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Understanding Mental Ill-health as Psychosocial Disability: Implications for Assistive Technology

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Abstract

Psychosocial disability involves actual or perceived impairment due to a diversity of mental, emotional, or cognitive experiences. While assistive technology for psychosocial disabilities has been understudied in communities such as ASSETS, advances in computing have opened up a number of new avenues for assisting those with psychosocial disabilities beyond the clinic. However, these tools continue to emerge primarily within the framework of “treatment,” emphasizing resolution or improvement of mental health symptoms. This work considers what it means to adopt a social model lens from disability studies and incorporate the expertise of assistive technology researchers in relation to mental health. Our investigation draws on interviews conducted with 18 individuals who have complex health needs that include mental health symptoms. This work highlights the potential role for assistive technology in supporting psychosocial disability outside of a clinical or medical framework.

Author Keywords

Depression; anxiety; mental health; psychosocial disability; social model of disability

INTRODUCTION

Anxiety, depression, and many mental health concerns can be categorized as psychosocial disabilities, recognizing the actual or perceived impairment these concerns produce in daily life [2]. Such disabilities manifest in relation to a diversity of mental, emotional, or cognitive experiences. Individuals with these disabilities also represent a large portion of the population, with 1 in 4 people diagnosed with a mental health condition worldwide [56]. In addition, many individuals may not meet the medical “threshold” for mental health

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conditions but may still find their daily living activities impaired by mental health symptoms [53]. Psychosocial disabilities also frequently go hand-in-hand with physical health conditions and disabilities [70], and this co-occurrence can produce a more complex experience of disability relative to those who have only mental or physical health concerns [90]. However, holistic support that addresses both physical and psychosocial disabilities is widely underdeveloped and understudied.

While individuals with disability still broadly face issues of stigma and oppression, psychosocial disabilities in particular are complicated by their invisibility and unique place in history [36]. Medical treatment of mental health conditions has historically neglected consideration of patients' autonomy, and its legacy includes institutionalization, as well as treatment practices that have at times been non-consensual, degrading, and violent [71]. While medical science has changed much in the last half-century, many individuals still hesitate to disclose their symptoms, adopt psychiatric labels, or seek mental health services [76,79].

Despite the considerable overlap between occurrence of mental and physical ill-health, the social service and healthcare delivery systems for physical and mental health care are largely separate [30,46]. Consequently, treatment and support options for each are often disjointed and disconnected from one another—meaning an individual might be able to get treatment for a physical condition, but not a mental condition. Likewise, development of treatments and assistive technologies for physical and psychosocial disabilities often proceed separately, conducted by distinct communities.

In the assistive technology community, there has generally been greater attention to physical disabilities than psychosocial disabilities [60]. This focus persists even as advances in computing have opened up a number of new avenues for assisting those with psychosocial disabilities beyond the clinic [35,106]. These tools continue to emerge primarily within the framework of “treatment,” emphasizing resolution or improvement of mental health symptoms. In contrast, the field of assistive technology has moved towards a focus on empowering disabled individuals, maintaining access to daily activities, and improving quality of life [6,63].

This work considers what it means to adopt a lens from disability studies and the expertise of assistive technology researchers in relation to mental health. Our investigation draws on interviews conducted with 18 individuals with complex health needs that include mental health concerns. Our results suggest that mental health symptoms are disabling for these individuals, as they disrupt a number of valued activities and roles. In addition, these disruptions often recur over time, and may be mutually reinforced by physical health symptoms. Yet, despite the challenges of mental health concerns, many individuals avoided medicalizing their mental health symptoms or discussing them explicitly as “disabilities.”

The contributions of this work are twofold. First, this paper gives an account of the lived experience of people with complex health concerns and psychosocial disabilities. While some of these lived experiences have been documented individually in other literature [15,53], we uniquely examine the differential framing of physical and mental concerns and

discuss ways that lived experience and framing influence how individuals seek treatment. The examination of mental ill-health as psychosocial disability has not been well-documented in assistive technology scholarship. Second, we explicitly highlight these lived experiences through a disability lens. We conclude with a call-to-action, highlighting the potential role for assistive technology in supporting psychosocial disability outside of a clinical or medical framework, and emphasizing the importance of finding ways to frame mental health support technologies to avoid evoking stigma while still motivating proactive self-management of recurring sets of symptoms and centering those with psychosocial disabilities.

BACKGROUND & RELATED WORK

Psychosocial disabilities are varied in nature. Anxiety, depression, and other mental health concerns can be categorized under psychosocial disabilities, which involve actual or perceived impairment [2]. They can impede ability to engage in education and employment, or to achieve self-determined goals and aspirations [3]. They may also impair cognitive and social functioning [52]. These disabilities are often invisible, poorly identified, and episodic [64,87].

Lenses of Psychosocial Disability

There are many different lenses through which psychosocial disability can be understood (e.g., medical, social, moral, or economic models of disability) [41]. However, for the purposes of this work, we draw on both the medical and social models of disability, which provide different accounts for the origins of disability and suggest different goals for managing or addressing disabilities [27,92]. Each perspective has broad implications for how assistive technology for psychosocial disabilities is conceived and designed [63]. Previous work in ASSETS has argued for a social rather than medical lens, which we build on and extend by using both models in this paper [6,63].

