

# From Treatment to Healing: Envisioning a Decolonial Digital Mental Health

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## ABSTRACT

The field of digital mental health is making strides in the application of technology to broaden access to care. We critically examine how these technology-mediated forms of care might amplify historical injustices, and erase minoritized experiences and expressions of mental distress and illness. We draw on decolonial thought and critiques of identity-based algorithmic bias to analyze the underlying power relations impacting digital mental health technologies today, and envision new pathways towards a decolonial digital mental health. We argue that a decolonial digital mental health is one that centers lived experience over rigid classification, is conscious of structural factors that influence mental wellbeing, and is fundamentally designed to deter the creation of power differentials that prevent people from having agency over their care. Stemming from this vision, we make recommendations for how researchers and designers can support more equitable futures for people experiencing mental distress and illness.

## CCS CONCEPTS

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

## KEYWORDS

decolonial theory, digital mental health, health inequities, artificial intelligence, medical pluralism

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**Content Warning:** This work includes descriptions of mental illness, involuntary hospitalization, and suicide. This work also includes descriptions of colonialism, racism, slavery, and police brutality in the context of mental health. Additionally, Aboriginal and Torres Strait Islander readers are advised that the following article may contain the words of people who may have died.<sup>1</sup>

## 1 INTRODUCTION

“So [I’m] being assessed for my behaviour, not for what I’m feeling. Not for my story. They’re not interested in that.”—Stolen Generations survivor Auntie Lorraine Peeters [269]

With many arguing that there exists a universally large gap in treatment for mental illness [179], digital mental health tools [27, 205, 223, 316] are commonly presented as a potential means to meet a widespread need for care and facilitate access to support and other resources [30, 203, 239]. Research around mental health and mental illness has thus become ubiquitous in the field of Human-Computer Interaction (HCI) [55, 60, 87, 262, 311, 318, 345]. Questions are centered around innovative and diverse premises, including investigations into how people seek technology-mediated support [54, 84, 264], predictive analyses of when someone may be at risk of severe distress [68, 83, 311], and interventions to improve individual health [87, 296, 342]. Together, these lines of inquiry explore how technology might be able to improve mental health and prevent symptoms of mental illness.

<sup>1</sup>This is following guidance around describing members of Aboriginal and Torres Strait Islander communities in text, stemming from Indigenous cultural protocols created in collaboration between the Australian Broadcasting Corporation and members of Aboriginal and Torres Strait Islander communities [1].

Although the concepts of “mental health” and “mental illness” are frequently used to motivate research directions, investigations in HCI around how these concepts have been constructed and stabilized [188, 266, 340] are only just beginning [66, 67, 98, 192, 313]. It is well documented in literature around the history of psychiatry [110, 199] that colonial power relations have been defining factors for what forms of distress have been validated by clinicians as being “mental illness” and provided care, and what forms of distress have been ignored. Definitions of mental health and mental illness have been used by institutions of power to exclude multiply marginalized people from care [140], infringe on human rights [158, 198, 229], and silence political dissidents [23, 212, 231]. More work is thus needed to investigate the conceptualizations of health and illness that underlie the design of digital mental health tools, and understand whose needs those conceptualizations might marginalize. To do so necessitates a deeper look into the history of how power relations have influenced the conceptual definition and categorization of mental health.

The veil of scientific objectivity that psychiatry provided was often used to justify oppression by state and medical actors who worked for colonial governments, and link definitions of mental health to racist categories. For example, British colonial psychiatrists diagnosed patients and created mental health policies by generalising diverse African cultures as “tribal” and measuring the extent to which a person was “detrIALIZED”<sup>2</sup>. Colonial psychiatrists argued that one could judge an individual’s propensity to mental illness based on this racist metric, and would later use it to argue that rates of schizophrenia were higher among Black populations [140, 199, 308]. Though these assumptions were racist and false [35, 193, 194], the scientific framing that they took on had an influence on future mental health discourse and rhetoric around the world [111, 308]. That influence survives today through racial and other identity-based biases in constructs used to diagnose mental illness [200, 243]. Diagnostic scales derived from those constructs, including those with identity-based biases [50, 200, 243, 256], are often used uncritically in digital mental health applications to measure the efficacy of interventions [138, 189, 203, 275]. The use of these scales and their underlying frameworks around mental illness can also often be seen in mental health research done within HCI [68, 311].

Recent work in computing has sought to understand how historical and contemporary forms of exclusion, marginalization, and oppression are propagated [31] or augmented [53] by the design of different algorithms and technologies [74, 248]. A growing body of research within HCI also works to understand how colonialism and coloniality might underlie how HCI is conceptualized and practiced [90, 150], and envisions what practices to decolonize HCI might look like [10, 190, 234, 339]. Bhambra et al. [33 in 222] define coloniality as being the continued power dynamics that are a legacy of “the historical processes of dispossession, enslavement, appropriation and extraction [...] central to the emergence of the modern world”. Understandings of what a decolonizing process might look like are polyvocal, and Lazem et al. [190] conceptualize it as being

<sup>2</sup>Colonial psychiatrists rarely engaged with the cultural specifics of different indigenous communities, and any studies done reproduced racist assumptions about social orders and hierarchies of intelligence or ability [140, 169, 298].

“concerned with how researchers, wherever located, might contribute to dismantling and re-envisioning existing power relations, resisting past biases, and balancing Western heavy influences in technology design” in the context of HCI.

By being a core rationale for the first classifications of mental health and illness [96, 107, 110], coloniality lies at the center of how mental health and illness are understood and treated [72, 111, 199]. Following past explorations of power dynamics, coloniality, and mental health [28, 65, 105, 120, 238], we turn a critical lens to how the concepts of mental health and illness are understood and practiced in the emerging field of digital mental health. We ask two questions:

- (1) How might current methods in digital mental health propagate historical power relations and patterns of oppression?
- (2) How might we design technology-mediated mental health methods and spaces that are fundamentally *decolonial*?

To address the questions above, we proceed to analyze the underlying coloniality of three components of popular digital mental health applications—interfaces that connect people in distress to resources, applications that evaluate or classify individual mental health, and applications created to predict and intervene in an individual’s future mental health states. We choose these specific components as a result of them being the most prominent application areas within digital mental health that have been studied in prior HCI research [55, 59, 68, 311, 318]. We situate the design of these components in historical patterns of marginalization around the identification, treatment, and care of mental distress or illness. Through foregrounding the underlying colonial history of how mental health and illness are understood, we argue that digital mental health applications—as currently designed—are complicit in propagating historical patterns of exclusion and inequality.

Anchoring our understanding of these applications in past work around coloniality and decolonization [33, 190, 214, 320], and following past work in HCI [10, 90, 150, 190, 234, 339], we provide recommendations for designers and researchers in digital mental health to take steps towards creating what we conceptualize as a *decolonial digital mental health*. Given the long history associated with intersections between colonialism and mental health, we draw on a diverse and global set of research in our conception of a decolonial digital mental health, including work around the history of psychiatry and colonialism, literature from medical anthropology, cultural psychiatry, and empirical work in clinical science and HCI.

To ensure that marginalized forms of distress are recognized and validated in these tools, we urge researchers and designers to center lived experience, center power relationships, and center structural factors in their work. By moving from models of care centered around treatment to models of care centered around broader and more holistic healing, we argue that a decolonial digital mental health can empower people experiencing mental distress<sup>3</sup> to have more agency over their own care and wellbeing.

<sup>3</sup>Following Pendse et al. [261], we use the term “mental distress” to refer to symptoms of mental illness without a formal, psychiatric diagnosis. However, we recognize the power dynamics and privilege that go into the ability to be diagnosed formally by medical professionals.

## 2 COLONIALITY, COMPUTING, AND A DECOLONIAL DIGITAL MENTAL HEALTH

In this section, we begin by discussing past work around marginalization within HCI and computing. We then look specifically at how coloniality and colonialism have been understood within HCI and computing, with a particular focus around how decolonial theory has been interpreted and integrated into HCI research. We end by describing our understanding of colonialism, coloniality, and decoloniality as they apply to digital mental health.

