Stakeholders' Perspectives on Partnering to Inform the Software Development Lifecycle of Smartphone Applications for People with Serious Mental Illness

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Abstract

Serious mental illness is a leading disability worldwide. Partnering with people with SMI to co-design smartphone apps to support mental health outcomes throughout the software development lifecycle may support patient engagement with smartphone health app interventions. Partnering with this community is often challenging and requires a highly specialized skillset. The purpose of this study was to identify stakeholders' perspectives on partnering to inform the software development lifecycle of smartphone health app interventions for people with serious mental Illness. We conducted thirty-five semi-structured qualitative interviews with 20 mental health patients and 15 peer support specialists. We identified six themes: (1) co-produce health app intervention content; (2) selection of app technology features; (3) integration of human factors in digital health apps; (4) consideration of personalized patient preferences in digital health apps; (5) identify unrecognized concerns early in the software development lifecycle; and (6) inclusion of real-world social, cognitive, and environmental contexts. Integration of these considerations may elucidate the partnering process to facilitate engagement among vulnerable populations that commonly disengage from mental health smartphone apps use such as people with SMI.

Introduction

Serious mental illness (SMI; a diagnosis of schizophrenia spectrum disorder, bipolar disorder, major depressive disorder) is a leading disability worldwide. Smartphone application designed to support mental health treatment and offset disability for people with SMI has shown promise in clinical settings; however, when these apps are implemented in the real world they seen limited engagement among people with SMI. Partnering with people with SMI to co-design smartphone apps may support engagement and positive mental health outcomes. Partnering for co-design includes a variety of participatory stakeholder methods --- from focus groups, to community engagement studies, to community-based participatory research [1]. A rule of thumb has been the greater disenfranchisement experienced among a community, the need for a more extensive participatory research method. Berry et al. [2]

emphasize that digital tools such as a smartphone app with high acceptability and likelihood to fit patients' needs, will have to consider the end-users' perspectives to increase uptake and spread. This is of particular importance to the field of digital mental health as vulnerable groups such as people with SMI commonly disengage from digital technologies designed for health and recovery before intervention effects and improved outcomes are achieved [3-4]. Within the realm of smartphone app interventions, evidence indicates a combination of a highly involved participatory research approach and user-centered design throughout the software development lifecycle has shown promising evidence of leading to the highest levels of engagement among people with SMI [5].

However, working with people with SMI as partners in the software development lifecycle can be challenging as many this vulnerable population reports high levels of mistrust in the traditional mental health system and technologies developed for this system. This is due to the historical development of the mental health system. Briefly, after deinsitionalization on the global stage (i.e. closing state mental health hospitals), groups of patients came together in rejection of the traditional mental health system due to experiences within institutionalization to support one another through sharing their lived experience of a mental health challenge and reintegration in the community. These experiences include forced medication and restraints. As a result of this history, in working with people with SMI as community stakeholders, engaging, hiring, is all impacted, and requires a specialized skillset and approach to engage with this community in the software development lifecycle.

The purpose of this study was to identify stakeholders' perspectives on partnering to inform the software development lifecycle of smartphone health app interventions for people with SMI. The research aims to elucidate the partnering process to facilitate engagement in co-design of mental health smartphone apps. Patients and peer support specialists (i.e., peer support specialists is a global workforce of people with SMI who offer support services to patients) pose knowledge about the mental health service delivery system and they have lived experiences of mental illness which place them in a unique position to participate in the development of digital smartphone health app interventions. In this paper, we will present the study results from a qualitative interview study with mental health patients and peer support specialist. We will discuss our finding in relation to research on smartphone app interventions, address potential study limitations as well as discuss the value of stakeholder inclusion in all aspects of smartphone app technology development, including selection of app features and implementation in real-world environments.

Methods

We conducted a qualitative interview study including thirty-five semi-structured interviews (*N*=20 mental health patients and *N*=15 peer support specialists). Service user participants and peer support specialists were recruited from one community mental health center in an urban area of the United States. Agency staff reviewed case files of potential patients that met study participant criteria and discussed the study with potential participants who met eligibility criteria. If interested, an in-person meeting with research staff was scheduled on-site at the community mental health center to assess for a one-time screening, complete informed consent, and participate in the semi-structured interview. Peer support specialists within the same agency were approached by agency staff to discuss the study to gauge interest. If interested, peer support specialists were scheduled for a one-time screening, complete informed consent, and individual interviews with research staff.