Originating within the medical community [96], the medical model of disability is the clinical perspective of disability, wherein diagnosis (labeling), treatment, and cure of the individual is the directed course of action [37,96]. Goodley states that the medical model perceives disability as a flaw of the body that is “inherently abnormal and pathological,” or as the physical and functional limitations that an individual may experience [41]. Under the medical lens, psychosocial disabilities are pathologized as mental ill-health (e.g., depression, anxiety), cognitive impairments (e.g., Alzheimer’s), or neurodevelopmental (e.g., autism). Individuals in these categories need to be “normalized” or rehabilitated to become a part of society or their disorder must be eradicated [37,96]. A common critique of this model is that, through the medical lens, an individual is reduced to their limitations and these limitations are viewed as leading to a necessarily impoverished experience that they must be supported in overcoming [71,92].

In the social model of disability, limitations are identified not with the individual, but rather with the ableist social context in which the individual lives (e.g., not given the right to make an informed decision, overprotective family, discrimination, or harassment) [71,92]. Society itself creates the barriers that make individuals who may be different “disabled” [41].

Further, in the social model, limitations and their solutions are identified by individuals with disabilities, promoting autonomy, empowerment, and self-advocacy. Like the medical model, the social model positions assistive technology as a means to support individuals in accessing activities and life experiences; however, the social model emphasizes realizing self-directed objectives and retaining one's own autonomous sense of self, rather than correcting or normalizing oneself according to others' prescriptions.

The social model also highlights social factors that exacerbate individuals' experience of disability, such as stigma and associated discrimination or ostracism. Social stigma involves disapproval or discrimination against an individual based on their perceived difference from others [4,85]. Stigma may correspond to membership in a devalued social group (e.g., a gender, or age group) or to a disability or health condition. While many stigmatized identities have physical markers, or can be inferred via visible assistive technologies [33,78], other devalued identities are "invisible" to those encountered in daily life [28], as with certain physical disabilities and with psychosocial disabilities. Inhabiting a concealable stigmatized identity often involves a tension between efforts to avoid stigma by hiding that identity, and to pursue acceptance, support, and accommodation via disclosure of that identity [17,79,103].

The social model of disability and, consequently, the role of stigma in disabling experiences has particular salience for psychosocial disability. Individuals with psychosocial disabilities face a number of distinct experiences of stigma. Public stigma relating to mental illness often centers on negative stereotypes, as where individuals with psychosocial disabilities are seen as characteristically weak, incompetent, or dangerous [21,93]. Stereotypes may also deemphasize that symptoms are treatable and often temporary [93]. To the extent that stigma manifests behaviorally, individuals with psychosocial disability may face discrimination in employment, housing, or during help-seeking [67,85,97].

Individuals need not face active stereotyping, prejudice, or discrimination in order to be affected by psychosocial disability-related stigma. Outside of specific experiences of unfair treatment by others, many individuals with psychosocial disabilities have awareness of the possibility of others' mistreatment and judgment, and they may avoid situations where they could face stigma. Self-stigma can also occur as individuals with stigmatized identities come to internalize public stereotypes and attitudes about their identities [23,59]. Stigma can therefore affect help-seeking and access to support and can broadly impact the experience of psychosocial disabilities including effects on self-esteem and motivation.

Individual Experience of Psychosocial Disability—Individuals with mental ill-health may experience a range of symptoms from sub-threshold (i.e., mild symptoms below diagnostic criteria) to severe. While research suggests that impairment increases with symptom severity, it is widely recognized that sub-threshold symptoms are associated with disability in employment, relationships, and overall psychosocial domains [53]. Reports indicate that individuals with mental ill-health experience substantial persistent sub-threshold symptoms [55]. Many also experience asymptomatic periods in which functioning may return to "normal" [53]. This non-permanence of disability can interfere with individuals' ability to receive appropriate benefits or support [8]. While some people find

themselves temporarily or intermittently unable to complete activities of daily living due to their mental health status, others face more persistent difficulties that limit their ability to live and work independently [8,73].

Around the world, the disability associated with mental ill-health is immense. Conservative estimates suggest mental health conditions are the leading contributor (21.2%) to years lived with disability [98]. More inclusive estimates (e.g., addition of deliberate self-harm and suicide) increase the proportion due to mental ill-health to 32.4%. Psychosocial disabilities have particular impact when they are reinforced by physical health concerns. Individuals with mental ill-health are at an increased risk for physical health conditions including ischemic heart disease, stroke, and diabetes [26,74]. Indeed, approximately one third of individuals with psychosocial disability also have a medical condition [107].

Assistive Technology for Psychosocial Disability

Past research has suggested relatively rare use of assistive technologies for psychosocial disabilities [54,105]. For example, a survey of assistive technology use amongst almost 2,000 individuals with disabilities found that those with psychosocial disabilities were less likely to report using assistive technologies than those with other disabilities [54]. The authors acknowledge that the survey may have lacked appropriate prompts for assistive technologies specific to mental health but note that few individuals reported using “other” assistive technologies for psychosocial disabilities (a few used noise canceling headphones or a day planner).

