument” (Patton, 2014). I am uncomfortable with the practice of listing a series of categories or labels that apply to me as a shorthand for my “positionality”; yet, this is precisely what I and other researchers ask of (or do to) research participants.

What I believe to be most relevant, both in service to practicing self-reflexivity as well as for audiences seeking to contextualize and interpret my work, is my own experience being psychiatrically hospitalized, as well as those of loved ones. While this makes me an insider researcher, my experience as a “calm and cooperative”⁶ cis white woman voluntarily hospitalized for a few days at a private hospital is far from universal. Throughout this work, I have kept this in mind as a reminder of the value of the range of experiential knowledge that people with these experiences possess; knowledge that comes from the unique standpoint of a complex human being who is not solely defined by their experience(s) with psychiatric hospitalization.

⁶ Per clinical notes.

Chapter 2: Related Work

In this section, I begin by providing historical and critical context for psychiatric hospitalization, followed by an overview of the state of research on experiences of psychiatric hospitalization. Next, I describe patient-centered care, patient-centered expertise, shared decision making, and questions of power in patient-centered care. I conclude with ethical considerations of work with sensitive topics and marginalized people.

I follow the terminology for people experiencing hospitalization (psychiatric or non-psychiatric) that is used in the referenced work, as it has particular meaning in those respective fields (e.g., “*patient*-centered care”). “Service user”—as in, a person who uses a health service—is preferred in psychology and psychiatry, and “patient” is typically used in general healthcare and health informatics research.

2.1 Background

2.1.2 Historical and Critical Context

The history of psychiatric hospitalization is one thread within the larger history of what has historically been referred to as “madness” in Western societies. This history is not a straightforward narrative of progress in our knowledge and treatment of mental illness. While primary sources offer insight into how madness was conceptualized in a given time and place, “society” is not a monolithic entity that uncritically assumes a single position on a topic; the delineation of this history into discrete periods should be

understood as a simplification. It is within this context that I provide a brief history of psychiatric hospitalization in Western countries, focusing on the US in particular, which is most relevant to this dissertation.

While segregation or containment of the mad existed in various forms prior, critical scholars locate the genesis of the asylum in the 17th century (e.g., Eghigian, 2010; Warren, 2024; Whitaker, 2001). This period—what Foucault (1961/2009) termed “the Great Confinement” (c.1650-1800)—was characterized by a rise in the confinement of the “asocial” or undesirable⁷ in hospitals, hospices, workhouses, and correctional institutions. In the traditional narrative of modern psychiatry, the shift of the asylum’s function from mere containment to providing treatment began near the end of the 18th century when reformers such as Philippe Pinel and Samuel Tuke introduced humanitarian changes to asylums using a new approach to mental illness called moral treatment.⁸

Over the course of the 19th century, Western countries built hundreds of new public asylums while any use of moral treatment was increasingly replaced by more “scientific” approaches as psychiatry developed into a medical profession (Eghigian, 2010; Whitaker, 2001). Physicians, however, reinscribed the “undesirables” historically grouped together in institutions since before the reforms as “mentally unfit,” justifying their continued internment in insane asylums.

⁷ Including the insane, poor or unemployed, infirm, criminal, sexually deviant, etc.

⁸ Tuke provided a succinct description of his own philosophy undergirding moral treatment: “So much advantage has been found in this institution from treating the patient as much in the manner of a rational being, as the state of his mind will possibly allow” (qtd. in Whitaker, 2001).

By the turn of the century, the increase in patients had outpaced the increase in asylums, which were once again notorious for overcrowding and poor conditions. Against this backdrop, physicians continued to advance and refine new diagnoses, diagnostic methods, and therapeutic treatments. The advent of pharmaceuticals in the 1950s,⁹ alongside financial and societal pressures, led to the era of deinstitutionalization in the second half of the 20th century: a process of reducing the number of psychiatric facilities, to be ostensibly replaced by increased outpatient and community care (Whitaker, 2001). During this time, critics like Erving Goffman, R. D. Laing, and Thomas Szasz were influential in the development of what is now called the antipsychiatry movement, which questioned the premise and power of mainstream psychiatry. Was mental illness “real”? How do we decide what behavior is normal or abnormal? What right do psychiatrists and other authorities have to treat someone against their will?

Mental health law went through a massive upheaval in the 1960s-1980s through the advocacy of ex-patients and psychiatric survivors, investigative journalists, groups like the Mental Health Law Project, and many others in the Mad movement, which emerged alongside other civil rights movements of the 1970s (Appelbaum, 1994; Bracken & Thomas, 2001; Whitaker, 2001). Critical legal reforms included shifting the purpose of involuntary commitment from treatment to the prevention of harm, creating new

⁹ Most notably, the antipsychotic chlorpromazine, or Thorazine (Whitaker, 2001).

liabilities for mental health professionals, and expanding patients' rights to informed consent and the refusal of treatment (Appelbaum, 1994).

Since 1970, the population in US state psychiatric hospitals dropped from approximately 370,000 to 40,000 by 2014,¹⁰ and lengths of stays shortened as the focus shifted from long-term rehabilitation to crisis stabilization (APA, 2022). Barriers to effective and quality care remain, spanning from a lack of resources both within and outside of hospitalization (APA, 2022) to the negative effects of institutionalization itself¹¹ (Chow & Priebe, 2013; Goffman, 1961; Whitaker, 2001). While not as prevalent as it was a century ago, psychiatric hospitalization has remained a common solution for acute crises—or, less generously, as a place to send away and contain people who cannot be managed through other psychiatric services (Lelliott & Quirk, 2004).

2.1.2 Experiences of Psychiatric Hospitalization

Researchers in health-related fields—such as psychology, psychiatry, and health services—have conducted studies of peoples' experiences with psychiatric hospitalization, focusing on improving quality of care by, for example, better understanding peoples' experiences of feeling shame (Jones & Crossley, 2008), perceptions of the therapeutic milieu (Thomas et al., 2002), and service users'

¹⁰ It is important to note that this drop coincided with the rise of mass incarceration in the US (Lain, 2024).

¹¹ E.g., institutionalism, which comprises “a set of maladaptive behaviours that are induced by the tensions of living in any institution” (Chow & Priebe, 2013, p. 9).

experiences of involuntary hospitalization (Stylianidis et al., 2018). Service users' relationships with mental health professionals—particularly nurses—are central to defining a person's positive or negative experience in a psychiatric facility (Gilburt et al., 2008): mental health professionals' attitudes toward and interactions with service users influence the recovery process and feelings of safety—physical and psychological—while in the psychiatric facility (Berg et al., 2017; Keogh et al., 2015; Wood & Pistrang, 2004). However, factors specific to psychiatric hospitalization, such as loss of autonomy, coercion, and time constraints, can have a negative effect on the development of therapeutic relationships in a psychiatric facility (Harris & Panozzo, 2019; Roche et al., 2014; Theodoridou et al., 2012).

People with experiences of psychiatric hospitalization and clinicians have differing perceptions on aspects of hospitalization. These include risk factors for readmission (Mgutshini, 2010) and the experience and necessity of forcible medication (Haglund et al., 2003). Pariseau-Legault et al. (2025) explain clinical issues surrounding involuntary commitment and treatments as a result of differences between service users and psychiatric nursing in how care is conceived, and that a lack of recovery-oriented and trauma-informed care is not only due to a lack of resources, but also “the dominance of the biomedical authority and consequent constraints related to work organization, professional hierarchies, and institutional expectations” (p. 174).

Several researchers have suggested recommendations to improve the psychiatric inpatient experience. Hallett et al. (2025) highlight the ways that systemic,

environmental, and individual factors contribute to psychiatric hospitalization experiences and outcomes, and suggest revising procedural protocols on the use of restrictive and coercive practices, and providing staff training to emphasize the importance of supporting patient autonomy. Liberati et al. (2023) also argued that systemic and institutional forces in mental health services erode mental health professionals' capacity for compassion, which is essential for positive therapeutic relationships and better clinical outcomes. They proposed improving training and organizational support, endorsing collaborative therapeutic approaches, and similar interventions as a starting point for broader policy change.

2.2 Patient-Centered Care

Patient-centered care is a broad care model that emphasizes the role and experience of individual patients in their own care, rather than exclusively or primarily focusing on disease or biomedical data (Jayadevappa & Chhatre, 2011). In the field of health informatics, researchers have adopted the principles of person-centered care, shifting the focus to inclusive processes and holistic approaches, through the use of user-, human-, and value-centered design. This includes understanding and designing for patient information work (Burgess et al., 2019; Kendall et al., 2015; Park & Chen, 2016; Unruh et al., 2010) inpatients' and caregivers' roles during hospital stays (Miller et al., 2016; Mishra et al., 2016), and supporting patient-provider communication and collaboration (A. B. Berry, 2019; Chung, 2017; Park et al., 2017; Pollack et al., 2021). Research in mental health care has generally focused on integration into primary care settings (Halдар

et al., 2022; Lattie et al., 2021) as well as designing for involving peers with similar mental health experiences as care providers (i.e., peer support; O’Leary et al. [2017]).

Patient-centered care is care that is “respectful of and responsive to individual patient preferences, needs, and values and ensur[es] that patient values guide all clinical decisions” (Institute of Medicine (U.S.), 2001). In health informatics, this work is often done using the framework of Value-Sensitive Design (Borning & Muller, 2012; Friedman et al., 2002, 2013), and “values” are defined as what a person “considers important in life” (Friedman et al., 2013). Health informatics research in this area has included investigating and supporting communication about values between patients with multiple chronic conditions and their providers (A. B. Berry, 2019; N. Berry et al., 2017), visualizing connections between personal values and self-management tasks (Ryu et al., 2023), and designing tools to support providers in value elicitation and integration (Doyle et al., 2025).

2.2.1 Patient Expertise

Hartzler and Pratt (2011) defined *patient expertise* as “experiential knowledge gained from personally managing the day-to-day experience of illness,” in contrast to clinician expertise, which takes the form of “knowledge gained from professional training and practice.” Patient expertise-sharing takes place in a variety of contexts, including sharing with one another in patient-led support groups (Diamond & Little, 1984), as instructors in disease self-management programs (Lorig et al., 1999), as peer supporters/peer specialists (O’Leary et al., 2017b), and on the Internet in online health

communities (Civan & Pratt, 2007) and other social platforms. Hartzler & Pratt (2011) distinguish this patient-expertise sharing with one another as *informational support* rather than other forms of social support (e.g., emotional support) Patient expertise has also been recognized as critical to patient-centered care and shared decision-making (A. Berry et al., 2017), and supporting patient expertise-sharing with health professionals can improve care and patient outcomes (Ruland, 1999).

2.2.2 Shared Decision Making

Shared Decision Making (SDM) is a clinical approach that aims to increase patient and family agency in interactions with clinicians. Scholars and clinicians debate what exactly SDM consists of and how it should be applied, but the general consensus is that it is “a process in which decisions are made in a collaborative way, where trustworthy information is provided in accessible formats about a set of options, typically in situations where the concerns, personal circumstances, and contexts of patients and their families play a major role in decisions” (Elwyn et al., 2017, p. 1). SDM has been promoted as a gold-standard approach in healthcare policy^{12,13,14} and physicians tend to have positive attitudes towards its use. However, researchers have found that many physicians do not fully understand SDM, and encounter other barriers, including cultural and institutional

¹² <https://www.ahrq.gov/sdm/index.html>

¹³ <https://www.nihcr.org/analysis/improving-care-delivery/prevention-improving-health/shared-decision-making/>

¹⁴ <https://www.england.nhs.uk/personalisedcare/shared-decision-making/why-is-shared-decision-making-important/shared-decision-making-to-comply-with-national-legislation-and-policy/>

ones, to implementing it in practice (Berkowitz et al., 2021; Joseph-Williams et al., 2017).

SDM in mental healthcare faces further barriers. The “doctor knows best” culture that pervades the healthcare system is reinforced by the very structure of psychiatry and the concept of a psychiatric “patient” as someone who cannot make decisions for themselves by virtue of their mental state or diagnosis. Someone who has been admitted to a psychiatric facility has essentially forfeited, however temporarily, their right to autonomy. As Slade (2017) pointed out, among other challenges, the training and culture of healthcare professionals typically emphasizes deontological ethical frameworks, while patients emphasize teleological frameworks—meaning that clinicians will prioritize beneficence and non-maleficence over patient autonomy.¹⁵

2.2.3 Power Imbalances in Psychiatric Care

Shared decision making, patient-centered care, and values-based practice are supposed to combat the traditional, paternalistic model of healthcare by centering the patient, recognizing their expertise, values, and goals, but a purely democratic process is difficult to implement in practice. Stacey et al. (2016) pointed out that psychiatrists tend to be successful when they position themselves as “the most knowledgeable group” in shared decision making processes. Mental health professionals are not always cognizant of their epistemic privilege in these settings (Faissner et al., 2025; Prebble et al., 2015;

¹⁵ This is further incentivized by concerns over legal liability.

Theodoridou et al., 2012; Valenti & Giacco, 2022; Wynn, 2006). For example, Faissner et al. (2025) found that psychiatric staff and patients have different conceptions of “coercion”—staff typically used the term to refer to formal processes of coercion, such as involuntary commitment, treatment, or restraint; patients, however, used a broader definition that included informal pressures (e.g., “voluntarily” taking medication due to the implicit threat of involuntary commitment if they do not).

Patient-centered care approaches are, at their core, about shifting power in the patient-clinician relationship. Psychiatric facilities, as total institutions, necessitate a hierarchy of power that places the patient at the bottom (Goffman, 1961). Can addressing the challenges researchers (and people with experiences with psychiatric hospitalization) have identified “fix” this institution? There are many validated interventions for improvement, but the main difficulty lies in implementation in a system that requires coercive power to function—does it matter how well you led the horse to water if it refuses to drink?

2.3 Ethical Considerations

2.3.1 On Research with Marginalized and Underrepresented People

In their paper on HCI research with marginalized people, Liang et al. (2021) explain that marginalization can be broadly understood as “how a person experiences the world around them based on their identity and how others perceive them,” and harm can range from microaggressions to “the development of systems that keep entire groups of people

down.” Other contributions for research with marginalized people in HCI include frameworks for including the “community voice” of marginalized or underserved communities (Saha et al., 2023) and questions to ask when working with vulnerable populations like children in poverty (Antle, 2017) considerations for equitable participatory design (Harrington et al., 2019), and ethics toolkits for community-based design (Henriques et al., 2025).

Of course, there is a vast body of literature outside of HCI on the same topic. For example, (Barron, 1999) discusses ethical issues in qualitative research on marginalized groups using the example of intellectually disabled women, noting the issues that can arise when a researcher’s “alliance” with a group they are not themselves a member of masks the researcher’s position of power. Elsewhere, Wiles et al. (2007) reflected on the problematic nature of informed consent, including a lack of consensus among researchers on what comprises it, and whether those components are universally applicable to different groups and methodological frameworks.

Discussion of ethics in qualitative mental health research includes calling for clearer descriptions of research methods and ethical considerations in published studies (Carlsson et al., 2017) and using alternative ethical paradigms (Stevenson et al., 2015). Mental health researchers have contributed reflections on ethical issues encountered in research with mental health service users and their relatives (Potthoff et al., 2023), debates about classifying mental health service users as a “vulnerable” population

(Allbutt & Masters, 2010), ethical conflicts for ethnographers in psychiatric hospitals (Oeye et al., 2007), and more.

Additionally, with the growth of “third-wave HCI,” more attention is being brought to how research results benefit the communities they work with, and how results should be disseminated to them as well. Researchers should consider research participants and their communities to be among their intended audience. What community members might want from the research they participate in can vary, and they may not even agree: Erete et al. (2018) called for researchers to demonstrate greater attentiveness and sensitivity to differences and dissent when working with underserved communities—keeping in mind that, like the other ethical challenges discussed, there is not usually a one-size-fits-all approach. This is not to say that it is enough for researchers to just “try their best,” but more so that researchers should reflect throughout the research process on why they are doing their research and what can happen when it is published, and be prepared to take responsibility for any unintended impacts of their research.

2.3.2 On Researcher Wellbeing

While other professionals working in mental health typically receive training and mentorship about how to cognitively and emotionally handle the heavy and disturbing topics they have to discuss with clients, many people in research involving mental health do not. However, like the conversations about research impact, conversations about the effects of mental health research on researchers are increasing in visibility. Prolonged exposure to content about mental illness, trauma, self-harm, suicidality, and similar topics

can be detrimental to anyone's mental health, and researchers are no different (Pendse et al., 2022).

Researchers with lived experience of mental illness may be especially vulnerable to potential mental distress or worse when conducting this research, which brings up an uncomfortable question: at what point could it be unethical for a researcher with mental illness to conduct research involving mental illness? While past scientific research involving self-injury "for the sake of science" is often mythologized, it is now widely discouraged and generally recognized as unethical; e.g., self-experimentation like Marie and Pierre Curie's or Nobel Prize winner Barry Marshall's self-infection of *H. pylori* (Marshall & Adams, 2008). If a researcher who experiences suicidal ideation chooses to conduct research that they know has a high likelihood of triggering them, could this be considered a form of self-harm?

Ultimately, these questions must be carefully considered by the researcher themselves in addition to their care team (e.g., a therapist). I believe that it is important that it remains the decision of the individual researcher, and does not become the purview of, for example, an Institutional Review Board (IRB). While a researcher's decision-making could be compromised because of a number of factors, including pressure from more senior researchers or funding sources to continue a project, removing their agency out of paternalism would further stigmatize them, and likely deter them and other researchers from seeking help in cases of mental distress.

Chapter 3: Investigating How People with Experiences of Psychiatric Hospitalization Connect on TikTok

Contributions:

This chapter examines the nature of the connections and community that people with experiences of psychiatric hospitalization created with each other on TikTok through an analysis of TikTok posts and comments. The chapter's findings contribute to **RQ1** by revealing the ways that TikTok serves as a community-building platform for people to connect around psychiatric hospitalization, share their experiences and humor, celebrate their recovery, identify with others with similar experiences, and to provide and receive peer support. These findings suggest that this population needs creative, hopeful, and humorous ways to connect with each other, and that these goals should be supported by digital platforms.

Research Question:

- **RQ1:** What can we learn about people's experiences with psychiatric hospitalization through narrative accounts across different mediums?

Publication:

Schaadhardt, A., Fu, Y., Gennari Pratt, C., & Pratt, W. (2023). "Laughing so I don't cry": How TikTok users employ humor and compassion to connect around psychiatric hospitalization. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems* (pp. 1-13).

In this chapter, I address **RQ1** by presenting findings from a qualitative content analysis study in which I worked with Chris Fu, Cory Gennari Pratt, and Dr. Wanda Pratt to examine a random sample of 140 TikTok posts related to psychiatric hospitalization. The details of this study were published in a paper under the title "Laughing so I don't

cry’: How TikTok users employ humor and compassion to connect around psychiatric hospitalization” (2023). This paper is reproduced verbatim beginning in Section 3.1. Our work was supported by the National Science Foundation (NSF) Graduate Research Fellowship Program, Grant No. DGE-2140004.

We found that people utilized humor, namely gallows humor and satire, and affordances specific to TikTok to build community and share their experiences. We also found that this community was largely supportive and did not tend to encourage “harmful” behaviors. We used our findings to contribute design provocations for social media designers and developers: (1) design features should encourage creative expression, (2) support networks should support serendipitous connections, and (3) moderation should consider the community context.

3.1 Introduction

According to the World Health Organization in 2019, over 970 million people—1 of every 8 people—live with mental health disorders, such as depression, anxiety, eating disorders, etc. (WHO, 2022). Since the COVID-19 epidemic those numbers have risen significantly, especially among youth. In particular, psychiatric hospitalizations and mental-health related emergency visits for youth under 18 in the U.S. have increased 24-31% (Ibeziako et al., 2022; Leeb et al., 2020). People with a variety of mental illnesses, diagnosed or not, can be recognized by healthcare and psychiatric systems as potential recipients of psychiatric hospitalization. These hospitalizations may be voluntary or involuntary, and may be a decision determined by an individual and their healthcare

providers or one determined by others without the individual's consent. Psychiatric hospitalization can be a significant and often traumatic event (Cohen, 1994), but little research has focused on its representation in social media in general or specifically on TikTok, where youth aged 10-19 are the largest user demographic, comprising 25% of TikTok's active users in the U.S. (Shepherd, 2022).