Inclusion criteria and study participants

Our criteria for service user eligibility to participate in a semi-structured interview included the following: (1) participants will be adults age 18 or older with a medical chart diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, or persistent major

depressive disorder; (2) been enrolled in treatment at the community mental health center for at least 3 months; (3) able to speak and read English. Peer support specialists' eligibility included the following: (1) peer support specialist in the state of [blinded for review] (i.e., to qualify to be a certified peer specialist a person must self-report any mental health diagnosis, be in active treatment, and complete an 80-hour training that includes classes, small group activities, and homework on fundamentals of peer support, cross-cultural partnering, and human experience language. All peer support specialists must pass a written examination to become a [blinded for review] certified peer support specialist); (2) speak and read English; and (3) must provide voluntary informed consent for participation in the study.

The study sample consisted of 17 service user participants and 15 peer support specialists. Service user participants had a mean age of 51 years and were primarily men (n=12), white (n=14), and included people with a self-report diagnosis of major depressive disorder (n=5), schizophrenia, (n=4), bipolar disorder (n=4), or schizoaffective disorder (n=3). Eight service user participants reported smartphone ownership. Peer support specialists had a mean age of 40 years. The majority were female (n=10) and white (n=13). All peer support specialists had completed 80 hours of certified peer specialist training and were currently employed. All peer support specialist reported smartphone ownership.

Interview guide and data collection

The interview guide was co-produced with two peer support specialists using the Peer and Academic Model of Community Engagement [6]. The interview guide focused on topics related to perspectives on community engagement to inform the software development lifecycle of digital interventions for people with SMI. The interview guide included four broad questions and probes, including the following: *(1) what is the role of patients or peer support specialists in developing digital health app interventions? If they do not have a role, how do you think they could play a role? (2) how could you help develop digital health app interventions? (3) have you ever helped or contributed to developing a digital intervention? If so, what was your role? What was your experience in this role? and (4) Do you want to help in the development of digital health app interventions?* All interviews were conducted in person on-site and were performed in January 2019. The interviews lasted between 30-60 minutes. All interviews were audio-recorded and transcribed. Qualitative interviews were conducted until we researched the saturation of data (i.e., saturation means that sampling more data will not lead to more information related to research questions). Member checking was employed to assess validity of findings.

Research ethics

The data collection and research project were conducted following the ethical standards of the Institutional Review Board at [blinded for review] and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Interview participants were included based on their interest and willingness to participate in the study. Written informed consent was obtained from all interview participants before each interview. Participants were compensated with $30 for participation.

Data Analysis

Our data analysis was informed by a thematic analysis approach [7], which is a method for identifying, studying, and communicating patterns in the data material. The first author (blinded for review) and the last author (blinded for review) read all the interview transcripts independently to familiarize themselves with the data. The two authors assigned data-driven codes to segments of the text that represented relevant findings in the data aligned with the research purpose. The codes were collated and grouped into preliminary themes documenting reoccurring concepts or statements about the research subject. (blinded for

review) met virtually and discussed the codes, their relations to the themes, as well as characteristics to and naming of each theme. Including two researchers in the coding process is considered important for validation purposes and for broadening the breadth and depth of the analysis [8]. All authors agreed on the naming of the themes.

Results

We identified a final set of six broad themes describing patients' and peer support specialists' input on developing a digital app health intervention for individuals with a SMI. The themes include the following: (1) co-produce digital health app intervention content; (2) selection of app technology features; (3) integration of human factors in digital health apps; (4) consideration of personalized patient preferences in digital health apps; (5) identify unrecognized concerns early in the software development lifecycle; and (6) inclusion of real-world social, cognitive, and environmental contexts.

Co-Produce Digital Health App Intervention Content

The first and most predominant theme was the incorporation of lived experience in the development of digital technologies. One peer support specialist stated, *"incorporating lived experiences into a [smartphone] app and organize the [intervention] process to address lived experience because that's what it's all about".* Participants also stated their role could assist scientists in developing digital intervention content and related technology features to reinforce this content that addresses not only mental health recovery, but also overall physical health. A peer support specialist stated, "*recovery is layered; its health and wellness, it's about having access to coping skills whenever you want and need, it's about support for medication use, and it's about reducing loneliness."*

Selection of App Technology Features

According to several interview participants, patients and/or peer support specialists can assist in the selection of app features that may support individuals' personalized goals. One peer support specialist stated, "*app features that could help to reduce anxiety, for example, guided meditation, breathing exercises, or positive affirmation* [may be] *useful*." Specific features of digital app technologies presented as potentially helpful included the following: (1) reminders about upcoming appointments with service providers in primary care, mental health services, or meetings with peer support specialists; and (2) taking medications or other types of health behaviors.