In recent years, accompanying the tremendous growth in personal computing devices and internet access, we have seen advancement in a range of computerized and internet-supported assistive technologies for cognitive impairments and specific mental health conditions. For example, a number of assistive technologies have targeted cognitive effects of traumatic brain injury and dementia, such as through aids to memory or wayfinding [16,49,84,104]. In the ASSETS community, researchers have studied how to support people with aphasia by using applications such as AphasiaWeb to create a specialized social network [68]. Researchers have also applied assistive technology to support children with ADHD and autism through the social use of shared screens [47,65] and social media and games [13,82,83]. Some efforts have also addressed serious mental ill-health, such as smart apartments to support independence among inpatients with schizophrenia and schizoaffective disorders, with videoconferencing allowing nursing staff to conduct “check-ins” on activities like cooking and taking medications [25]. Among individuals with autism, schizophrenia, and post-traumatic stress disorder, digital job interview simulations have also been applied as preparation to secure employment [5,42].

Digital interventions have also addressed other common mental health concerns such as mood disorders and anxiety, often translating psychotherapeutic techniques into digital form (e.g., online and app-based programs that draw on Cognitive Behavioral Therapy (CBT), a psychotherapeutic approach that helps people understand how their thoughts and feelings influence their behavior [35]). However, most of these are conceived outside of the assistive technology framework. For instance, digital mental health tools may augment or replace

treatment sessions with a clinician, and they often aim to reduce the severity of mental health conditions over time [51].

In lieu of assistive technologies, research suggests that individuals with psychosocial disabilities have appropriated a range of commercial and specialized technologies to assist with their day-to-day lives [86]. For example, individuals with schizophrenia report using music to help block or manage voices, web-based technology to identify coping strategies, and digital alarms and reminders for medication management [38]. Similarly, individuals with bipolar disorder often track their symptoms and behaviors by engaging with a range of tools that are both paper-based (e.g., journals, calendars, sticky notes) and digital (e.g., apps, spreadsheets [72,89]). Further, communities supporting children with autism have appropriated social media and computer games as platforms for play [80,82].

The ASSETS community has largely focused on physical disabilities, with less emphasis on psychosocial disabilities. This emphasis persists despite the ubiquity of mental health concerns, their substantial impact in terms of impairment and stigma, and their co-occurrence alongside physical health challenges. Where technology has been designed for psychosocial disabilities, more “severe” concerns are the focus of the literature (e.g., schizophrenia, bipolar disorder [34,72]). Therefore, this paper suggests areas where the field of assistive technology could expand.

METHODS

Participants and Procedure

To better understand how individuals with complex health needs experience and address their mental health symptoms, we recruited a group of individuals through a care management service within a large health system in the Midwestern USA. Care management programs aim to improve population health outcomes by targeting service delivery on the basis of individuals’ health status [7,40]; patients in care management often have complex health needs and/or high health service use. Participants learned of the study through an invitation letter or directly through a care management coordinator. Once in contact with the research team, interested individuals completed a short screening questionnaire to determine eligibility.

Individuals were eligible if they were aged 18 years or over; were currently experiencing symptoms of depression or anxiety, as measured by a score of 10 or higher on the Patient Health Questionnaire (PHQ)-9 [58] and/or Generalized Anxiety Disorder (GAD)-7 [95], or reported experiencing depression or anxiety within the last 12 months; and were comfortable completing the interview in English. The screening survey also included a brief set of demographic questions and questions about current mental health treatment. This study was approved by our institutional IRB.

Of the 19 participants who took part in the study, 18 completed the interview. One participant requested the interview be stopped after 10 minutes due to fatigue, and their data was not included in the analysis. The remaining 18 participants ranged in age from 33 to 88, with a mean age of 58 (SD 16.25). Eleven participants were female, 6 male, and one non-

binary. Fourteen participants self-identified as White, three as African American, and one declined to respond. Six participants reported currently receiving psychotherapy, while nine reported taking medications for their mental health. Although not directly asked, additional physical and mental health conditions were discussed by participants. In fact, patients freely described a range of complex health conditions. For example, P19, a 39-year-old female, alongside previous experiences of depression and anxiety, has type 1 diabetes, multiple sclerosis, and arthritis.

Data Collection

All interviews took place over the telephone. Interviews lasted between 30 and 60 minutes and were audio recorded with permission of the participants. The interviews focused on participants' experiences of mental health symptoms (e.g., "Can you tell me a little bit about yourself and the kinds of difficulties you've experienced with stress, depression, or anxiety?"), how they supported their mental health through treatment (e.g., "Tell me a little bit about any treatment you're receiving or have received for stress, depression, anxiety or any other mental or emotional health concerns?"), how they self-managed their mental health (e.g., "What are things you do on your own to try to manage your stress, depression, or anxiety?"), and the impact of mental ill-health on their lives (e.g., "How has that depression, anxiety, or stress affected your day-to-day life?"). Participants were compensated up to \$50 for their time.

Data Analysis

Interview transcripts were analyzed using a collaborative approach based on the thematic analysis process described by Braun and Clarke [11]. Two members of the research team immersed themselves in the data before systematically identifying individual codes through open coding of two transcripts, allowing codes to emerge from the data. The two coders then met to compare codes and arrived at a preliminary codebook through dialogue and consensus. The codebook was trialed and refined by each coder coding a further two transcripts. After a brief discussion, the remaining transcripts were divided evenly between the pair to code using a qualitative coding software program. Coded excerpts were read by both coders who then met to discuss, name, and define the emergent main themes and subthemes discussed in this paper. Validity and rigor were ensured throughout the process through emphasizing prolonged engagement with the data [10,32] and regular discussion about the codes and emergent themes [32].