TikTok is a video-based social media platform that was launched in 2019 by ByteDance. It is a globally popular app with over 1 billion users, largely youth and people under 30 (Shepherd, 2022). Unlike other social media platforms like Facebook, Instagram, or Twitter, a TikTok user's primary feed (the "For You Page" or FYP) does not solely or even primarily consist of posts created or shared by users they follow, but instead shows the user posts that that TikTok's algorithm predicts the user would be interested in, based on the user's prior behavior (e.g., finishing a video, liking or commenting, etc.). Instead of requiring the user to search for creators or hashtags relevant to the user's interests, although they are able to do that as well, the For You Page can lead a user into communities by continuing to show them posts they like. These communities are often referred to as [interest]-tok, e.g., "booktok" for users and creators interested in book recommendations and reviews. However, these are not explicit and clearly bounded online communities as HCI or CSCW researchers would define them, but rather are implicit and amorphous "support networks" which may or may not involve supporting harmful behaviors (J. A. Pater et al., 2019). These networks are largely formed around particular hashtags and viewing patterns, rather than explicitly named communities that can be joined. We need to improve our understanding of how such loose support

networks like TikTok are used when people, particularly vulnerable youth, connect around serious mental health topics, such as psychiatric hospitalization. For the purposes of this paper, we will use the term “community” in its colloquial sense, as that is the word many posters and commenters used to describe these TikTok networks.

Humor has long been thought to boost people’s mental health. Borchardt (2002) documents fifteen specific avenues that humor can contribute to people’s mental well-being, including “unconditionally accept yourself”, “develop a decent respect for human limitations”, and “the ability to live with uncertainty.” Humor also assumes a social function that helps people in communities gain acceptance, status, and promotes group cohesiveness (Ziv & Labelle, 1984). Social networks employ a large amount of humorous content generated by users currently, and research shows online communities use humor to deal with health-related struggles (Herrick et al., 2021; Hwang et al., 2010; Josefsson, 2005). Humorous content is also common on TikTok; creators often use humor to express themselves and attract followers. Because of this prevalence as a form of communication and its potential for connecting people, understanding how different online support networks or communities use humor is an important yet understudied area. We seek to explore this gap through our study of the use of humor in TikTok for people who are connecting around psychiatric hospitalization. Social media outlets such as TikTok have the potential to connect people who would otherwise be physically or socially isolated. Although many fear the potential negative effects of social media, we also need to explore its potential positive effects. We seek to understand all these effects by first

studying TikTok posts and comments regarding the serious mental health topic of psychiatric hospitalization.

In this study, we ask the following research questions about the community of TikTok users who connect around psychiatric hospitalization:

- How do TikTok creators and commenters connect around psychiatric hospitalization?
- How do TikTok creators express their thoughts, feelings, and experiences through humorous rhetorical devices supported by TikTok’s unique features?

3.2 Related Work

3.2.1 Health and Social Media

Researchers have extensively studied online health communities (OHCs) and people sharing health experiences on social media (Johnson & Ambrose, 2006; Maloney-Krichmar & Preece, 2002). Prior research has included online communities of people with breast cancer (Høybye et al., 2005; Rodgers & Chen, 2005), HIV/AIDS (Mo & Coulson, 2008, 2010), irritable bowel syndrome (Coulson, 2005), and ALS (Loane & D’Alessandro, 2013), among others, finding that OHCs empowered patients and provided social support in addition to information. Researchers recommended that clinicians discuss OHCs with patients as a form of rehabilitation.

Past research has investigated the characteristics and extent of the empowerment people can receive from OHCs. Mo & Coulson (2010), for instance, found that “lurking”

in an online support group may be just as empowering as being a more active poster in the group, which suggests that the content on its own can be beneficial, not just the act of participation. Van Uden-Kraan et al. (2008) investigated disempowerment as well as empowerment in online support groups for people with breast cancer, arthritis, or fibromyalgia, and found that while some disempowering processes included being unsure about information quality and being confronted with negativity and “complainers,” these happened far less frequently than empowering processes, which included amusement, finding emotional support and understanding, and helping others.

Others examined the nature of individuals sharing health experiences on social media. Liu et al. (2013) studied video-based social media in this space by examining interactions between chronic illness vloggers and their viewers, finding that unlike in closed OHCs, vlogging did not promote sustained connections with viewers, and left vloggers open to harsh comments from outsiders. They recommended designs to support vlogger-viewer connections. Additionally, as early work in video-based social media in this space, they noted affordances video provided that text could not, like building rapport with viewers through nonverbal cues and capturing “in-the-moment” scenes of the vlogger’s life, which is applicable to our analysis of TikTok posts.

Much of this work has highlighted the positive effects of these experiences. Yet, in the mental health arena, many researchers have identified negative effects of social media. In the following sections, we highlight the research on mental health in social

media in general as well as mental health in TikTok specifically; then we close with related ethical considerations for social media research.

3.2.1.1 Mental Health and Illness in Social Media

Much of the scholarship on mental illness and social media in health-related fields has focused on understanding the relationship between social media use and suicide or self-harm risk, primarily in adolescents and young adults. Multiple systematic reviews in this space have had mixed results, finding some association among certain variables but no causal relationship (Macrynika et al., 2021; Nesi et al., 2021; Picardo et al., 2020).

Scholars' work in HCI and CSCW on the intersections of mental health/illness and social media has included exploring content moderation subversion (Chancellor, Pater, et al., 2016; Feuston et al., 2020; Stewart et al., 2017) and detecting mental illness with machine learning (Balani & De Choudhury, 2015; Chancellor et al., 2017; Chancellor, Lin, et al., 2016; De Choudhury et al., 2014, 2016). Some research has explored the design of social media systems and how they can fuel negative effects, particularly in the pro-eating-disorder (pro-ED) or self-harm online communities (Chancellor et al., 2017; Chancellor, Lin, et al., 2016; Chancellor, Mitra, et al., 2016; Chancellor, Pater, et al., 2016; De Choudhury, 2015; J. A. Pater et al., 2016, 2019; J. Pater & Mynatt, 2017; Stewart et al., 2017). Other research, more closely aligned with scholarship on online health communities, characterizes the ways people with mental illness use social media (Ernala et al., 2021, 2022; Feuston & Piper, 2019) and investigates the social support and other benefits people with mental illness can get from social media (Andalibi et al., 2017;

Balani & De Choudhury, 2015; N. Berry et al., 2017; De Choudhury & De, 2014).

Although Ernala et al. (2021, 2022) studied individuals' recovery and social reintegration on social media after experiencing psychiatric hospitalization, little research has examined psychiatric hospitalization as characterised in social media, which is the focus of our research.

3.2.1.2 Mental Health in TikTok

Recent research on expressions of mental health and illness on TikTok has primarily come from healthcare-related fields. Clinicians are concerned about youth on TikTok “performing sickness” and self-diagnosing (Harness & Getzen, 2022), as well as negative representations of mental health services, specifically the U.K.’s NHS Children and Adolescent Mental Health Services (CAMHS) (Chadee & Evans, 2021). Scholars note a need for more professional public health content (McCashin & Murphy, 2023) or online intervention by healthcare professionals (Basch et al., 2022). Other research has found that, like OHCs, people with mental illnesses can be empowered by sharing experiences and destigmatizing mental health discourses (Gallagher, 2021; Herrick et al., 2021).

3.2.2 Ethical Considerations in Social Media Research

Recent scholarship has begun to describe the ethical tensions inherent in studying mental illness and social media, as part of a greater conversation in HCI about studying marginalized populations online. (Fiesler et al., 2020) investigated the ethical and legal

implications of violating a platform's Terms of Service in the process of data collection, and proposed that ethical decision-making of data collection methods should look further than Terms of Service and include contextual factors such as research purpose and the nature of the collected data. Pater et al. (2022) discussed the limitations of relying on institutional review boards for ethical decision-making, using design fiction to prompt questions and reflections for the research community to consider ethical concerns in HCI research that is deemed "not human subjects research."

In a systematic review of research studying data from Reddit, Proferes et al. (2021) suggest that researchers should consider the risks to subjects when including usernames and direct quotations in published work, especially if the data could be considered sensitive. They noted that maintaining the anonymity of subjects is more difficult with smaller communities. Additionally, Ayers et al.'s (2018) review of 2015-2016 PubMed articles using Twitter as a data source found that 72% quoted at least one tweet, and searching for the quoted tweet identified a participant 84% of the time. They noted that this does not violate Twitter's data sharing policy, but does violate the ethics standards set by the International Committee of Medical Journal Editors.

Chancellor et al. (2019) identified areas of tension in research predicting mental health states in individuals based on their social media behavior. Feuston and Piper (2018) challenged research practices that further other and sensationalize expressions of mental illness by using the "coded gaze," which assumes that experiences of mental illness can be inferred and classified, and can be categorized objectively. Instead, they

argued for methodological approaches that emphasize individual, lived experience and alternative interpretations. Similarly, Pendse et al. (2022) analyzed how the concept of “digital mental health” reinforces colonial logics and power inequities.

Together, this work on social media research ethics calls on researchers to move from a compliance-based mindset to more considered and nuanced approaches, and to question how terms like “human subjects” and “anonymity” may be applied to digital platforms and social media.

3.2.3 Rhetoric of Humor

In this section, we first focus on types of humor and their mechanisms, particularly in the audiovisual context. Then we describe how using humor can influence people’s mental health. Finally, we discuss the prevalence of humorous content on the Internet and social media.

3.2.3.1 Typologies of Humor

Categorizing humor techniques or mechanisms is difficult since humor is incredibly complex, subjective, and dependent on an individual’s cultural background and personal taste (Berger, 2017). Humor typologies created by different researchers vary because of diverse research purposes and motivations. Humorous content may include more than one type of humor, and researchers argue it is the combination of multiple humor types that generates humor (Berger, 2017; Buijzen & Valkenburg, 2004; Juckel et al., 2016).

When analyzing verbal jokes, Berger (2017) generated a typology of humor that includes four basic categories: language, logic, identity, and action, and identified 45 mutually-exclusive humor techniques (e.g., absurdity, exaggeration, and repetition). Drawing on Berger's typology, Buijzen and Valkenburg (2004) identified 41 humor techniques used explicitly in audiovisual media (television commercials). The authors subsequently clustered humor into 7 categories: slapstick, clownish humor, surprise, misunderstanding, irony, satire, and parody. Juckel et al. (2016) developed a typology of humor for sitcoms that included four categories (adopted from Berger, 2017), and 22 techniques. Since the data used to generate these typologies are primarily from traditional media (e.g. verbal narratives, TV commercials, TV shows) and our research focuses on social media, those humor categories are not entirely applicable to our dataset. Nonetheless, we examined and considered each typology before determining codes for the types of humor in our study.

3.2.3.2 Humor and Mental Health

Humor has long been regarded as a way to improve people's mental health and well-being. Humor can lift people's mood or provide relief to daily boredom and miseries. Research shows humor has a wide range of effects on perceptions, attitudes, judgments, and emotions, which may benefit people's physical and psychological health (Lynch, 2010). One study found that humor as a response (e.g., laughter) can reduce existing mental problems, and that a sense of humor can moderate the perceived intensity of difficult life experiences (Galloway & Cropley, 1999). However, other research shows

that self-defeating humor is negatively correlated with mental health (Schneider et al., 2018). Increasingly individual and group psychotherapy uses humor in treating patients with serious mental illness in a clinical setting. However, empirical studies regarding the potential therapeutic use of humor are limited, especially with regard to serious mental health illnesses (Garrick, 2006; Lynch, 2010).

3.2.3.3 Humor in Social Media

Online humor is prevalent in digital platforms focusing on capturing people's attention and time (Shifman, 2013). Social media is filled with humorous content in the form of text, audio, photos, memes, audiovisual media, etc. Currently, the Internet has become a major way of distributing humorous content, especially through user-generated content on social network platforms. Internet humor often features irony, incongruity, and superiority (i.e., making the audience feel superior) (Vásquez & Aslan, 2021).

Humorous content is extremely popular on TikTok; when analyzing 1000 video posts on TikTok, Shutsko (2020) found that the highest number of videos (32.4%) belonged to the "Comedy & Joke" category, and noted that "having fun" is one of the most common motivations for using TikTok. Similarly, a previous study shows that people post humorous content on TikTok regarding mental health issues. When analyzing TikTok posts associated with eating disorders, Herrick et al. (2021) found that 24% of posts use **gallows humor**, which Dictionary.com defines as "humor that treats serious, frightening, or painful subject matter in a light or satirical way." Instead of being just seen as humorous, gallows humor is also a powerful coping mechanism (Roaldsen et al.,

2015), and is often perceived as a cry for help (Craun & Bourke, 2014). Herrick et al. (2021) argue that this type of humor is intended to create and maintain a group and an in-group status in an eating disorder community.

Building on this foundation, we strive to understand how TikTok users connecting around psychiatric hospitalization employ humor in their posts, and how humor, especially gallows humor, influence their way of connecting and sharing within the community.

3.3 Methods

3.3.1 Data Collection

To find the popular hashtags and keywords used in TikTok’s mental illness network related to psychiatric hospitalization, the first author searched for straightforward terms such as “psych ward” and looked for frequently-occurring hashtags used in those posts to identify new search terms, and continued this until no new terms were being discovered. This list included 12 hashtags that were specifically about psychiatric hospitalization, while others that frequently occurred could also be used in posts not specific to psychiatric hospitalization (e.g., other hospital inpatient experiences or other mental-health related experiences). Because certain hashtags (including “#psychward” itself) are blocked from direct searches on TikTok, we will not provide the exact hashtags we discovered, as several of them utilize in-group euphemisms to avoid censorship.

Due to the unavailability of an official TikTok API, the first author used a third-party script to collect posts containing the hashtags specific to psychiatric hospitalization, as well as those not-specific but which were most frequently co-occurring with the specific ones (e.g., “#mentalhealthmatters”). The data gathered for each post included the post’s unique ID, URL, caption text, creation timestamp, author’s username, number of likes, number of comments, and the name of the audio used. From this corpus of 5031 posts, the first author created a dataset of 2475 posts using these hashtags that were created between December 1, 2021 and May 30, 2022.

3.3.2 Ethical Considerations and Researchers’ Positionality

We acknowledge that this first phase of our study is an analysis of public content on TikTok without interacting with creators and commenters. Thus, our results are a reflection of how *we* as researchers—some members of this community, some not—interpret these posts. All authors of this paper have at least one close connection to someone who has been hospitalized in a psychiatric unit, and we have discussed their experiences with them. Thus, we all had some background knowledge of the topic before embarking on this study and could relate what we have heard to what we observed on TikTok. All authors also have direct experience in receiving mental health care. One author is a LGBTQ+ youth who uses TikTok. In addition, the last author of this paper has done extensive research on the benefits of various online health communities, which likely led her to noticing the positive effects of this informal community as well. She also has prior research on peer support for mental health.

The TikTok posts we analyzed are public, and we received institutional review board (IRB) approval from our institution. Yet, as others have argued (Ayers et al., 2018; Fiesler et al., 2020; J. Pater et al., 2022; Proferes et al., 2021), we should protect the privacy of people within the community. Thus, we chose not to disclose all the hashtags we used to identify our dataset because it risks exposing the people in this community and risks censorship from TikTok.

Unlike results from analyses of textual data that include quotes to justify themes, textual quotes would be insufficient to describe the complexities of multimedia TikTok posts. Although pointing to the TikTok posts would help to justify the link to our themes, we do not want to call attention to the posts, particularly when the post authors have not provided consent to share their posts in this way. Instead, we describe what we saw, read, and heard in the posts and how that connects to our themes.

3.3.3 Analysis

Each of the four coders reviewed 10 out of 40 random posts pulled from the dataset of 2475 posts to develop codes. We filtered out posts which were not in English or not about psychiatric hospitalization (e.g. non-psychiatric inpatient care) or related mental illnesses and behaviors (e.g. eating disorders). We discussed these posts as a group and noted common themes found and similarities in our codes. Next, we pulled 100 random posts from the dataset of 2475 posts, which all four coders reviewed individually, and regrouped to discuss the themes together, generating and revising codes to include types of humor, “mechanisms” used on TikTok such as lip-syncing or dancing to convey

meanings, and the perceived purpose or motivation behind each post. Finally, we reviewed all 140 of the posts by deductively coding for the themes we decided to focus on. We found that we reached data saturation after analyzing these 140 posts; other qualitative analyses of TikTok have used 28-150 posts (Basch et al., 2022; Chadee & Evans, 2021; Gallagher, 2021; Herrick et al., 2021; McCashin & Murphy, 2023).

3.4 Results

In this section, we describe how TikTok creators and commenters connect around psychiatric hospitalization as well as express their thoughts, feelings, and experiences through humorous rhetorical devices supported by TikTok's unique features as a platform. First, we describe our dataset, including what the demographics are for TikTok in general and what we observed in our dataset as well as what data we filtered from the initial sample based on relevancy, access, and our humor assessments. Next, we characterize the humor in these posts, the perceived motivation of the creators of the posts, and the support we identified in the comments on the posts,

3.4.1 Dataset

According to Shepherd (2022), as of September 2021 the demographics of TikTok in the U.S. (global statistics did not capture users under 18) are as follows: 25% of users are ages 10-19, 22.4% are 20-29, 21.7% are 30-39, 20.3% are 40-49, and 11% are 50 years or older. As of August 2021, according to Statista (Ceci, 2022), the global distribution of TikTok creators skews very young: 18-24 year olds comprise 52.83% of

creators, with the next largest group being 13-17 year olds as 18.67% of creators, then 25-34 years at 15.03%, 13 and under at 8.7%, and people 35 and older making up only 4.76% of all creators. As we only observed the posts instead of interacting with the creators and commenters, our demographic knowledge of the creators and commenters in our dataset is limited. Some creators included demographic information (e.g., age, gender, nationality) in their account bios, but this was not consistent or widespread enough to make any significant conclusions. Nearly all creators appeared to be under 30 years old, with many appearing to be under 20 years old. Based on further hashtags used, such as #lgbt and #trans, and information disclosed in account bios, many creators also appeared to come from the LGBTQ+ community. Based on these hashtags and account bios we found that 23 of the 101 creators explicitly disclosed LGBTQ+ identity.

Of the 140 posts the coders reviewed, we removed 28 from the dataset: one post was a duplicate, 3 were not in English, 9 were deemed irrelevant, and 15 were unavailable (either from deletion or because the creator's account was private). Irrelevant posts contained the relevant hashtags, however the content was not connected to psychiatric hospitalization (for example, one of the irrelevant posts found was a humorous cat video). After this processing, 112 posts remained in our dataset. For each of these posts, we coded whether we believed them to be humorous, the post's type of humor, TikTok-specific mechanisms used to express that humor, the perceived motivation for posting, and the types of connections formed in the comments section. One post became unavailable midway through the coding process, so its comments were not included in analysis.

3.4.2 Humor

In assessing the 112 remaining posts, we determined which posts were humorous, what type of humor they used, and what TikTok mechanisms they used to express humor. Determining whether a post is humorous was challenging, partially because the brief videos in TikTok can be difficult to interpret but also because humor depends so much on contextual factors including the culture and experiences of the person viewing it. TikTok videos employ various mechanisms such as music, in-video captions, sound effect, dance, role play, etc., which add ambiguity to what the creators want to say. The coders' different life experiences, and thus different interpretations of these TikTok mechanisms, result in occasional divergence on whether some posts are humorous or not. Thus, in assessing humor, we found points of contention. The four coders agreed that 51.79% (58) of the posts were humorous, and 36.61% (41) were not, but we were divided on the remaining 11.61% (13). Of these 13 contested posts, 8 were coded as humorous by three of the coders, 1 was coded as humorous by two coders, and 4 were coded as humorous by just one coder. After discussion, we left these 13 posts as contested; without talking to the post's creator, we cannot know whether a post was meant to be humorous.

We coded the type of humor expressed in each humorous post using Buijzen and Valkenburg (2004) categorizations. Each post could be tagged with multiple types of humor. We found that the most frequent code used was *satire* (32 posts), and the next most frequent codes were *surprise* (14), *peculiar face* (12), *exaggeration* (11), and *eccentricity* (10). Separately, we assessed whether each humorous post utilized gallows

humor—a meta category that portrays very serious and often dark content in a humorous way—and found that 37 of the 58 humorous posts used a form of gallows humor, as well as 2 of the 13 contested posts. See Fig. 1 for results, excluding codes used on less than 4 posts.

We compiled a list of TikTok mechanisms that creators used to express humor. We noted that most posts used in-video captions (49 humorous, 11 contested), which is text overlaid onto the video itself. The other most popular mechanisms were “performing role play or sketches” (26 humorous, 3 contested), and “lip-syncing to music or another audio” (28 humorous, 5 contested). Additionally, 14 (13 humorous, 1 contested) posts used a form of cinematography to express humor; for example, utilizing multiple camera angles or humorous camera movement throughout the video. Twelve (9 humorous, 3 contested) posts also had humorous post descriptions. While the use of video filters and dancing seem to be popular across TikTok, only 3 humorous posts used filters and 5 posts (3 humorous, 2 contested) included dance. Further details of these results are shown in Fig. 2.