Integration of Human Factors in Digital Health Apps

The interview participants considered digital health apps to facilitate human connection between patients and service providers, as needed. One peer support specialist stated, *"apps are just one more avenue to more open and a piece to add to communicating better...".* Text messaging was viewed as an easy way to connect with patients, one peer support specialist stated, "*a lot of people I work with like texting, and they use emojis and different things like that to signify what they're feeling... That allows me to communicate with them at that level, to determine whether I should go ahead and see if I can reach them by phone".* Another peer support specialist stated, *"I love group messages or group chats; you know different things like that. I try to formulate game nights and stuff because I feel like the biggest thing for people is just to feel connected with other people".*

Consideration of Personalized Patient Preferences in Digital Health Apps

Interviewees emphasized by that smartphone apps were useful supplements that were not to replace meeting in-person and personal contact. Peer support specialists and patients emphasized authenticity and fear that digital technologies could impact the authenticity of real-world interaction. One service user said, *"there are moments when you need to see that person face to face because you have so much on your mind that you can't even concentrate even texting it".* Patients expressed concerns that connecting with people, chatting, and

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messaging could be overwhelming and increase negative mental health symptoms. One service user told his way of taking control when he said, *"if they text you, you don't have to answer right away".*

Identify Unrecognized Concerns Early in the Software Development Lifecycle

Peer support specialists and patients were concerned with the protection of privacy when using digital health app interventions. One peer support specialist said, *"To use a smartphone app with a client I would want to make sure it's secure before going any further".* Another peer support specialist added, *"I think people would do it when they feel like their privacy was protected".* Interviewees were also concerned with apps tapping into contacts, apps that monitor use, and artificial intelligence that were to replace human interaction. Costs related to using mobile phone and apps, patients not interested in using apps in health interventions, users having limited experience with using apps, and digital technologies other than cell phones were other concerns.

Inclusion of Real-World Social, Cognitive, and Environmental Contexts

Of interest, participants noted the importance of developing health app interventions within the social, cognitive, and environmental needs and contexts of patients. One service user stated, "[digital technologies] *must fit with the user groups' needs, be user friendly in terms of not including too much information, as it can be overwhelming".*

Discussion

The objective of this study was to explore stakeholders' perspectives on partnering to inform the software development lifecycle of digital smartphone app health interventions for people with SMI. The themes include the following: (1) co-produce digital health app intervention content; (2) selection of app technology features; (3) integration of human factors in digital health apps; (4) consideration of personalized patient preferences in digital health apps; (5) identify unrecognized concerns early in the software development lifecycle; and (6) inclusion of real-world social, cognitive, and environmental contexts.

To develop a smartphone app that facilitates health and recovery where a key theme in our study. Our results show that the interview participants provided thoughtful suggestions for key elements to be included in an app (i.e., lived experiences, opportunities for social connectivity to reduce loneliness, appointment reminders and support for medication use, access to tools to reduce anxiety and enhance coping with symptoms, guided meditation, breathing exercises or positive affirmation). Berry et al. [2] emphasized that mobile health apps needed to include activities that are fun, positive, and foster health behaviors useful for self-management of the illness. Our results show that the interviewees perceived texting, chatting individually or in groups as useful for connecting patients with peer support specialists and service providers. A systematic review by Berrouiguet et al. [9] documents that text messaging can be used for reminders, information provision, supportive messages, and self-monitoring procedures and a combination of these features. Text-messages could be delivered after discharge to enhance continuity of care, in between counseling sessions, or function as brief counseling sessions, or deliver a preventive message to an at-risk population. Text messaging was also reported to have positive effects in terms of increased treatment adherence and symptom surveillance, increased appointment attendance, and enhanced satisfaction with care delivery.