Positionality and Terminology

In this work, the research team represents a variety of backgrounds including behavioral scientists, human-computer interaction researchers, and one specialized in assistive technology, all of who had prior experience working with individuals with psychosocial disabilities. At least one author of this paper has a psychosocial disability.

To clearly differentiate between the medical model and social model of disability in this paper, we refer to *mental health* or *mental ill-health* when specifically speaking within the contexts of the medical system. We use the term *psychosocial disability* to refer more

broadly to the set of mental health-related concerns and barriers as they are impacted by society, and challenges accessing the activities of daily life, as described below.

RESULTS

In this section, we will discuss three themes which emerged as participants discussed their experiences with physical and mental health concerns. We first explore the ways in which participants' physical and mental health concerns were disabling and how physical and mental health were inextricably linked. We then describe how participants framed their experiences of mental health and how, at times, others in their lives had conflicting framings. Finally, we describe how our participants cared for their mental health, including their experiences seeking mental health care.

Personal Health as a Disabling Experience

In discussing their physical and mental health, participants gave descriptions about how illness caused disability in their daily lives. Disabling experiences did not happen in isolation, but were interwoven; participants described not only how their mental health was disabling on its own, but also how mental ill-health experiences manifested as physically disabling. In this section we discuss how participants described both physical and mental health as disabling and the blurred lines between these experiences.

Disabling Physical Health—Echoing what we know of disability [14,50], participants described disabling experiences related to their physical health concerns. This experience was seen both among participants who had undergone recent medical procedures that had significantly affected their ability to perform activities of everyday life and those describing chronic health conditions. As often seen with physical disabilities [6], at times circumstances required adjustments and reassessments of what was possible in light of their changed physical capabilities. For example, P09 indicated that a recent traumatic brain injury (TBI) had *“negatively impacted her disability”* and noted that *“changes are harder to manage. Processing is worse. Noise is an issue. I’ve had a business, and certain things for my business I’ve had to change and get help with, let alone taking two years off from doing everything.”* This aligns with other ASSETS research that has found people with disabilities often adapt their environment and routines in order to accommodate their changing ability [45,48,82].

It is important to note that participants did not openly label themselves as being disabled. Rather, this came up within the contexts of describing their everyday lives. Only one participant discussed being “disabled,” and only to reject the label:

“...no, I’m not disabled. Disabled means crashed and burned, category eight damage, salvage, and only for parts. I’m handicapped. In other words, just like with golf or bowling, you give me a few strokes or pins or whatever, and I’m competitive. So, I don’t move fast, but I get where I’m going.”

(P12)

While there are many reasons our participants might or might not adopt the label of “disability,” their lived experiences still echo the challenges of being disabled in today’s society.

Disabling Mental Health—Most participants spoke about their mental health difficulties as disabling and disruptive in their day-to-day life. In line with psychological literature discussing the negative impact of mental ill-health on people’s lives [53], participants discussed the detrimental effect that symptoms had on their relationships, work, and ability to participate in everyday activities. This debilitating impact was summarized by P17 who found that her depression “*limits my ability to be productive at work, be productive at home, my ability to go out and... engage in social activities.*” Similarly, P10 described mental health symptoms that affected “*being able to go out to the grocery store, to enjoy life, taking care of the house. It took over everything.*” For some, the disruptive, psychosocial consequences of their mental ill-health were predictable and discussed as an inevitability:

“I know that I typically am not going to be taking on major events in February because I’m going to be pretty much upset or - not upset, probably depressed. So, I try to avoid doing things in February”

(P15).

Similarly, at times, participants described acute or severe symptoms that impacted their lives to the point where they were “*pretty much incapable of doing anything*” (P19).

Other participants spoke specifically about struggling to enact certain activities due to their mental health. The activities that participants struggled with often required concentration, or involved triggers for their mental health difficulties, most commonly anxiety. For example, “*it comes on in like certain large task-oriented environments. I had to go to the airport and that was a bit challenging*” (P09). Continued engagement in these types of tasks in periods of mental ill-health required planning and organization, as discussed by P09, “*my routines have to be much more regular.*” Such strategies or workarounds were developed by participants in order to enable themselves to complete required activities.

Finally, even though some participants had “mild” symptoms of mental ill-health, they still found these symptoms impacted their lives:

“I was diagnosed bipolar and I do not have the massive swings type of thing but I do experience periods of mania and then periods of depression. Never have I been suicidal, and the mania has not been outrageous, but it has impacted relationships. It’s impacted concentration, and it’s impacted my drinking because I use drinking as a way to manage some of those thoughts and feelings that I couldn’t handle.”

(P13)

This echoes research indicating that even mild symptoms of mental ill-health can be disabling [53]. However, a few participants did not describe their mental ill-health as disabling: “*Is the anxiety the type of anxiety that hinders me on, like, daily activities? I know some people it does - no it does not. But it’s not a good feeling*” (P14). In this way,

much like with physical health, most participants described the disabling effects of mental ill-health on their daily lives but did not adopt the label of “disability.”

Blurring the Lines Between Physical and Mental Health—While our participants clearly delineated between physical and mental health concerns when it came to labeling themselves as having particular illnesses, the lines became blurred as they discussed the more nuanced details of living daily with these challenges. For example, P19 said,

“I also have two autoimmune diseases, so after researching and talking to the therapist, I realized that with these two diseases that I have, they impact my life pretty dramatically and they also increase the chances of depression. ... I’m on the way to being good. I’m pretty much good, but still a work in progress.”

