
Lessons from the Deployment of the SPIRIT App to Support Collaborative Care for Rural Patients with Complex Psychiatric Conditions

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Abstract

We report the design and deployment of a mobile health system for patients receiving primary care-based mental health services (Collaborative Care) for post-traumatic stress disorder and/or bipolar disorder in rural health centers. Here we describe the clinical model, our participatory approach to designing and deploying the mobile system, and describe the final system. We focus on the integration of the system into providers' clinical workflow and patient registry system. We present lessons learned about the technical and training requirements for integration into practice that can inform future efforts to incorporate health technologies to improve care for patients with psychiatric conditions.

Author Keywords

mHealth; mental health; Collaborative Care; primary care; remote symptom monitoring; post-traumatic stress disorder; bipolar disorder; depression; participatory design; CommCare.

ACM Classification Keywords

J.3 [Life and Medical Sciences]: Health.

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Figure 1. Collaborative Care Workflow

Introduction

Post-traumatic stress disorder (PTSD) and bipolar disorder cause more disability than nearly all other health conditions worldwide[2]. There are effective treatments for these conditions but rural Americans lack access due to a severe shortage and geographic maldistribution of specialty providers[17]. Thus, rural primary care providers feel obligated to manage these complex patients; however, they typically are unprepared to do so effectively. Telemedicine offers a promising method to bridge this gap and offer individualized specialty mental health services in rural settings; however, there is uncertainty about how best to organize such services and what type of mental health use cases mobile technology can amplify to yield the best patient outcomes.

Due to the substantial public health burden of PTSD and bipolar disorder and uncertainty about how best to provide care in rural settings, we are conducting a large-scale trial, the Study to Promote Innovation in Rural Telepsychiatry (SPIRIT; NCT02738944) to test the relative effectiveness of two care models. SPIRIT will be the largest clinical trial ever conducted of rural Americans with psychiatric disorders, and is now enrolling 1,000 patients from one of 12 community health centers across Washington, Arkansas, and Michigan. Patients are randomized to one of two care delivery models: telehealth care by off-site specialists (psychiatrists and psychologists), or an integrated primary-care based model called Collaborative Care.

Collaborative Care is a team-based model for delivering treatments for common mental conditions in primary care that is twice as effective as usual depression care[4,18,21]. It has been regarded as a best practice

for nearly two decades and has been widely disseminated[13,16,19]. Collaborative Care is defined by core principles, which specify that care is population-based, measurement-based, and patient-centered[3].¹ To support the Collaborative Care workflow (Fig. 1), the University of Washington developed the Care Management Tracking System (CMTS), a web-based registry that helps providers track patient visits and outcomes using standardized measures, such as the Patient Health Questionnaire-9 (PHQ-9) for depression[14]. CMTS provides reminders to guide proactive outreach and follow up for patients who not engaging in care and identifies patients who have not improved and may benefit from treatment changes. CMTS differs from an electronic health record (EHR) in its design for effective management of an entire patient population, key features that EHRs lack, and CMTS' specific support for providers' Collaborative Care workflows. CMTS is used in 22 programs in 24 states throughout the United States and Canada and has helped over 90,000 patients receive better care. To date, CMTS has been entirely a clinician-facing tool. However, given that empowering patients to improve self-management is a key goal of Collaborative Care, a patient interface is a logical use of health technology to facilitate effective, whole-person care[6,10,20].

In addition to potential improvements in patient engagement, a patient app may increase satisfaction by offering a convenient, asynchronous method for patient-provider communication. Because remote symptom monitoring is timely, it can enhance

¹ This is in contrast to usual primary care in which patients may "fall through the cracks". PTSD and bipolar disorder are under-recognized; care is not measurement-based; follow-up is infrequent and ad hoc; and there is no proactive outreach.

Proof of Concept

- Pilot depression mHealth study (Interview 1 care manager, 17 patients)
- Partner with Dimagi to build depression Collaborative Care app
- Partner with 1 rural health center (Interview 1 care manager, 1 patient)
- Link depression app to CMTS
- Pilot test depression app – CMTS link (focus groups with 3 care managers, interviews with patients)

SPIRIT App Design Process

- Focus group #1 with CAB to propose SPIRIT App
- Focus group #2 with CAB to refine SPIRIT App concept
- Partner with 12 community health centers in 3 states
- Define SPIRIT App scope
- Build SPIRIT App v0 prototype and storyboard
- Focus group #3 with CAB to elicit feedback on storyboard and prototype
- Refine prototype design
- Develop usability testing framework
- Conduct usability tests with 5 participants
- Incorporate feedback into App
- Review prototype with physicians and study team
- Finalize SPIRIT App v1
- Develop patient and provider materials
- Launch SPIRIT App in 3 states

measurement-based care, which itself is an evidence-based practice [9]. Finally, because patients enter their own symptom scores, provider efficiency may improve by reducing their documentation and time-consuming synchronous telephone outreach and follow-up.