### 2.1 Marginalization and HCI

Scholars in computing have noted the potential for technology-mediated support (particularly support that makes use of AI) to hide structural inequities and broaden gaps in access [100], make resources less inclusive or accessible [24], and further propagate forms of marginalization from society [53, 248, 285]. Recent explorations of technology-mediated marginalization have included racial and gender identity biases in facial recognition algorithms [53, 285] and in natural language processing (NLP) algorithms [47, 48]. Other work within HCI has described the role of marginalization in how computing research is conducted and practiced, and its implications for researchers, stakeholders, and users. For example, Ogbonnaya-Ogburu et al. [247] discuss the implications of racism (both individual and systematic) on how HCI is researched and practiced, noting the implications of critical race theory for the field. Similarly, Rode [280] and Bardzell [22] consider the implications of feminist theory for HCI, and Light [197] and Spiel et al. [299] consider the role of queer theory for HCI. Researchers have also discussed the implications of intersectionality on how computing research is conducted, particularly with regards to who is able to participate in research and benefit from its products [97, 184, 273, 274, 286]. Other researchers have leveraged theories from philosophy to better understand power dynamics within HCI, including anarchism [170] or humanism [21]. This work is broadly oriented towards creating a field of computing and designing technology that is much more inclusive, equitable, and conscientious of past injustices, and explicitly choosing not to design technology that supports oppression or marginalization [24, 74, 123].

### 2.2 Coloniality and HCI

One dimension of marginalization that scholars in computing have begun to more deeply analyze is the impact of colonialism and coloniality on computing. In particular, an interrogation of computational artifacts as laden in cultural and political constructs influenced by colonialism has gained significant attention in computing research [8, 40, 44, 90, 150, 190, 222]. Though colonial relationships may (in some cases) have been discontinued, the unequal power dynamics between former colonial powers and their former colonies as initially expressed in the physical exploitation of human, land, and natural resources have morphed into modern ways of being, of doing, and of knowing; one in which computing is a culprit. The persistence of power dynamics influenced by colonialism, as well as the structures designed to uphold and propagate those power dynamics, are what decolonial theorists dub *coloniality* [33, 214].

Despite the glaring input of ideas and resources from former colonies in the design and production of technology in the West,

these technologies are implemented and deployed with the intention to erase and dominate the cultures, pedagogies, and languages of the former colonies [16]. For example, the fields of ubiquitous computing [90] and artificial intelligence [222] have been largely driven by expansionist framings and outlooks which foster a universalized system of knowledge production and its computing applications, erasing local knowledge. Coloniality in computing as practiced today manifests itself in the assumption that knowledge is unevenly distributed, that one-sided computing solutions can have universal relevance, and that certain parts of the world should mirror the “development” in other parts. As Ali [8] puts it, “It is not so much that computing has a colonial impulse, but rather—as decolonial thinkers might argue—it is colonial through and through.”

Researchers in HCI have taken different approaches to understand the nature of colonialism and coloniality in computing, including leveraging both postcolonial theory [150] and decolonial theory [222]. As Lazem et al. [190] describe, while related, there are important differences between these related forms of inquiry. Postcolonial theory forms its basis in analyzing “the colonial legacy left behind once colonialist structures have been removed,” whereas decolonial theory is centered around fundamentally “[dismantling] epistemological and ontological coloniality” [132, 190, 215]. Rather than centering the impacts of colonialism or colonialist structures (and thus, the institutions who created those structures) as postcolonial theory often does, a decolonial lens seeks to shift towards decentering the dominance of any given institution, and foreground those power relations that create centers [8] to work towards eliminating them.

### 2.3 Decoloniality and Decolonization

Tuck and Yang argue that the only route to decolonization is “reparation of land simultaneous to the recognition of how land and relations to land have always already been differently understood and enacted; that is, all of the land, and not just symbolically” [320]. Through this work, we hope to foreground how the power relations of colonialism are reproduced within and through digital mental health applications, with those power relations being rooted in the continued extraction of land and the domination of Native, Indigenous, Aboriginal, First Nations, and Adivasi peoples.

Citing Cesaire [63], Tuck and Yang note the importance of answering what colonialism is “specifically” when discussing decolonization, given the potential for language around decolonization to be co-opted to hide complicity in the extraction and appropriation of land stolen from Indigenous, Native, Aboriginal, First Nations, and Adivasi peoples. In this paper, our specific scoping of colonialism is how “the historical processes of dispossession, enslavement, appropriation and extraction [...] central to the emergence of the modern world” [33] continue to disempower those experiencing mental distress and deny them their needed care. In formulating pathways towards a decolonial digital mental health, we foreground how these continued power relations (or what other theorists [33, 214, 222] have called *coloniality*) have an influence on digital mental health applications, technologies, and algorithms.

We are conscious of the potential for our argument in this paper to be complicit in colonization without a recognition of the role of stolen land in decolonization, and explicitly affirm the fundamental

role that land and resources play in colonialism and coloniality. As Tuck and Yang [319, 320] and Fanon [104] argue, mental distress is inseparable from the colonization of land. This has been abundantly discussed in the context of occupation and conflict, both historical and present day [125, 136].

We also recognize that different incarnations of oppression [343], though rooted in the conquest of land, do not exist in a vacuum and are interconnected with each other as well as with their roots in land and resource theft. As described by past theorists and historians [33, 104, 214, 238], colonialism included the subjugation of knowledge, culture, and Indigenous practices, all built upon land-based oppression, but also including harms that cannot be amended or repaired solely from the repatriation of land. Put simply, how useful is repatriated land if an individual still does not have any freedom or sufficient resources to practice their knowledge, culture, or any other traditional practices?

Nonetheless, with nationalist politics on the rise globally [42, 95], we are also conscious of the potential for our argument to be used to propagate harm in the name of a return to some imaginary of a pre-colonial form of society or governance [237]. Following Oyedemi's writing on decoloniality in the South African academic context and the concept of polycentrism as decolonization [257], we understand decolonization not necessarily to be a return to pre-colonial culture, but to "go to the past, as Mungwini [230 in 257] notes, not in order to stay there, but solely to excavate knowledge that can be of value to the present" [257].

We intentionally choose to call our vision of a digital mental health that is non-hierarchical, inclusive, community-centered, and allows for greater agency over wellbeing a *decolonial* digital mental health. We do so to explicitly acknowledge the role that colonialism and coloniality have played in creating a mental health (and consequently, a digital mental health) that has prevented people from accessing care based on their own experiences of mental distress and illness, or risk harm in pursuing care on their own terms. As we conceptualize it, a decolonial digital mental health fundamentally resists the impulse of technology-mediated care to abstract people's forms of expressing and experiencing distress based on what can be easily treated and ignore those forms of distress that do not fit into Western models of distress or care, such as structural or social forms of distress [155, 177, 219] that may require social, political, or economic change for relief.

As the field of digital mental health begins to expand globally [62, 239], a lack of attention to these colonial impulses runs the risk of causing people experiencing minoritized forms of distress to continue to have their distress unheard, particularly as Western ways of evaluating mental health or illness continue to be globalized. Like Ali notes [8] in his description of decolonial computing, through a decolonial digital mental health, we hope to decenter the dominance of models of illness and care that are predicated on the treatment of individual symptoms, and progress towards a digital mental health that thinks holistically about healing, including the importance of structural or identity-based factors. Our vision of a decolonial digital mental health thus differs from a theoretical post-colonial digital mental health in that we urge designers to both respond to historical power relations *and* disable continued power inequities from propagating or taking on new forms when creating new digital mental health interventions.