While their own discourse about diagnostic labels and framing these health conditions implied distinction, in practice it was harder to distinguish between these two aspects of health.

Additionally, mental ill-health often manifests in physical symptoms. For example, P16, in response to anxiety found that their *“muscles will tighten up and I don’t intend to do that. It’s just all of a sudden, I notice I’m tensed up.”* Physical and mental health both might result in disabling experiences for an individual. However, when these become intertwined to the point where mental health concerns are causing physical health concerns and vice versa, it becomes less obvious for participants where the line between the two experiences is drawn.

Understanding that physically disabling symptoms might also impact someone’s mental health was important for taking appropriate measures to care for one’s health. P08 discussed how being able to go out for walks could improve their health overall, and they needed an assistive walking device to be able to accomplish this:

“I have a rollator. You know, one of the walkers on wheels...I don’t have the independence to go out and walk...I think the concept is wonderful of walking for health, but I don’t particularly like doing it myself. But I realize that it would be so great to get outside and just walk around the block.”

In this way, an assistive device for a physical disability also became an assistive device for a psychosocial disability. This participant used walking to improve their mood along with their overall health.

Participants described disabling experiences associated with both their physical and mental health concerns. Although participants often discussed physical and mental health concerns as distinct, they, and their associated disabling effects, were often intimately interconnected.

Discourse Around Personal Health

Although disabling experiences related to both physical and mental health, participants’ discourse around their health differed when discussing physical and mental health concerns. Participants discussed physical health-related experiences and diagnoses in a matter-of-fact manner. Diagnostic labels were readily used, and participants rarely provided detailed explanation or elaborated on contextual circumstances. Indeed, existing frames for physical

health conditions seemed to match people's experiences of their physical health concerns and helped frame participants' physical health as something ongoing, but also being taken care of. Despite the range of different conditions experienced, there was little hint of stigma or reservation about disclosing physical health concerns. In contrast, when participants spoke about their mental health, they adopted a wide spectrum of framings. In this section, we explore the ways participants experienced and framed mental ill-health and how these framings influenced consideration of actions taken to manage their mental health. We also discuss the tension that emerged when others in participants' lives had alternative framings of their mental ill-health.

Framing Mental Health—Unlike discussions around physical health, participants rarely spoke about their mental health in binary terms (having or not having a condition). Instead, acceptance fell on a spectrum from rejection of a diagnostic label, “*I don't honestly think I'm depressed*” (P08), to partial acceptance “*Not depression really, anxiety off and on. The only depression is because my grandson passed away last Christmas*” (P16), to matter-of-fact acceptance, “*It really didn't occur to me until I was in my mid-20s that this was maybe something that most people didn't feel, or other people didn't experience the same kind of persistent anxiety*” (P18). The variety of ways that our participants perceived and framed their mental health reflect the recurrent, episodic nature of many mental health conditions. While all participants recognized that symptoms might ameliorate at times, some framed intermittent symptoms as belonging to a recurrent mental health condition: “*depression has been a constant companion*” (P06) or “*my whole adult life I have struggled on some level with hyperactivity, ADHD, and periods of depression*” (P13). Participants who recognized these issues as recurrent were more often actively engaged in their own mental health management, including having sought treatment through the health system.

On the other hand, some viewed the resolution of symptoms as suggesting that diagnostic labels were only applicable under specific circumstances rather than as descriptive of the entirety of their experience. For example, many emphasized the situational factors that they felt led to changes in their mood or emotion, as P15 described, “*...far as anxiety goes, it's primarily just the current economic situations and just a lot of uncertainties in the workplace, and the changes with the family and home.*” Similarly, P11 expressed, “*I really don't have - I have just like a seasonal depression or situational depression more than anything.*” In this way, some participants framed their mental health difficulties as a response to circumstantial or environmental factors.

Within this framing, the re-emergence of symptoms was hard to predict or prepare for. For example, P17 identified that specific “incidents” trigger their mental ill-health, “*But generally, there's some type of ... incident that happens that kind of tends to, I'll say push me over the edge or whatever.*” In addition, for this participant, situational framing prevented them from actively managing their mental health during periods of relative wellness and may have contributed to their inability to predict recurrence:

“I think I'm through this now. Now, I don't have to deal with this again. And then, in a year down the road or something, it happens again. And I'm like oh, wait a

minute. This is kind of similar to what happened last time, but I didn't really expect that it would happen again."

(P17)

While many participants did seek mental health support when situations exacerbated symptoms or negative moods, this pattern of waiting until their mental ill-health is severe or in crisis before seeking treatment may lead to a greater amount of time spent experiencing associated disabilities.

While study eligibility criteria were such that all participants were experiencing moderate symptoms of depression and/or anxiety or acknowledged a past experience of depression or anxiety, a handful of participants did not identify themselves as having any mental ill-health. In these cases, participants framed the difficulties they were experiencing as just a normal part of life. For example, P12: "*did I feel that I was depressed? No. I just saw these as another set of challenges I needed to meet and overcame.*" For others, their understanding of a given mental health condition did not match their personal experience, as with P07: "*it almost feels like I'm depressed, although I really don't think that's what it is.*" For the participants who felt they had not experienced depression or anxiety, others in their lives often had conflicting views of the participants' mental health status, as P08 explained, "*my daughter is certain that I'm depressed, but I don't think I am. But I don't know, you know?*" Most commonly these others were spouses and caregiving family members who potentially had insight into the participants' lives and behaviors or were medical professionals outside of the mental health specialty (e.g., primary care providers). For these participants, despite meeting our eligibility criteria, their lived experiences did not match what might be assessed and documented in a clinical context, causing a conflict between their framing and that of the health system.