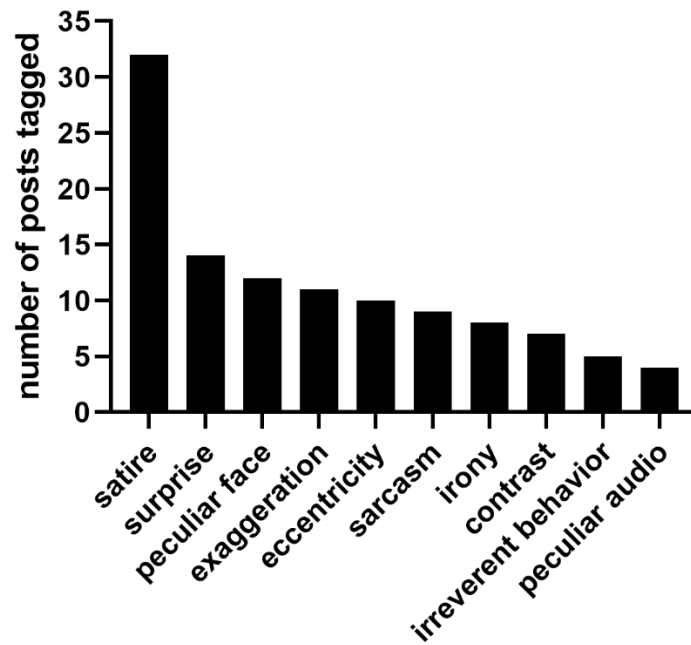


Fig. 1. Distribution of the 10 most common types of humor tagged in 71 humorous and contested videos.

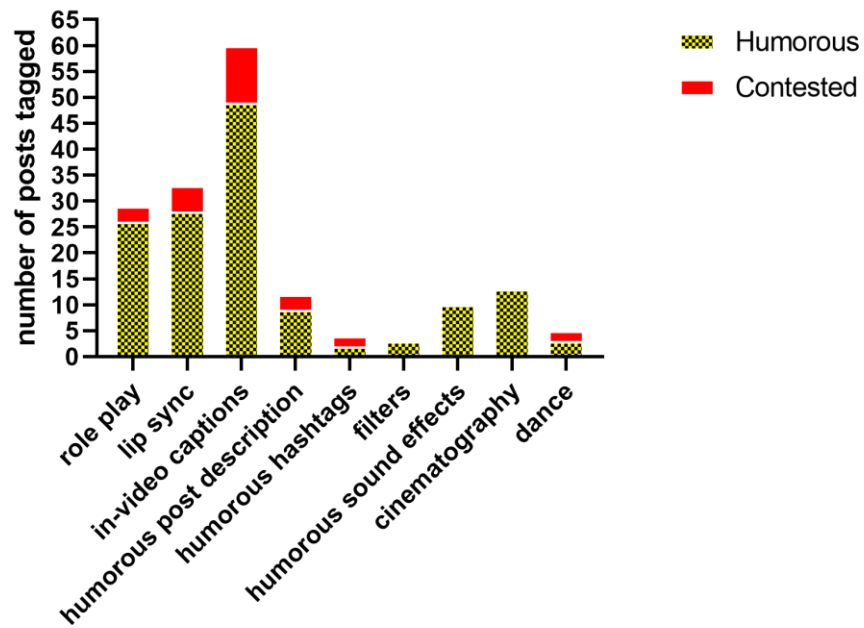


Fig. 2. Distribution of the 9 most common mechanisms used in expressing humor among 71 humorous and contested videos.

3.4.3 Perceived Motivation

For all 112 posts remaining in the dataset, we coded what we perceived the creator's motivation to be for posting the video. Posts could be given one or two codes. The 13 possible codes were "sharing their experience," "making fun of (psych) ward life," "community building," "making fun of their own mental health," "seeking support," "expressing frustration," "making fun of a bad experience," "celebrating," "laughing so you don't cry," "self-deprecation," "giving support," "making fun of provider behavior," and "expressing self-acceptance" (see Fig. 3).

"Sharing their experience" included mostly non-humorous posts describing what the creator had gone through or was going through. "Making fun of (psych) ward life" included posts describing silly events that occurred while they were hospitalized, as well as creators relaying serious or frustrating events that occurred in humorous ways. "Community building" covered TikTok posts that primarily or secondarily focused on connecting with viewers. This connection could be through discussion of a shared experience, and often included an explicit call to the viewers to engage with the post or ask questions. Posts in which creators were "making fun of their own mental health" used the creator's mental health status or diagnosis as a focus for humor, often in a self-deprecating manner. Several posts using this code involved the creator reflecting on or reenacting a previous time in which they acted irrationally due to the state of their mental health at the time. "Seeking support" posts either explicitly requested help from viewers or were about something the creator could not handle on their own, with what we

perceived as an implicit request for help and support (e.g., posting that they're "in a bad place" or "really struggling right now"). TikTok posts that "expressed frustration" included creators that seemed frustrated by the state of the world or things that were going on in their life, as well as posts that described specific microaggressions they faced. Posts that "made fun of a bad experience" illustrated or reflected on a bad experience the creator had through the lens of humor. "Celebration" posts often included an announcement of a return from the psychiatric ward, a big step made towards recovery, or a celebration of friendships built. "Laughing so you don't cry" included posts using gallows humor, particularly around suicide. "Self-deprecation" covered posts in which the creator criticized themselves or talked about themselves in a negative way. "Giving support" included posts giving tips for inpatient living and encouraging others toward recovery. "Making fun of provider behavior" included posts poking fun at negative experiences creators had with healthcare providers, including nurses, counselors, therapists, etc. "Self-acceptance" covered posts showing determination towards recovery and self-love.

We coded 33 posts as sharing their experience (9 humorous, 22 non-humorous, 2 contested). 23 posts were coded as making fun of (psych) ward life (20 humorous, 3 contested). 20 were community building (7 humorous, 10 non-humorous, 3 contested). 20 were coded as making fun of their own mental health (16 humorous, 4 contested). 14 were seeking support (5 humorous, 9 non-humorous), 13 were expressing frustration (3 humorous, 8 non-humorous, 2 contested), 10 were making fun of a bad experience (9 humorous, 1 contested), 9 were celebrating (1 humorous, 7 non-humorous, 1 contested),

8 were laughing so you don't cry (all humorous), 8 were self-deprecation (4 humorous, 3 non-humorous, 1 contested), 8 were giving support (2 humorous, 4 non-humorous, 2 contested), 6 were making fun of provider behavior (all humorous), and 4 were expressing self-acceptance (3 non-humorous, 1 contested). Fig. 3 shows these findings.

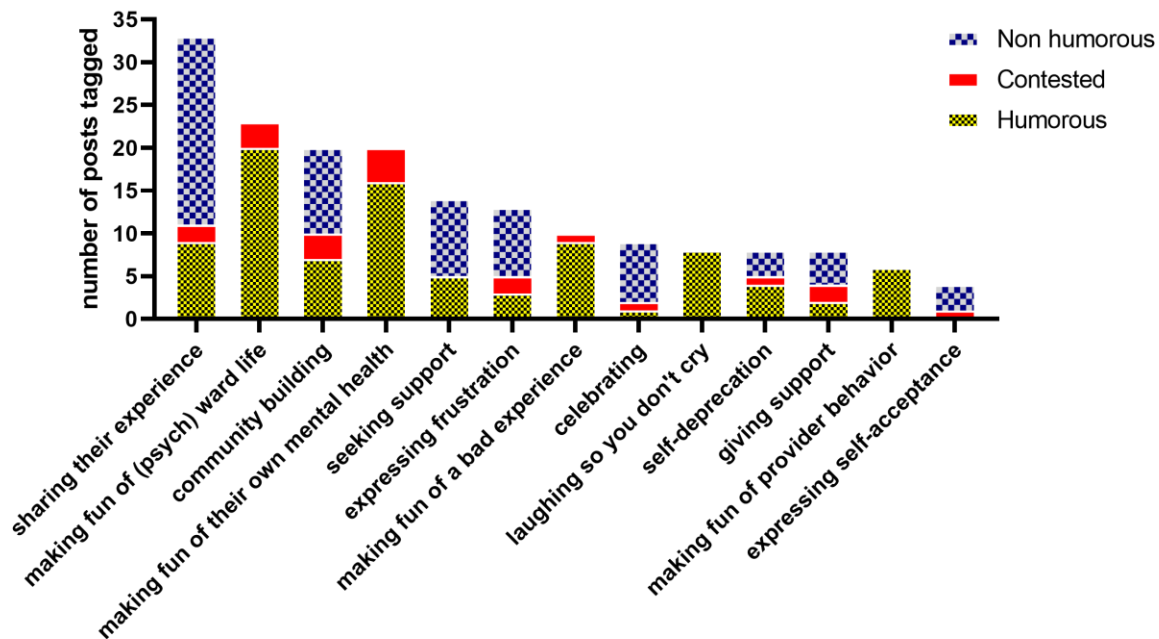


Fig. 3. Distribution of creators' perceived motivations for the 112 TikTok posts.

3.4.4 Connections Through Comments

Finally, we analyzed the comments sections of the 112 posts. We used one or two codes to describe their comments. The seven possible codes we utilized were “identifying with the video content,” “supporting health behavior or recovery,” “reacting positively to the post,” “supporting the creator where they are,” “showing concern for the creator,” “two sides of an argument,” and “expressing unhealthy behavior” (see Fig. 4). In addition to the TikToks with these codes, two posts became unavailable partway through the

coding process, so we were unable to analyze their comments, and seventeen posts had no comments.

In coding the posts, we found that fifty posts had comments that identified with the video content (34 humorous, 9 non-humorous, 7 contested). Examples include *The memories of dbt just hit me like, “you look like you haven’t been getting any sleep” WONDER WHY, legit me im gunna be out soon but i feel like ill be back, because why be sad when you can laugh at yourself 😂😂 and Hahaha accurate*. Twenty-four posts had comments supporting healthy behavior or recovery (3 humorous, 19 non-humorous, 2 contested). Examples of these include *I’m sorry u relapsed, but remember that doesn’t mean recovery isn’t possible, you’re a rockstar! keep up the fabulous progress 🥰*, and *I just wanted to stop by and tell you how amazing you’re doing and how worth it it will all be at the end! Keep going ❤️🥹*. Twenty-one posts had comments that portraying a positive response in another way (15 humorous, 4 non-humorous, 2 contested), including *YOU WILL NOT BE OFFING YOURSELF ON MY WATCH!!!*, and *I really shouldn’t laugh but*. Seventeen had comments supporting the creator where they are (8 humorous, 9 non-humorous). Examples include *truly the best vibe I’m so happy you’re feeling good!! :))))*, and *I am sorry honey :(you are incredibly beautiful! inside and outside*. One humorous post had comments that showed concern for the creator (e.g., *ARE YOU OK*), and one non-humorous post had comments that contained two sides of an argument, in which commenters discussed whether an ED recovery post that included photos of the creator was triggering for others with EDs.

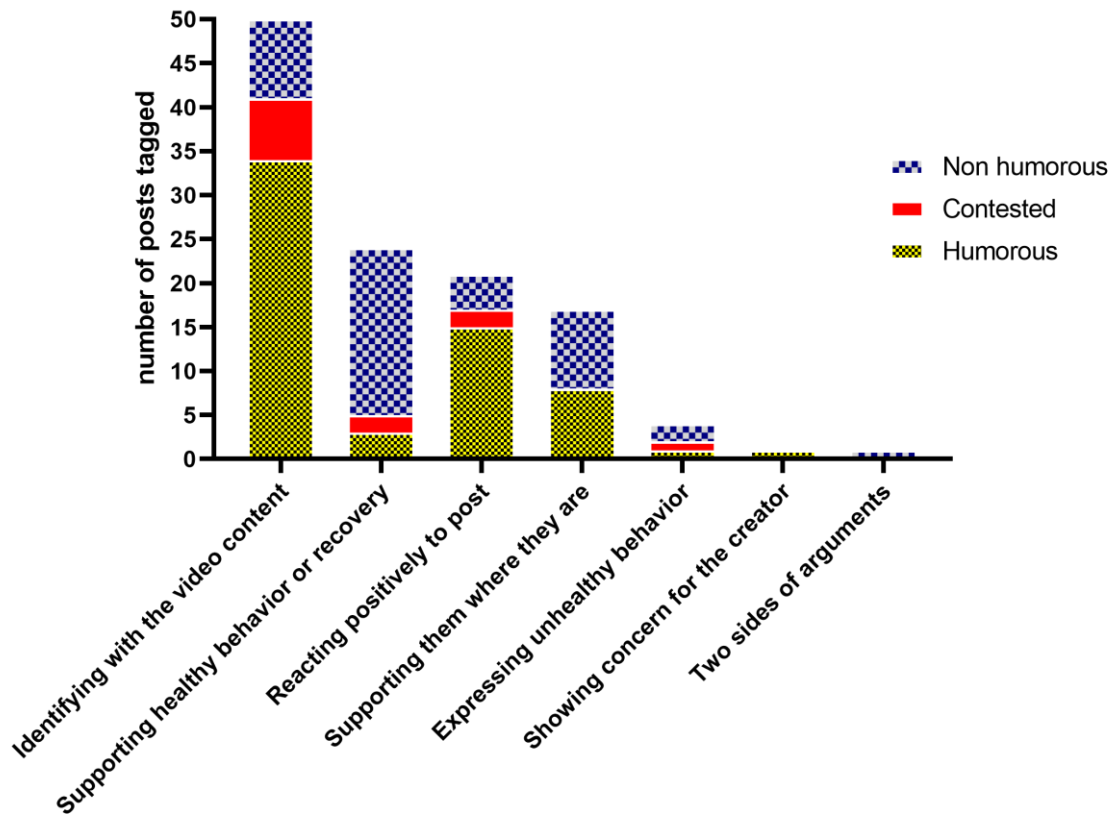


Fig. 4. Distribution of comment section codes for 110 TikTok posts (excluding those without comments).

We carefully analyzed all these comments for any digital self-harm, as defined by Pater and Mynatt (2017) as “online communication and activity that leads to, supports, or exacerbates, non-suicidal yet intentional harm or impairment of an individual’s physical wellbeing.” We did not find any comments that explicitly fit this definition on any of the videos, however we did find a few comments on 4 posts (1 humorous, 2 non-humorous, 1 contested) expressing unhealthy behavior. Examples include *I’m “enlist him in the army” crazy 🤪 shoulda never gave me his ssn, I said listen to music...that’s a lie I actually just*

cut myself 😊 and *ed are a choice*. Fig. 4 shows our findings from the comments, not including the 17 videos with no comments.

3.5 Discussion

Numerous research papers and news articles claim that social media use is detrimental to people's mental health, particularly for youth (Kalbitzer et al., 2014; Nitzan et al., 2011; Rosen et al., 2013). However, few studies have examined the impact of TikTok, as a unique video-based and highly creative social media platform that is particularly popular with youth, on people connecting around psychiatric hospitalization. In this discussion, we describe ways TikTok has been used regarding this aspect of mental health. We first explore how creators use humor to build community and then detail how users form positive connections within that community.

3.5.1 Using Humor to Build Community

Comedy and musical content are the most popular and frequent categories on TikTok (Shutsko, 2020), which is reflected by TikTok's official mission: *Inspire Creativity and Bring Joy*. Previous research found the major reason people use TikTok is to watch "interesting content" (Liang et al., 2021). In our study, we also found that the community of people connecting around psychiatric hospitalization frequently employ humor in their posts, as we coded at least 51.79% of the posts in our sample as "humorous". Based on our analysis, the perceived primary motivation for posting humorous TikToks was to make fun of the creators' experiences of hospitalization,

provider behavior, or their own mental health (see Figure 3). Other researchers have noted that such usage of humor and joking can contribute to community building by smoothing group interactions and separating themselves from outsiders (Fine & Soucey, 2005), as we saw in our sample of posts. In particular, satire, the most common type of humor in our data (see Figure 1), best exemplifies showing how humor supports community building. In these satirical posts, creators usually employ role-play and other mechanisms to mimic their mental health experiences or highlight comical interactions with health providers (e.g., nurses, therapists, etc.), both in and out of the hospital setting. These posts often attracted positive reactions, such as likes and comments in which others identified with the satirical content and showed support, often using words like *same* or *accurate*. For example, in one post a creator role-played as a nurse coming into a patient's room to check on them frequently while they were sleeping, sometimes even to draw blood for labs. Several commenters identified with this experience, and also found the depiction humorous (*"you look like you haven't been getting any sleep" WONDER WHY*). We noticed this form of humor playing an important role in helping people connect around psychiatric hospitalization and build their community online.

We found humorous posts frequently utilizing gallows humor. One of our motivation categories, "laughing so you don't cry," reflects the self-protective aspect of gallows humor in which the creators cope with their bad experiences by identifying their humorous aspects. For example, one post in this category involved the creator role-playing as themselves waking up in the morning, ignoring the loud, anthropomorphized manifestation of "horrible thoughts [they] can't even tell their therapist," and

begrudgingly deciding to go to work instead of being hospitalized. This shift in perspective can serve as a powerful stress-coping mechanism (Roaldsen et al., 2015) and contribute to their self-acceptance. It also supports community building by providing a way for people to connect with each other around shared experiences: commenters responding to the previously-mentioned post made comments like *Atleast I'm not alone* and *accurate as fuck sir!*

3.5.2 Forming Positive Connections

People with severe mental illness, such as people who have experienced or are considering psychiatric hospitalization, often suffer from loneliness and seek connection (Jaremka et al., 2014; Segrin, 2000; Vanderhorst & McLaren, 2005). Additionally, psychiatric hospitalization is a unique and often traumatic experience that few can relate to (Cohen, 1994), particularly for young adults and youth, who represent the majority of TikTok users' demographic. Online platforms provide an opportunity, that is often unavailable offline, for them to connect to others who have similar experiences.

Because of the short-video format, TikTok makes it easy for creators to post and share their immediate experiences with the community, and use their creativity to express their emotions freely. Although it is difficult to determine creators' motivation without asking them directly, the perceived motivations we coded align with previous survey research which shows the major motivations of TikTok users are: archiving, self-expression, social interaction, and peeking (Omar & Dequan, 2020).

Another characteristic of these posts is the ambiguous boundary between private and public content. On one hand, since the topic of mental health is usually personal and sensitive, creators' perceptions of whether or when the posts should be public could change frequently. In our sample, more than 10% of our posts became unavailable before we could code their comments. Although some posts may have been censored by TikTok, others seem to indicate that the creator chose to remove them, or changed their accounts' privacy settings. Creators could hide or delete posts due to the blurred boundary between perceived private and public content, which leads to the transient nature of these posts. On the other hand, researchers have noted that one motivation of TikTok creators is to log and archive their daily life (Omar & Dequan, 2020), similar to writing a personal diary. However, unlike a diary, which assumes the audience and the author to be the same person, TikTok videos are open to public audiences. As demonstrated in our results, the nature of public-oriented expression encourages the content to be more about sharing and support-seeking, rather than self-documentation or self-reflection as in a diary.

Our analysis of users' comments did not find substantial numbers of what we determined to promote digital self-harm or unhealthy behavior. Only a few comments on four respective posts expressed unhealthy behavior or ideas, and no comments showed explicit signs of digital self-harm. However, we also note that "unhealthy" behavior may have very different definitions depending on the perspective of the researcher. For example, many posts and their respective comments discuss hiding behavior from providers to avoid consequences like law enforcement conducting "welfare checks" or a person being involuntarily admitted to a psychiatric facility. Although some people

perceive such hiding behaviors as harmful, for multiple marginalized communities, the potential consequences can be equally or more harmful, traumatic, or even life-threatening. Additionally, without talking to members of this community (including “lurkers,” or those who view or like posts and comments but do not create their own), we cannot say whether *unintentional* harm could occur based on the behaviors and attitudes modeled by creators.¹⁶ Ultimately, we must emphasize that unhealthy and harmful behavior must be discussed and determined within the context of this community, with this community.

Over a third of the posts had comments explicitly supporting the creator (e.g., *There are brighter days ahead love 🥰*), including offers to talk with the creator if they need a supportive ear and explicitly discouraging harmful behavior (e.g., *YOU WILL NOT BE OFFING YOURSELF ON MY WATCH!!!*). Commenters also demonstrated connection by matching the humor and tone expressed by the creator; sometimes also including references to their own similar experiences (e.g., *legit me im gunna be out soon but i feel like ill be back*). However, even on posts that had a humorous tone, some commentors would show more serious concern (e.g., *are you ok??*). The large amount of positive support and the absence of digital self-harm or other toxic interactions seem to establish TikTok as a generally welcoming environment for people to connect around psychiatric hospitalization.

¹⁶ That is, through vicarious learning (Bandura, 1977); see Limitations.

3.6 Design Provocations

Rather than providing explicit design recommendations for TikTok or other social media platforms, our contributions are at a higher level. We suggest that design features should encourage creativity and that support networks should support serendipitous connections. We close with some provocations around moderation in the community context.