### 3 ACKNOWLEDGING STOLEN LAND AND OUR POSITIONALITY

**Land Acknowledgment:** We begin by acknowledging and affirming the centrality of stolen land and resources, the displacement of Indigenous, Native, Aboriginal, First Nations, and Adivasi peoples, and the denial of Indigenous, Native, Aboriginal, First Nations, and Adivasi autonomy over the land in both colonialism and colonization.<sup>4</sup> We acknowledge and affirm Indigenous, Native, Aboriginal, First Nations, and Adivasi peoples (also noting that these terms and abstractions are those created by Western, colonial powers in the pursuit of land theft [20, 265, 278]) as the traditional stewards of the land. This paper was written by authors sitting on the native lands of Indigenous peoples. In North America, this includes (but is not limited to) the indigenous lands of the Muscogee Creek Nation. In Namibia, we acknowledge all tribal groups and the Indigenous groups of former times [3, 7, 235]. Additionally, as part of this land acknowledgment, we hope to also acknowledge the role that caste has played in subjugating the land rights of Dalit and Adivasi communities by upper caste individuals and communities, a continued process that has stretched millennia [43, 64, 157, 175, 209]. In foregrounding the role that land plays in colonization, we also encourage readers to investigate the Indigenous and colonized lands where they may be reading from and contemplate their relationship with it.<sup>5</sup>

Following Tuck and Yang [320], we recognize and affirm that colonialism (in its external, internal, and settler forms) are rooted in the (continued) pursuit of land stolen from Indigenous, Native, Aboriginal, First Nations, and Adivasi peoples by colonizers. Consequently, we also recognize and affirm that complete *decolonization* can never be independent from the repatriation of land to Indigenous, Native, Aboriginal, First Nations, and Adivasi peoples from colonizers. We also note that framing land as property (historically done along with designating the bodies of enslaved peoples as property [319, 320]) is a colonial ontology, and that decolonization and repatriation of land must operate within Indigenous, Native, Aboriginal, First Nations, and Adivasi ontologies around repairing and re-establishing traditional relationality [57].

**Our Positionality:** This paper includes authors from diverse backgrounds, including diversity in national origin, citizenship, caste, race, and gender identity. These simple terms, however, were constructed by colonial powers, influenced by coloniality, and by other oppressive power relations and thus do not necessarily do justice to the nuanced ways that the authors of this paper engage with the multiple identities and/or privileges they hold. Given the topic of this paper, we believe it is important to note that some of the paper's authors have lived experience of mental illness, of identity discrimination, and interacting with care systems created for those experiencing mental illness globally. We view our work as part of a broader decolonizing agenda within HCI [10, 190, 339], one that indeed affirms the centrality of land in decolonization [320]. We also acknowledge that by choosing to publish this work at a specific

<sup>4</sup>This land acknowledgment is adapted from that of the collective authors of *Decolonial Pathways: Our Manifesto for a Decolonizing Agenda in HCI Research and Design* [10].

<sup>5</sup>Though limited in scope, one such place to do so can be found at <https://native-land.ca/>.

academic venue (within HCI) that requires us to write in English and with limitations on authorship among other constraints, we may be complicit in supporting an elite academic space that often also perpetuates colonial inequity [150, 190, 247]. However, by publishing this work at such a venue, we also hope that our research will spark discussions around coloniality and mental health that lead to greater inclusion of minoritized perspectives and people in both mental health and in the field of HCI.

## 4 THE CREATION OF A DIGITAL “MENTAL HEALTH”

There exists significant enthusiasm among medical professionals and clinicians when considering the potential for technology to make mental healthcare more accessible. Some psychiatrists have argued that the use of artificial intelligence (AI) might result in more standardized and objective measures of mental health, going so far as to say that AI could “save” psychiatry and “solve” national mental health crises [92]. This excitement, a response to historical criticisms arguing that psychiatry is not a real medical science [167], underlies the field of digital mental health. In this section, we describe the development of the field of digital mental health, outline primary application areas, and describe common methods. We then outline the history of the creation of mental health as a concept, highlighting the influence of colonialism on its construction and methods used to study mental health and illness.

### 4.1 A History of Technology-Mediated Care

**4.1.1 Early Forms of Technology-Mediated Care.** Tal and Torous describe digital mental health (also often called mental health technology [272], computational psychiatry [226], or digital psychiatry [137, 315]) as broadly being the field of research into technologies that “advance mental health, and especially psychiatric rehabilitation” [309]. Digital mental health technologies do so through the use of new sensors and data to better understand the “functional, social, and emotional experiences of illness and recovery at a personalized and quantified level” as well as through “[assessing] and [monitoring] mental health on a population level and [providing] early interventions and resources to those in need, regardless of their location” [309]. Following past research in digital mental health, we take a broad view of what constitutes a digital mental health technology, adding online support groups [27, 124], teletherapy [344], and suicide hotlines [262, 264, 344] to this definition.

Much of the work done to provide care *en masse* across long distances was pioneered in the wake of the Second World War, when there was a new biomedical [340] awareness of mental illness and a greater need for accessible care. As Zeavin [344] notes in *The Distance Cure*, this sudden widespread need for mental health care after World War II led psychoanalysts to experiment with providing their services over distance to groups of people (rather than individuals), such as letters, news columns, or radio broadcasts. Zeavin notes that radio in particular was framed by revolutionary psychiatrists Fanon [103] and Guattari [133] as being a means to unite people in revolution against colonialism and deterritorialization, towards better quality of life and mental health. Their framings of how technology could benefit mental health were clearly linked

to how colonization has a continued influence on mental health, outside of solely individual factors.

Following World War II, clinicians began to experiment with technology-mediated psychiatric services, including using video-conferencing to provide psychiatric services [116, 295] to people in rural areas, Indigenous communities, and communities of veterans, beginning in the late 1950s. In parallel, it was also in the 1950s that suicide hotlines began to operate [322, 344], beginning with Chad Varah’s Samaritans helpline in 1953. Mental health professionals began to utilize the affordances of these new media technologies to provide care to more people than was previously possible. However, the nature of how potential users were understood had an influence on the design of the care system—for example, the second American suicide hotline was created by a member of the queer community in the context of widespread stigma against the LGBTQ community of San Francisco [344]. The hotline was entirely volunteer-led (unlike other hotlines at the time), and prospective volunteers had to prove that they were not “prejudiced against people of color and gay people, or judgmental about sex” [208, 344]. These intentional design decisions had a significant influence on both the kind of care that was produced by the hotline system broadly, and the people who availed care from it.

**4.1.2 Computing and Mental Health.** Recent developments in computing have led to new forms of technology-mediated care. These include chatbots [117], which have their roots in Joseph Weizenbaum’s explorations of the Turing Test via ELIZA [335, 344], or online mental health support groups, which have their roots in specific boards within broader online communities [113] and an older tradition of peer support from the ex-patient, mental health consumer, and psychiatric survivor movements [4, 5]. However, unlike earlier iterations of technology-mediated care in which data was never necessarily meant to be kept long-term or analyzed [344], these new forms of care produce significant amounts of data, or what is often called *digital trace data* [211]. This data can come from diverse sources, including posts on social media [67, 68] or in support groups [81, 268], wearable technologies [141, 187, 323], or passively collected smartphone data (also called personal sensing) [49, 202, 244, 317, 328, 329]. The use of this data to better understand and classify lived experience is often called *digital phenotyping* [148, 249]. This framing draws on both the concept of a phenotype from genetic science, or an organism’s observable characteristics, often observed as “appearances, signs, and symptoms of disease” [338] in medical contexts, as well as Dawkins’s conceptualization of extended phenotypes [79, 156]. Through a strong grounding in concepts from life sciences, psychiatrists have expressed enthusiasm about the potential for digital phenotyping to be a more accurate and objective measure of an individual’s mental health [149], as utilized in digital mental health interventions. Digital mental health interventions are used broadly in both the Global North and Global South [62, 164, 239, 331], and much has been written about the potential for digital mental health tools to connect people to care in resource constrained environments globally [30, 203, 316]

Researchers have begun to critique technosolutionist approaches to designing and evaluating digital mental health interventions. For example, Bemme et al. [29] urge researchers and practitioners to

think more deeply about the futures that digital mental health applications that make use of passive sensing data promise, whose labor those futures may depend on, and who might be excluded from those futures. Mohr et al. [224] critique the top-down approach associated with digital mental health tools, rooted in a traditional belief that clinical experience supersedes lived experience. They urge practitioners to work alongside people with lived experience with mental illness when creating new applications. Chancellor et al. [67] discuss predictive algorithms that make use of social media data, and note the potential for these algorithms to be used for surveillance and discrimination by bad actors, such as to increase insurance premiums for those who appear to be at a higher risk of depression. In addition, Ernala et al [98] note that, in an attempt to scale mental health predictive algorithms to large datasets, researchers have been misled to use behavioral proxies as ground truths of mental health state, often resulting in poor construct validity or practical utility for the person with lived experience of a mental illness. Most recently, building on these perspectives, Thieme et al. [311]’s systematic review advocated for providing “concrete suggestions for a stronger integration of human-centered and multi-disciplinary approaches in research and development” of digital mental health interventions and mental health predictive algorithms.

