

Design Opportunities for Mental Health Peer Support Technologies

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ABSTRACT

Barriers to accessing mental health care leave the majority of people with mental illnesses without professional care. Peer support has been shown to address gaps in care, and could scale to wider audiences through technology. But technology design for mental health peer support lags far behind tools for individuals and clinicians. To identify opportunities for design, we interviewed 18 people with a diverse range of mental illnesses about their use of technology for peer support, and invited them to design technologies that could improve their experience of peer support. We found that technology could enhance peer support for mental health by: (1) matching peers on similarities beyond diagnosis; (2) enhancing accessibility; and (3) proactively mitigating risk through training and intervention. We discuss these findings in the context of the broad peer support literature, and present design opportunities for making mental health peer support tools empowering, accessible, and safe.

Author Keywords

Mental health; mental illness; online community; social media; behavioral interventions; peer support

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous

INTRODUCTION

Mental illnesses affect as many as 1 in 5 American adults [7]. Demand for mental health care substantially exceeds supply of care providers, with a ratio of 1 psychiatrist to 30,000 people in need of care in some areas¹. One of the most promising ways to meet the demand for mental health care is through **peer support**—involving peers who have experienced and are recovering from mental illnesses as providers of care. Peers’ positions as role models with firsthand experiences of disability, stigma, and recovery

provides hope to people with mental illnesses, and enhances their engagement in self-care [17,35]. Moreover, peer support transcends traditional health care delivery settings, making it especially appropriate for outreach to minority and underserved populations [20]. Such peer support can take many forms, including the many-to-many interactions that take place in online health communities, as well as the one-to-one relationships that are facilitated through peer matching services.

Technology has played a role in facilitating mental health peer support through crisis telephone lines, online communities, and social media. However, technology design for peers to help each other lags far behind the design of interventions for individuals—such as online cognitive behavioral interventions—despite substantial evidence that peer support is effective and beneficial for long-term recovery [19,26,60,66,79]. Human-computer interaction researchers and designers are well-positioned to design technologies for and *with* mental health peer supporters to create tools that enhance collaborative strategies to address the unmet need for mental health support.

To better understand the roles, risks, and opportunities for technology in mental health peer support, we conducted a design activity and interview with 18 people who have mental illnesses and use technologies (e.g., phone, video, SMS, online forums, and social media) for peer support. Participants were between the ages of 22 and 68, and had a range of mental illnesses, including bipolar disorder, anxiety, schizophrenia, depression, Posttraumatic Stress Disorder (PTSD), and eating disorder. Our sampling of diverse diagnoses enabled us to see patterns of technology use across mental illness experiences, and to include people with multiple diagnoses who represent almost half of people with mental health issues [38]. Participants shared their experiences of current technology use for peer support and designed technologies that would help them connect with peers. This mixed-method approach helped us to gain insight into the peer support strategies, values, and unmet needs of people with mental illnesses.

In this paper, we present findings of how people engage with technology for mental health peer support without

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¹ <http://www.hrsa.gov/shortage/>

involvement of therapists and traditional health-care providers. We identify opportunities for designing technology to foster peer support for mental health that are unique from other peer health communities: enabling peers to match based on fine-grained in-the-moment characteristics, making support accessible through various media, and mitigating risks of self-harm and stigma. We contribute a detailed understanding of how to design for these opportunities to address gaps in mental health care and empower peers to support each other. Our contributions are:

1. An in-depth description of how and why people use technology for mental health peer support, across a range of experiences of living with mental illness.
2. Design opportunities based on our analysis of participants' experiences and their sketches of envisioned technologies for making mental health peer support tools more empowering, accessible, and safe.
3. Explicit connections between our design considerations for online peer support for mental health and an assessment of how they are similar and different from existing research on online communities.

RELATED WORK

In this context, we use the word **peers** to mean individuals living with similar abilities and limitations pertaining to their health conditions; specifically, people with mental health challenges. Hartzler et al. [31] define and distinguish expertise of patients and clinicians as serving different but important informational needs for patients; the former being "experiential knowledge gained from personally managing day to day experiences of illness," and the latter being "knowledge gained from professional training and practice." Peers with mental illnesses share their experiential knowledge with each other to gain insights, emotional support, and hope [18,44].

Peers have played various roles in mental health care delivery, from organizing mutual help groups to occupying traditional roles in clinical settings [19,69]. Peers were declared essential to the future of mental health care in the U.S. in the President's New Freedom Commission on Mental Health [33]. Referred to as "peer supporters," "peer specialists," and "consumer-providers," peers in mental health care are individuals who are in recovery, and "can offer assistance and support to promote another peer's own personal recovery journey" [35]. Peer interventions, *across a range of mental illnesses*, have a greater or equivalent effect on treatment outcomes than usual care or alternative treatments, including reduced frequency and duration of hospitalizations, reduced symptoms, improved prosocial behaviors, and better treatment engagement [10,66,69,73,78]. Moreover, peer-provided services are well-attended by clients from ethnic and racial minorities [37,64] who are underserved by status quo services [8].

People with mental illnesses value technology for support. For example, a recent survey found that people with

schizophrenia rated texting and phone calls as the most useful technologies for getting social support from family, friends, and peers [27]. This survey also revealed that technology use by people with schizophrenia and psychosis is comparable to that of the general population, and suggests that their attitudes toward using technology are generally positive [27]. In addition, attitudes toward the use of mobile phone interventions for mental health have been positive, and these interventions are expected to become more important in people's recovery journeys [25]. More work is needed to best take advantage of mobile technologies for use among peers to achieve mental health goals.

Beyond the use of texting and phone calls for support, people with mental illnesses go online to find peers. Online peer support communities are beneficial in management of illnesses such as breast cancer [14,31], rare diseases [43], and epilepsy [32]. Mental illness is no exception. Peer support is a primary motivation for people who go online for mental health [59]. Peers find each other in online communities for mental health conditions to seek information, emotional support, and advice [6,16,29,42,58]. People with mental health conditions often prefer going online for support because of the benefits of anonymity and convenience [34,49,58,59]. However, research suggests that participating in online communities for mental health can be distressing, even when people report having positive experiences [36,63,70]. Evidence of online interactions between peers with depression show that people have negative experiences with unsupportive members, negative content, and conflicts of beliefs [42].