3.6.1 Design features should encourage creative expression

As a short-video-based social media platform, TikTok provides many features to help creators easily integrate videos with music, still images, animations, captions, as well as employ special effects. These diverse features encourage creativity and afford various novel expressions that traditional media cannot support. For example, we found that TikTok creators frequently used in-video captions and lip-syncing, which utilizes lyrics to express and explain their emotions and experiences. For lip-syncing, instead of making their own narratives and stories, creators use music lyrics as a proxy to speak for themselves. The ability to use sounds memetically, which can be paired with photos, videos, and text, also allows users to participate in the construction of community without needing third-party tools to, for example, digitally alter an image-based meme. The various in-app features that support creators repeating and adding to other creators' work makes for a more inclusive construction of community.

There is a long history of the therapeutic use of creativity, which has been shown to help individuals cope with stress and trauma (Corry et al., 2014). Expressing oneself

creatively can aid in concretizing nebulous or abstract thoughts and feelings, and can also make individuals feel connected to the broader human experience (Blatner, 1991). When a suicidal person creates a TikTok post about their experience of suffering, implicit in this creation is an assumption—or, at least, a hope—that this is an experience that others can understand. The creators of posts in our study made extensive use of TikTok’s creativity features, and the ease of infusing such creativity into their posts could be a substantial draw to the platform, particularly for youth. Thus, other tools that attempt to support people with mental health challenges, especially youth, should consider including features that encourage such creativity.

3.6.2 Support networks should support serendipitous connections

Unlike social media platforms that require a person to self-categorize to find others with shared interests or identity, (i.e., a person must know that they have an eating disorder to search for and join eating disorder related spaces on Facebook, Reddit, Twitter, or Instagram), TikTok clusters people according to shared interests inferred by its algorithm. This feature can spur the creation of networks such as the one we observed that connects people around psychiatric hospitalization. This automatically connecting feature deprioritizes clinical designations like official DSM diagnoses in favor of a shared psychiatric experience. Thus, it allows for the inclusion of people who do not have a diagnosis, those who have a misdiagnosis, and those who have multiple diagnoses. It supercedes the dominant hierarchies of knowledge that privilege professional, “technical” knowledge over experiential knowledge. Although such an effect was unlikely

consciously planned by TikTok, it arguably follows Pendse et al.'s (2022) “Designing for Healing” guideline to center lived experience over colonial clinical constructs.

Social media that allows users to find others with similar identities, interests, and needs without forcing them to categorize themselves in the process could potentially support other marginalized communities who may otherwise have difficulty finding each other, or are even unaware that there are others with whom they can connect.

Additionally, algorithmic clustering can encourage creativity and playfulness—a common sentiment expressed on TikTok is that “the algorithm brought you here for a reason” and feeling “called out” by the algorithm for showing a viewer what they feel is very niche content. At the same time, users are not entirely at the mercy of the For You Page; they have the freedom to search for terms they’re interested in, and to follow popular hashtags and sounds from posts they like to find similar content. Promoting such serendipitous connections could help support people from marginalized communities as well as socially or physically isolated people who need to connect with others but don’t necessarily know how to find such connections.

3.6.3 Moderation should consider the community context

Many social media sites, including TikTok, moderate or censor content considered dangerous or potentially harmful. In particular, TikTok censors posts with some hashtags related to mental illness, including #suicide, #suicideawareness, #selfharm, and #eatingdisorder. When users try to search these hashtags, TikTok displays helplines on the search page in lieu of results. Other hashtags are censored without explanation or

providing an intervention like a helpline, most notably #depression, as well as a few common antidepressant brand names, such as Prozac, Zoloft, and Paxil. To bypass the censorship, TikTok creators routinely use acronyms or different terminologies to avoid being automatically flagged: e.g., “self-harm” becomes “SH,” and “eating disorder” becomes “ED.” Other orthographic and lexical variations of censored terms also occur; this phenomenon has been studied on other platforms, such as Instagram as well (Chancellor, Pater, et al., 2016; Stewart et al., 2017), but we are choosing not to make these alternate terminologies visible to those outside of this network, to avoid further censorship (as has been noted in Feuston and Piper [2018]). Such censorship tends to discriminate against marginalized communities talking about their own experience, and TikTok specifically has been criticized for such actions (Botella, 2019; Ohlheiser, 2021).

The highly contextual nature of any community means that top-down, outsider moderation will inevitably fail. While communities should have freedom for creative expression, including the freedom to post dark or negative content, harmful and hateful content still necessitates moderation. However, a simplified, “one-size-fits-all” approach to content moderation often ends up causing harm rather than removing it (Feuston & Piper, 2018). As other scholars have argued, allowing people in these communities to help create moderation guidelines and algorithms will result in much more effective moderation (Pendse et al., 2022). Understanding what content is actually harmful instead of making assumptions without knowledge of the community’s culture and context can better support people as they seek support. We have shown that many people, often youth who have more limited access to resources for support, creatively express themselves—

often through humor—and reach out to others in their community for much needed support concerning serious mental health challenges. Largely, these TikTok creators appear to be receiving that support from others within the community. Therefore, we ask: Who should be defining and determining what content is harmful? Should such a creative and supportive outlet be censored because of the serious mental health topics covered? Does such censorship cut off a valuable creative outlet and source of support, particularly for vulnerable youth? How do we balance supporting the need for positive connections against the potential for harm?

3.7 Limitations

As with many creative works, such as paintings or poems, the meaning of TikTok videos are often ambiguous and difficult to interpret, which led to our contention on some of the categorizations. A contributing factor to that ambiguity is the short length of TikTok videos, typically around 30 seconds or less. When compared to other video platforms such as YouTube where videos can be many minutes or even hours long, many TikTok videos do not form a well-established narrative or story. We tried to address the ambiguity by having all four authors code all videos; nonetheless, others could interpret the TikTok videos differently.

In terms of our sample, as Feuston and Piper (2018) reported, methods relying on keywords to collect data excludes individuals who do not explicitly signal their posts as having to do with mental health or illness, which can be a significant percentage of the

population under study. The method we have chosen has, in many ways, constructed the population we are attempting to observe.

Although we have shown that people connecting around psychiatric hospitalization form group connections and support networks on TikTok, our research cannot determine how using TikTok will impact any given individual's recovery. While we found what we interpreted as largely healthy and supportive behavior in posts and comments around this topic, there are important factors that we did not include.

First, we do not know the broader context in which individuals are participating in this community, as there is overlap between this community around psychiatric hospitalization specifically and other mental health communities. The bespoke nature of the For You Page can act as a double-edged sword, providing communities supportive to individuals' needs, or ones that compound harm, and will continue to lead individuals to the kind of content that receives higher engagement. Even if an individual is seeing helpful, recovery-oriented content, it can often be out-competed by more sensational and harmful content (Gay, 2026).

Secondly, while a creator or commenter may not intentionally or explicitly endorse unhealthy or harmful behavior, they can still cause potential harm by modeling certain attitudes or behaviors. Through vicarious learning—a process in which people learn by observing or communicating with others (Bandura, 1977)—an individual may learn unhealthy attitudes and behaviors from creators and commenters, even if they do not

seem on the surface to be promoting unhealthy behavior (Feuston & Piper, 2018; Gay, 2026; Jia et al., 2024; Seko et al., 2015).

We hope that this study provides an entry point into describing this particular community, centered around experiences with psychiatric hospitalization in particular. Future work could address the limitations described above through interviews with individuals engaged in this community, whether as creators, commenters, or observers.

3.8 Conclusion

In our content analysis of TikTok posts by people connecting around psychiatric hospitalization, we describe types of humor and mechanisms creators utilized to build community and share their experiences. Creators and commenters tend to use gallows humor and satire to connect with each other and cope with serious and stressful circumstances, such as mental distress, crises, and hospitalization. Our study also demonstrates the ways that TikTok serves as a community-building platform for people to connect around psychiatric hospitalization, share their experiences and humor, celebrate their recovery, identify with other inpatients, receive peer support, and support each other's mental health journey. We found that TikTok's content creation features encourage playfulness and creativity that help people connect and support one another. Additionally, TikTok's clustering of users with similar interests seems to stimulate the creation of support networks centered on lived experience, rather than medical diagnoses. We found largely healthy and supportive behavior in this community, rather than the assumed harmful behaviors. Thus, we question the common practice of censoring

communities that discuss serious mental health topics. People, particularly vulnerable and often isolated youth, need more rather than fewer creative, hopeful, and humorous ways to connect with each other, especially about serious mental health concerns. In this work, we contribute new insights for social media design features that support creativity, humor, and serendipitous connections, particularly to help youth with serious mental illnesses who often lack adequate social support. Designers and social media platform developers need to collaborate with mental health communities to value and support the sharing of mental health expertise that comes from lived experience. Such support could provide one avenue for helping people with serious mental health challenges to survive and thrive.

Chapter 4: Investigating Information Pathways in Personal Online Narratives of Psychiatric Hospitalization

Contributions:

This chapter examines written narrative accounts of people's experiences with psychiatric hospitalization published through Mad in America. The chapter's findings contribute to **RQ1** by providing analysis of these rich, written narratives, and contributes to **RQ2** by providing a framework of information flows and pathways based on that analysis. These findings indicate that both psychiatrically hospitalized individuals and their clinicians encounter different barriers to effective information seeking and sharing. For hospitalized individuals, however, these barriers were more severe: their basic information needs often went unmet, and their patient rights and expertise were routinely disregarded, contributing to negative experiences and subsequent loss of trust in their clinicians and the psychiatric system. The information pathways framework further illustrates how missed opportunities for collaborative care can happen for multiple reasons, from negative clinician attitudes to rigid institutional processes, which should be considered in future work and design.

Research Questions:

- **RQ1:** What can we learn about people's experiences with psychiatric hospitalization through narrative accounts across different mediums?
- **RQ2:** How do people who have experienced psychiatric hospitalization perceive information flows in the hospital environment?

Publication: To be submitted

In this chapter, I address **RQ1** and **RQ2** by presenting findings from an inductive analysis study of personal stories of psychiatric hospitalization. I collaborated with Dr.

Wanda Pratt, Dr. Justin Karter, Dr. Akansha Vaswani-Bye, Dr. Emma McDonnell, and Shirin Amouei in a partnership with the non-profit mental health organization Mad in America¹⁷ to conduct the analysis using personal stories of psychiatric hospitalization published in Mad in America's online Personal Stories section.¹⁸ This work was supported by the Garvey Institute for Brain Health Solutions.

4.1 Introduction

When people in the United States experience an acute psychiatric crisis, they often are hospitalized in a psychiatric facility (i.e., an inpatient ward or psychiatric hospital) to undergo treatment. Psychiatric facilities operate differently from general hospitals in several ways: notably, people can be hospitalized involuntarily and can be legally subjected to coercive measures such as forced medication, seclusion, and physical or chemical (e.g., sedative) restraints. Negative experiences during psychiatric hospitalization can cause or exacerbate trauma and decrease individuals' trust in healthcare professionals and the healthcare system, leading to avoidance or refusal of healthcare services and, consequently, negative clinical outcomes, such as worsening symptoms and increased likelihood of rehospitalization (Hennessy et al., 2023). Yet, people admitted to psychiatric inpatient care are excluded from national patient

¹⁷ <https://www.madinamerica.com/mission-statement/>

¹⁸ <https://www.madinamerica.com/category/personal-stories/>

experience measures and datasets,¹⁹ resulting in a poor understanding of the magnitude of negative experiences.

Health informatics researchers could address these gaps in understanding and improving psychiatric hospitalization experiences through patient-centered care models. Informaticians have long collaborated with traditional healthcare researchers to design patient-centered healthcare technologies, such as patient portals (e.g., Kendall et al., 2015), informed by the lived experience of patients. Health informatics researchers have made contributions for improving inpatient experiences (e.g., Pollack et al., 2021) and outpatient mental health care (Haldar et al., 2022; Lattie et al., 2021), but more research is needed around *inpatient* mental health care or psychiatric hospitalization.

To respond to this gap, we partnered with the non-profit mental health organization Mad in America, whose mission is to serve as a catalyst for rethinking the current system of drug-based psychiatric care by centering scientific research and lived experiences.²⁰ We explore the problem of negative experiences of psychiatric hospitalization through the lens of “*information pathways*,” specifically, patterns in which clinicians and people experiencing psychiatric hospitalization seek, share or disregard information between each other, and the effects these patterns have on these individuals and their subsequent perceptions of psychiatric care.

In this paper, we investigate the following research questions:

¹⁹ Such as HCAHPS (Shields & Beidas, 2022).

²⁰ <https://www.madinamerica.com/mission-statement/>

- What common information pathways in psychiatric hospitalization contribute to frictions in care?
- What opportunities exist to design technologies to facilitate better information pathways between providers and people hospitalized for psychiatric treatment?

4.2 Methods

4.2.1 Data Collection

Four authors (AS, EM, SA, and WP) reviewed Mad in America’s public archive of 424 personal stories published between January 2012 and September 2024 to identify stories that met our inclusion and exclusion criteria. Specifically, we included narratives that had a description of a writers’ experience of hospitalization in a psychiatric facility, whether or not it was the primary topic of the personal story. We excluded stories that briefly mentioned a hospitalization experience but did not include substantive detail (e.g., a writer notes in one sentence that they have been hospitalized but does not elaborate further or refer to it again). We also excluded stories that we identified as discussing experiences that occurred before 1990.

4.2.2 Demographics

Each Mad in America story writer included a short biography at the end of their narrative. Due to the variance in what writers chose to include (and not include) in these biographies, we could not collect comprehensive demographic information. Descriptions of writers and their stories in the rest of this paper use the pronouns the writer used in

their biography when applicable. Specific writers are identified throughout this paper using the format “W##.”

4.2.3 Analysis

From the initial set of 424 personal stories, we identified 121 that satisfied our inclusion and exclusion criteria. We conducted an inductive analysis on those stories to iteratively develop a framework focused on information flows, which was then applied to the data using deductive analysis. Collectively, four authors (AS, EM, SA, and WP) read and generated high-level themes across all 121 stories. In our first round of inductive coding, we identified patterns of “escalation” (in which a situation was made worse by another person) and “de-escalation” (in which a situation was made better by another person). We noted how information played a role in these patterns, and conducted a second round of coding focusing on themes related to flows of information in the psychiatric hospital setting. After generating these information-focused themes, we scoped the detailed analysis to 60 randomly-selected stories which were coded by AS with EM reviewing and discussing coding of every fifth story; 11 in total.

4.2.4 Ethical Considerations

All authors of this paper have at least one close connection to someone who has been hospitalized in a psychiatric unit, or has been hospitalized themselves. We received permission from Mad in America to curate and analyze the dataset of personal stories, with the understanding that authors know their stories will be publicly available on the

Mad in America website, and we received Institutional Review Board (IRB) approval from the University of Washington.

4.3 Findings

We anchor our analysis of inpatient psychiatric experiences in *information pathways*, tracing the ways that information flows through people in psychiatric hospitals and shapes the experiences writers described. These pathways describe patterns of *information flows* that surfaced during our analysis.

Flows of information are exchanged between two or more *actors*—in this paper, we focus on the personal story writers who experienced psychiatric hospitalization (referred to as “writers” for the rest of this paper) and the clinicians in the psychiatric hospital or ward, although we found in our analysis that there were many more actors involved in information flows during writers’ hospitalizations, including non-hospital clinicians (external psychiatrists, external therapists, general practitioners), law enforcement and security guards, family members, lawyers, and peers or people who were hospitalized alongside the writer.

In our analysis of the 121 personal stories that met our inclusion criteria, we identified three primary flows of information: *seeking*, *sharing*, and *disregarding*. All actors may respond to the result of an information flow in different ways; we focus here on writers’ responses as that is what we had access to: positive or negative reactions, satisfaction or dissatisfaction, and increased or decreased trust in clinicians or institutions.

We identified patterns involving information flows that occurred in multiple stories, which we refer to as *information pathways*. These pathways involve sequences of flows (e.g., information seeking followed by information sharing) as well as the effects of a flow (e.g., clinician is satisfied with the information they received).

4.3.1 Information Pathways

In this section, we describe four particularly salient information pathways generated through our analysis. The first two pathways (*Clinician Seeks Information, Writer is Unsatisfied*; *Writer Seeks Information, Writer is Unsatisfied*) focus on information seeking, and the second two (*Clinician Seeks Information, but Disregards what Writer Shares*; *Writer Shares, Clinician Disregards*) focus on information sharing and disregarding.

Table 1. Description of Information Pathways

Information Pathway	Description
Writer Seeks, Writer Unsatisfied	Pathway initiated by the story's writer attempting to seek information, but they are left unsatisfied with the process and results of their attempt.
Clinician Seeks, Writer Unsatisfied	Pathway initiated by a clinician seeking information from the writer, but the writer is unsatisfied with the process and outcomes from the clinicians' attempts.
Clinician Seeks, but Disregards what Writer Shares	Pathway initiated by a clinician seeking information from the writer. The writer shares the information the clinician requested, but the clinician disregards the information they share, which leads to missed opportunities for connection
Writer Shares, Clinician Disregards	Pathway initiated by the story's writer sharing unsolicited information with a clinician, but the clinician disregards the information they share.

4.3.1.1 Pathway: Writer Seeks Information, Writer is Unsatisfied

Writers perceived their information seeking methods and behaviors as very different from those of clinicians. Unlike clinicians, writers were often unable to find official methods within the hospital system for seeking information. Under HIPAA,²¹ individuals have the right to access their health information: clinicians are required to

²¹ Health Insurance Portability and Accountability Act of 1996. Pub. L. No. 104-191, § 264, 110 Stat.1936.

enter information into portals that patients can access, provide summaries or fact sheets about diagnoses, tests, prescriptions, and so forth, and answer patient questions. Outside of psychiatric facilities, patients are also able to do their own research online, accessing not just informational websites or academic papers, but also online communities. Inside psychiatric facilities, however, writers often described these rights being temporarily withheld. In the US, people in psychiatric facilities often have their personal devices confiscated and are allowed limited, if any, access to the Internet. Because of this lack of access to information, writers described encountering an opaque hospital system in which they were dependent on hospital clinicians or staff for access to information or information-seeking methods, often leading to dissatisfaction in their seeking.

During their hospital stay writers interacted with a variety of actors, most often including a psychiatrist, other clinician or hospital staff. The frequency and durations of these meetings were inconsistent across writers. The quality of information shared seemed to be impacted by the writers' perceptions of their interpersonal relationship with the hospital actor. W43 said that he “*got off on the wrong foot*” with the nurse practitioner in charge of the ward when he asked to see a doctor to talk about the severe side effects of his medication, and “*she refused, stating she had been assigned [his] case.*” W43 acknowledged that due to feeling “*confused and foggy*” from Risperidone (an antipsychotic whose side effects include dizziness and drowsiness), he assumed that “*she felt she had observed enough.*” She “*dismissed*” him after talking to him for a few minutes, and refused to see him for the rest of the day.

Like W43, W53 also had interpersonal problems with one of the nurses, who “*seemed hell-bent on making [her] time there miserable.*” She could only make two phone calls per day, but even though her case manager had said that two she had already made for a care plan meeting did not count against the limit, the nurse refused to let her use the phone again and ordered another staff member not to let her use the phone. W43 and W53’s experiences reflect an opaque system, with a lack of transparency about the hospital rules and policies, and no clear processes for reporting or accountability.

4.3.1.2 Pathway: Clinician Seeks Information, Writer is Unsatisfied

Writers described clear, official, structured methods that clinicians used to seek information from the writers, primarily during their intake as well as regular meetings during hospitalization (with varied frequency depending on the clinician or hospital). However, information-seeking methods that focused on quantitative data or semi-structured interviews often left writers feeling unsatisfied with the process, as they felt that these methods missed the most important contextual and personally relevant information that clinicians needed for efficient and effective treatment.

Clinicians had easy access to a lot of information about writers, as structures for their information-seeking needs were built into the hospital system. Health records, intakes, diagnostic questionnaires, other exams, individual and group therapy, and labwork are all formalized information-seeking methods for clinicians to utilize. However, writers noted that these methods focused on a surface-level collection of background and symptom information, but did not include an appreciation of context,

desires, goals, and other challenges the writer was facing. W59's description of the process represented many writers' experiences:

I was asked the same questions over and over, as if the doctors didn't have my case history in their folders. I felt like a piece of data, with a backstory that bore little or no relevance, another person to plop into an existing profile or mold. They asked me "yes/no" questions and "how often" questions because "why" questions weren't on the checklist as they were too open-ended. But why is what really matters. It's what stands between yes or no, happy or sad, by the fence or in the river.

W59 felt that this focus on data collection processes over understanding him as a person gave him a sense of dehumanization ("*I felt like a piece of data*"), and he felt that the underlying issues that produced the symptoms he was being treated for were disregarded in favor of efficiency ("*another person to plop into an existing profile or mold*").