Building on past critiques, we draw attention to the influence that colonialism and coloniality have had on how the concept of mental health and illness are defined within digital mental health interventions. We argue that, through uncritically leveraging concepts and metrics of mental health from psychiatry, digital mental health interventions risk reproducing biases from the history of how (Western) psychiatry has been practiced, hide the influence of structural factors on mental health, and place users at risk of surveillance-related harms.

## 4.2 The Colonial Origins of “Mental Health”

**4.2.1 The Creation of Mental Illness as Threat.** The framing of psychological distress as part of a broader “health” that was within the domain of treatment by community healers can be seen throughout the world historically [72], with beliefs generally being rooted in a paradigm that situated distress as the result of imbalances in the body. Some examples include the concept of depression being the result of an affliction of the heart in Ancient Egypt [240] and of black bile in Ancient Greece [144], or traditional African medicine’s focus on intersections of disharmony between spiritual environments, social contexts, and the body [284, 304]. Though there were some early forms of institutional care, such as medieval Islamic hospitals that treated those who could not afford home care [72, 88], pre-colonial care was often provided by community members or healers, and took place at the home or at religious sites [72, 221]. Treatments (at institutions, religious sites, or the home) varied with regards to their level of humaneness, with some treatments being characterized by psychosocial and holistic interventions, and others centered around chaining [72], exorcism [109], or internment in a cellar [267].

The carceral and European<sup>6</sup> [109] framing of mental distress and psychiatric symptoms as an innate and individual threat to the general public led to the creation of the asylum system [267], in which individuals were thought to be beyond treatment and that segregation was thought the only way of averting societal violence. People interred in asylums were thought by many to be cursed or lacking in humanity, were called “lunatics” or “mad” [267]. As part of this paradigm, treatment of what was understood to be an innate and unchangeable flaw was not seen as possible [140].

As a result of massive worldwide European colonialism, the mental illness as societal threat paradigm became the prevailing paradigm concerning people experiencing mental distress or psychiatric symptoms globally, to the point that even countries that were not colonized by European states (such as Japan or Thailand) created asylums [72]. Asylums were primarily used as places for the treatment of European nationals, leaving Indigenous people to traditional and home care. This was a result of both the high expense of maintaining asylums for colonial governments, as well as the colonial belief that Indigenous people were less-developed and thus less likely to experience mental illness [140, 169, 284]. However, asylums were also used as facilities for incarcerated people to be moved to when prisons were too full [140], and it is likely that asylums were also used to imprison political dissidents who were speaking out against colonial rule [99], as a form of social control.

These beliefs around racial inferiority motivated the creation of classification systems for mental illness. Emil Kraepelin, widely deemed “the father of biological psychiatry” [340], created some of the first models to abstract and classify mental illness [110], and arguing that mental illness was the result of genetics and biological abnormality. However, in an endeavor to see how presentations of mental illness differed between populations [96], Kraepelin found that the Indigenous Javanese population did not express guilt along with depressed affect. He rationalized this difference through a racial lens, calling the Indigenous Javanese population “a psychically underdeveloped population” and equating them to “immature European youth” [107, 181]. Kraepelin later helped create the German Psychiatric Research Institute, which framed people with mental illness as being an innate threat to society, and worked to create a database of people who might have mental illness [110, 334]. This work ultimately resulted in “the sterilisation campaigns of the 1930s and finally the actual medical killing of people diagnosed by psychiatrists as incurably schizophrenic.” [110].

**4.2.2 A Movement Towards Mental Health.** The global deinstitutionalization of people interred in asylums happened in parallel with widespread global movements towards independence, self-rule, and decolonization, and in parallel with the paradigm shift towards managed treatment of “mental illness.” Cohen et al. [72] note that several factors influenced the movement from a custodial to a treatment based model in the Global North, including widespread awareness of the violent nature of the asylum, the discovery of chlorpromazine as the first medication that targeted specific symptoms found in asylums. Goffman, though known well in HCI

<sup>6</sup>As Fernando [109] notes, “there is no evidence that the brutalities connected with how mental health was seen in medieval Europe, such as burning of witches or the inquisition of the Catholic Church, existed in (say) the Mughal Empire in India or the Empire of Mali in West Africa.”

for his writings on self-presentation [129], was a core thinker of the deinstitutionalization movement, writing several books on the topic [127, 128]. However, deinstitutionalization itself was not always independent of colonial values—Keller [169] describes how the “foundational myth” of Pinel’s “liberation of the insane” from their chains in France became a justification for French psychiatrists as part of France’s “civilizing” mission in Algeria, Tunisia, and Morocco. As Keller goes on to note, “violent forms of oppression could be construed by their practitioners as humanitarian interventions designed to save the colonized from wretchedness and disorder” [169].

With the global deinstitutionalization of asylums, movements around “mental hygiene” and wellbeing, tied to the idea that outpatient treatment and prevention can be helpful for people experiencing mental distress, also became popular in this time [106]. These initiatives were championed by activists with lived experience with mental illness, such as Clifford Beers [28], and were spread globally (and reinterpreted in different cultural, societal, and political contexts) via Western-educated psychiatrists [23, 140, 340] who went back to their native countries after their education abroad. Stemming from contemporary developments in medical sciences, such as germ theory or vaccination [106], the mental hygiene movement took on a biomedical framing to mental distress. Contemporary writings use the terms mental health and mental hygiene interchangeably, with Beers himself using the term “mental health” to refer to his own states of health and “mental hygiene” to refer to a broader movement towards public mental health [28] in 1929.

War and conflict were also central to how this new concept of mental health was understood and practiced. Wu [340] notes that the push by British and American psychiatrists to screen out potential soldiers who may have mental disorders from fighting in World War II, as well as later efforts by American psychiatrists to treat combat neurosis or shell shock, were instrumental to the idea that mental illness can be treated and is not an innate quality. Many war psychiatrists later became influential in the creation of how mental health was understood and defined at the WHO [340]. It was also in this period after the deinstitutionalization of asylums, a period in which different actors looked to rehabilitate individuals with mental illness, that forms of psychotherapy (such as Freudian psychoanalysis, psychodynamic psychotherapies, or cognitive-behavioral therapies) became popular for mental distress [75, 121, 122, 340, 344].

The first recorded use of the term “mental health” as a field of health was in 1946 [32]. As a result of the 1948 International Congress on Mental Health [340], by 1949, the World Health Organization (WHO) had an Expert Committee specifically devoted to issues around mental health [251, 340]. In parallel, the World Federation for Mental Health was founded in 1948 to investigate local understandings of mental illness, towards “[diverting] psychiatrists away from the ‘psychiatric imperialism’ that attempted to impose Western standards of behavior on other cultures” [340]. It was not till 1950 that the WHO released a definition for “mental health,” defining it as “a condition, subject to fluctuations due to biological and social factors, which enables the individual to achieve a satisfactory synthesis of his own potentially conflicting, instinctive drives; to form and maintain harmonious relations with others; and to participate in constructive changes in his social and physical environment” [32, 252].

Though conscientious of contextual factors, this definition was not untouched by colonial factors—of the nine people on the Committee that created this definition, only one was not from a country in the Global North, and all members of the Committee were from the Americas [252]. Just three years later, the WHO published a report by the ethnopsychiatrist J. C. Carothers entitled *The African Mind in Health and Disease: A Study in Ethnopsychiatry*, which framed “Africans” as being more likely to have “mental breakdowns” [140] as they moved to cities and were “detrribalized” [61, 140]. This work used theories from Carothers’s psychiatric practice in Nigeria to try to suggest and justify that Black Americans had higher rates of schizophrenia or psychosis as a result of a higher rate of “detrribalization” [61, 140], ideas that were later adopted by American asylum administrations [308]. Wu [340] notes that even though contemporary anthropologists spoke out against this racist belief in inferior intellect among members of indigenous African communities, Margaret Mead and other prominent WHO stakeholders researching culture and mental health remained silent. The bias associated with these racist writings (such as the idea that Black individuals are more predisposed to psychosis or schizophrenia) can be seen in contemporary diagnostic and classification tools [200, 243], such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) [14], a common tool for psychiatric classification and diagnosis<sup>7</sup>.