Moreover, people who have the goal of going online for emotional support experience a tension between self-presentation and help-seeking [39,53]. Seeking emotional support requires sensitive disclosure, anonymity, and more *implicit* rather than explicit requests for support [6]. Such sensitivities are especially true in the mental health domain wherein stigma deters people from seeking help [5,62]. Sometimes these sensitivities can result in lurking in online communities, rather than actively asking for support or disclosing personal issues, such as was the case of veterans who also faced mental health challenges transitioning back to civilian life [67]. Although previous work shows that people are motivated to seek peer support for mental health, research from an HCI and CSCW perspective is necessary to help understand how to help people achieve the benefits of peer support for mental health without the potential drawbacks, and what role technology can play in facilitating successful support.

Many digital interventions for mental health care focus on solitary use or use with clinicians [2,24,45,46,50,55]. Several systems provide an aspect of peer support, but often that support is either moderated or facilitated by health care professionals. For example, Lederman et al. [39] designed the first online social therapy featuring peer support integrated with psychoeducational content in a closed social

network moderated by clinicians. They designed this moderated online social therapy to ensure safety, clinical efficacy, and supportive accountability among its members. Peer support combined with a behavioral intervention is also found in MindBalance [21], where peers can comment on and “like” psychoeducational content, and Koko (itskoko.com), where peers compose positive alternatives to each other’s negative thoughts [51]. Alvarez et al. [1] piloted an online support tool (HORYZONS) that includes both professional and peer support for individuals with schizophrenia. They found high engagement in the use of the peer-to-peer social networking features. Interestingly, 85% of the patients considered it beneficial to include peer moderators who were previous users of the tool, and 90% reported wanting to become online peer moderators. Furthermore, a plethora of online chat-based websites are connecting peers to relieve negative emotions in conversations, such as 7 Cups of Tea (7cups.com) and Blah Therapy (blatherapy.com). However, attrition rates limit the effectiveness and success of these online tools [3]. Understanding the factors that influence adoption, use, and abandonment of such tools could provide valuable insights to improving engagement and participation in peer-based interventions online.

Finally, design guidelines for mental health technologies primarily target the design of systems for individuals or client-clinician interaction [15,22]. Some research has provided insight into the tradeoffs of designing for peer supporters, such as tensions between privacy and social connection [21], and between inclination toward positive self-presentation and necessity for honesty and disclosure [39]. However, more work is needed to understand design considerations for enabling peer support in online mental health systems, particularly research that engages people with mental illnesses as designers. Previous work has conducted focus groups and pilot studies in formative stages of design. In contrast, research that engages peer supporters in sketching and design ideation is likely to be particularly fruitful for generating designs that reflect the needs and values of these stakeholders.

Overall, prior work raises important questions about the role of technology in mental health peer support, the challenges of using technology among peers with mental illnesses, and the opportunities for designing tools that enhance peer-to-peer mental health care. Our research goal was to answer these questions and to broaden the understanding of technology use for mental health support beyond solitary or clinician-mediated internet use.

METHODS

Participants

To answer these questions, we recruited participants with a range of mental illnesses who used technology for peer support. People with mental illnesses can be wary of participating in research because of their experiences with stigma, marginalization, and oppression [74]. To build trust

and gain access to participants, we used a referral sampling technique whereby gatekeepers who established our trustworthiness and who controlled access to mental health peer support communities spread the word to individuals in their peer support networks. We contacted gatekeepers through an organization for mental illness and through in-person peer support groups in a large metropolitan area. The inclusion criteria approved by our Internal Review Board stated that participants had to be 21 years or older, and had to use technologies for mental health peer support. Word of the study spread to diverse networks of peers of both younger and older adults, yielding a sample with an age range of 22-68: ($M=42.8$). We included diverse gender identities: 10 male, 6 female, and 2 gender queer/transgender. Participants self-reported diagnoses of mental illnesses. Table 1 summarizes these conditions, and the key characteristics and treatments as described by the National Alliance on Mental Illness [52].

Many diagnoses have overlapping symptoms and treatments (see Table 1). Comorbidities with different mental health conditions, multiple diagnoses, and struggles with misdiagnoses are common among our target population [54,57]. For example, in a national survey of the prevalence of co-morbidity in Americans with mental illness, 45% had 2 or more diagnoses [54]. Also, social challenges such as stigma, withdrawal, and loneliness, as well as needs of peer support are common across mental health conditions, which is the focus of this study. Therefore, we recruited participants and analyzed our data across conditions. We also did not measure or report on the severity of these conditions for our participants as the same individual may experience exacerbated symptoms at some points and function comfortably at others.

Participants also had other comorbid health conditions that they mentioned affected their access to technology and support. These include physical impairments ($N=3$), hearing impairments ($N=1$), substance abuse ($N=2$), and Autism Spectrum Disorder (ASD) ($N=3$). Two participants experienced psychotic symptoms and three struggled with cognitive impairments (such as confusion, difficulties with memory and comprehension), which they specifically reported as interfering with their technology use.

Ethical considerations

Our participants face high risk of disclosure of identifiable information, and we need to be mindful of participant experiences and perceptions of societal stigma and respect their confidentiality. Therefore, we refrain from listing participants’ potentially identifiable details—such as illness, comorbid condition, age, and gender—in our summary tables, rather we provide pooled data. In this paper, we use pseudonyms when reporting participant quotes. We also do not provide individual details of participant diagnoses and demographics in the quotes to protect the identity of our participants. However, we stay true to the data pertaining to our research questions and describe technology use and symptoms experienced by the participant as context.

Study Procedures

We conducted six face-to-face interviews in people’s homes, eight at their peer support group meetings, three in a university setting, and one interview over the phone to accommodate the participant’s request for feeling comfortable during the interview. An American Sign Language (ASL) interpreter was present at one interview with a participant whose first language is ASL. Interviews began with a short survey of the types of tools used for peer support and demographic information. Interviews focused on a discussion of the tools the person used to give and receive peer support, their positive and negative experiences of using tools for peer support, and their reasons for avoiding tools.