However, our interview participants were concerned that smartphone health apps could end up replacing in-person meetings and contact. Nurses have been concerned that digital tools may reduce the quality-of-care provision by creating distant forms of communication and superficial relationships [10]. Our results suggest that health app interventions for individuals with SMI needs to be hybrid and include, for example, modules containing videos and psychoeducation and coping skills training in combination with in-person appointments with service providers, peer support specialist or therapists [1-2].

Gammon et al. [11]) developed and tested a hybrid solution combining a secure e-recovery portal "ReConnect" and real-life "ReConnect café" where the digital patients could meet socially to discuss their uses of the portal and their recovery processes. The ReConnect recovery portal also included an online communication channel [11].

Interview participants had experience in app programming and graphic designing, web page development, and marketing of digital tools. They had a personal desire to use their experiences and skills to facilitate the development of smartphone apps for individuals with SMI. Community-engaged research and participatory action research designs acknowledge that perspectives of key stakeholders (researchers, patients, peer support specialists, system developers /software engineers, and programmers) are important for a common understanding of the patients' health needs and for developing digital tools and smartphone health apps that address these needs [6,12]. Our study shows that peer support specialists and patients pose knowledge about the technology system and design process. They understand the mental health service delivery system, they have lived experiences of mental illness, and they have skills enabling them to participate in the system or software development of digital health interventions and smartphone apps. We believe this place them in a unique position for developing, refining, and tailoring the user interface and content of a smartphone app to patients' needs in a digital health intervention.

Interview participants had concerns about the use of smartphone apps in digital health interventions (protection of privacy as apps can tap into contacts and monitor the use and health-related data, users might not be interested and has limited experience in using apps as well as prohibitive costs related to smartphone and app use). When health-related data becomes easily available to patients, patients and healthcare professionals, this also entails an increased risk that sensitive information may get lost [13]. Digital health requires ethical awareness and presupposes that technology ensures users' confidentiality.

Regarding smartphone use, previous studies have documented that mobile ownership among individuals with SMI and certified peer support specialists is relatively high and that there is interest to monitor mental health using smartphone apps [14-17]. Torous et al [19] found that 97% of the 100 surveyed psychiatric outpatients reported owning a phone, 72% reported that their phone was a smartphone, and over 50% reported that they were interested in using their smartphone application to monitor their mental health regularly. In our study, 8 patients reported smartphone ownership. Mean age of the service user participants were 51 years, and thus may be less likely to own a smartphone and use smartphone apps. Interview participants mentioned that there were smartphone health apps that were costly to download and use over time and that this could limit use. Text messaging and mobile technology interventions have been described as inexpensive and less costly than physical visits [9,14]. However, the issue of costs for patients is a concern that will need be addressed when developing smartphone apps for health interventions. Digital interventions including smartphone apps that are developed for non-profit and no cost for the service user, reimbursable for professionals and peer support specialists, as well as integrated with existing services and electronic platforms will be important.

Study limitations

As most qualitative research, our findings are not broadly generalizable and should be interpreted with caution. Yet, this study offers guidance on the role stakeholders may have in participatory research to develop smartphone health apps in digital interventions for individuals with a SMI. While the sample size meets qualitative study requirements, our study sample was limited by a lack of greater recruitment of ethnic or racial diversity as well as not including family members or other mental health providers. We also used a convenience sample that was derived from one agency, within one state/one country. The diagnosis of peer support specialists is not reported on (due to their employment status and protection under the

American Disability Act). The smartphone app development phase can include a mix of data collection methods including focus groups and workshops with stakeholders over some time [12]. Usability testing including task analysis measurements and Think Aloud procedures, performed in both simulated and real-time environments are also important steps to design a smartphone health app intervention [20].

Conclusion

Community partnerships within digital health app intervention development include stakeholder preference in the integration in all aspects of the smartphone app development, including selection of app features and implementation in real-world environments. These academic/community partnerships build trust, mutual respect and facilitates future research participation in particular among vulnerable populations excluded from health research. Incorporation of stakeholders' perspectives and engagement in research may produce higher quality interventions tailored to the setting and population of interest with higher level of uptake and spread, translation and dissemination of research evidence. As the field of digital peer support is nascent, the study findings can be used as a starting point for organizations (e.g., hospitals and community mental health centers) and businesses (i.e., peer-lead or co-produced telehealth commercial start-ups or software development companies) in developing these types of technologies.

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