Though extremely common in psychiatry, as Jadhav [153] notes, simple scale-based questionnaires and categorizations ignore the existence of diverse epistemologies across cultures around emotion and mental health, and can result in the unintentional pathologization or treatment of ordinary (non-distressing) emotion. Even in open-ended methods of creating and evaluating emotion (such as Expressed Emotions research [159]), validity is evaluated via inter-rater reliability of how the (often Western) researchers evaluate the qualitative data and create concepts from them. As a result of inter-rater reliability privileging the concepts created by the majority, important minority cultural variations end up being erased. Rather, Jadhav proposes an alternative method of determining that factors in identity-based or structural factors, or what he dubs cultural validity:

“If the validity of an instrument refers to actually measuring what it purports to measure with reference to the truthfulness of a theory, cultural validity extends to contextualise validity within the specific community being studied. It follows that theories and instruments need to be ‘grounded’ within that culture, if they have to be considered valid. Grounding implies researchers do not begin with a priori notions but instead develop theoretical constructs that reflect local concerns including indigenous theories, participant voices, priorities and values.”

In the following section, we describe how Western epistemologies around illness and care are operationalized in digital mental health applications, and how those applications create and propagate identity-based bias. We leverage cultural validity as one core method in transitioning to a decolonial digital mental health.

<sup>7</sup>A full glossary of acronyms from psychiatric, clinical, and related literature can be found at the end of this work.

## 5 THE COLONIALITY OF DIGITAL MENTAL HEALTH

In this section, we analyze the coloniality embedded in three separate application areas within digital mental health—the design of personal interfaces to connect people to care, the design of systems to classify mental illness based, and applications created to predict or intervene in future mental health states. We argue that current methods in digital mental health can erase minoritized forms of distress, make it more difficult for people to find care, and potentially put individuals in distress at risk of surveillance or harm.

### 5.1 Personal Interface Design

**5.1.1 Current Methods in Digital Mental Health.** Following research done in digital health [185, 233], digital mental health tools are often conceptualized as clinical interventions, similar to medication or a course of therapy. Researchers tend to evaluate these interventions using similar methods as in clinical science to test the effectiveness of a given digital mental health tool through randomized controlled efficacy trials [224]. To quantify efficacy, researchers often use scales from psychiatry or related fields [62, 183, 189, 224, 279], which would be used in a clinical setting to measure changes in symptom intensity or prevalence after administering an intervention.

Unlike interventions in clinical settings, digital mental health often makes use of “naturalistic” [38, 224, 321] data. This data is collected throughout the daily life of a participant rather than solely by a professional in a clinic. Analysis of that data is then tied to some measure of efficacy, either created by the research team or borrowed from a clinical construct in psychiatry. Some researchers and practitioners will relate variations in data to symptoms as measured by a psychometric screening scale [62, 183, 189, 279] or to a diagnosis [205] as grounded in the DSM or International Classification of Diseases (ICD) [253]. Still, others will not go so far as to make correlations with clinical constructs, and instead use the level of the end user’s engagement with the application as a measure of supposed efficacy [69, 242]. These researchers and practitioners argue that the underlying therapy provided has been shown to be effective, and posit that any amount of engagement with the interface must result in positive benefit to the user. However, this argument ignores that their specific interface for that therapy has not yet been shown to be clinically effective [314].

If digital mental health practitioners make use of clinical constructs, the efficacy of an intervention is often judged solely on whether specific symptoms are reduced, or if a clinical ground truth and the intervention’s predicted diagnosis associate, statistically. Given the remitting and relapsing nature of mental illness, a simple reduction of symptoms over a short period of time does not mean that there is sustained relief [165]. Mohr et al. [223] thus urge practitioners and researchers in digital mental health to move towards a solution-based approach, or “prioritizing the development of a solution to a practical problem over the production of generalizable efficacy knowledge that might be correct in abstract but does not represent or translate to any specific real-world setting.” They argue that mental health technologies must move towards leveraging the unique affordances that technology presents and

provide experiences that are not directly transposed from clinical interventions.

Given the importance of identity in how people experience and express mental health [36, 176, 245, 261, 264], a solution-based approach must consider more carefully how identity might influence user engagement with an interface and what kind of care they might need over time. Rather than engaging with static representations of a solution, interventions must think broadly about the character of long-term healing for a user, given the identities they have and account for the diverse forms of care that might bring them relief [37]. Models for creating interfaces directed towards long-term healing can be seen in historical forms of resistance towards colonization or colonial power dynamics. In the next two subsections, we describe the implications of two examples how decoloniality has been practiced when creating new forms of mental health care—Thomas Adeoye (T.A.) Lambo’s pioneering work incorporating Indigenous and biomedical models of care in post-independence Nigeria [140, 284] and global psychiatric survivor/user and ex-patient movements towards peer-based models of recovery, formed in response to widespread involuntary commitment and institutionalization [28, 65, 85, 118, 154, 246, 336]. In each subsection, we discuss how these pioneering forms of offline care might translate to digital contexts.

**5.1.2 T.A. Lambo and the Decolonization of the Nigerian Mental Health Care System.** Newly formed states in the Global South, often left with the relics of colonial healthcare systems (such as asylums or psychiatric hospitals), suddenly had the power to implement new visions of mental health care [72, 210]. T.A. Lambo’s work to transition Nigeria’s psychiatric system from being colonial and ethnopsychiatric to transcultural [140, 284], including a renewed focus on blending traditional methods of healing with psychiatric methods of treatment, was particularly influential globally [140]. Lambo’s paradigm also has important implications for the design of inclusive interfaces for digital mental health.

Lambo became the head of a colonial mental hospital in Abeokuta in 1954 in a newly independent Nigeria, having been educated under Maudsley Hospital’s patient-centered paradigm in the UK. Lambo returned to Nigeria at a time when psychiatry was associated with incarceration and colonial dominance, particularly given extensive media coverage of the poor treatment of institutionalized people at Yaba asylum [140, 284]. Taking over the administration of care at Aro Mental Hospital, Lambo sought to create an outpatient experience for people who needed care that involved hospital staff as well as family members, local community members, and traditional healers in several villages adjacent to the Aro grounds [140]. To empower care seekers, as part of a new decolonial psychiatric system, patients were admitted on a voluntary basis and could leave whenever they wanted [15], including those who were labeled as being “dangerous.”

Lambo recognized the importance of local context and cultural understandings of illness, and integrated them into the Aro model of mental health care, including involving traditional medical practitioners. Lambo was particularly focused on the therapeutic process of healing rather than treatment. As Heaton notes, integrating community medical practitioners alongside European trained medical practitioners “allowed for patients to be treated within cultural



frameworks with which they were familiar and comfortable” [140]. Given a colonial and essentialist history of framing African individuals as less able to have mental health issues, Lambo saw his role in combating these racist narratives to be a part of the decolonization process. He tied his research paradigm to the universality of human psychology, but was considerate of differences in illness experience and care.

Subsequent studies around this paradigm included those of the 1960 Cornell-Aro Mental Health Research Project, which sought to compare incidence of psychiatric disorder between the Yoruba community in Nigeria and a small rural community in Canada [193, 194], a pioneering paper for research methods in the emerging field of transcultural psychiatry [140]. In particular, the Cornell-Aro study was successful because it intentionally kept diagnosis as general and malleable (based on incoming research results) as possible, choosing to “employ a general category for affective disturbance and see what patterns turned up in it” [140, 193] rather than predetermined diagnostic categories. The team was able to show significant similarities between both the Canadian and Nigerian population, working against racist narratives about comparative prevalences of mental illness.

Research in digital mental health is often oriented towards achieving generalizable and scalable outcomes [98, 249]. As a result of this push towards generalizability and scalability, interventions often target specific symptoms [147], instead of exploring holistic forms of care that might more sustainably help a person experiencing mental distress or illness, as Lambo considered when decolonizing Nigeria’s mental healthcare system.

Pruksachatkun et al. [268] and Pendse et al. [263] describe how NLP algorithms created to predict whether someone is feeling better on an online mental health forum fail when data is disaggregated between people from primarily countries in the Global North and people from India. De Choudhury et al. [84], along similar lines, found through psycholinguistic analysis of social media disclosures of mental illness, that people in countries of the Global South self-disclose and express themselves differently compared to their peers in the Global North, although both selected groups spoke in the same language, English. Taken together, if attention is not paid to the specific ways that people in the minority express distress, it is possible that NLP algorithms created to match people to care might fail to detect distress in posts from users in the minority group. In turn, this prevents their access to the same resources as others in the community. Users in the minority are thus forced to frame their distress in ways that are recognized and validated by the interface, often rooted in clinical constructs [263], rather than Lambo [193, 194] or Jadhav’s [153] focus on keeping labels general, malleable, and culturally grounded.