After this discussion, participants were prompted to imagine a tool that would help someone with a mental health challenge to participate in peer support. This design activity was intended to elicit the motivations, needs, and values that should influence design. Participants were asked to complete a worksheet about the features, users, and values relevant to their design idea, and then use the pens, pencils, and markers provided to sketch their tool. Finally, they were asked to write a short scenario when the tool would be used. This activity was based on Woelfer’s method of engaging people who are marginalized in design [77].

All interviews were conducted one-on-one with the first author. Interviews lasted between 25 and 112 minutes; short interviews happened in 8 cases when participants had already completed the design activity ahead of time during the peer support group meeting where they were recruited. The participant who interviewed over the phone emailed her design to the first author. Participants were given \$25 cash for participating.

Analysis

We analyzed the transcripts using an inductive approach [65]. First, to derive codes representing dominant concepts in the data, the first author read and coded through each transcript. She then clustered related codes into overarching categories using an affinity diagramming approach, wherein she arranged coded excerpts printed on strips of paper into piles according to similarity. To validate the coding scheme, she iterated on the affinity diagramming with the second author – an independent researcher, who was not involved in study design or data collection but who has volunteered in peer support groups for mental health challenges. The categories that emerged from our affinity diagramming served as a set of codes that we used in a second round of coding the transcripts. Discussions were conducted with all authors at every stage to further ensure validity.

| Mental illness | N | Characteristics | Common treatments |
|--------------------------------------|---|--|---|
| Schizophrenia | 5 | Hallucinations; delusions. Negative symptoms often include being emotionally flat or speaking in a dull, disconnected way; Cognitive issues/disorganized thinking. | Antipsychotic medications, psychotherapy, electroconvulsive therapy |
| Bipolar disorder | 4 | Unusual and intense shifts in mood from extreme highs, to extreme depression. Manic episodes can include hallucinations and depressive episodes can include social withdrawal. | Antipsychotic medications, mood stabilizers, antidepressants, psychotherapy, electroconvulsive therapy |
| Eating disorder | 2 | Severe disturbances to a person’s eating behaviors, often with obsessions with food, body weight, and shape. Can include low self-esteem. | Antidepressants, anti-anxiety medication, psychotherapy, nutritional counselling |
| Dissociative identity disorder | 1 | In response to trauma, significant memory loss of specific times, people and events; a sense of detachment from emotions, and a lack of a sense of self-identity. | Psychotherapy, eye-movement desensitization and reprocessing |
| Depression | 4 | Changes in sleep, appetite, concentration, energy. Social withdrawal. Feelings of hopelessness and low self-esteem. | Antidepressants, antipsychotic medications, mood stabilizers, psychotherapy, electroconvulsive therapy, light therapy |
| General anxiety | 4 | Persistent, excessive fear or worry in situations that are not threatening. Avoidance and social withdrawal. | Anti-anxiety medication, psychotherapy, exposure therapy |
| Posttraumatic Stress Disorder (PTSD) | 3 | Intrusive memories, avoidance, dissociation, hypervigilance, changes in sleep, concentration, energy. | Antidepressants, antipsychotic medications, mood stabilizers, psychotherapy |

Table 1. Mental illness diagnoses of participants with characteristics and common treatments as described by the National Alliance on Mental Illness [52]. N is the number of participants. Three participants self-reported multiple diagnoses.

FINDINGS

Overall, we found that participants used a variety of technologies for mental health peer support. Table 2 summarizes types of technology used by participants and age range of individuals using them. The most prevalent technologies used among our participants were Facebook (N=9) and online communities (N=8). Most technologies were used by all age ranges. Snapchat (N=2), however, was not used by participants over 30 years of age and participants under 33 years of age did not use phone calls. We did not observe trends in technology use by mental illness in our sample—all technologies were used by participants with different mental health issues.

We identified four major themes from our analysis: (1) peers access just-in-time support through technology; (2) peers are empowered by technology to define themselves beyond diagnostic labels; (3) peers value accessible communication channels; and (4) peers find it challenging to manage digital risk. We describe each theme, and include examples of design sketches from participants.

Peers access just-in-time support through technology

Participants used a variety of technologies for peer support as a just-in-time lifeline during crises and in times of isolation. The all-hours availability of peer support through technology proved essential. For example, Terry explained how he uses Facebook when he's depressed: *"It could be three in the morning, and you're lonely, and you're feeling bad and may be suicidal. And you can turn on the laptop and you can chat with people all over the world, where it's the middle of the day."*

The global reach of technology also helped Sarah connect with a peer in Brazil at a crucial moment. She was having a relapse in symptoms, and went on Skype to see if her peer was online: *"One time I remember is that I was sort of in a lapse. I just hadn't eaten anything all day. And then it was 9:00 PM. And then I'm on Skype. And then he messaged me online, and it's actually like 3:00 AM in Brazil or something. But he stays up all night 'cause his PTSD. He can't sleep."* In another example; Sue described the global reach of technology as *"excruciatingly crucial"* to communicate with the outside world because of her situation of being restricted by lack of resources in a rural area: *"I was living in a really rural area. And the resources I need, they're very limited. But when I found people in Australia and people in Africa and all over the world that were sharing these common experiences, it really, literally opened up my world."*

Fred, who was dealing with depression and anxiety, found that technology enabled low-barrier connection to peers he knew locally, and used phone calls with a peer to meet his need for support at a crucial time in the morning: *"It just was such a lower barrier, and you don't need to get in the car or whatever. So the fact that you just get on the phone and do it – that's pretty amazing. It opened up the opportunity for things like having a counseling session first thing in the*

| Technology | N | Age range |
|-------------------|---|-----------|
| Facebook | 9 | 22-68 |
| Online forum | 8 | 24-63 |
| Texting | 7 | 22-68 |
| Phone call | 6 | 33-68 |
| Email | 5 | 24-68 |
| Instant messaging | 4 | 22-68 |
| Blogs | 3 | 22-68 |
| Video call | 3 | 22-63 |
| Snapchat | 2 | 22-30 |

Table 2. Technology used by participants for peer support. All participants used more than one technology.

morning. I had a series of them with a friend that, literally just, first thing in the morning, 7:30 AM, you have like, just a couple minutes, and you know, stuff like that's really unique because I think a lot of people have problems getting up."