However, he laid blame not just on the clinicians, but on the limitations of their information-seeking methods—as he observed, the qualitative questions he thought were more important "*weren't on the checklist.*" W59 pointed out that while the process the clinicians followed seemed to value efficiency, it did not actually produce efficient processing, since he was "*asked the same questions over and over.*" Consequently, instead of an information-seeking process that built on previous information provided, W59's clinicians seemed to be starting over each time they talked to him.

Writers also described feeling that their clinicians missed opportunities to seek information from them through observation of their behaviors in the hospital setting: W30's clinicians missed an opportunity to check in with her about her eating habits, and she went several days without eating because of her eating disorder. W18 thought that more careful observation and questions about her behavior would have helped clinicians determine that her symptoms stemmed from a physical health problem, not a psychological one. These experiences decreased writers' trust in clinicians' abilities to provide effective care for them.

W29 had mixed feelings about the mental health professionals she interacted with. She described the ward's mental health technicians as her "*favorite people*" because they were in the ward for 12 hours at a time, "*not just taking notes about us, writing prescriptions for us, or calling us out every two to three days to talk.*" She valued the type of therapeutic relationship that involved getting to know her as a complex individual, and not, as W59 said, "*a piece of data.*" However, she described an instance when she was crying, and one of the mental health technicians approached her to ask if she wanted any medication. She said that "*It felt like there was something innately wrong with the question,*" but W29 "*didn't have any better questions or answers*" so she told the technician she did not want medication, and he left. For W29, there were contradictions in her experiences of clinicians who spent so much time with her, yet were limited by inadequate information seeking. She also implied that part of the problem in the scenario she described was her own inability to seek or share relevant information in that moment

(she “*didn’t have any better questions or answers*”)—neither she nor the mental health technician were equipped to handle the situation satisfactorily.

Sometimes, clinicians were stymied by the writers’ mental state during clinicians’ information seeking. When W43 was being admitted into a psychiatric ward, the psychiatrist doing his intake “*got nothing out of [him] but a stupid grin and [him] repeating the word ‘reality’ over and over.*” Because he could not share more information about his symptoms and history himself, the psychiatrist made a decision without that relevant information and changed W43’s medication to an antipsychotic that worsened his symptoms. However, W43 noted that the physician did have access to relevant information—his wife had explained his medical history and his medicine intake over the last several days, she was not allowed to stay with him to inform treatment decisions “*to the misfortune of us both*” and the intake happened without her present. It was unclear from the story we reviewed whether what W43’s wife had shared was documented, whether the psychiatrist reviewed it, and if so, whether it was enough information for the psychiatrist to make a decision. W43’s story described clinicians prioritizing “efficient” processing and leaning on their own expertise and assumptions about the writer, over more ecologically valid attempts to seek information—which resulted in prescribing medication that worsened his symptoms, convincing them throughout his stay that the side effects he experienced were in fact symptoms of mental illness.

4.3.1.3 Pathway: Clinician Seeks Information, but Disregards What Writer Shares

In this pathway, a clinician would seek information about a writer's symptoms and history. The writer shared their symptoms, and sometimes their personal history, and then the clinician focused only on their symptoms, ignoring context when they made a diagnosis and prescribed treatment. This caused writers to feel that the clinician disregarded some of the most important information that they had shared. Writers in this pathway felt confused and frustrated when they *were* asked the more open-ended questions that others like W59 had wished for, only for that information to be inexplicably ignored or invalidated by their clinicians.

W1 wrote about her experience with a hospital psychiatrist who met with her once a day, and she remembered “*our meetings being short and curt.*” The psychiatrist asked if W1's medication was working and when she first began experiencing her suicidal symptoms. After W1 shared her history, including her symptoms worsening after COVID, her psychiatrist told her that she could ask the hospital staff for more sleeping medication if she needed it. W1 was disappointed that this was the only help the psychiatrist decided to provide, and she was not offered “*any form of counseling*” during her stay. Her subsequent meetings with the psychiatrist were focused on whether W1's sleep was improving. In this scenario, W1 indicated that she wanted extended time with a clinician so they would have sufficient information and context for diagnosis and treatment, but felt the clinician was instead focused on treating what they conceptualized

as her most immediate problem, insomnia. W1 felt that her desire for more collaborative care was ignored, and the questions about her history were merely a formality.

However, clinicians disregarding what writers shared could not always be blamed on ineffective information-seeking methods or writers struggling to share information. Writers like W22 described clinicians who explicitly said that the writer was lying about their experiences, overreacting, or that the writer's mental state or diagnosis invalidated what they shared. W22 described one such interaction with a psychiatrist:

A few days before my discharge, my psychiatrist asked me what was on my mind. I instantly said, "The restraints." I went on to say that the restraints were harmful, and that I had suffered greatly under them. She told me to lighten up, to join the other patients in a game of ping pong. I became angry. I told her that she did not take what I had undergone seriously – that she was minimizing the harm restraints can do. She told me that this was my illness speaking: I was having a pathological overreaction to the restraints. I walked out of her office.

W22 lost trust in her psychiatrist's ability to listen to and help her, and was faced with additional weeks in the hospital after the meeting, so she focused on finding another way to get released. After receiving advice from a nurse's aide to "*play along*" in order to be released, W22 returned to apologize for walking out, and "*agreed with everything [her] psychiatrist said.*" Her psychiatrist decided that she "*had made a remarkable turnaround,*" and she was discharged shortly after. W22 illustrates how her clinician's active disregard for and pathologization of her experience further undermined her trust in

the psychiatric facility's ability to provide healing, leading her to perform compliance in order to be discharged.

4.3.1.4 Pathway: Writer Shares, Clinician Disregards

When writers sought out clinicians to share information with them, it was often about harmful side effects of their medications or other negative experiences they were having at the moment, which was sometimes perceived as threatening or questioning the clinicians' expertise and authority. Writers described clinicians' attitudes towards the writer in these encounters as anywhere from generally dismissive or invalidating to combative or threatening. Doctors did not seem to care about W34 feeling like she was “*dying*” while on the medication they prescribed; W24 was coerced into taking hers under threat of being labeled “*non-compliant*.”

W24 described being given medication during her hospitalization that caused vertigo severe enough to impede her ability to walk. When she told her nurse about it, the nurse asked if W24 “*really want[ed] to be non-compliant*,” so W24 felt coerced into taking the medication under the threat of being labeled “*non-compliant*.”

Similarly, W34 continually told her doctors that she did not want to take the medication that caused her to not “*even know where [she] was or what day it was anymore*” and made her feel like she was “*dying*,” but they ignored her. Post-hospitalization, she said that she was able to stop taking the medications and learned that she had been misdiagnosed, and felt that her doctors were more focused on finding the “*right*” medication for her symptoms rather than arriving at an accurate understanding of

her situation. The harm was both physical and psychological, as she had long-lasting concentration problems, headaches, and body pain as a result of the treatment. Her clinicians prioritized their belief in their own expertise over W34's own expertise, which came at the cost of her own physical and psychological safety, as well as her trust in doctors and pharmaceutical treatments.

W36 wrote that the information she shared about her feelings and needs during her involuntary hospitalization was dismissed by clinicians as symptoms of her mental illness and, therefore, invalid. She attributed this to the psychiatric concept of "insight," which:

... rests on the assumption that the psychiatrist, designated sane, knows what's best; while the patient, designated insane, needs to pay attention, listen and learn.

Like W22, she described using this assumption to fake compliance by agreeing with anything her psychiatrist said, eventually leading to her release. She became disillusioned with the "psychiatric machine," but cycling in and out of hospitalization led to her "conceding defeat." However, while her trust in the larger system had been broken, she said that, at the time of writing:

[F]or the first time, I have a psychiatrist for whom I have a very high regard. Although I am currently an involuntary outpatient, within that framework he treats me both kindly and respectfully. I trust him.

Like W29 and the mental health technicians, the therapeutic relationship W36 had with an individual clinician alleviated some of the frictions she experienced with the psychiatric system and its structures.

There were also writers who told their clinicians that they did not interpret what they were experiencing as a psychiatric issue. Writers were frustrated by their clinicians not listening to or validating their experiences, and perceived being treated in disrespectful and infantilizing ways which caused breakdowns in their relationship with their clinicians.

W22 insisted during her hospitalization that she did not have a mental illness: what her doctors called a “*psychotic break*,” she considered her “*passage*”—a “*sacred*” and “*profound*” experience that was, at the same time, “*a great deal to endure*.” In response, clinicians forcibly medicated and restrained her during her hospitalization, which left her feeling that her experience was dismissed rather than met with empathy. Because of this, she experienced post-traumatic stress after she was discharged, “*constantly afraid of being recaptured by the psychiatric ward*.” She completely lost her trust in the psychiatric system for decades; at the time of publishing the story, she noted that her experience had occurred 22 years ago.

When W9 told her doctor that she was Buddha, and “*feeling light, happy, full of life*,” her doctor “*didn’t even smile (or laugh, which would be even more appropriate)*,” and instead told her she was “*mad*.” In her narrative, W9 acknowledged that she had not really been Buddha at the time, but her doctor’s refusal to validate her positive feelings or try to understand what she was experiencing made her regret telling him about it. She felt that, in retrospect, her mental state had been pointing to her wish to be free from a society

“based on accumulation, statuses and endless consumption,” something that she and her doctor could have explored together.

4.4 Discussion

We provide design provocations for designers for addressing frictions we identified in the information pathways detailed in the Findings. Unlike explicit design recommendations, these contributions are higher-level provocations for grounding further design and informatics research in this area. We emphasize that there are existing frameworks for addressing these issues, but they require system-level changes. Behaviors that lead to the information breakdowns are incentivized by systems of incentives and ideological commitments (Whitaker & Cosgrove, 2015)—but there are lower-level changes that can still be made to encourage providers to slow down in their interactions with patients and respond differently.

Table 2. Description of information pathways, identified frictions, and example interventions.

Information Pathway	Frictions	Unique Solutions	Cross-Cutting Solutions
Writer Seeks, Writer Unsatisfied	• Difficulty seeking information due to opaque hospital system, dependency on people in power for access to information	• Printouts of schedule, rules, patient rights • Whiteboard listing care team, shift changes, who is in charge • Internet access for patients	• Inpatient portals • Allow people to enter data directly into their EHR (Pollack et al., 2021) or allow trusted others access too • Ambient scribes (Seth et al., 2024) • Automatically document information shared by all parties • Support for creating and implementing Psychiatric Advance Directives (Braun et al., 2023) • Psychiatric Advance Directives could indicate electronic access permissions as well • Decision aids (Kaar et al., 2019; Müller et al., 2023)
Clinician Seeks, Writer Unsatisfied	• Methods for seeking information are focused on obtaining data, leaving the writers feeling dehumanized. • Seeking methods can be inadequate when someone is having difficulty communicating.	• Narrative approaches (Bhattacharjee, 2025; Dunbar, 2024; Roberts et al., 2021; Zou et al., 2026) • Using clinical measures through a thoughtful, person-centered model like Collect-Share-Act (Barber & Resnick, 2023) • Group therapy, downtime could be used for people to collaborate with nurses to produce meaningful notes • Augmented and alternative communication (AAC) • Protocols should include loved ones in care when possible	
Clinician Seeks, but Disregards what Writer Shares	• Important information does not appear to factor into clinician decisions, and invitations to share seem perfunctory	• Reporting and accountability tools, e.g., ambient technologies to sense disregarding behaviors and make them visible to clinicians or	

	• Lack of accountability leads to lack of trust	administrators (Bedmutha et al., 2024)	• Clinician training in de-escalation and therapeutic approaches emphasizing compassion and reflexivity (Araci & Clarke, 2017; Eisen et al., 2022; Johnstone & Dallos, 2013; Liberati et al., 2023)
Writer Shares, Clinician Disregards	• Sharing urgent information about negative experiences is dismissed • Writers sharing information often sought help or validation, but did not receive it		

4.4.1 Designing for Centering Patient Values

Eliciting and honoring patients' values is a key element of patient-centered care, but has not been largely adopted in clinical practice, much less in the psychiatric hospital setting (A. Berry et al., 2017). Anchoring care in patient-defined values necessitates (1) designing structures for seeking and listening to those values, and then (2) integrating them into care. While HCI researchers have researched and designed tools for values elicitation, Doyle et al. (2025) found that formal and informal clinical norms often constrained providers in creating and managing values-based care plans. Personal narratives do not give us insight into clinicians' perspectives on their values, but their actions communicated certain values and priorities to the writers regardless of origin, and frictions often occurred when these conflicted with the writers' expressed values.

Clinicians are trained and incentivized to align their values and priorities with those of the systems they are part of (both the institutions of psychiatry and healthcare, as

well as their specific clinical context). Systemic and institutional forces—working conditions, policies, and so on—can erode mental health professionals’ capacities for compassion and empathy (Liberati et al., 2023). There is limited room within these structures for including patients’ values in decision-making, as seen in writers’ stories about clinicians focusing on quick, efficient processing over that of the writers’ desired health outcomes. Writers often connected these interactions to the structured processes clinicians are meant to follow (i.e., the standard operating procedure), necessitating that their patients become, as W59 put it, “*another person to plop into an existing profile or mold.*”

In this setting, people become problems to be solved: clinicians do not work *with* people, but *on* them. Risk, liability, and safety are often top-of-mind and prioritized over all other considerations, including rehabilitation or recovery. Many writers shared that interactions with clinicians left them feeling dehumanized because of this perspective: for example, when W9 told her doctor she was Buddha, he reframed what she shared with him through a medicalized lens (what she said proved that she was “*mad*”). Her words were not seen as meaningful except as data or evidence, and he missed an opportunity to foster a connection with her.

Designing for better information pathways and outcomes must take into consideration these power imbalances and assumptions. For instance, measurement tools to track symptoms over time are often treated as neutral, and improving these tools is seen as the best—or even the only—way to address problems like clinician bias by

providing “objective” data. However, they are founded on the assumptions described above, in which the individual is an object of study rather than a person who can provide their own expertise and participate in their own care. Measurement tools, such as screening questionnaires, divert attention from the broader context of a person’s experience by pushing clinicians to ground their assessment in the disease model of care (Vaswani et al., 2018). Writers observed that procedural use of these tools and protocols rather than grounding them in thoughtful models like measurement-based care (Barber & Resnick, 2023) created missed opportunities for collaboration and connection.

Alternatively, narrative medicine approaches can allow people to share rich data with their clinicians (Bhattacharjee, 2025; Dunbar, 2024; Roberts et al., 2021; Zou et al., 2026). One barrier to implementation of narrative approaches is limited clinician time, which designers and researchers have sought to design for (e.g., Roberts et al., 2021; Zou et al., 2026). In the psychiatric hospital setting, narrative medicine interventions could be introduced in group programming, or as an individual activity.

Some questions that designers should ask themselves when designing around patient-clinician communication include considering situations in which patients’ and clinicians’ values come into conflict:

- How is this discussion handled, and who has the decision-making power? Who has the final say?
- What are the long-term impacts of the conflict, and how could issues be alleviated?

- How might a clinician's or patients' values change or not change in a discussion where they try to mutually understand where the other is coming from? Is there space for them to do so?

4.4.2 Framework of Collaboration and Care

In their stories, writers expressed a desire for collaboration with their clinicians, involving a relationship based on mutual trust and respect for each other's expertise, in which the writer could be actively involved in decision-making about their treatment. Collaboration is easier when all parties see each other as equals and deserving of respect, which is difficult in most clinical settings, much less in psychiatric hospitals, where psychiatrically hospitalized individuals often experience stigma and could be viewed *prima facie* untrustworthy and unable to make their own decisions by virtue of hospitalization (Goffman, 1961; Kruse & Dodell-Feder, 2025). W36 provided a succinct description of this paternalistic approach that many writers discussed: “*the psychiatrist, designated sane, knows what's best; while the patient, designated insane, needs to pay attention, listen and learn.*”

Establishing mutual trust arises from fostering collaboration between a person and their clinician instead of pressuring them to cooperate with what their clinician thinks is best. Writers like W22 described responding to a loss of trust by changing their behavior (“*playing along*”) to get discharged. A design solution focused on cooperation may seek to convince W22 that her clinicians are trustworthy and know what is best for her. The “problem” is located with W22's nonidealized behavior in this scenario, rather than

considering the frictions that occurred at multiple points along the way. Some questions a designer could consider for this scenario might include:

- How is the problem being framed: is it that W22 did not trust her clinicians, that her clinicians did not trust her, or both?
- What is the goal of establishing mutual trust in this case: to exact compliance, to promote understanding?

Being in a hospital or experiencing a mental health crisis or altered state can be very disempowering experiences on their own, and this disempowerment is compounded when someone experiences psychiatric hospitalization. Empowering someone can happen at multiple levels, from giving them access to information to being able to make decisions about their own care. Writers were often frustrated by opaque systems: murky processes, unclear hierarchies, and obstacles to accessing basic information. W43 and W53, for example, would have benefited from a clear explanation of the care team hierarchy, transparency about ward rules, and a system for accountability. Low-tech solutions may include printouts of the ward schedule, rules, and their rights, and a whiteboard listing care team members, shift changes, and who is in charge. Additionally, ambient technologies can provide accountability interventions that account for power imbalances in the clinician-patient relationship by sensing disregarding clinician behaviors and making them visible to clinicians or administrators (Bedmutha et al., 2024).

In several stories, writers found themselves at times unable to speak, focus, remember information, or comprehend what was happening around them, whether due to a mental

health problem or the medications they were on (or both). W43's clinician had to conduct an intake that relied on their own assumptions about the writer, despite W43's wife's attempts to report relevant information. W43 said that she was not allowed to stay with him at the hospital, and it was unclear why. Design interventions should address how patients can choose to include their caregivers and loved ones in collaborative care. Additionally, interventions should consider how to support people before, during, and after psychiatric hospitalization in communication and decision-making. These could include augmentative and alternative communication (AAC) methods, devices, or strategies, psychiatric advance directives (PADs), decision aids (Kaar et al., 2019; Müller et al., 2023) or community-based support for caregivers (Bearman et al., 2022; Kopelovich et al., 2021).

We have highlighted example solutions to address specific frictions writers described. We also identify examples of cross-cutting solutions that would address all four of these pathways (see Table 2). These solutions include inpatient portals, psychiatric advance directives and decision aids, clinician training, and caregiver support.

During psychiatric hospitalization, people do not typically have access to personal devices, the Internet, or their electronic health records (EHRs). An inpatient portal that allows people to enter data directly into their EHR (Pollack et al., 2021) or an ambient scribe (Seth et al., 2024) that documents information that the writer, their care team, and loved ones share with each other could mitigate power imbalances, the inclusion of patients' voices and values, and clinician accountability.

Decision aids and psychiatric advance directives (PADs) can provide support for people experiencing communication and comprehension difficulties, like W43, and can address issues around accountability and including caregivers in care. Decision aids can increase communication and collaboration between people and their clinicians by facilitating not only information sharing, but also communicating and discussing values and goals (Kaar et al., 2019; Müller et al., 2023). Users of mental health services have positive views of and experiences with PADs, but PAD completion rates remain low, and further work is needed to support both creating and implementing PADs (Braun et al., 2023). Additional elements to include in PADs could also be studied, such as indicating electronic access permissions for EHRs so that loved ones could be further included in care when desired.

Cultivating compassion is necessary for building positive therapeutic relationships, but cultural and structural barriers can cause burnout, disillusionment, and erode empathy. Liberati et al. (2023) suggested that, in addition to other interventions, training emphasizing reflexivity as well as trauma-informed, recovery-based, peer-led, and compassion-focused therapeutic approaches can foster compassion. Brief staff training in, for instance, Cognitive Behavioral Therapy (CBT) and related approaches and interventions has been shown to reduce burnout and improve ward culture as well (Araci & Clarke, 2017; Eisen et al., 2022).

Shifting the hospital framework from risk management to collaborative care would require environmental and systems-level changes. As long as psychiatric facilities

maintain control over patient information and care decisions—especially through involuntary commitment, or the threat of it—vast power imbalances between patients and clinicians exist that can only be mitigated, not removed. Writers shared different perspectives on these issues of institutions and power, and on whether psychiatric hospitalization could be reformed, reimagined, abolished, or something in between.

4.5 Limitations

The stories in this dataset are inherently skewed toward negative experiences by virtue of being submitted and published to Mad in America, an organization that encourages questioning traditional psychiatry. Studying positive experiences could prove useful in finding and validating potential solutions for frictions we identified, but perspectives from people who have had negative psychiatric experiences are often underrepresented.

Additionally, these stories are from the perspectives of the individual writers, and clinicians' perceptions of the same or similar experiences are not included. Our research emphasizes the experiences and often unrecognized voices of people who have been psychiatrically hospitalized, but it would also be valuable to investigate the clinician perspective, particularly with respect to the institutional mandates and systems that lead them to make their decisions.