Others framing of mental ill-health—Regardless of their framing of mental health, participants were cognizant that others may have a different framing of mental ill-health and that disclosures of mental health symptoms might therefore be scrutinized. That is, participants made careful decisions about who they would talk to about their mental health. One participant described, "*there's some things you talk to family about, some things you talk to friends about, and other things you're not comfortable talking to anybody about*" (P16). As part of their decision-making process, participants typically sought interactions in which they anticipated they would not be judged but understood and accepted by others. This echoes literature which has found that, within an existing network of social contacts, individuals who have mental health concerns strategically approach friends, family members, or acquaintances deemed most likely to be supportive [75].

Participants also cited specific concerns related to the expectation of encountering stigma. Considerations of disclosure often evoked fear, including "*fear of what someone might say*" (P11). Participants also feared other consequences of disclosure, such as potential negative impact on employment, or general concerns that information about their mental health could "*go against me*" (P04). These fears were driven both by past experience and observed reactions of others to similar disclosures. A few participants discussed how such concerns hampered their desires to feely request help. For example, P11 stated, "*I also wanna be able*

to say, ‘hey, you know what? I’m going through this. Can you help me?’” This strongly echoes literature suggesting major barriers to disclosure from stigma in mental ill-health (e.g., [12,29]). Concerns about stigma therefore related to how participants felt that others framed mental ill-health more generally and would frame *their* mental ill-health specifically. Further, these concerns about how others view mental ill-health can potentially influence an individual’s own framing of their mental health difficulties [24,93].

While participants were matter-of-fact when it came to discussing their physical health, mental ill-health was framed in a range of ways, some of which suggest discomfort with medicalization and psychiatric labels. Participants often contextualized their experiences of mental ill-health by providing circumstances or explanations. While some of this context was provided in response to the interview questions, it was also often unprompted, as if our participants were used to, or felt the need to, provide explanation for their experiences surrounding mental ill-health.

Caring for Personal Mental Health

As participants’ framing of their mental health varied across a spectrum, so too did their thoughts about mental health management. The medical system, under the medical model, has viewed medication and psychotherapy as the prevailing options by which to manage mental health. More recently, like the social model has for disability, the recovery perspective in mental ill-health has put more emphasis on patient autonomy and factors such as quality of life when making illness management decisions [101]. With this understanding, in this section, we explore how participants managed their mental health and whether and how the health system supported this management.

Most participants indicated a need to take steps beyond their current practices to manage their mental health. Overall, most participants reported managing their mental ill-health through contact with the health system, with psychotherapy or medication. Most participants saw value in receiving psychotherapy for their mental health difficulties. However, a handful of participants expressed that they would not engage in psychotherapy, most often due to a negative experience that left them without “*a whole lot of faith in the talking therapy end of things*” (P12). As such, for some, previous experiences with therapy did not meet their needs, or were not found to be beneficial, motivating other ways to manage their condition.

Similarly, participants varied in their openness to treating their mental ill-health with medication. Those who had a negative view of using medication for mental ill-health raised concerns about the effect it had on their quality of life or expressed concern that medication would not treat the cause of the condition, instead suggesting that, “*medications just cover up the issues and don’t get to the root of them*” (P12). Others worried about side-effects or reported that medications would make them feel not like themselves, or “*out of it*” (P18). This hesitance over medication may also be directly tied to the effects of self-stigma on these individuals—treating mental ill-health with medication means admitting to having these concerns to begin with [97].

Although participants’ views on support options traditionally associated with the medical model varied, common across all participants was the use of self-management practices to

manage their mental health and continue their engagement in daily activities. In fact, a number of participants either felt they already had the skills and resources necessary to manage their mental health or were interested in receiving additional support for these skills. Participants discussed a broad range of skills and practices for mental health self-management including exercise, being social, meditating using apps, posting reminders for themselves in frequented spaces, and cognitive exercises such as thought restructuring.

Regardless of this active management, at times participants felt pressured to try different options, and these pressures came from “*everyone, including nurses and doctors and family members and friends*”(P07). In response to the various management options available for mental ill-health, participants wanted others to respect their autonomy and to understand that they were doing what they felt was best for them, their circumstances, and goals.

Exploring views on health management options requires time to understand the goals and perspectives of each individual. However, as a whole, the healthcare system was perceived as overstretched and unable to dedicate the necessary resources to participants’ unique needs. P18 described, “*I never really got the feeling like I was actually being listened to.*” Within this strained system, many still sought acceptance of their mental health concerns, in the form of validation and understanding. To support this, participants suggested an adoption of a more holistic view of the patient within the healthcare system. For example, P14 wanted the care system to see the “*whole picture*” and proposed that richer contextual information about individuals could allow providers to “*see more of the patient than just the numbers.*” However, this picture is only gained through recurrent, engaged contact with patients in which they can share *their* personal experience of mental ill-health.