Interestingly, one participant also used technology to transition to just-in-time support offline. Casey used Facebook messenger to connect with a trusted peer in the park when he was experiencing a crisis during a depressive episode: *"I was depressed. So I took off. I went to the park, and I was like, 'Hey, I know someone who goes here a lot. Let's go on Messenger.' And I found her and I sent her a message that says 'I'm at the park if you want to come over.' And she came over and we chatted. [...] So I used technology to get over a crisis, and I got together [with her]."*

Peers are empowered by technology to define themselves beyond diagnostic labels

Participants felt empowered by technology to choose peers depending on their needs and state of mind at a given point in time. Diagnostic labels were not usually perceived as the primary means for finding affinity with peer supporters. Sue described the advantages of being able to use technology to seek support beyond diagnostic labels: *"You don't have to have a referral, you can just on your own kind of scope what there is out there. There's a lot of freedom in choosing. You get to have enough power to say I don't go by that label because that label doesn't serve me. That way it lets me kind a see what fits to my life."*

This was particularly true for individuals with multiple diagnoses or challenges of misdiagnoses. For example, Sally, who went through several diagnoses by clinicians, said, *"I'm less likely to talk about a diagnosis today because I sort of feel like they're really immaterial."* Sally explained her trials with misdiagnoses: *"I had been diagnosed previously with depression. And then my first hospitalization they [clinicians] said repetitive, major depression. Previous to that it had been dysthymia. So I was diagnosed with bipolar type II after my third hospitalization."* Ultimately, Sally received a subsequent diagnosis that remains her official diagnosis to this day.

The ability to tailor peer support to changing needs and recovery orientations was highly valued. Sarah described how she would choose peers who were an exact match: *"I'm sort of more inclined to use technology rather than in-person because it lets me quickly find people who are an exact match for me. Because I have been to in-person support groups, but of course I don't really control the overall ideology of the group or the setting or who comes and who doesn't. But with the forums, I can choose to message the person whose posts I like the best."*

Yvonne explained another reason why characteristics other than diagnosis were important: *"I'd have to say that the reason I do all women [support groups] is that I think often there are things that women want to talk about such as sexual abuse or other personal things like that, that they won't talk about if there is men present. That's why I have a tendency to focus on the women's group."* She regularly connected with a group of women over group conference calls and video chats.

However, in contrast to these perspectives on seeking support beyond diagnostic labels, Clayton expressed that he would feel safer in a dedicated online support group associated with his illness, *"The importance of that is we're all delicate people and if you were on this website, you're putting your info out there and you're putting trust out there. So you need your info to be verified and you need the trust to be reciprocated 'cause you'll need to believe the advice you're getting and people need to believe what you're gonna tell them."* For Clayton, labels were an important badge of trust and reassurance that supporters were like him.

Participants' designs reflected the importance of being able to identify similar peers according to salience of need, recovery orientation, and current feelings. Sarah designed an app called *Shared Feelings* (Figure 1a) that matched peers with similar in-the-moment feelings and urges. She explained, *"people could check mark the feelings that they're having and any reasons that they think it's happening and then basically the app would match them behind the scenes."*

Similarly, Kelly designed an app called *Connect Us* that would allow users to scan topics related to life situations so that peers could organize around common struggles regardless of specific mental health challenge (Figure 1b): *"If somebody was feeling isolated or lonely or had a topic that they couldn't go to their friends or relatives to talk about it, they could go on a station and the stations would have topics like job, divorce, like life situation type thing. Then they could click on it and see if anybody's there and then they could have questions."* Her tool was a radio connected to a keyboard and screen so that the user could tune into peer conversations via audio, video, or text.

Riley created an app called *Something Fishy* (Figure 1c) that *"forms communities based on what your need is,"* that enabled peers to leverage each other's strengths: *"Basically people would sign up for whatever support they felt like they could offer. Like I'm good at making coffee for this person,*

or I'm good at whatever...So it's basically going to connect all the people to the things they need." Additionally, this tool featured automatic translation of peer conversations and posts to create access regardless of language.

Leveraging people's strengths to help each other was also emphasized by Coleen, who designed an app that matched peers on the basis of shared belief systems and goals, *"You could pull up the app to see what this person's accomplishments were, what their belief system is, how long have they been working, where did they get their training, and then they would be like, 'I think I might be a good fit.'"* This tool was more directed at finding a peer to begin a mentoring relationship, rather than a one-off conversation. Thus, participants' designs reveal that different characteristics can become more or less salient to finding similarity depending on the time horizon of support. Peers' perceived agency in finding a match was one of the most important advantages of using technology to seek peer support for mental health.

Peers value accessible communication channels

Accessibility through multiple communication channels was another reason that technology was empowering for participants. In addition to mental health challenges, several participants experienced impairments that affected their support-seeking strategies. For example, Riley is hard of hearing, and uses American Sign Language as well as speaks English. She explains, *"I think being not really in the hearing community, not really in the deaf community, computers were really how I connected with people. So I found the old AIM chat and that was the first experience [with mental health peer support]. And it was a new way to communicate. And for deaf folks and hard of hearing folks, you can't call people on the phone or don't have access to people one-on-one in person the same way."*

In another example, Alex described how technology helped him to use visuals on platforms such as Facebook to express himself: *"I have Asperger Syndrome. Sometimes people with Asperger Syndrome find it difficult to express themselves. I tend to sometimes be one of those persons. [...] Facebook and other services on the internet are sometimes very visual. I'm a person that likes to think in pictures. I really like that about Facebook."* Drew experienced physical impairments that made technology the ideal form of peer support for him: *"My husband and I are both mobility-impaired. So, we use a technology called [video chat app], and it basically is a way to gather with people of like minds...And so, we have a group of people that we kinda – it's sorta like an e-AA meeting."*

For some participants, accessibility needs varied with changes in their mental illness experience. As Kelly recovered from medication withdrawal, she found accessing peer support over the phone was preferable to face-to-face meetings: *"The [peer support crisis line] is over the phone. So that was another piece that was still part of my recovery from this. So the little steps that I was ready to do that were*

available instead of actually driving to go see somebody or being face to face yet.”