**5.1.3 Psychiatric Survivor Movements As Responses to Coloniality.** Though mental health and illness were often framed as biomedical issues, over the course of the 19th and 20th centuries, it was common for judicial and carceral bodies to be the deciding factor in an individual’s diagnosis of mental illness [5, 267]. In their history of psychiatric survivor movements, Adame et al. [5] note that individuals were institutionalized in asylums for non-medical reasons, such as “poverty, race, culture, sexual orientation, or the failure to meet gendered expectations in one’s marriage” [5, 131, 287]. In

these institutions, individuals were often subjected to trauma and abuse, including involuntary commitment, sedation, and coercion into treatment by staff [5].

In the 1970s, enabled by a combination of deinstitutionalization and greater U.S. national consciousness around marginalization, ex-patients began to organize “to speak on behalf of themselves and to reassert their rights after being subject to involuntary psychiatric treatment” [5]. They characterized themselves as *psychiatric survivors* (also called the *consumer/survivor/ex-patient or user/survivor* movement [5]), or people who had survived their encounters with an abusive or inconsiderate approaches to psychiatry. In analyzing and speaking about the power dynamics of their treatment within the psychiatric system, survivors often leveraged analyses of colonialism [93], and understood themselves to be people colonized by the psychiatric system. In the context of these movements, peer support became popular [332]. A peer support model, or one in which people with similar lived experience are able to support others, was well-suited to the diverse ways that survivors understood their experiences [5]. In a peer support model, influenced by the values of the psychiatric survivor movement, recovery is self-defined and centers “hope, identity, and personal responsibility” over functioning or the elimination of symptoms [271, 332].

Psychiatric survivor movements, like grassroots and community-based movements, have aims that are localized to regional contexts and needs [85, 118, 246]. For example, the Cape Town Declaration [246] from the Pan African Network of People with Psychosocial Disabilities draws attention to the intersections between colonialism, slavery, and psychiatry: “*The history of psychiatry haunts our present. Our people remain chained and shackled in institutions and by ideas which our colonisers brought to our continent.*” A common value among these movements is the principle that individuals must have agency over how they achieve recovery, with care itself arising out of mutual and consensual interactions with various sources of aid, including both biomedical and community-based institutions. This complementary “coexistence of multiple medical subsystems” [18] is often referred to as medical pluralism. It is often discussed in the context of creating mental health interventions globally that are conscientious of cultural factors and power relations [255].

The values of medical pluralism, grounded in diverse understandings of recovery and care, could serve to make digital mental health interventions more accessible and inclusive. It has been observed that searching for symptoms is one method that individuals experiencing the early stages of mental distress or illness come to better understand what they are experiencing, and look for care [46, 56]. However, in many cases, the recommended resources from search engines for mental illness are often linked to specific symptoms, such as expressions of suicidal ideation [71, 201, 264]. For example, Google offers the nine item Patient Health Questionnaire (PHQ-9) to users who have searched for keywords associated with depression [126], and directs those who might have severe symptoms to seek help from biomedical resources. Similarly, social platforms like Tumblr provide public service announcements containing pointers to helplines and related resources on searches concerning DSM-enlisted symptoms [80]. A medically plural approach might be expansive with regard to when resources are recommended, given the diversity of symptoms that are expressed when experiencing

mental distress or illness. Additionally, search engines could enable people to try different psychometric scales outside of solely the PHQ-9, and particularly make use of those that have been validated, both clinically and culturally, with diverse populations [256]. With regards to resources recommended, a medically plural approach to health information might recommend specific online support communities based on the ways that an individual has expressed their distress [263], rather than solely recommending psychiatric resources.

There are strong associations between poverty, income, and mental illness. However, support provided via digital mental health interfaces often does not address this important factor in the kind of care people need when in distress. As Haushofer et al. [139] note, cash transfers and aid are particularly impactful for mental health. In their comparative study of cash transfers and psychotherapy in Kenya, Haushofer et al. found that stable cash transfers increased psychological wellbeing more than solely psychotherapy, and at equal level of psychotherapy and cash transfers. The benefit of financial aid for mental health can be seen in the case of peer support, in which members can support each other through mutual financial aid [13]. Though these structural factors are an important part of care, digital mental health interventions are often more focused on treating individual symptoms rather than thinking more broadly about care. As Jain and Jadhav [155] argue in their examination of programs for widespread care in India, psychiatric medication is often used as a primary measure to help people experiencing mental illness due to the ease of delivery. However, this approach and the framing of mental illness as solely biomedical obscure structural factors that continue to cause trauma among people with mental illness, and could be mitigated via policy. Similarly, as Mills and Hilberg note in their analysis of government-designed digital mental health applications in India [220], there is an emphasis on symptom-based care in these tools that obscures structural aspects that influence distress and wellbeing.

Lazem et al. [190] describe the belief of HCI communities in the Global South that Indigenous and local knowledge should be complementary to Western knowledge [6, 25, 135, 151, 166, 180, 225, 303, 306, 307]. As Lambo's work to integrate Indigenous healing and work from the psychiatric survivor movement show, there are feasible ways to integrate diverse models of how people understand care. Care can foreground complementary forms of healing, both from Indigenous and biomedical sources, validated clinically or culturally (or through some user-driven combination of the both), towards an individual's understanding of what their own recovery might look like. As demonstrated by Lambo's work, it is most important that care is culturally and contextually sensitive, and as demonstrated by psychiatric survivor movements, it is important that individuals have agency over how their distress is understood, the kind of care they receive, and how that care is administered.

## 5.2 Classification and Measurement

*5.2.1 The Use of Diagnostic Scales in Digital Mental Health Interventions.* Citing Bowker and Star's work interrogating how medical disorders are created through measurement [51], Alkhatib [9] describes how AI algorithms represent the world as a collection of

simplified metrics that ignore important parts of personal experience. This argument can be extended to how mental distress and illness are classified in digital mental health applications. Through leveraging clinical constructs and psychometric scales that do not incorporate local forms of distress, digital mental health interventions can globalize Western forms of care and marginalize minority forms of distress by design [74].

A first approach to measuring symptoms of mental illness is the use of psychometric scales [261]. These scales<sup>8</sup> (such as the Beck Depression Inventory [26], PHQ-9 [182], or GAD-7 [301]) are often created to be short and easy to answer; validated based on how well they correlate with a formal diagnosis with a Structured Clinical Interview [302] done by a clinician or medical professional trained to diagnose mental illness. As a result of their brevity, these scales are often used in digital mental health studies to screen or evaluate the symptoms of people experiencing mental illness, such as in the case of cognitive-behavioral therapy apps [204, 217], chatbots [76, 293], and to validate that someone has a mental illness in the case of predicting mental illness from social media [45] or wearable data [73, 328–330]. As a result of their use in clinical contexts, these metrics are framed as an objective standard for a ground truth in measuring whether a person is experiencing mental illness although, in recent years, HCI scholars have advocated for moving away from this approach [66, 98]. Critically, the clinical constructs these scales are based on (such as the DSM [200, 243]) and the derived scales (such as the PHQ-9 [256]) have notable identity-based biases. We describe the social and colonial origins of these identity-based biases, and their implications for measuring the efficacy of digital mental health tools.

*5.2.2 Societal Biases and Classification.* Hirshbein [143] describes how societal assumptions about gender and mental illness were instrumental to how depression was first measured and formalized as a diagnostic category. Prior to the introduction of medication in clinical practice, patients were not routinely given specific diagnoses—if at all, they were classified as either having “dementia praecox” (an early framing of schizophrenia) or “manic-depressive psychosis” [143]. “Melancholia,” an early precursor to depression, was framed as a symptom of one of these classifications [152]. Depression was separated into a diagnostic category based on how specific clusters of symptoms were responding to specific types of medication, and more participants were recruited with those symptoms to confirm the efficacy of the treatment.