Common across all participants was the use of strategies and skills to manage their own mental health in order to participate in the activities of daily life. However, when it came to interacting with the health system to support their mental health, participants expressed varied opinions about the acceptability of treatments, especially psychotherapy and medication. Participants also observed that there were limited resources in the health system, impeding providers’ holistic understanding of the participants’ condition.

DISCUSSION: ASSISTIVE TECHNOLOGY FOR PSYCHOSOCIAL DISABILITY

Understanding how individuals are disabled by their mental ill-health, how they frame their discourse of it, and the ways in which they care for their mental health all point to how we can shift the view of mental ill-health beyond the medical model to support individuals and their goals. We now expand on ideas of moving the field towards a more holistic view of the individual with disabilities, unpack the social context of psychosocial disability, and outline design considerations for assistive technology for psychosocial disability.

Towards a Holistic View of the Individual

Although physical and mental health were conceived of and discussed differently from each other, our results indicate that they were deeply intertwined. Consistent with the biopsychosocial model of health [9,31], participants described how strategies for managing mental ill-health were impacted or impeded by physical disability (e.g., inability to achieve

mental health benefits of walking due to physical limitations), and how the management of physical health conditions was influenced by psychosocial disability (e.g., reduced control of blood glucose levels due to anxious eating). Despite this interconnectedness, physical and mental health are still largely conceived as distinct. The siloed nature of the medical system exemplifies this distinction. Similarly, there is a dearth of research, within ASSETS and also more broadly, on how technologies can simultaneously support physical and psychosocial disability.

To address this disconnect, efforts to integrate mental and physical health care are increasing within medical health systems (e.g., integrated and collaborative care) [44,46]. Within mental health research, interventions or strategies aimed at increasing physical health and supporting the self-management of mental health have been recommended to reduce physical and psychosocial disability [43,69]. However, these approaches are grounded solely in the medical perspective, which, as we will discuss further below, can be problematic. In response, not only should the ASSETS community begin to focus on assistive technology research and design within populations experiencing psychosocial disability, but ensure that assistive technology research studies are designed to also consider the mental health of individuals with physical disabilities and the impact assistive technologies may have on associated psychosocial disability. To do so, an understanding of the discourse and framing of mental health and how it is influenced by social context is critical, and discussed in the following section.

The Social Context of Psychosocial Disability

Using a social model of disability to understand the disabling effects of mental ill-health allows us to explore the various ways in which individuals are impacted by their psychosocial disability. How individuals frame and label their experiences occurs in, and is influenced by, the social context in which they live. Further, departure from the medical model expands our view of the difficulties associated with mental ill-health beyond symptoms to the impact these conditions have on individuals' daily lives, as influenced by social context.

The social model and prior research suggest that stigma is one social factor that contributes to an environment in which individuals may be hesitant to disclose symptoms or adopt labels in regard to mental ill-health and disability [20,88,100]. In our study, stigma explicitly influenced to whom our participants chose to disclose their mental ill-health, with many expressing fears of negative reactions from others. This deliberation about disclosing mental health issues extended to participants' relationships within the health system, as they carefully considered how and when to manage their concerns. In this way, societal pressures can impact how individuals make decisions about their own care and support, and who they reach out to. Moreover, who, and under what circumstances, they choose to disclose mental ill-health may impact individuals' abilities to receive appropriate accommodations for their circumstances, thus increasing associated psychosocial disability [77]. This could have far reaching consequences as individuals with psychosocial disabilities may experience a spiral of negative feelings and isolation the more they hide their experiences, including low self-

esteem, shame and anxiety, and hesitance to pursue social and personal ambitions [20,22,99].

More subtly, self-stigma can also occur as individuals with stigmatized identities come to internalize public stereotypes and attitudes about their identities [23,59]. Self-stigma may have influenced how our participants related to psychiatric diagnoses, including their openness to adopting medical labels, and how they framed their mental ill-health. Although both physical and mental ill-health were described as having disabling effects on their daily lives, participants spoke very differently about these two elements of health. While medical terms were readily and comfortably used when participants discussed physical health, participants appeared much less at ease adopting diagnostic labels for their mental ill-health. Instead, participants described a deliberative process of determining whether a given mental health label fit their experience. As such, the application of labels and their framing of their mental health difficulties was fluid over time, in response to symptom change. Thus, stigma and the chronic, cyclic nature of many mental health conditions likely influences individuals' relationships to labels as well as how they frame their health. This is similar to work highlighting those with episodic physical disabilities who only need to use assistive devices some of the time (e.g., a person who only needs to use a wheelchair for longer journeys, but not around the office or house) [33,61].

In addition to stigma and societal pressures, individuals with psychosocial disabilities are often faced with the fact that these disabilities are, by and large, invisible. This invisibility can lead to concerns that one's behavior might be perceived by others as erratic and creates pressure to disclose one's disability to every new person in charge of their care.