4.6 Conclusion

In our analysis of personal stories by people with experiences of psychiatric hospitalization, we describe particularly salient *information pathways*, or sequences of information flows that appeared in multiple stories. The writers of these stories described barriers to effective information seeking for both themselves and their clinicians, as well as missed opportunities for collaborative care when they shared information with their clinicians. While the conditions for these frictions in information pathways are created by the institutions and systems in which they take place, we offer design provocations with examples of already-existing solutions that could mitigate these breakdowns.

In this paper, we contribute a framework for understanding how information flows within psychiatric facilities, and present patient-centered design provocations to address frictions in information pathways we identified. We emphasize that designers and health informaticians bring unique perspectives and expertise to the topic of psychiatric hospitalization—and that people with experiences of psychiatric hospitalization should be included and centered in research on this topic. Through this work, we seek to bring these voices together to envision a healthcare system that centers patient values and creates frameworks of collaboration and care.

Chapter 5: Co-Designing Ideal Care Futures with People with Experiences of Psychiatric Hospitalization

Contributions:

This chapter presents findings from interview and co-design sessions with people who have experiences of psychiatric hospitalization. This chapter's findings contribute to **RQ1** by providing further descriptions and analysis of people's experiences with psychiatric hospitalization through narratives elicited in interviews. These narratives build on the previous chapters in their descriptions of the barriers participants encountered to accessing information, and the ways in which their own expertise and experiences were dismissed by clinicians. This chapter also contributes to **RQ3** by providing patient-centered informatics interventions co-designed with people with experiences of psychiatric hospitalization, which include 1) improving access to information both inside and outside psychiatric facilities to improve continuity of care, 2) supporting patient-defined and -controlled collaborative care networks, and 3) considering whether interventions are collaboratively implemented with institutions or outside of them.

Research Questions:

- **RQ1:** What can we learn about people's experiences with psychiatric hospitalization through narrative accounts across different mediums?
- **RQ3:** How do people with experiences of psychiatric hospitalization envision ideal, patient-centered informatics interventions related to psychiatric hospitalization?

In this chapter, I address **RQ1** and **RQ3** by presenting findings from interview and co-design sessions with people with experiences of psychiatric hospitalization. I

collaborated with Dr. Wanda Pratt, Dr. Akansha Vaswani-Bye, Jiayi Su, Cristine Talin Karapetyan, and Chantal Murthy in a qualitative inductive analysis of joint interview and co-design sessions with 29 participants that I designed and conducted. This work was supported by the Garvey Institute for Brain Health Solutions.

5.1 Introduction

People have poor, often traumatic, experiences in psychiatric facilities. In the field of health informatics, researchers have been using patient-centered approaches to try to address negative outcomes and adverse events through patient-centered care approaches, which center the patient's expertise and agency in decision-making. There is an opportunity here for informatics to provide its perspective and tools (like co-design) on psychiatric hospitalization, while acknowledging that it is a complex problem that will not be "fixed" by a handful of informatics interventions.

To pursue this opportunity, we conducted an interview and co-design study with people who experienced psychiatric hospitalization to re-imagine acute mental health care, including preventing hospitalization from occurring in the first place. We present design interventions and directions based on participants' designs for ideal care.

This paper investigates the following research question: How do people with experiences of psychiatric hospitalization envision ideal, patient-centered informatics interventions related to psychiatric hospitalization?

5.2 Related Work

5.2.1 Co-Design and Utopianism

Co-design comprises a variety of design methods that aim to bring end users into the design process as collaborators (Sanders & Stappers, 2008). Goals of co-design can be varied, depending on the stage in the design process in which a specific method is being employed. For instance, design activities employed earlier in the co-design process to be focused on eliciting and utilizing the experiential knowledge and expertise of stakeholders over that of designing “feasible” design artifacts.

Design cannot be divorced from its social and political context. Participatory design and co-design practitioners have noted challenges when it comes to ensuring equal participation in design, such as which stakeholders are included or excluded, power imbalances, and diverging or even contradicting needs and values (Ayobi et al., 2022; Bray et al., 2022; Krüger et al., 2021). One approach to these challenges that practitioners have engaged in is to understand them as part of the co-design process; not a bug, but a feature. Forlano & Mathew (2014) referred to such tensions as “design frictions,” which can prompt re-examination of practitioners’ own values and assumptions, as well as allow for different kinds of participant engagement.

Design is inherently future-oriented, and could even be described as a form of utopianism. Design approaches such as speculative design (Dunne & Raby, 2024), design fiction (Blythe, 2014), and futuring (Mankoff et al., 2013) highlight this imaginative aspect of design. Bardzell (2018) pointed out parallels between utopianism and “design

thinking,” and emphasized that feminist utopianism in design work should be viewed “as an activity rather than a completed image.” The act of utopian/design thinking is the important part, not the end result.

Design toolkits are tools that provide a “guided approach,” based on designer expertise, for use in co-design (Bray et al., 2022). Bray et al. (2022) developed the Building Utopia toolkit as an Afrofuturist, liberatory speculative design resource for designers and non-designers working with and for marginalized communities. Grounding co-design in liberatory, utopian thinking can allow participants to think critically about their current and past experiences without focusing on re-living negative or traumatic experiences.

5.3 Methods

5.3.1 Positionality & Ethical Considerations

All authors of this paper have at least one close connection to someone who has been hospitalized in a psychiatric unit, or has been hospitalized themselves. We received Institutional Review Board (IRB) approval from the University of Washington for this study.

Per instructions from the IRB, we created a suicide risk mitigation plan for use during study sessions, as we worked under the assumption that all participants were at higher-than-average risk. As part of the plan, we provided a Mental Health Resources sheet to all participants, and indicated which resources may contact emergency services

so that participants could make an informed decision if needed. The researcher conducting the study sessions (AS) was not qualified or mandated to make a formal assessment of suicide risk, but instead would, in the case of a participant showing signs of distress or suicidality, judge alongside the participant whether it was in their best interest to end the session, and ask the participant if they would like to contact an emergency contact or therapist if they had one, as well as point the participant to a warmline or hotline on the provided resources list. In participant consent forms, we made sure to clarify that the research team would not break participant confidentiality by contacting a warmline or hotline for them, and our responsibility was limited to encouraging them to seek support.

5.3.2 Participants

For participant recruitment, we distributed an online screening questionnaire through the website for Mad in America, the University of Washington (UW) Center for Suicide Prevention and Research, and a UW intensive outpatient program. People, including participants, who asked to distribute the questionnaire to other groups or contacts were encouraged to do so as well. The inclusion criteria was that potential participants must be English-speaking adults (18+) in the US who self-reported at least one experience of being psychiatrically hospitalized.

In the screening questionnaire, people who met the inclusion criteria were asked, but not required, to self-report gender, age, and race/ethnicity, all of which were write-in answers. Participants were also asked for the approximate date of their most recent

hospitalization, the number of hospitalizations they have experienced (from the options 1, 2-5, or 5+), and asked to indicate “Yes” or “No” in response to the question “For any of your experiences, were you coerced or forced to be psychiatrically hospitalized?”

There were 29 participants in total. Of these participants, 18 self-identified as female, 4 male, 2 non-binary, 1 fluid/nonbinary, 1 genderqueer, 1 nonconforming, 1 femalish, and 1 woman. At the beginning of the study sessions, some participants shared their pronouns; in this paper, we use those pronouns for participants when applicable, and “they/them” for those who chose not to share, noting that an individual’s reported gender does not necessarily imply a particular set of pronouns.

Twenty-one participants identified as white or Caucasian, 2 Hispanic, 1 Hispanic/latina, 2 Asian, 1 Southeast Asian/Indian, 1 raised white with black and native blood, and one did not respond. Participants’ ages ranged from 21-65. 12 participants were between 21-29, 7 were 30-39, 5 were 40-49, 3 were 50-59, and 2 were over 60.

Participants also had a range of psychiatric hospitalization experiences. Five had been hospitalized once, 11 had been hospitalized 2-5 times, and 13 had 5 or more hospitalizations. Reports of participants’ most recent hospitalization spanned from 2012-2025. Three occurred before 2020, 4 between 2020-2022, 10 in 2023, 3 in 2024, and 8 in 2025. 22 of the 29 participants reported experiencing at least one coerced or forced hospitalization. Participants named 22 unique states in which hospitalizations occurred, and at least 49 unique hospitals or rehabilitation facilities in the US. Two participants

also had experiences in non-US facilities in addition to ones in the US; one in Canada and one in South Africa.

5.3.3 Study Procedure

The first author (AS) conducted 29 interview and co-design sessions. These 90-minute sessions consisted of a 20-minute interview about their previous hospitalization experience(s), followed by 60 minutes of co-design activities that facilitated re-imagining psychiatric hospitalization. All study sessions were conducted over Zoom, and sessions were recorded with the consent of participants.

5.3.3.1 Interview

In the interview, participants were asked to describe a timeline of their most recent or most memorable hospitalization (if they had had more than one), broken into admission, during their stay, and discharge. Participants were also able to choose to compare multiple experiences or generalize based on their preference. The timeline helped contextualize the participants' co-design activity, and acted as an artifact to be referred back to by the researcher or the participant during co-design. Considering admission, during the stay, and discharge also provided a scaffold for participants to think about specific parts of the experience that could be reimagined.

5.3.3.2 Co-Design

The co-design portion comprised three phases: participants first elucidated their personal values, followed by describing their utopian world, and lastly, envisioned what

psychiatric hospitalization and mental health care would look like in that world. For each phase, participants were told that they could respond to co-design prompts through writing, drawing, or verbal discussion with the researcher. Prompts were taken from the Building Utopia deck (Bray et al., 2022) and were iteratively adjusted during the course of the study based on participant response and feedback.

The goal of the first phase was to provide a positive, values-based foundation to inform participants' utopian thinking in the following phases. To achieve this goal, participants were given two prompts from the Building Utopia "Liberation" cards and could choose to answer one or both of them. This process was later adjusted to explicitly elicit participants' values by asking for their "top five" values, and a description of how each value showed up in their own life. Participants were provided with a list of values (see Appendix A) and also were given the option to come up with their own.

The goal of the second phase was for participants to create a utopian world as the setting for re-imagining psychiatric hospitalization. Participants were asked to consider what their utopian society would look like and how it would be structured, what their life and community might look like, and were encouraged not to feel constrained by what they felt was most "feasible." Participants were also encouraged to consider how the values they chose in the previous phase would inform their utopia.

The goal of the final phase was for participants to envision what acute mental health care would look like in their world. Earlier participants were given the choice of two "Method" prompts for identifying particular topics to focus on first, and then to

consider how those topics would be different in their world, but it became apparent that this guidance took additional explanation that was often more confusing than necessary. Instead, participants were encouraged to consider first, whether psychiatric hospitalization would exist or not in their world, and then to re-imagine the hospitalization “timeline,” referring back to the one they constructed during the interview. Participants were provided with a storyboarding prompt to encourage them to consider minute details, interactions, and tools in their design. As the study progressed, participants were encouraged to use it if it was helpful, or could choose not to and the co-design facilitator (AS) prompted for detail as needed. Additional questions were also provided when participants needed more scaffolding (see Appendix B).

5.3.4 Data Analysis

We conducted an inductive thematic analysis on auto-generated transcripts from session Zoom recordings, with the recordings available for confirming precise wording as needed. In the first phase, two authors (AS and JS) used open coding to generate initial codes for a codebook, which they discussed together with WP, CM, and CK. In the second phase, AS, JS, CM, and CK collectively reviewed all 29 transcripts while iteratively discussing, generating, and refining codes, and then applied the final codebook to all of the transcripts. AS coded 12 transcripts, JS 8, and CM and CK coded 6 each. All four coders coded and discussed three of the same transcripts.

5.4 Results

We found multiple themes in the rich data from 29 interview and co-design sessions: final codes included system failures, information access, physical environment and affordances, coercion and autonomy, peer connection, staff quality and trust, and ideal care futures. For the purposes of this paper, we narrow our focus to participants' discussion and co-design around information. The results suggest participants had a strong need for interventions that treat them as complete, thinking, and imaginative human beings, along with the potential for leveraging some of their capacities to effect change not only in themselves but in their peers.

In the following section, we describe themes that arose in participant interviews around information, and then summarize themes we found in participants' utopian care futures. Participants reported encountering barriers to information access, including a lack of clear care plans, various kinds of barriers to communication, and the prevalence of misinformation in their interactions with clinicians and staff. Participants also described clinicians dismissing their expertise and experience, instead prioritizing medical records and third-party narratives when they came into conflict with what patients told them.

Lastly, we summarize themes found in participants' utopian approaches to desired care, including structural changes to care conditions, improved crisis mitigation strategies, providing individualized treatment plans with diverse therapeutic options, and integrating peer and community support in care.

5.4.1 Barriers to Information Access

Participants described different ways in which information was made inaccessible to them during the psychiatric hospitalization process, from admission to discharge. These included unexplained care plans, including hospital protocols and treatment information, active misinformation, as well as easily-preventable communication barriers.

5.4.1.1 Lack of Clear Care Plans

Many experienced confusion, disorientation, and increased distress when hospital protocols, including rules, patient rights, schedules, and discharge criteria went unexplained. For example, P14 described discharge protocols as:

Really... abstract, you know what I mean? Like, not... I didn't really understand what was the protocol for how they were deciding who, who was leaving, you know, or how long they were staying.

Clinicians and staff did not always ensure informed consent, so the onus was often on the hospitalized person to ask for information about their treatment. P12 and P21 said that they were not told up-front what medications they were being given during their stay. P21 said that they were only told if they asked directly, while staff dispensing the medication told P12 “*don't worry about it, just take it.*”

Difficulties in accessing information did not end at discharge. Several participants described leaving the hospital without a clear understanding of their care plan or the resources available to them. P6 and P28 reported receiving little discharge guidance; in

P6's case, the lack of clear instructions meant they were unable to figure out how to continue the medications they had been prescribed and ultimately stopped taking them. P13 described the broader landscape of post-discharge resources as difficult to navigate. Even retrieving one's own records proved arduous: P14 reported that it "*took forever*" to obtain her hospital records because they had been "*thinned*," a process she did not know existed and could not have anticipated needing to ask about.

5.4.1.2 Prevalence of Misinformation

Beyond outright omission, information was sometimes presented in ways that constrained rather than enabled participants' decision-making. In these cases, the issue was not that information was withheld, but that it was framed to foreclose meaningful choice, undermining the very autonomy that informed consent is meant to protect. P14, who did not want to undergo electroconvulsive therapy (ECT), recalled being told that she and her daughter "*might not be alive if [she] dared to come out of the hospital without agreeing to it.*" The framing positioned refusal as a threat to her child's life rather than as a legitimate exercise of medical decision-making. P22 encountered a similar dynamic around her legal status. Although classified as a voluntary patient, she was warned that any attempt to leave would result in a 72-hour hold; as she recounted:

The guy said, if you're on an involuntary hold here, you will have a harder time getting out of here, so, like, functionally, I recommend you just stay voluntary, and I'm like, wait, so I'm stuck here.

The “choice” to remain voluntary was thus a choice in name only, and one with material consequences: legal protections afforded to involuntary patients, including access to a lawyer, did not apply to her precisely because she had been steered into the voluntary designation.

5.4.1.3 Communication Barriers Between Patients and Providers

Communication barriers compounded the difficulties participants faced in accessing information and asserting their needs. For P13, an augmentative and alternative communication (AAC) device was confiscated without explanation, cutting off his primary means of expression. Language access was a recurring concern as well. P12, a fluent English reader, described being rushed through admission paperwork at a pace she found difficult to follow, and extrapolated from her own experience to others on the ward:

It was bad enough that I can read English and they were rushing me through it so fast. How about people that can't read English at all? Like, you can't make them sign things that they don't know what they're signing.

P3 raised related concerns about cultural considerations going unaddressed in the clinical encounter. Even where communication infrastructure was nominally available, it was not always usable: P5 noted that although phones were accessible on the ward, she had not memorized her therapist's phone number and could not spell his last name; thus, she was unable to reach the clinician most familiar with her care at the moment she most needed continuity.

5.4.2 Dismissal of Patient Expertise and Experiences

A recurring theme across interviews was the dismissal of participants' own knowledge of their conditions, histories, and current states. Instead, clinicians prioritized clinical expertise and narratives from third-parties, such as participants' family members, when those came into conflict with patient expertise.

5.4.2.1 Elevation of Clinicians' Voices over Patients'

P26 and P28 described being assigned diagnoses without what they considered an adequate assessment or meaningful consultation, leaving them with clinical labels they did not recognize as accurate reflections of their experiences. P5, P22, and P24 described related but distinct dynamics in which their accounts of their own symptoms and mental states were actively dismissed when offered, rather than incorporated into clinical reasoning.

Other times, documented medical histories and co-occurring conditions were ignored, despite participants bringing clinicians' attention to them. P1, P14, P18, and P27 each described instances in which relevant aspects of their medical history were disregarded in the course of inpatient psychiatric treatment. The consequences extended beyond the individual: P2 and P12 recounted advocating on behalf of fellow patients whose dietary needs (tied to diabetes and celiac disease, respectively) were going unaccommodated despite being grounded in well-documented medical conditions.

Over time, the experience of having one's expertise discounted appeared to shape participants' subsequent behavior in clinical settings. P19 described having largely

stopped advocating for herself, adopting instead a posture of compliance designed to minimize her time on the ward: she now tries to be "*very, like, passive and very calm and very cooperative, because I just want to get out of there as soon as possible.*" P24 articulated a similar calculus with one of their clinicians in more explicitly structural terms:

There is a power dynamic that needs to be recognized. Both my skills and this power dynamic keep me from saying to his face, I think you should consider my concerns here. But I wouldn't mind saying in a survey.

P19 and P24's thoughts illustrate how, in the psychiatric inpatient setting, mere dismissal is not the only consequence of disagreeing with or challenging a clinician; both participants had to balance self-advocacy with fear of reprisal and their desire to be discharged.

5.4.2.2 Precedence of Third-Party Narratives

Participants expressed frustration about clinicians and staff believing third-party narratives over participants' firsthand accounts, particularly when these narratives were recorded in medical records. Clinicians seemed to focus on documentation that confirmed their own biases or goals, such as when P14 found that an old diagnosis, recorded years earlier and contradicted by later documentation, was reactivated at a new ER visit and used to justify a legal hold. Similarly, P12 described how a "drug seeker" label entered her chart during an early hospitalization and continued to shape subsequent clinical encounters long after the situation that produced it had passed.

These narratives were not just limited to clinicians, but also participants' family members, who were considered to be more reliable than participants. P5, P18, and P26 described admission being prompted by colleagues (P5) or parents (P18, P26), whose accounts about their respective mental states were believed over the participants'. P18 learned years after the fact that her mother's statement to paramedics had entered her medical record and shaped her psychiatrists' treatment of her. P14 also described how her ex-husband was able to pass written notes to staff and have them placed in the comment box of her medical record, shaping her care while she was not told what was happening behind the scenes.

5.4.3 Utopian Approaches to Desired Care

Participants designed a variety of solutions and interventions, from concrete, practical solutions to specific problems to “pie in the sky” utopian worlds, based on their own values and expertise that came from their unique lived experience—of hospitalization, mental health care, socioeconomic and cultural backgrounds, and more. Here, we highlight themes in participant designs that work to address some of the challenges described in the previous sections. These include structural changes to care conditions, improved crisis mitigation strategies, providing individualized treatment plans with diverse therapeutic options, and integrating peer and community support in care.

5.4.3.1 Structural Changes to Care Conditions

Participants' utopias tended to include changes in structural conditions that acted to reduce crises. P14 spoke on how housing instability and domestic abuse could have been addressed instead of sending her to a hospital. P23 stated that in her utopia, the trauma that generated the need for support would simply not exist. P13's ideal society was designed to meet people's needs before they reach crisis points. For P18, more supportive families of people with mental health problems could prevent people from reaching a crisis point.

5.4.3.2 Improved Crisis Mitigation Strategies

Several participants designed non-judgmental and empathetic interventions to *mitigate* crises. P21 said that, in a crisis, they “*really just wanted to talk to a trained professional for more than 30 minutes*” and that they could have done without the hospitalization. P10 stated the importance to “*call a warm line, get a peer navigator, find someone who can point you to resources instead of relying so heavily on 988, who, frankly, they're useless*” and shared concerns about data collection during 988 calls. In P13's utopia, instead of receiving “*help*” from a person with “*institutional power over them,*” he would have access to 24/7 support from a trained community member to help him with daily tasks, as well as a roaming crisis team if needed.

5.4.3.3 Individualized Treatment Plans

Some participants included positive previous experiences as components of ideal care, describing instances of collaboratively creating care plans with their clinicians. P27

highlighted a positive experience in which a plan was offered to them to work on “*getting them down from a 10 to below a 5*,” and said they still use this plan to this day. P28 described the value of a collaborative crisis and care plan that they developed during one of their hospitalizations, and P18 similarly praised a positive interaction in which their discharge date was negotiated collaboratively with their psychiatrist. P6 and P25’s utopian care involved collaborative discussions with their clinicians in which they decided together what the individuals’ treatment plan would look like and what the discharge criteria would be. Both participants described this process as coming to a consensus with their clinician, whose clinical expertise was valuable in informing their decision, although P25 was not so much focused on the collaborative aspect as they were on transparency about treatment plans.