However, as Hirshbein describes, common societal beliefs that women were more likely to experience depression resulted in more women being recruited for these new clinical trials without question, and researchers created psychometric scales that were specifically meant to measure improvement of specific observed symptoms of depression in women. This carried on past the 1950s, with even the creation and validation of the PHQ-9 having two samples of participants that were 60% and 100% women as recently as 2001 [182]. Hirshbein describes this as a self-fulfilling cycle in which diagnostic tools that were fit to gendered expressions of depression were used to select participants for medication trials. As a result of the primarily female sample used to create those tools, and the differences

<sup>8</sup>Extended descriptions of these scales can be found in the Glossary of Terms at the end of this work.

in symptom presentation between men and women, more women were selected for psychiatric research.

The perceived psychiatric objectivity of these metrics resulted in a common belief that women were simply more “depressed” than men. The PHQ-9, derived from this societal belief, is commonly used in a variety of digital mental health applications [73, 76, 82, 204, 217, 293, 330]. Though the PHQ-9 has been shown to measure depression at similar levels of clinical validity between cisgender and heterosexual men and women [50, 310], it is possible that a strict use of the PHQ-9 as a diagnostic tool might ignore other symptom clusters that are not present in the PHQ-9. For example, Borgogna et al. [50] find that the PHQ-9 is not as sensitive to the depression symptoms experienced by gay men, questioning women, queer men, and genderqueer-M (male assigned at birth) individuals.

**5.2.3 Racial Biases and Classification.** Racism has influenced how schizophrenia has been historically framed and measured, particularly its movement from being framed as primarily a gendered illness (in which women were framed as having schizophrenia more than men) to a racialized illness. As Metzl [212] writes, the first edition of the DSM (DSM-I) framed classifications of illnesses in vague terms and left much of diagnosis to the expertise of the clinician. As a result, diagnoses were not particularly consistent across clinics. As part of a push to reduce bias in clinical diagnosis of mental illness, the American Psychiatric Association aimed to make diagnoses more specific in the next iterations of the DSM, and sent out revised versions of the DSM to clinicians in the early 1960s (before its formal publication). Schizophrenia was now characterized in the DSM-II by “masculinized hostility, violence, and aggression” [212], including using universally male pronouns to describe patients with schizophrenia. “Projection,” the supposed process of blaming other people for one’s distress, was also called a symptom of paranoid schizophrenia.

Though the DSM was framed by psychiatrists as an objective text, it was implicitly racist in that the conflation of male violence with the diagnosis of schizophrenia also overlapped with contemporary racist beliefs about Black men being more violent. This racist belief was academically supported through work and writings from colonial ethnopsychiatrists. According to Summers [308], the American school of ethnology was founded upon a goal of finding racial differences in ability and intellect, looking to find evidence of “Black inferiority and the immutability of racial types.” This work would often cite racist ethnographies from colonial Africa as evidence or as justification. Analogous to arguments made by colonists outside of the U.S., pro-slavery advocates in the U.S. argued that enslaved Black individuals would be more predisposed to violence and mental illness if free out of a lack of a “benevolent master,” basing their arguments on studies “demonstrating” a higher rate of mental illness among freed Black individuals [308]. Racist colonial writings on African and Black inferiority were used as justification for the racial segregation of asylums in the U.S., and writing around asylum administration and psychiatry explicitly framed Black individuals as being more violent than white occupants. As Summers notes, “by suggesting that people of African descent coped with their psychological turmoil not by turning inward but by directing it outward, psychiatrists contributed to a discourse on black criminality” [308].

Additionally, “violent” projection being a core part of the symptomatology of schizophrenia allowed psychiatrists to frame the Civil Rights Movement in the U.S. in an explicitly psychiatric way. In 1968, two New York City psychiatrists described an illness they called “protest psychosis”, which they characterized a psychosis that was “colored by a denial of Caucasian values and hostility thereto.” [52, 212]. Bromberg and Simon went so far as to even say that the act of participation in civil rights protests caused “violent schizophrenic symptoms” among Black populations [52, 212]. Mainstream psychiatric literature treated it as fact that Black men were more likely to have violent schizophrenia than the general population, and in fact, research was done to find differences in presentation of schizophrenia between white and Black men [212]. Ads for anti-psychotics even featured Black men in the 1970s [213]. This bias towards a disproportionate diagnosis of Black men with schizophrenia has been consistently observed in applications of the DSM-IV [200, 243]. More research is needed to understand the persistence of this bias in revisions of the DSM, given little change in diagnostic criteria.

**5.2.4 Designing Culturally Valid Metrics.** Several researchers working in transcultural psychiatry and global mental health have also criticized psychometric scales as a form of ground truth for mental illness, arguing that the scales invalidate important culturally-bound symptoms by not categorizing them [174]. Empirically, Osborn et al [256] compare the applicability of the PHQ-9 with a locally co-created scale to measure experiences with depression among the Luo people of Western Kenya. Through grounding interviews with community members in the DSM-5’s open-ended cultural formulation approach [196], Osborn et al. identified how the Luo people conceptualized depression, including their specific idioms of distress and explanatory models of illness. To do so, Osborn et al. used each of the symptoms measured by the PHQ-9 as starting points for conversation, and asking individuals from the community how they expected someone who experienced those symptoms to behave or express distress, their underlying explanation for those symptoms, and how they might care for someone experiencing those symptoms. The research team then utilized an analysis of responses to create a set of 17 questions that might indicate whether a Luo individual was experiencing symptoms of depression, entitled the Luo Depression Questionnaire (LDQ-17).

The team then did community surveys to understand how related the LDQ-17 was with the PHQ-9 and other traditional Western diagnostic instruments. There were strong correlations between certain PHQ and Luo symptoms of depression, such as “little interest or pleasure” in the PHQ and “*geno ni orem* [inadequate hope]” among the Luo people. However, when doing a multidimensional scaling analysis of overlap between PHQ and LDQ symptoms, some seven LDQ-17 and three PHQ-9 symptoms were distinctly separate from the cluster of overlapping symptoms, and would never have been detected if solely using the PHQ-9.

As the researchers note, ensuring that a classification system or intervention is culturally valid cannot simply consist of adding on locally derived symptoms to existing Western diagnostic tools, as doing so might actually “over-extend the category of clinical depression to include symptoms best understood [locally] under other classifications” [173 in 256]. Rather, researchers must understand

how people understand certain symptoms, how they express those symptoms, and the kinds of care that they believe are most efficacious for those symptoms, and derive locally grounded diagnostic tools from this data. As Lazem et al. note [190], one important piece to decolonial methods in HCI is ensuring that individuals are not forced to fit their experiences to Western classification systems, and incorporate Indigenous forms of knowing.

Owing to the potential to quickly capture and perform linguistic analyses of open-ended responses to questionnaires, the field of digital mental health has significant potential to support the creation of locally grounded and culturally validated scales. For example, following past work analyzing the role of identity in how people express mental distress and illness online [84, 263, 268], digital mental health tools could perform similar analyses to that done by Osborn et al. [256]. Applications could ask individuals open-ended questions about how they are feeling or the types of distress they are experiencing, parse responses, and create clusters of expressions of distress. Analysis of the clusters and their prevalence, along with information from individuals on the kinds of care they need, could influence what resources a digital mental health tool provides users with when they are experiencing a specific cluster of distress.

Designers must also be considerate of the meaning that app-provided classifications and diagnoses might have to both the user as well as to society. This is particularly important given how diagnoses can be used as scapegoats for social, political, or economic forms of distress. As seen in the case of how depression scales were created to be more sensitive to women [143] and how schizophrenia was weaponized as a means to silence political dissidents [212], diagnoses can be used as tools to medicalize and delegitimize valid forms of societal oppression or marginalization [220]. Mills argues that this “psychiatrization” of ordinary distress [218, 219] might allow governments to ignore poverty or other structural factors by painting distress as biological rather than societal, and treating it with medication or technological solutions alone [220], instead of structural reforms.

Designers must also be cognizant of the potential for sociopolitical factors to cause over- or underdiagnosis of disorders, and work to better explain to users what specific factors might be contributing to a diagnosis and where there may be errors. This is particularly important given the far-ranging implications of a mental health diagnosis, including stigma and associations with criminality, particularly for marginalized individuals [161, 163]. Through foregrounding that diagnoses are best-effort categorizations and not always accurate, designers can ensure that users have agency over their diagnosis and subsequent care, and also prevent diagnoses from being used to erase social or political issues.