Interestingly, despite speaking of disabling effects of both physical and mental health concerns, the majority of participants did not bring up or seem to identify openly with the concept of "disability." They did not use the term when referring to the impacts of their health conditions on their lives. Like in physical disability [91,102], there is a wide variety in the experiences of psychosocial disability. While some form communities and cultures around their disabilities (e.g., autistic communities [57,81]), others experience their disability as an illness that needs to be treated, or even cured, in order to live a "normal" life. In addition, perhaps the universality of the symptoms of depression and anxiety impacts their recognition as disabling, or even as a sign of mental ill-health. Rather, individuals may assume the moods and thoughts they are experiencing are a result of their life circumstances and just try to "get through it." What is clear is that we do not yet fully understand the interplay between these various labels (e.g., psychiatric disorders and disability labels). While adopting labels may facilitate access to services, it may also make individuals subject to stigma. No matter the reasoning behind the labels and identities these individuals with psychosocial disabilities have adopted, this does not lessen the impact of these experiences on their daily lives. Researchers and designers need to meet people where they are and allow people to adopt their own language for their experiences.

For ASSETS researchers moving into this space, our results indicate that avoidance of medicalized terms in favor of allowing individuals to explain and label their own experiences is vital. This includes being conscious of how the research is framed and presented. It is also

important to recognize that these experiences are dynamic; when bringing together support for physical and mental health conditions, single discussions and assessments for mental health needs are likely not adequate to capture the whole picture. The social context and the cyclic nature of mental ill-health both affect individuals' framing and understanding of their experience. Viewing mental ill-health through a social model lens as a psychosocial disability allows us to move towards supporting these individuals with technology designed to enable their goals and aspirations.

Design Considerations: Towards Assistive Technology for Psychosocial Disability

To conclude this discussion, we bring together these themes and tensions to illuminate some considerations for researchers and designers working towards assistive technology for this population. This includes: viewing the whole person beyond a medical context; reframing research and design to match user experiences; and moving away from a medical model lens of psychosocial disabilities.

Viewing the whole person beyond the medical context.—Our findings indicate that the complex co-occurring nature of physical and psychosocial disability should be recognized, such that ill-health is viewed holistically. Such an understanding requires health professionals to gather and understand rich contextual information about individuals, as would likely occur through recurrent, engaged contact in which individuals can share *their* personal experience of their physical and psychosocial disabilities. Assistive technologies could support this interaction by facilitating documentation of patterns and experiences occurring outside of health appointments, potentially contributing to care providers' understanding of lived experiences of both mental and physical ill-health, and their interrelationship, and informing clinical conversations that are more person-centered and responsive to impairments in daily life [19]. Recognizing that stigma may also impede these conversations, technologies could aim to empower individuals to speak about their psychosocial disability within the health system and more broadly. In the physical health domain, some research has explored how individuals with invisible disabilities manage demands to repeatedly disclose their disability [94], as well as how this might impact the design of assistive technology [33]. For example, assistive technology may help disclose or partially disclose a disability in order to help a person gain access or get support from people around them as needed (e.g., business cards explaining a psychosocial disability [33]). In addition, technologies could support individuals gaining skills and experience relevant to disclosing a psychosocial disability, for instance through simulations of conversations with health providers, or by facilitating peer-to-peer communication so that individuals gain positive initial disclosure experiences that empower them to disclose further [18,66].

Reframe research and design to match user experiences.—Given the variety of ways that individuals with psychosocial disability use and view labels, and the numerous factors that influence these framings, designers of assistive technology must be mindful of how resulting tools are introduced to target populations. Framing in terms of “wellness,” for example, rather than mental ill-health or psychosocial disability may increase acceptability. It will also be important to frame technologies such that they appeal to individuals when they are not actively symptomatic, but when they might nonetheless maintain their good

health through self-management. Within this exploration of framing, there is opportunity to meet individuals with disabilities where they are and find rhetoric and labels that work for them, rather than adopting a top down application of labels from the medical model. Future research might more directly investigate how individuals make decisions about adopting labels related to psychosocial disabilities and mental health diagnoses.

Moving away from a solely medical model of psychosocial disabilities.—Within the assistive technology community, tools to support those with psychosocial disability are rare [60]. However, within behavioral science, interest in the use of technological tools to support mental ill-health is rapidly expanding. Digital mental health is the use of information and communication technologies to improve mental health [35,69,89,106]. However, the majority of digital mental health tools are developed to address mental health concerns from a medical perspective (i.e., a focus on psychopathology and symptom control [1]). By viewing technology through this purely medical lens, designers may overlook opportunities for technologies to enhance rehabilitation related to functional roles, learning to live with mental illness, and achieving a desired quality of life. In order to find common ground in medical and social research and design for people with disabilities, we propose bringing the medical and assistive technology communities together to learn from each other [8]. Adopting a view informed by a psychosocial model may suggest different outcomes of concern, centering the experiences and values of the individual with a disability.

CONCLUSION

Our participants were flagged as having difficulty with their health care due to experiencing multiple, sometimes recurring, illnesses and impairments. Results from this work have shown that, in order to assist people—especially those impacted by multiple disabilities—we must create more holistic support systems for them. Researchers in medical fields, such as behavioral health, have done a great deal of work in creating support, tools, and care for individuals with psychosocial disabilities (e.g., [39,62]). And, in fact, some assistive technology has been based directly off this work [89]. However, more work can be done to help merge a social model view of psychosocial disability with this work in medicalized fields. With a social lens, creating assistive technology for people with psychosocial disabilities can be supportive, empowering, and will re-center people with disabilities, allowing their experiences to be the catalyst of technological change.

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CSS Concepts

- **Social and professional topics~ People with disabilities;** • Human-centered computing~ Empirical studies in HCI; • Human-centered computing~ Collaborative and social computing.