Similarly, early in her mental illness experience, Sally found it difficult to connect with people in person. She found that online connection was more accessible at that point: *“I didn't know how to reach out to people in person and was really too sick for a long time to do that. I was trying to find out how I could reconnect with people. But it had to be in a way that was safe and within the time constraint that I had, which was that in those days I did a lot of sleeping.”*

During the design activity, participants created tools that could scaffold access to peer support through different modes of engagement. For example, Fred designed an app that would allow people to slowly ramp up their engagement through the mode of listening to group conversations. He explained, *“I'm sorta picturing this tool you can enter as a lurker – just like a listener, you can at least get that safety. You're not put on the spot where you need to be doing anything actively. I think that's a barrier too – that'll make you kinda scared to participate. [...] And there's a richness in listening to other people.”*

Another pathway to engaging in peer support were tools that scaffold narrating experiences. These tools, like *The Pen* and the *Insightful Inquiry*, enabled people to express themselves, and connect emotionally. Daniel explained *The Pen* (Figure 2a), *“I mean it can take you places in your mind and in your emotions. And I think that's what's really important for a peer-to-peer is to learn to express themselves and that's why I put a pen.”* Similarly, the *Insightful Inquiry* (Figure 2b) was a tool Paul imagined could help him understand and reflect on his thoughts: *“These are diodes connected to his head and this is a computer, and [...] visualizations come through on the screen—things people see in their mind's eye then they can observe it with their physical eyes.”* He explained the advantages of this: *“Then I can make mention of things that I've observed in meditation or noticed in conversation that would prove beneficial to the [peer support] interaction.”*

Finally, Alex, who found visual information accessible, designed a tool called *Visual Connection* (Figure 2c) for video communication that enabled immediate support. *“Something like a Nintendo machine. It's something you carry in your pocket. You press it and it comes on, and automatically, the person you are talking to is right there, so the person will always have supports if they need them.”* When asked about why a dedicated tool was preferable to a smartphone, Alex replied that it was more accessible, *“some people find phones complicated to use, this is just easier.”*

These designs highlight the importance of designing peer support technologies with accessibility in mind. Participants had a range of accessibility needs and media (e.g., text, audio) preferences that shaped how participants engaged with technology for mental health peer support.

Peers find it challenging to manage digital risk

Participants had many positive experiences with using technology for mental health peer support. However, technology was experienced as risky at times. Perceived risks varied according to participants' attitudes and past experiences with online threats. Unfortunately, perceived risks often resulted in participants limiting use, avoiding, and even abandoning technology for peer support, with the consequence of furthering isolation.

Exacerbation of symptoms

Participants found it difficult to anticipate risks of reputation damage, exacerbation of symptoms, and self-harm online. For example, Clayton described how triggering content unpredictably exacerbated his symptoms: *“I have actually really a lot of problems with technology so... I mean even yesterday morning I got emails that sent me into a rage almost so I mean I think there's a lot of ways that these things could be improved, no doubt about it.”* At one point, his rage resulted in using a tone and writing content that damaged his relationship with a peer: *“I finally had a breakdown where I sent [her] a bunch of bad stuff.”*

These experiences of being triggered caused him to withdraw from technology-based support and limit his use by: *“turning it [texting] on and off kind of. Like I check texts almost like they're emails kind of.”*

Unanticipated triggering content can also result in self-harm, as Matthew said: *“I might hear something I don't want to hear from somebody and harm myself. That's generally the safety issue.”* To deal with this, Matthew limits his use of Facebook: *“I don't touch Facebook in certain situations. I'll try and just back off Facebook lately all-around.”* In one case, a participant was warned by a peer that content could trigger her because of the trauma she had experienced, as Sally explained, *“I actually had one person who had a part who warned me about further involvement with this group because of a particular kind of trauma that I have. I really heeded that.”* The stewardship of her peer supporter enabled her to avoid harm and re-engage with online support when she was further into recovery.

Safety concerns, cyber-bullying, and harassment

Participants also found it difficult to detect and thwart cyberbullying. Riley described the dangers of being invited to meet a stranger offline early in her use of technology for peer support: *“There was a little bit of trouble, too, because I would just find people to chat with. And they were – I was really young, and they were random strangers. And so one guy invited me to a university to meet him. [...] So it was a little bit scary situations that I would get myself into.”* Alex tried to be wise about false friends by being cautious with information sharing, *“I'm careful as to any information I give out. Facebook, in a way, is a bit like that. If you were to sign on to friends that aren't friends and strangers instead, that might not be the best thing. There are some, I don't know how to put it, weirdos out there that take advantage of people and that's not cool.”*