In their utopian designs, participants highlighted the benefits of individualizing treatment approaches that included taking rich patient histories and respecting patient preferences. For P26, taking a thorough patient history was important to rule out other causes of a person’s mental symptoms and not induce iatrogenic harm through wrong medications. P26’s ideal care included first determining whether a person’s symptoms were due to circumstances like abuse, malnutrition, or effects of drugs before assuming mental illness, and then screening any medication for adverse effects by using genetic testing before administering them.

P17 noted that while group activities (e.g., games, art therapy) abounded in certain inpatient settings, individuals should have the option of which they chose to participate

in. Similarly, P10 pointed out that therapies such as DBT were uniformly applied to all patients, but may not always be applicable to a person's reason for hospitalization. This view was shared by P24, who said that they would have preferred to do cognitive work to consider specific circumstances in their life rather than participate in groups where the advice given may have been too general for them. Participants talked about several alternative therapies they thought should be available to patients. These included light therapy and therapists trained in trauma-informed polyvagal theory (P14), neuroarts and Zentangle (P14), group activities like yoga (P7), and classes supporting creative hobbies such as piano or drawing (P11).

5.4.3.4 Integrated Peer and Community Support

Participants also emphasized the therapeutic value from peer-to-peer interaction and community. P17 noted the healing impact to them of forming novel connections with others and being there for others and having it reciprocated. P14 also emphasized the benefit from small but meaningful activities like “kindness rocks,” in which individuals write positive messages on rocks that can be placed outside for others to find. Similarly, P14 also described participating in a “*co-arting*” group in which group members met online to work on their own art projects together, finding that there was “*a synergy that happened there; there was a magic.*” P23's vision of utopia featured mental health support as indistinguishable from other communal care, in which patients helped with aspects of running the facility, such as working in the kitchen.

5.5 Discussion

Healthcare and legal systems often enforce assumptions that people with experiences of psychiatric hospitalization, by virtue of being hospitalized, do not know what is “best” for them and require a healthcare professional or a designated “sane” person (e.g., a family member) to make treatment decisions for them. Any resistance to treatment is attributed to mental illness, while cooperation/compliance means that treatment is “working.” Entering a ward removes a person away from the “rest of the world,” both physically and socially. The locked doors cut off access to other spaces, ostensibly for safety, and the highly-controlled information environment cuts off access to a person’s life/community/etc. Socialization—with peers or staff—is not prioritized and not often encouraged as part of therapy. They are entirely removed from society.

The physical separation is one that many participants did desire as part of crisis treatment: most participants included psychiatric hospitalization as an existing institution, and/or safe houses and peer respites, citing the need in a crisis for, as P26 put it, “*a space in between ... to catch your breath.*” Isolation, loneliness, feeling as if there is no one to help or turn to—these are experiences that can lead someone to become psychiatrically hospitalized, and participants’ designs for ideal care instead emphasized the opposite as critical to stabilization and healing.

The path in—and out—of psychiatric hospitalization is different for every person. Popular understandings of who makes up the hospitalized population do not necessarily align with reality—even some participants described being surprised by this. People may

be hospitalized for suicidality or psychosis, but also for other reasons, from abuse, the “troubled teen” industry, etc. Our findings demonstrated that participants, and their co-design solutions, vary widely because of this variety of experiences. Informatics solutions and interventions can address this heterogeneity by centering patient values, preferences, and autonomy in considering 1) accessing information both inside and outside psychiatric facilities 2) designing for patient-defined collaborative care networks, and 3) designing without/against institutions.

5.5.1 Information Access Inside and Outside Psychiatric Facilities

While participants were directed to create a “timeline” of their hospitalization experience(s) (see Fig. 5), this linear framework can be misleading when considering design solutions. Rather than thinking of hospitalization as a discrete event with a clear beginning, middle, and end, many participants approached it as a cycle (see Fig. 6): first, something occurs that is interpreted as a mental health crisis (by the individual or by people around them), in which hospitalization is the best—or only—solution. After hospitalization, the individual is discharged back into the setting in which the crisis occurred. Depending on a multitude of factors, including their hospitalization experience and post-hospitalization support, the cycle either continues or is stopped.

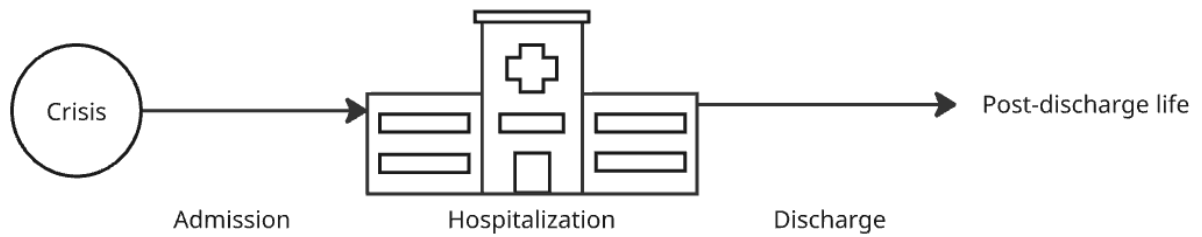


Fig. 5. Visualization of the hospitalization experience as a timeline.

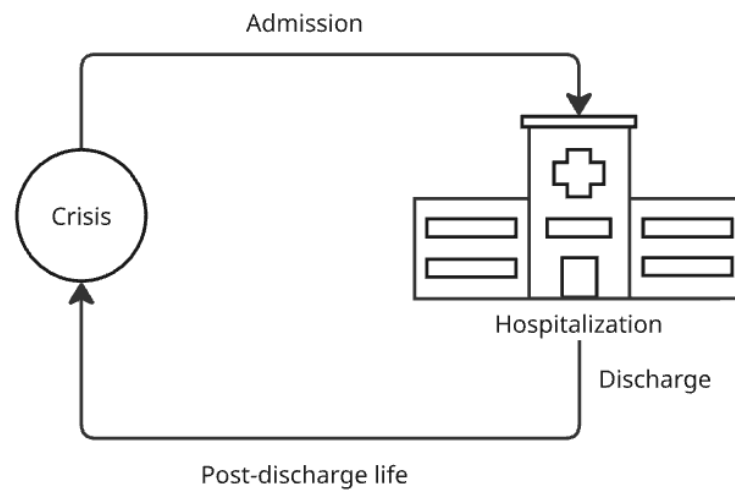


Fig. 6. Visualization of the hospitalization experience as a cycle.

Participants did not all agree on whether this cycle could be “broken.”²² Most participants designed their utopian models of care under the assumption that such crises will inevitably occur, but would be extremely reduced by preventative care, including providing for people’s basic needs like food, shelter, and access to healthcare.

²² I’ll note that there is a lot of work on recidivism/re-hospitalization that could be referenced here, as well as the recovery model of mental health care.

This cycle is spatial, it moves an individual through different locations, but it is also temporal, and information generated during one hospitalization persists across the cycle in ways participants often could not access, correct, or anticipate. Informatics interventions located inside a single hospitalization will not address this if the records produced inside that hospitalization remain inaccessible and uncorrectable to the participant afterward, patient access to and ability to contest one's own record is a cycle-level intervention, not a stay-level one.

The cycle surfaces two locations for design work: inside the psychiatric facility and outside of it.

5.5.1.1 Inside

Information seeking was inaccessible to participants in multiple senses of the word. This included physical lack of access, such as Internet and personal devices, as well as a lack of accessibility (in the disability sense). Protocols, treatments, rules, and resources may have been clear to clinicians, but were not made clear to patients.

5.5.1.2 Outside

Design solutions for the points in the cycle outside of a psychiatric facility were primarily about preventative care and managing symptoms (and life in general). Designers can consider the “outside” to include anyone who could *potentially* be hospitalized, whether or not they have in the past. Some participants envisioned utopias

in which hospitalization did not exist, and discussed how alternative structures, systems, and resources would render such facilities unnecessary.

We found that a key problem was that not only was information seeking difficult inside psychiatric facilities, it was also difficult outside—despite the additional tools, such as the Internet, that people lacked inside. Individuals often did not know that there was information that they were missing until after it would have been helpful.

5.5.2 Patient-Defined Collaborative Care Networks

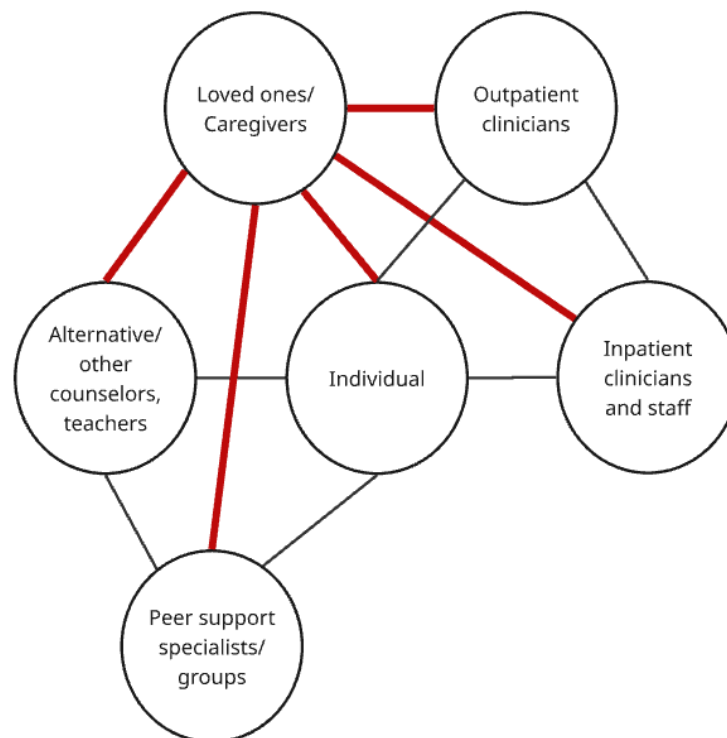


Fig. 7. A potential care network emphasizing support and education for loved ones/caregivers.

Patient-centered care is not limited to interactions between an individual and their clinician. Previous work has considered how other stakeholders can be included in an individual's care and support system. Participants emphasized both the need for including

“outside” stakeholders (those who are not located in the inpatient setting) in collaborative care networks, as well as the need for patient control over *who* is included and *how*. Examples include education, training, and support for caregivers (see Fig. 7); community-based care (see Fig. 8); facilitating peer support and connection; and so on.

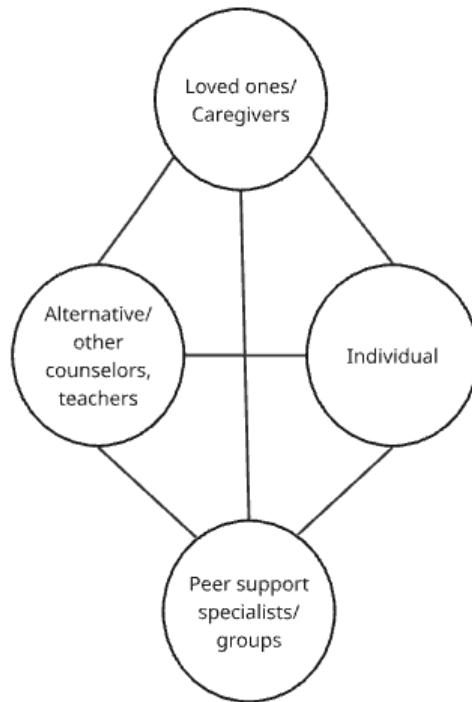


Fig. 8. A potential care network involving people outside of the psychiatric hospital.

Peer support, in particular, was an important part of care networks for several participants, who described peer connection as among the most meaningful parts of their hospitalization experience (see Fig. 9). Participants often took on roles that were therapeutic for others as well as for themselves. However, this support was not always approved by staff. Peer activity in inpatient settings appeared to be tolerated when it remains craft-like (puzzles, music, shared games) and discouraged or punished when it

begins to resemble clinical assessment. Designing for peer connection, then, is not only a question of creating space and time for it; it requires taking a position on an institutional line that distinguishes "acceptable" peer activity from peer activity the institution reads as encroaching on its authority.

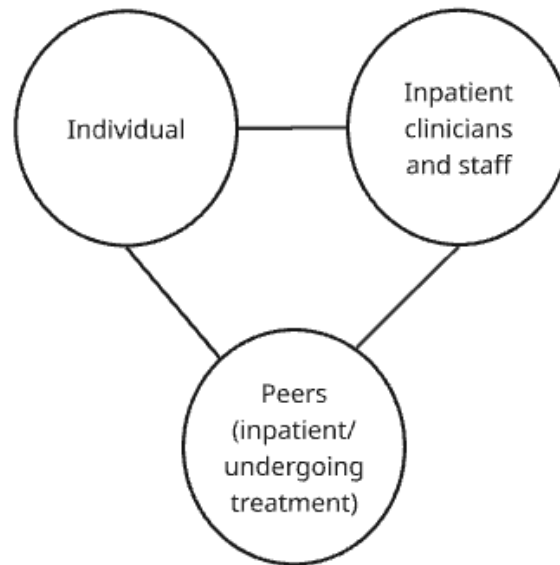


Fig. 9. A potential care network within a psychiatric facility that includes connections between peers in addition to clinicians and staff.

A care network may explicitly exclude certain people, or place guardrails or limitations on their involvement (see Fig. 10). Facilitating further involvement of other parties in an individual's care may initially seem to be a goal everyone would want. However, particularly in this setting, third parties such as caregivers, therapists/psychiatrists, etc. can (and are often legally allowed to) override an individual's decisions. Equitable, collaborative patient-centered care must consider how to account for the paternalism and power differential built into this system.

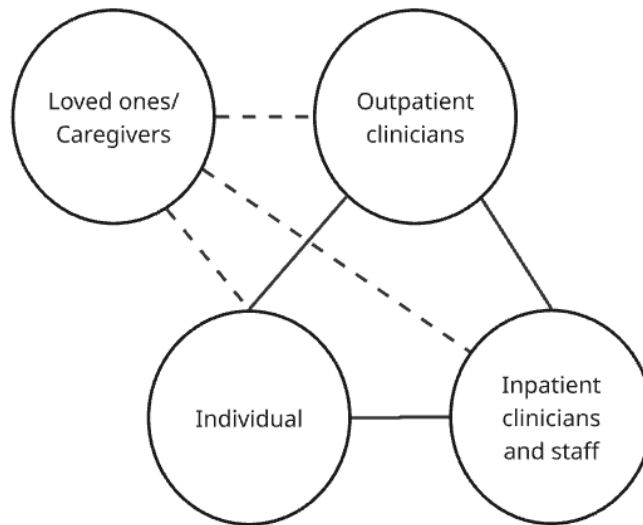


Fig. 10. A potential care network that limits the involvement of loved ones/caregivers.

What these accounts surface is that the boundary of the care network is not a neutral filter. Certain external influences pass through with relatively little friction, such as abusive parents' or spouses' statements to clinicians. Permeability runs in one direction, toward those with institutional standing, rather than along lines that the individual themselves would draw. This suggests that designing patient-defined collaborative care networks may require working at (at least) two levels: who is included in the network, and how each person is involved, including who can write into the participant's record, who can only read from it, and who can do neither. Mechanisms like psychiatric advance directives offer one starting point, but the design space could extend further, giving participants meaningful control over how information about them flows, who is authorized to act on their behalf, and under what conditions those authorizations can be exercised.

5.5.3 Designing without/against institutions

This paper, being for an audience of health informaticians and designers, makes the general assumption that its audience works with or within healthcare institutions and would design and implement informatics interventions in those settings. However, in our emphasis on supporting patient autonomy, expertise, and values in their own treatment, we must acknowledge that many participants did not include psychiatric facilities in their utopian design, and several explicitly excluded “professionalized” care in their ideal worlds.

Critical design approaches like Design Justice (Costanza-Chock, 2020) push against dominant systems, processes, and institutions involved in design work, instead emphasizing design that is community-led and -owned. While many participants designed utopias that improved traditional institutions like psychiatric facilities, others divested from them entirely and instead emphasized non-clinical, de-medicalized care through community, family, and peers.

Designers should consider how the perceived trustworthiness of the source of an intervention may affect its uptake and efficacy. Questions to ask during the design process include:

- Who is involved in the design process—including the funding and institutional support?
- How are stakeholders identified and included (or not included)?

- Who provides/hosts/implements the solution (peers, community, non-profit, government, healthcare professionals), and how is that factored into the design?
- Who interfaces with the solution? Who can access and control data?

5.6 Limitations

People with negative experiences are presumably more likely to participate in a study about “re-imagining psychiatric hospitalization,” although there were a few participants who were eager to share their positive experiences as well. Participants were primarily white, female, and most were under 40 years old. While the goal of qualitative research is not to provide generalizable results based on representative samples, previous work has identified a variety of racial and ethnic disparities in Western psychiatric inpatient care, particularly for Black individuals (Hua et al., 2025). Additionally, people who are currently hospitalized, particularly those facing long-term hospitalization, were not recruited for this study. Participants had to have Internet access to participate in the study, and a private location for the session.

5.7 Conclusion

We contribute patient-centered informatics interventions and design directions based on our analysis of participant interviews and their co-designed utopian care futures. This paper also provides a basis for future work that could build on our contributions by deliberately partnering with marginalized communities in a long-term co-design process around psychiatric hospitalization and acute mental health care.

Our work highlights the wealth of experiential knowledge of people with experiences of psychiatric hospitalization and their visions for ideal care through interview and co-design sessions. We found that participants encountered multiple barriers to accessing information about their care and rights, and they emphasized that these barriers are not just present inside the psychiatric facility itself, but followed them outside of it, contributing to negative clinical outcomes and rehospitalization. Participants also described how their own expertise and experiences were devalued by the healthcare system and their clinicians. In their utopian designs, participants broadened their scope of solutions to include society, community, loved ones/caregivers, and peers in holistic care tailored to the individual, envisioning systems that were centered around respect for patient autonomy and dignity at every level.

Chapter 6: Conclusion

“You have to act as if it were possible to radically transform the world. And you have to do it all the time.”

– Angela Davis

6.1 Research Findings and Contributions

Evidence-based solutions exist for improving and providing alternatives to psychiatric hospitalization as it exists in the US today. However, as discussed in this dissertation, implementation faces many challenges. Change is possible, and alternatives exist, but awareness and education are necessary first steps to get more stakeholders involved in pushing for broader cultural and systemic reform (or revolution). My work brings this topic of psychiatric hospitalization into conversation with health informaticians and designers, and emphasizes its differences from general inpatient settings and its unique challenges. It is in this context that I provide the following contributions in answer to my research questions:

1. Analyses of rich accounts of people’s experiences with psychiatric hospitalization across multiple mediums.
2. A framework of information flows and pathways based on people’s psychiatric hospitalization narratives.

3. Provocations for patient-centered informatics interventions co-designed with people with experiences of psychiatric hospitalization.

RQ1: *What can we learn about people's experiences with psychiatric hospitalization through narrative accounts across different mediums?*

Contribution: Analyses of rich accounts of people's experiences with psychiatric hospitalization across multiple mediums.

In this dissertation, I familiarized myself with a variety of narrative artifacts across very different mediums: 140 TikTok posts and their comments, 121 online written narratives, and 29 interviews. As with other kinds of rich texts, we can learn a lot from these accounts, and I have shared what I feel is most relevant for the purposes of this dissertation, although there was much more that I did not include.

One thing that we can learn about people's experiences with psychiatric hospitalization through narrative accounts across different mediums is that a person's choice of medium leads them to focus on different aspects of these experiences. TikTok, for instance, affords users with creative mechanisms for sharing their stories and experiences, and the population we examined tended to utilize humor and satire when they shared and connected around their experiences. Narratives tended to be shorter²³ and focused on specific moments or feelings around psychiatric hospitalization both during and after the experience, rather than a complete, linear narrative of their experience from admission to discharge.

²³ Gay (2026) aptly describes TikTok posts as "micro-narratives."

All three studies in this dissertation addressed this question through qualitative analysis of people's descriptions of their experiences with psychiatric hospitalization, as addressed to different audiences. **Chapter 3** described and analyzed the aspects of their shared experiences that connected people on TikTok, focusing on in-group rhetorical strategies and mechanisms. In our analysis of our dataset of TikTok posts and their comments, we found that people built community primarily by using humor to process their experiences, celebrate recovery, identify with others, and to provide and receive peer support.