It is additionally important to foreground how identity might play a role in the evident success or failure of a given digital mental health application, particularly through making demographic attributes in studies clear, and collaborating with individuals with lived experience from user communities. For example, it is possible that a given intervention may only provide relief to upper-caste, Western-educated, or male individuals. If the study team is primarily from a High Income Country or male (as most practitioners and policymakers in global mental health tend to be [134]), it might be easy to miss how these demographic attributes influence perceived success. If “successful” applications are used widely, this

has the potential to exacerbate existing difficulties in the ability of marginalized people to access care that recognizes their unique expressions of distress. Critiques of the Movement for Global Mental Health (MGMH) have, therefore, argued that interventions from the MGMH center Western [333] and biological framings of illness and medication-based treatment [155, 218], while marginalizing traditional forms of healing [336], potentially as a result of the influence of pharmaceutical companies [108]. Similar critiques could be leveled against digital mental health tools that are not considerate of structural and identity-based factors in classification, diagnosis, and care.

### 5.3 Surveillance, Privacy, and Safety

In their discussion of ethical tensions in social computing and mental health research, Chancellor et al. [67] address the dangers of placing the ability to predict mental health states in the hands of “bad and unaccountable actors” who could use this power to harm people with mental illness. The authors describe possible threats of discrimination against people with mental illness in the provision of healthcare insurance, in credit-worthiness for loans, for targeted advertising, and in job search. However, Chancellor et al. do not discuss the potential harms of institutional and state surveillance.

Foucault [119, 120] understands the asylum to be a tool of domination over people who do not fit societal or behavioral norms, and are framed as being mentally ill by those in power, such as colonizers. In Foucault’s view, psychiatry forms a seemingly scientific justification for the punishment and continued subversion of those that might threaten the dominance of those in power. Foucault argues that this subversion extends past a global abolition of physical asylums. After abolition, the chains of the asylum are replaced with what Foucault calls “orthopedic instruments”—apparatuses that facilitate the surveillance and control of human bodies and ability—particularly of those with mental illness. Over time, these disciplinary apparatuses are able to make themselves invisible, unlike the chains of the asylum [120]. In Foucault’s framing, this invisible surveillance is a form of punishment for those who society might be afraid of, and a form of control over people who may become dangerous to societal norms in the future.

Rhetoric that fits into Foucault’s framework can be seen in government reactions to mass shootings in the U.S. After the 2012 Sandy Hook mass shooting, a NRA representative was quoted as asking why the United States had not yet made “an active national database of the mentally ill” [178]. The connection between mental illness and violence is a common media narrative in the wake of mass shootings. However, of all violent crimes committed in the United States, only three percent are committed by people with serious mental illness, and people with mental illness are more likely to harm themselves than someone else, let alone commit a mass shooting [178]. In 2018, in the wake of the Parkland shooting, then U.S. President Donald Trump argued in favor of the reopening of asylums, being quoted as saying “part of the problem is we used to have mental institutions...where you take a sicko like this guy [the shooter]” [172]. Similarly, after the 2019 mass shootings in El Paso, Texas and Dayton, Ohio, the President was briefed on the use of AI, cell phone, and smartwatch data to detect and predict who might be experiencing mental illness [327]. This program was





data with outside authorities (including law enforcement [281]) without informing a user when outside actors have been mobilized due to risk of harm. As Lamb et al. [186] note, law enforcement officers are used in crisis support as a result of a historical absence of funding for other means to deescalate and intervene. Additionally, many officers are not sufficiently trained to support people in crisis. Though it is important to intervene when an individual is at risk of crisis, alternatives to the use of “lethally armed agents” are possible, and may result in more sustained relief after a crisis [270]. These measures may include warm lines [77], unarmed crisis intervention teams, or community response teams that are more situated in a local context.

In alignment with Chancellor et al. [67], we advocate a greater involvement of people with lived experience in the creation of symptom- and risk-prediction algorithms. However, given the risk of surveillance by institutional or state actors, we urge designers to more deeply consider how their applications might be complicit in the monitoring of people with mental illness, and could contribute to discourse around criminality and mental illness. In particular, we urge designers to incorporate features into their tools that allow users to have full control over their data, what analyses are done with their data, and the ability to erase (including potentially through data poisoning [78, 324]) sensitive analyses or predictions of their mental health state.

This protection of user agency and privacy must be championed by institutional actors (such as, but not limited to, the state), such as through the implementation of policies that prohibit surveillance and prediction without consent. However, given the propensity for state-based actors to surveil users, and the inherent lag between policy and technological development [78], responsible design must primarily happen at an individual and community level when designers build digital mental health tools. Designers could incorporate the “right to be forgotten” [283] and the “right to explanation” [130, 162] in their design processes.

### 6.3 Centering Structural Factors

Popular digital mental health applications (such as chatbots [117]) require consistent internet access. This can be difficult in resource-constrained areas. We encourage designers to keep these technical constraints in mind when designing the interface for digital mental health tools, including a specific attention to how identity-based factors might marginalize individuals from accurate representation of their experience or access to care. Care must meet people where they are at, and in an accessible way that does not continue to marginalize individual or identity-related needs. Indeed, these structures represent and reproduce systems that work to oppose plural logics and practices about health. Unequal access to telecommunications and electrical infrastructures results from colonial legacies that are perpetuated by certain economic, legal and engineering priorities that inherently exclude diverse communities [41]. For instance, during the move to remote education during The Coronavirus Disease 2019 (COVID-19) pandemic [254], the National Campaign on Dalit Human Rights (NCDHR) and Dalit Adhikari Andolan found that the majority of surveyed Dalit and Adivasi students were not able to access or engage with online classes that their upper caste peers could [171]. Technology-mediated approaches

could use hybrids of online and offline resources that harness local strengths, such as providing the contact information of individuals in the community who might be willing to support an individual in distress when there is a lack of an internet connection or when a digital space may be difficult to navigate.

Understanding structural factors can help in establishing sustainable paths to effective care. Stressors can be social, economic, or political in nature and not always necessarily clinical [139]. As a result, the most effective care for distress may be an ecological approach that is considerate of individual context [168, 232]. In practice, this may look like a greater host of features included in digital mental health applications, such as financial support (possibly in the form of mutual aid [288]) alongside mental health support. Recognition of these connections would both be functional, in that it may benefit those experiencing mental distress by accommodating forms of care that meet their needs, and symbolic, as a recognition that structural and societal constraints are a core part of how mental health is experienced, and that an ecological approach [168, 232] to wellbeing is necessary. This recognition is particularly important given the potential for technology-based solutions (and their use of psychometrics) to biomedicalize mental illness and make structural factors invisible [219, 220]. For example, technology-based interventions may treat the symptoms of a given disorder, but not deeply consider or address the underlying conditions that cause the sustained presence of those symptoms. To ensure that structural factors are deeply considered, it is absolutely necessary that minoritized individuals and their perspectives be centered at each step of the design of a digital mental health intervention or study.

## 7 CONCLUSION

Designers, researchers, and practitioners in digital mental health have a common goal—helping people in distress find relief and live healthier and emotionally vibrant lives. Creating constructs that truly speak to how an individual subjectively experiences distress can be immensely challenging, with no straightforward answers and limited resources to support individuals in crisis. As a result of colonialism (and its historically propagated power dynamics), the tools and systems that currently exist to address mental distress and illness do not incorporate the diverse ways that people experience distress or support. In this work, through foregrounding how coloniality has had an influence on how we understand mental distress and illness, we analyzed how current tools—grounded in psychiatry and psychology—end up erasing and invalidating minoritized forms of distress. We drew specific attention to how social, political, and economic factors have influenced the creation of mental health classifications and treatments, while also erasing Indigenous ways of knowing and healing. Analyzing the presence of colonial classifications and tools in digital mental health tools, we argue that digital mental health maintains these colonial inequities. We urge HCI researchers to be conscious of these power dynamics when designing digital mental health tools, and to leverage the unique affordances of technology-mediated care to imagine and create more equitable methods of understanding distress and providing care. By doing so, we believe that a decolonial digital mental health could usher in a focus away from intermittent treatment, and towards sustained healing.





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