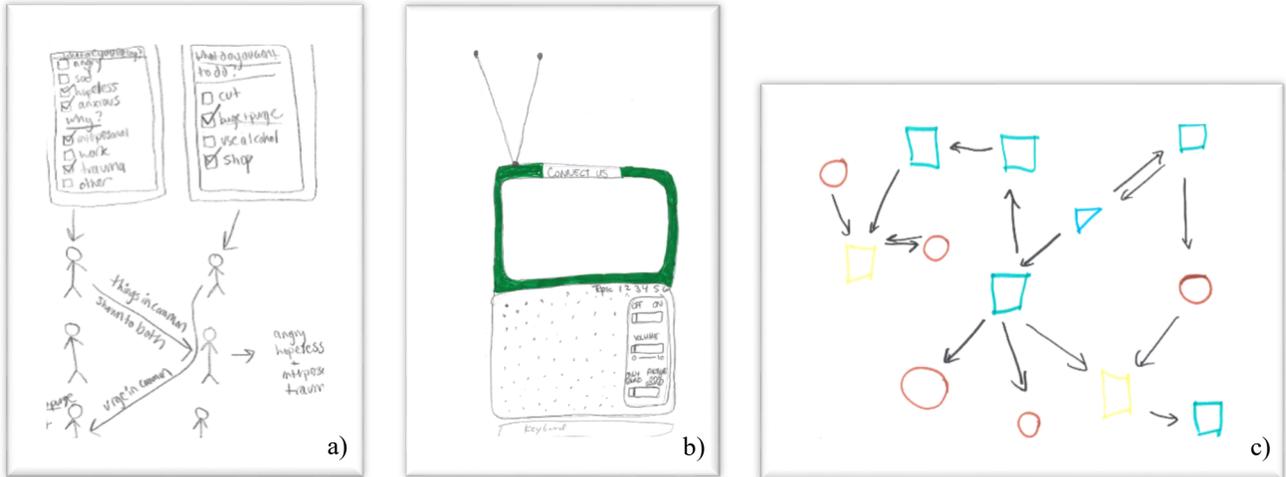


Figure 1. Designs for identifying similar peers: (a) *Shared Feelings*. (b) *Connect Us*. (c) *Something Fishy*.

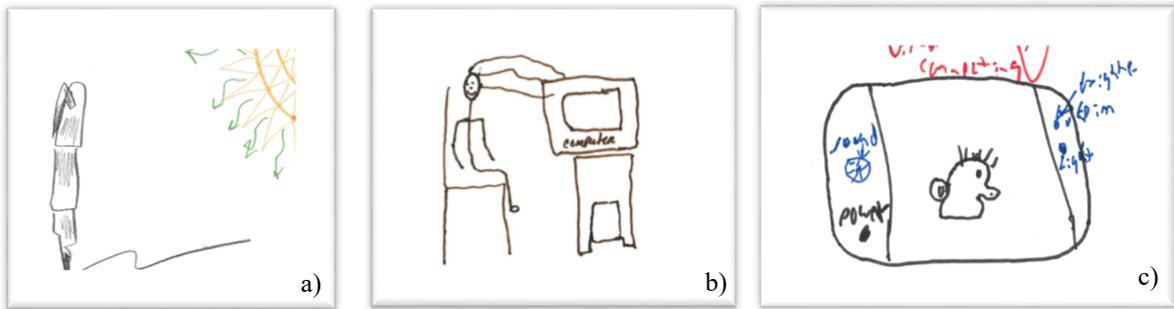


Figure 2. Designs for accessible engagement: (a) *Insightful Inquiry*. (b) *The Pen*. (c) *Visual Connection*.

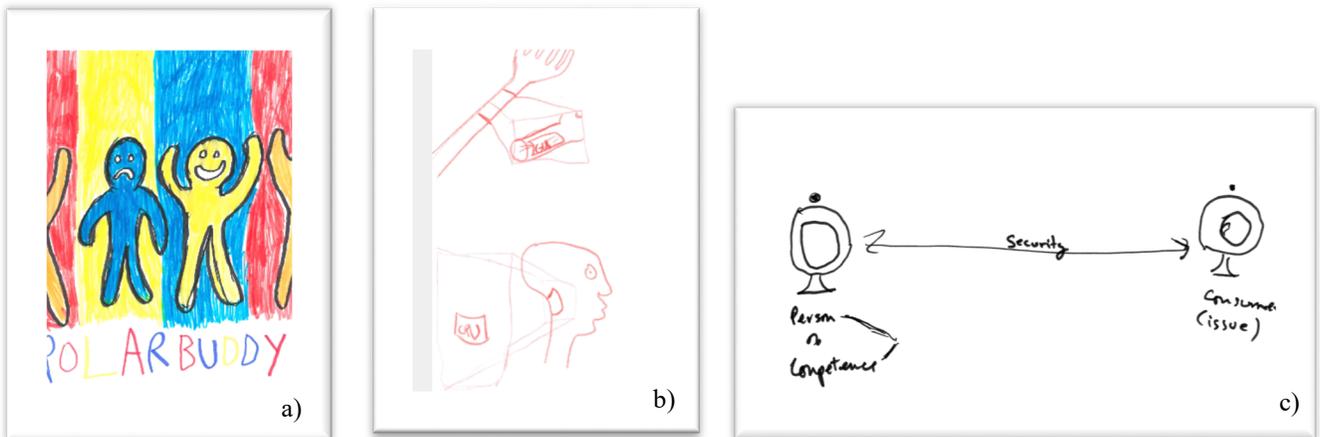


Figure 3. Designs for mitigating risk: (a) *Bipolar Bear*. (b) *Telepathator* (c) "person of competence."

Gary expressed a similar concern with being contacted by strangers on the internet: *"I don't feel comfortable talking to strangers on the Internet. I would rather talk to them in person in a safe place first so I don't get hurt and get taken advantage of."* His strategy was to find face-to-face peer support groups and use the phone to maintain relationships with peers within the group whom he trusted.

Another serious risk is explicit bullying and harassment. Terry described the consequences of trolls: *"I don't go in chat rooms much because – in fact, I haven't for about a year because there'll be some trolls in there that are trying to knock you down or making fun of you or – one thing or another, just to be pests."* Terry withdrew from the community under attack.

Sue described how the community she was a part of dissolved because of attacks: *"The people that had it [online bulletin board] there were doing it as a public service, but it was so popular they couldn't possibly moderate all of it. They didn't have enough money. They couldn't be on there 24/7. And on occasion it would get really out of hand. It'd get their attention. They'd erase things and delete things. But there was so much damage done. So, they took it down. But – so the viciousness of that was shocking. And so I got offline for quite a while."*

These experiences of cyberbullying demonstrate that online communities for mental health can become risk-prone because of attacks from people with malicious behavior who are hostile toward, or seeking to exploit people with mental illnesses. In contrast to maintaining contact with familiar peers using more personal, one-to-one technologies like texting and messaging, using online forums carries greater risk for exposure to outside threats.