Chapter 4 highlighted written narratives that included writers' experiences with psychiatric hospitalization. Like Chapter 3, these narratives were unsolicited and published online: publicly available, but with a specific target audience that included peers. In addition to peers, however, these stories were also aimed towards healthcare professionals and others who are part of the Mad in America community, and tended to be written as serious descriptions and reflections on negative experiences with the psychiatric system, often with the goal of increasing awareness and advocating for change.²⁴ Additionally, while the creators and commenters in our TikTok dataset appeared to skew younger (reflecting the demographics of TikTok users generally), we perceived a greater range of ages and life experiences in this set of stories. Ultimately, these stories built on the findings of Chapter 3 by providing further context for the setting in which these experiences of psychiatric hospitalization took place.

²⁴ Several stories also included positive narratives about how the writer found alternative paths to recovery outside traditional psychiatric treatment.

Participants in **Chapter 5** shared their experiences directly with me in synchronous, online interview and co-design sessions. Their narratives built on and corroborated similar themes and experiences described in Chapters 3 and 4, including positive and negative interactions with clinicians, peers, caregivers, and others; physical and psychological consequences post-discharge; and barriers to information seeking and sharing. Unlike the unsolicited narratives, I was able to ask questions to elicit further detail and context from storytellers, as well as to better understand the values and motivations that drove them.

I was able to identify what I believe are significant patterns and common themes in experiences of psychiatric hospitalization in the US. The diversity of mediums included across these studies also allowed me to understand specific aspects of these experiences. This included how TikTok creators use humor, other rhetorical devices, and platform affordances available to them to frame their stories; what details and stories writers for the Mad in America Personal Stories section deem most important for an audience interested in rethinking the current system of psychiatric care; and what interview and co-design participants remember and how they interpret psychiatric hospitalization experiences. Together, the findings across all three studies contribute to a further understanding of people's experiences with psychiatric hospitalization.

RQ2: *How do people who have experienced psychiatric hospitalization perceive information flows in the hospital environment?*

Contribution: A framework of information flows and pathways based on people's psychiatric hospitalization narratives.

In **Chapter 4**, I conceptualized how information flows in the psychiatric hospitalization setting by creating and applying the framework of “*information pathways*” to online narratives. While I focused on the four most salient information pathways, I identified others as well, including pathways that involved actors besides a writer and an individual clinician. Information pathways can be thought of as a narrative analysis approach, tracking the actions and effects of people across a single story, providing a richer understanding of how information flows in the hospital environment.

Mapping narratives to information pathways surfaced barriers to effective information seeking and sharing that people encountered in psychiatric facilities—both those hospitalized as well as their clinicians. This framework also served to elucidate the different reasons that clinicians miss opportunities for collaborative care, both at the individual and systemic level.

Writers of these narratives described psychiatric facilities as highly-controlled, information-starved environments.²⁵ While clinicians’ information behavior could be stymied by hospital processes and constraints, their institutional power also allowed them to disregard and override patient expertise, values, decisions, and rights with seemingly little-to-no personal consequence. Meanwhile, the people experiencing psychiatric hospitalization were actively disempowered, dependent on the goodwill of individual clinicians, staff, or outside advocates like loved ones and therapists to meet their information needs.

²⁵ A defining characteristic of the asylum, i.e., a total institution ((Goffman, 1961).

I used these findings to develop design provocations for consideration in future informatics work on psychiatric hospitalization, and provided examples of already-existing design interventions that could be further explored in the psychiatric hospital setting. I also emphasized the importance of including people with experiences of psychiatric hospitalization in any future research using these provocations.

RQ3: *How do people with experiences of psychiatric hospitalization envision ideal, patient-centered informatics interventions related to psychiatric hospitalization?*

Contribution: Provocations for patient-centered informatics interventions co-designed with people with experiences of psychiatric hospitalization.

Chapter 5 describes how participants, through co-design, utilized utopian thinking and speculative design to envision ideal, patient-centered informatics interventions related to psychiatric hospitalization. Participants envisioned utopian systems of care that involved not just their clinicians and psychiatric facilities, but their communities, caregivers and loved ones, and peers.

Their designs, however, were not simply based on broadening inclusion of stakeholders, but importantly on centering their own autonomy and right to be decisionmakers in their own care. This included being able to place guardrails and constraints on how others were involved in their care. The range and diversity of participant designs also demonstrated the heterogeneity of personal needs and values they identified for their own care—indicating that any interventions should center patient values, preferences, and autonomy.

Based on these designs, I developed and recommended design provocations for informatics interventions that include considerations for improving information access both inside and outside psychiatric facilities, supporting patient-defined and -controlled collaborative care networks, and considering whether interventions are collaboratively designed and implemented with institutions or outside of them.

6.2 Future Work

Moving forward, I see three future directions—though far from mutually exclusive—that I am deeply interested in pursuing: implementing interventions, including caregivers and loved ones in care, and improving access to alternative mental health care.

6.2.1 Implementing Interventions

Based on the work presented in this dissertation, I am deeply interested in designing to promote implementation of solutions and interventions in this space. I plan to use the provocations in **Chapter 4** and **Chapter 5** in future work designing and implementing an intervention. As I have seen while reviewing previous work, implementation is just as important a consideration as the efficacy of the design itself. There are many researchers working in implementation science whose work and expertise I can learn from, and I look forward to making my own contributions in that area.

6.2.2 Including Caregivers and Loved Ones in Care

The role of caregivers and loved ones in people’s mental health care—both wanted and unwanted—surfaced repeatedly throughout my work. Writers in **Chapter 4** and participants in **Chapter 5** described instances in which their loved ones were actively excluded from collaborating in their care and treatment plans against their wishes, and both chapters suggested designing for improving support for caregivers in this context.

Whether and to what extent an individual’s caregivers are included in their care, especially in the context of psychiatric hospitalization, has to be under the complete control of the hospitalized individual. Several writers and participants described negative experiences of unwanted caregiver intervention: for example, parents or spouses calling the police to have them involuntarily committed, or a parent or spouse misrepresenting the individual’s situation or mental state to clinicians. **Chapters 4 and 5** include provocations and examples of including caregivers, but future work needs to be done that includes caregivers in research to better understand their experiences and needs, and how they interact with the people experiencing psychiatric hospitalization.

6.1.3 Improving Access to Alternative Mental Health Care

While this work focused on improving experiences of psychiatric hospitalization, which I believe is extremely necessary given its current state, several writers and participants in **Chapter 4** and **Chapter 5** discussed alternative care and treatment, such as peer-led and community-led services, peer respite, and so forth. Barriers to creating and accessing these services include funding, insurance coverage, and geography—but

also, awareness and education for existing services. As mentioned earlier in this chapter, education about these evidence-based services is the first step not only for people to access those that are available, but also for more stakeholders—e.g., community members, policymakers, and local public health departments—to “buy in.”

6.3 Reflection

My dissertation catalogs a progression from indirect to direct, participatory approaches. While **Chapter 3** included member-researchers, there are several ethical considerations with social media research that have to be considered (which I discuss in 3.2). In **Chapter 4**, I initiated a partnership with Mad in America, whose story archive we ultimately used for our dataset. It was not until **Chapter 5** that I talked directly to people with experiences of psychiatric hospitalization. There are, of course, benefits and drawbacks to both direct and indirect approaches. I continue to wrestle with my belief that the first two studies could include voices of people who may be more reluctant to engage in academic research, or just more difficult to reach. However, in a sense I forced them to participate in research without their knowledge or consent. I believe that it is of utmost importance for research contributions to go back to the community that is the subject of research, which I intend to do with the findings in **Chapter 5**.

The stigmatization of madness is nothing new. “Mental health awareness” and destigmatization campaigns have risen to the mainstream in the last few decades, but do not appear to have had much impact—and can even backfire by promoting biomedical models of mental illness, which reinforce negative stereotypes of “mental patients” as

dangerous and unpredictable (Read & Harré, 2001; Tyler & Slater, 2018). While the concept of stigma, introduced by (Goffman, 1963), remains productive when understood and communicated with precision, its meaning as a form of power seems to have weakened in public understanding over time. Stigma is not “merely” negative perception, but a specific form of discrimination (Webb, 2016), which I frequently observed in my research. It permeated not only clinician attitudes, but those of loved ones, peers, and even the creators of the narratives I analyzed across all three studies.

The relationship between madness and disability is a contentious topic for many in the disability and Mad rights movements. However, highlighting the abject discrimination of people perceived as mad or mentally ill—and in particular, people with experiences of psychiatric hospitalization, not all of whom fit that description—dovetails with my previous work around disability. My research focus was originally in accessible and assistive technology for blind and visually-impaired people. While I pivoted to my current topic for a variety of reasons, I find looking back that I am still doing accessibility work. Design and informatics in this space can be considered as making psychiatric care accessible to the people who use it—not just as in “healthcare access” (i.e. availability/affordability, etc.): a psychiatric facility not being able to handle someone in an altered state, for instance, is not accessible to the very population that it is supposedly designed to serve. An intake that does not account for someone being unable to effectively communicate is not the fault of the patient; it is the fault of its designer.

6.4 Final Conclusion

My work provides informatics researchers and clinicians with further understanding of the community of people with experiences of psychiatric hospitalization, and aims to validate the embodied knowledge and expertise of this community and their right to be active decisionmakers in their own care. I demonstrate how we can use the rich and messy data from narrative artifacts, from short-form video to online stories to interviews and co-design, to create frameworks and design provocations for addressing the needs of this community with patient-centered care that centers their autonomy and agency.

In undertaking this work, I am, of course, guided by my own values—namely, that all people deserve autonomy, dignity, and respect. In our current healthcare system, far too many people experience significant levels of psychiatric harm during the process of hospitalization itself. Some see this as unfortunate, but ultimately subservient to the goal of ensuring physical safety and stabilization. But, in a psychiatric facility, the experience *is* the treatment. A thread that runs through the entirety of this dissertation is that people's experiences and the expertise that comes with them are of critical importance to ensuring effective care, and should be taken seriously by healthcare professionals and researchers. Through listening to and spotlighting the voices and expertise of people with experiences of psychiatric hospitalization to health informatics researchers, I provide frameworks and goals for much-needed future work—work that includes us in every step along the way.

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Appendix A: Interview and Co-design Activity Guide

Pre-Interview (5-10 minutes)

- Introduce myself (say my pronouns, but don't force pronoun disclosure)
- Go over consent form, re-affirm consent (including consent for recording)
 - Note the part about suicidality, and point them to the resources list we have
- Overview of what we're going to be doing today
 - We want to understand more about people's experiences with psychiatric hospitalization. We also want to work with you to find ways to improve those experiences.
 - This session will be 90 minutes. For the first 20, I want to ask you some questions about your last or most memorable hospitalization experience. Then, we'll spend the next hour doing some activities to help us with reimagining psychiatric hospitalization in general. Then we'll end with a short debrief.

Interview (20 minutes)

- Briefly confirm relevant demographic information from screening questionnaire, and any clarifications
 - Do you live in the US?

- Can I ask you some questions about your most recent/memorable/or only hospitalization?
 - How well do you remember it?
 - How long were you hospitalized?
 - [If multiple] I noticed in your questionnaire that you've had multiple hospitalization experiences. How would you say your most recent one compared to your previous experience(s)? Typical, or any differences?
 - I'd like to make a broad timeline together of your most recent/memorable hospitalization. Does that sound good to you? We can keep it as high-level as you want, or include some more details, but this can help act as a basis for the reimagining section of the session.
 - Can prompt: admission, during stay, discharge. What happened during each one?
 - Good experiences? "Amplification stories" – good experiences to build on

Co-Design Activities (60 minutes)

- Briefly explain what the next hour will look like
- (10 minutes) Goal: Consider and describe personal values
 - **Slide 1:** What are your top 5 values?
 - Put their values in chat for reference

■ Some options, or come up with your own:

- Autonomy
- Collaboration
- Community
- Creativity
- Curiosity
- Faith
- Family
- Friendship
- Freedom
- Health
- Honesty
- Kindness
- Relationships
- Respect
- Safety
- Service
- Stability
- Trust

- Privacy
 - How do those values show up in your life? Are there moments you can think of where you really felt those values show up?
 - Optional questions that can help:
 - When do you feel most free? How do you hold onto that feeling of freedom?
 - How do you build up others? How do you strengthen the people around you?
 - What do people in your community need to feel supported?
- (10 minutes) Goal: Sketch a utopian world as the basis for reimagining hospitalization
 - Note: While we're doing this, I'd encourage you to not feel constrained by what you think is most feasible or practical
 - **Slide 2:** Consider what a utopian world would look like for you—it could be a science fiction future, an alternate reality, a fantasy version of our own world, or whatever you prefer.
 - Don't need to think right now about how it relates to psychiatric hospitalization—what would life look like in this society in general? What would your life look like?
 - How do the values you chose show up in this world?

- (40 minutes) Think of alternative futures/scenarios
 - You can use what you've already created in the previous activities and interview to help here. We can also go back to those activities to spend more time thinking through them if that would help.
 - **Slide 3:** Think of one aspect of your timeline and consider how it could be different in your world
 - What is the state of this topic in your world?
 - How has it changed from our own world?
 - How do the values you chose show up in how this topic is addressed?
 - Storyboarding: Consider a scenario with the topic you came up with: how would it go in your alternate world? Discuss, draw out your idea in comic panel boxes, or create it in whatever way makes most sense to you. Take your time—you don't need to immediately have an answer
 - Example scenario:
 - Sophia wakes up feeling tired
 - Sophia makes coffee with her coffee maker
 - Sophia drinks her coffee
 - Sophia feels awake and ready to start her day!

■ **Slide 4:** Additional prompts if needed when thinking about alternate worlds:

- What do communities look like?
- What kind of technology is available?
- How is knowledge shared?
- How is data collected? What data would people benefit from?
- Optional questions from Activity #1
 - When do you feel most free? How do you hold onto that feeling of freedom?
 - How do you build up others? How do you strengthen the people around you?
 - What do people in your community need to feel supported?

■ **Evaluate:**

- What are the strengths of your idea?
- What opportunities open when creating it?

Debrief/End (5 minutes)

- How are you feeling now that we've finished? How do you feel the session went?

- If anything we talked about brought up traumatic memories/things from the past you weren't expecting, please be gentle with yourself after this
- Was there anything that you wanted to bring up during this session that you didn't get to?
- Would you want us to keep your contact information to send you results and/or potential future studies?
 - If I have any follow-up questions, can I contact you?
- Remind them about the resource list
- Encourage them to reach out to us with questions, concerns, etc.
- Save recording + transcript

Appendix B: Mental Health Resources List

Crisis and Support Services

Note: Some crisis line workers are mandated to report calls to the police if they believe there is immediate risk of harm to yourself or others. If this is a concern for you and you are unsure of their policy, you can first ask about their reporting policies before sharing your situation with them.

988 Suicide and Crisis Lifeline

- www.988lifeline.org

- Call or text: 988
- Provides 24/7, free and confidential support for people in distress, prevention and crisis resources for individuals in crisis or their loved ones, and best practices for professionals in the United States.
- **Note:** 988 may dispatch first responders (i.e., law enforcement and/or emergency medical services) if a counselor believes there is an immediate physical safety threat.

988 List of Resources

- <https://988lifeline.org/help-yourself/>
- List of self-help resources maintained by 988 Suicide and Crisis Lifeline.
Resources include: find a therapist/support group; build a support network; use your support network; make a safety plan; population-specific resources (e.g., neurodivergent; youth; LGBTQI+).

Mental Health America

- <https://mhanational.org/im-looking-mental-health-help-myself>
 - Provides guidance and resources for people in crisis as well as those in need of support but not in crisis.
- <https://mhanational.org/where-to-get-help>
 - When someone has decided to seek help, they can answer questions on this webpage to identify options for getting help.

National Alliance on Mental Illness (NAMI) – Support & Education

- <https://www.nami.org/support-education/>
- <https://www.nami.org/support-education/nami-helpline/>
- NAMI provides advocacy, education, support services and public awareness so that all individuals and families affected by mental illness can build better lives.

Substance Abuse and Mental Health Services Administration (SAMHSA)

- SAMHSA National Helpline
 - 1-800-662-HELP (4357) (Voice); 1-800-487-4889 (TTY)
 - A confidential, free, 24/7 information service for individuals and family members facing mental health and/or substance use disorders. Provides referrals to local treatment facilities, support groups, and community-based organizations. Callers can also order free publications and other information.
 - Note: SAMHSA will not call the police to intervene
- <https://findtreatment.samhsa.gov/>
 - A locator for alcohol and drug abuse and/or mental health treatment facilities and programs around the country. Provides information in English and Spanish for individuals and family members facing substance abuse and mental health issues.
 - Or, text your zip code to 435748 (HELP4U) to find help near you.

Peer Respite

- Peer Respite directory by state: <https://power2u.org/directory-of-peer-respites/>
 - Note that not all states have peer respites
- Peer respite is a voluntary, short-term, overnight program that provides community-based, non-clinical crisis support to help people find new understanding and ways to move forward. It operates 24 hours per day in a homelike environment, and are staffed and operated by people with psychiatric histories or who have experienced trauma and/or extreme states.

Wildflower Alliance Peer Support Line

- <https://wildfloweralliance.org/peer-support-line/>
- 888.407.4515
- Provides confidential support and resources by trained peer supporters with their own first-hand experience with psychiatric diagnosis, trauma, addiction, and/or other interrupting challenges. This line does not collect personal information, perform assessment, or call crisis or the police.

Violence Prevention Resources

Note: Neither of these resources will call the police to intervene.

National Domestic Violence Hotline

- <https://www.thehotline.org/>
- 800.799.SAFE (Voice); 800.787.3224 (TTY)
- Free, confidential, 24/7
- Webpage includes useful safety plans for keeping children and pets safe and internet safety. There are also links to deaf services, Native American services, and legal help.

National Sexual Assault Hotline

- <https://rainn.org/get-help/national-sexual-assault-hotline/>
- 800.656.HOPE (800.656.4673)
- Free, confidential, 24/7

Population-Specific Resources

LGBT National Help Center

- LGBT National Hotline
 - 1 (888) 843-4564
 - **Note:** Not 24/7 (check the hours on the website). Will not call the police to intervene.

- Provides a safe space that is anonymous and confidential where callers can speak on many different issues and concerns including, but limited to, coming out issues, gender and/or sexuality identities, relationship concerns, bullying, workplace issues, HIV/AIDS anxiety, safer sex information, and suicide. Staffed by LGBTQ+ identifying people.
- <https://lgbthotline.org/>
 - Includes links to the LGBT National Hotline, LGBT National Coming Out Support Hotline, LGBT National Youth Talkline, and LGBT National Senior Hotline.

Trans Lifeline Hotline

- <https://translifeline.org/hotline/>
- 1 (877) 565-8860
 - **Note:** Not 24/7 (check the hours on the website). Will not call the police to intervene.
- Trans Lifeline's Hotline is a peer support phone service run by trans people for our trans and questioning peers. Call if you need someone trans to talk to, even if you're not in a crisis or if you're not sure you're trans.

Face the Fight – Veteran Suicide Prevention Resources

- www.wefacethefight.org

- Link to the Veteran Crisis Line. Resources for: peer support; mental health treatment; military transition support; career support; finances; network connections (e.g., veteran spouse network); mobile apps.

Veteran Crisis Line

- <https://www.veteranscrisisline.net>
- 800.273.8255 (press “1”)
- Provides 24-hour assistance for Veterans, Service members or those concerned about a loved one by qualified by VA professionals. Individuals may phone, text or get online support.

Drug and Alcohol Use

STOPOVERDOSE.org

- <https://stopoverdose.org/>
- Information about opioid overdose prevention including a naloxone locator, overdose training video, and resources for treatment and family support.

National Drug Helpline – By American Addiction Centers

- <https://drughelpline.org>
- 1 (844) 289-0879

- 24/7 helpline for people suffering from addiction or their loved ones to guide them to treatment options in their areas. Not government-affiliated or funded. Hotline assistance free for all callers. Further referrals will focus on AAC services which have costs associated.
- **Note:** The National Drug Hotline will not call the police to intervene

National Institute of Alcohol Abuse and Alcoholism (NIAAA)

- <https://alcoholtreatment.niaaa.nih.gov/>
- Information about alcohol treatment and resources for finding quality alcohol treatment.

Substance Abuse and Mental Health Services Administration (SAMHSA)

- SAMHSA National Helpline
 - 1-800-662-HELP (4357) (Voice); 1-800-487-4889 (TTY)
 - A confidential, free, 24/7 information service for individuals and family members facing mental health and/or substance use disorders. Provides referrals to local treatment facilities, support groups, and community-based organizations. Callers can also order free publications and other information.
 - **Note:** SAMHSA will not call the police to intervene
- <https://findtreatment.samhsa.gov/>

- A locator for alcohol and drug abuse and/or mental health treatment facilities and programs around the country. Provides information in English and Spanish for individuals and family members facing substance abuse and mental health issues.
- Or, text your zip code to 435748 (HELP4U) to find help near you.