Self-stigma and reputation damage

Withdrawal from digital peer support was not only a reactive risk management strategy; many participants proactively avoided using technology to manage risk. Self-stigma and shame was a common reason for proactively avoiding support-seeking. For example, Matthew talked about risk to his reputation if he sought support: *"When I do really need help, it's usually like, then I feel even guiltier, like I'm feeling bad already and then I just feel guiltier calling for help. Especially if it's a crisis.... And then, even if you do reach out and it does go well, then people kinda know like, in your circle, okay, he's kinda extreme that way."*

Similarly, Trish described avoiding support because of perceived risks of reaching out: *"I had all these negative self-thoughts happening already and so the idea of putting myself out there and then getting rejected was like I couldn't handle that. It was like, I can sort of handle me rejecting me, but I don't know how much I can handle other people rejecting me. So yeah, it just felt like riskier."*

Finally, Paul described how negative emotional contagion could put him and his supporter in a risky situation, which he preferred to avoid: *"Sometimes I'm very cautious about*

opening up on heavier things because they [supporter] might start floundering in the water and panicking and want to take me down with them. Like oh no just won't do anything fancy in the conversation. I just keep it basic." This reveals a concern for creating triggering content, that parallels the concern of receiving it, as mentioned above. Later, he added, *"There's a lot of responsibility in conversation."*

Aside from avoidance, the most common proactive risk management strategy was anonymity. Anonymity was valued highly by every participant except for Casey, who did not perceive using technology for support as risky, *"I'm just such a social guy, I put myself way out there. And that's my comfort zone. If I'm here hidden from all the – my other friends, I'm not comfortable. I need to be out there exposed. ...All my information is out there with friends. And I've stayed safe just 'cuz I'm such a nice guy. I mean, people love me. They're not going to do anything to hurt me."* Later, he added, *"I would say that there's a possibility of an issue coming up. It just hasn't happened yet."* Thus, people's attitudes and past experiences with technology risk played an important role in online safety behaviors.

Peers created designs that helped them to mitigate the risks of seeking help online. These designs enabled proactive risk identification and intervention. Clayton found it difficult to control his rage that had resulted in reputational damage online. He designed a bear (Figure 3a) that would warn him of his feelings and intervene to keep him safe: *"The anger one's the one that I'm having trouble figuring out in my life. So if I'm trying to program this guy [Bipolar Bear], maybe he blows out so much that you simmer down. I've only got through three stages of the moods and modes and then, I don't know, this guy – there should be another version that is kind of like a computerized safety net, you know?"*

Matthew designed a tool called the *Telepathator* (Figure 3b) that would read his thoughts and warn the police if he was thinking of suicide: *"Basically, it's like a computer in your arm and one in the back of your head. And they connect to your neural system, and then you could – like, telepathically call 911. 'Oh no, I'm suicidal,' or if you need help like that. It'd be like an emergency measure thing."*

Two other designs by participants addressed safety concerns. *Freedom School* by Sue emphasized training and certifying peers so that they could *"turn trauma into growth,"* and *"stop the downward spiral of the medical model."* In her vision, peers would be able to take courses through an online portal to become consumer providers, increasing their capacity to help themselves and others. Similarly, Drew focused on developing the peer as a "person of competence" (Figure 3c) who could be trusted to coach people through issues. Both of these participants had completed peer support specialist trainings and had experienced how important it was for ensuring quality peer-to-peer care.

Overall, risk was difficult for peers to manage, often resulting in withdrawing from online support. Designs that

addressed risk focused on proactively detecting and intervening risk as well as training peers to give safe and effective support.

DISCUSSION AND IMPLICATIONS

Previous work in HCI, for example [1,21,39] has featured an extensive role of monitoring or moderating by therapists in their designs. The benefits of involving therapists are many, especially from a safety standpoint. However, one of the major limitations highlighted in these studies is scalability, availability, and time burden. The aim of this study has been to provide insight into how peers use current technologies *in the absence of traditional care providers*, and how we might design technologies to better enable peers to support each other to address gaps in care.

Based on our empirical findings and the designs created by our participants, we propose the following technology design opportunities for fostering peer support for mental health. We connect these design opportunities beyond the mental health domain to prior research on peer support for online communities. Rather than an exhaustive review of peer support research, our focus is on outlining key opportunities for fostering peer support for mental health, including nuances designers and researchers should consider as they develop peer support technologies for mental health.

Matching peers on similarities beyond diagnosis

In contrast to dominant approaches that organize health communities around diagnostic labels, many participants desired tools that would help them to find peers on the basis of more fine-grained characteristics, like shared feelings, beliefs, and needs. This finding resonates with Park et al. [56] who found that patients with depression followed users on Twitter who posted content that matched their emotions.

This design consideration is consistent with recommendations from Civan et al. for patients with breast cancer [13], and Hartzler et al. for individuals with various cancer diagnoses [30], and even for caregivers of individuals with cognitive illnesses (Tixier and Lewkowicz) [71], who recommend connecting peers in online communities on the basis of similarities other than disease label. For example, Civan et al., recommend enabling peers to search for each other on the basis of treatments, side effects, health knowledge, role, and lifestyle [13]. For people with mental illnesses, recovery orientation could be an additional characteristic that is particularly salient to peers. In contrast to physical diseases—such as cancer—that convey visible signs of the disease and have objective diagnostic criteria, mental illnesses are often invisible to others and provide no clear objective diagnostic criteria or biomarkers. Thus, identification of peers within mental health communities can be more heavily based on attitudes toward recovery than strict diagnostic labels [18,40]. Moreover, some groups for mental illnesses advocate for perpetuating behaviors that *prevent* recovery, such as online pro-anorexic communities [9,12]. Therefore, helping peers with mental illnesses to

declare their recovery orientation could be important for identifying healthy and safe peer relationships.

Another salient characteristic for matching peers with mental illnesses that differs from most research on health communities, is moment of need. Many participants' support-seeking had a noticeable temporal aspect wherein "just-in-time" support was crucial. Sometimes these moments of need were unpredictable, like when Casey felt depressed and messaged a peer to meet in the park. However, some participants had regular times when it was particularly difficult to cope, such as mornings for Fred, or middle of the night for Terry. Systems that enable peers to be matched on the basis of temporal aspects of need might be beneficial for intervening at the right time.

Due to our diverse sample of several mental illnesses, we were able to observe the desire for similarity beyond labels across conditions. An important difference between our findings and previous work is the inclusion of people with two or more mental health conditions. The standard for designing and evaluating mental health interventions, including digital interventions, is to *exclude* participants with co-morbid conditions. Based on our findings, excluding these participants will negatively impact the usefulness and usability of technologies for mental health peer support. Other technology designers have raised this issue, notably Doherty et al. [21], who voiced concerns over the ecological validity of designing for unipolar depression. In contrast to previous approaches, we recommend developing tools that enable people to explore and self-organize into groups based on similar in-the-moment characteristics and pain points, in addition to broad illness diagnoses, such as depression.

Enhancing accessibility for meaningful participation

Our findings demonstrate that people with mental health challenges face comorbid physical, sensory, and cognitive impairments that change their ability and access to support. Having access to support through various media (e.g., audio, visual, textual) was essential for sustaining participation in peer support.

Many participants' designs featured alternative modes of engagement that would enhance the accessibility of peer support technologies. For example, Kelly's design *Connect Us* provided several ways to engage in the community, through listening to different topics over audio, chatting over video, or using the keyboard to chat via text. Fred's design also featured listening in over audio feeds of peer discussions as a mode of engagement that was both accessible and safe. Alex's design of *Visual Connection* featured video communication with an interface that was easier to use than a smartphone. Clayton's *Bipolar Bear* also used visual feedback, in his case, to help him mitigate the risks of getting angry online. Riley's design featured automatic translation between different languages.

Traditional approaches to accessibility in HCI and CSCW that focus on physical and sensory impairments could benefit

users with mental illnesses. Accessibility was an issue for participants experiencing temporary motor and cognitive impairments from side-effects of medications or psychosis, and more permanent hearing, physical, or social impairments. Designers could draw on approaches like Ability-based Design [76], that account for situational impairments.

Moreover, as research in the medical literature shows [e.g., [28,48,72], people with mental illnesses particularly benefit from design approaches that account for cognitive impairments. Many of our participants mentioned difficulties with writing, reading, and interfaces due to medications and symptoms. Designing for cognitive impairments is beginning to emerge as a focus in HCI [41,47] and such work should include people with mental illnesses.

Proactively mitigating risk

Many participants shared with us the benefits of spaces of peer support that technology made possible, such as online forums and social media. Some participants explicitly mentioned the importance of excluding clinicians from these spaces to preserve the agency in defining one's self and advising each other. However, there are risks, as discussed by many participants, of designing for peers only. These risks represent an important area of opportunity for technology design and future research.

Technology design could better serve people with mental illnesses to proactively manage risk. Many participants described how their mental illnesses sometimes impaired their ability to censor their words and actions, resulting in reputational and relationship damage. Usable and proactive privacy tools (e.g., [75]) could be essential for helping people with mental illnesses to assess their online behaviors, such as the tone and language of their writing, *before* disclosing potentially harmful information. Such privacy tools could help people to reduce harmful interactions and online risks resulting from intense emotional reactions. Another need for proactive tools is when people are at risk for suicide. Automated intervention can be facilitated by on-going work by De Choudhury and her collaborators on the use and development of language processing tools and predictive models for detecting suicidal disclosures in online communities [4,11]. As other previous work by Peredes et al. suggests, it is unwise to detect an emotional problem for the user without offering solutions [55]. This may be particularly true in cases where users may be at risk for harming themselves.

Additionally, it will be crucial to train peers to ensure peer support systems are ethical and safe. This point was emphasized by participants who had received peer support training, and by those who had found it difficult to know with whom it was safe to open up about issues, or who to trust for advice. For example, Sue and Drew both designed tools focused on the competency of individuals using the system, while Paul, Matthew, Trish, and Clayton raised the issue of being able to trust a peer supporter to handle difficult and

emotionally sensitive topics. There is a plethora of online psychoeducational interventions for individuals that have shown to have high efficacy across a range of mental health conditions [2,23,45]. There is also a strong tradition of training peer supporters in face-to-face mental health care settings [17,61,68,69]. Our work suggests that designing online tools to train peer supporters and enhance their skills to help each other is an important step in making it safe and beneficial to access mental health peer support online.

Beyond training peers, mitigating risk could utilize machine learning techniques that suggest salient helpline numbers, alternative behaviors based on interests (e.g., going out for a walk or listening to music), strategies based on evidence-based therapy techniques (e.g., mindfulness and cognitive-behavioral therapy), or peers available to help. Approaches that detect malicious behavior or provide features for flagging, reporting, and blocking attackers of online communities will also ensure safe spaces for peers.

Overall, usable privacy, machine learning, and peer training point to several opportunities for innovating systems that promote safe peer-to-peer mental health support. These design opportunities do not negate the involvement of clinical expertise, rather they point to next steps for designing scalable mental health systems wherein peer expertise can develop and flourish.

CONCLUSION

Technology plays an important role in peer support for mental health. Innovations in peer support tools for mental health could make a substantial difference to people with mental illnesses for whom the role of technology is "excruciatingly crucial," "essential," and "lifesaving," as some of our participants indicated. Our research advocates opportunities to build tools that enhance supportive interactions for peers by: (1) surfacing similarities beyond diagnosis; (2) improving accessibility; and (3) proactively mitigating risk through training and intervention. The contributions of this work are an understanding of the expectations, roles, and risks of technology in peer support for people with a diverse range of mental illnesses, and identification of opportunities for technology design to foster mental health peer support. One of the major challenges facing mental health care today is the lack of professionals to meet the demand for care by 1 in 5 Americans. This work represents an important first step for informing the design of peer support tools that can bridge the gap in care, and empower peers to help each other.

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