In this paper, we describe our approach to designing a mobile health (mHealth) system for Collaborative Care in SPIRIT and our experience to date with deployment. In contrast to the majority of healthcare apps, our system allows patients to communicate asynchronously with their care team through an interface already in use by providers. We share lessons we have learned from this design experience and emphasize the need to integrate mHealth technologies into routine practice.

Proof of Concept

The SPIRIT App design was informed by earlier work with two mobile apps for Collaborative Care for depression. In one pilot study of 17 patients and one care manager[5], we learned that a depression mHealth platform was acceptable and easy to use, but some patients had difficulty understanding the role of the app in their care. Patients desired more customization and a feedback graph of their scores. The need to access a separate provider dashboard was a limitation for the care manager. We subsequently developed a depression Collaborative Care app on CommCare (described below) that links to CMTS. We tested it in one rural community health center with three care managers and their patients. The app transmitted data to CMTS, but care managers told us that it was difficult to locate mobile data in CMTS. They felt strongly that they needed to be alerted when new mobile data was imported. They were especially concerned that they might not see when a patient

reported suicidal thoughts on the PHQ-9 or that patients might expect an immediate response.

Our early work supported the overall feasibility and acceptability of a Collaborative Care app for patients and for providers. The SPIRIT App was built from a template design of the depression app for a larger scale implementation, and adapted for new contextual requirements. Unlike the depression app, the SPIRIT App supports multi-condition (depression, bipolar disorder, and/or PTSD) management. For use at large-scale in routine, rural practices, the installation process needed to be simplified and mapped to care managers' workflows so patients could install the app independently without direct support from the research team. Patient safety is a top priority, so we improved in-app messaging when suicidal thoughts are reported to inform patients that scores submitted are not viewed in real-time and direct patients in crisis to use national hotlines or contact their providers directly by phone.

SPIRIT App Design Process

The SPIRIT App was created through a human centered design process that put patients and providers at the center of each project stage, including requirements gathering, prototyping, refinement, and implementation[12]. Understanding the needs, challenges, and perspectives of Collaborative Care team members, especially the patient, was crucial to developing a mobile tool to extend this care delivery. Target users and domain experts were engaged in a participatory design process throughout development via focus groups and usability testing with national consumer advocacy groups and providers and patients in rural clinics[1]. Similar to the depression app, the SPIRIT App was built on an Open Source Software-as-

Digital Development Principles [7]

1. Design with the User
2. Understand the Existing Ecosystem
3. Design for Scale
4. Build for Sustainability
5. Be Data Driven
6. Use Open Standards, Open Data, Open Source, and Open Innovation
7. Reuse and Improve
8. Address Privacy & Security
9. Be Collaborative



Figure 2. SPIRIT App Main Menu

a-Service (SaaS) platform that enables agile software design and rapid prototyping, such that feedback from stakeholders could be readily and iteratively integrated into the final design. Our process also adhered to the Principles of Digital Development for technology-enabled service delivery programs[7].

To understand representative patients' and care managers' ease of using the SPIRIT App, we focused our usability testing on an insight-driven study of the new self-registration process and user self-navigation to the core components of the SPIRIT App without user training. There were four usability tasks tested with five representative users, and predefined metrics and goals to determine whether or not the functionality tested was usable or not, with success thresholds established. No more than three pieces of functionality were tested at a single time or contiguously to limit user burden and avoid missing vital feedback at the end of the test. Feedback informed the final SPIRIT App design.

The live SPIRIT App (Fig. 2) includes new features based on input from our preliminary work, three focus groups with the SPIRIT consumer advisory board (CAB; the CAB consists of eight consumers and consumer advocates who meet monthly to advise the SPIRIT scientific team on all aspects of trial design and conduct), and usability testing. Examples of the resulting changes include a broader range of educational materials, improved messaging about symptom score interpretation, addition of patient stories, creation of a new suicide safety plan module, and creation of graphs to track symptom scores. Based on feedback that some patients already knew they were doing poorly, we refined the graphs and muted the colors to represent high scores sensitively without

demoralizing patients. We also improved the CMTS provider interface (described below).

SPIRIT App Overview

The SPIRIT App is a free, password-protected Android app. It was developed on CommCare, an open-source, SaaS mobile data collection platform. Data from the SPIRIT App is transmitted securely with encryption standards consistent with HIPAA from the device to the CommCare server. CMTS pulls newly uploaded patient data from the CommCare server via an API hourly, or immediately if requested by the provider (Fig. 3). The SPIRIT App will be translated to Spanish.

The SPIRIT App has seven modules: Check In, View Progress, Learn More, Reach Out for Help, Safety Plan, Settings, and About SPIRIT (Fig. 2). The Check In module allows patients to self-monitor and report symptoms to their provider by completing rating scales for depression (PHQ-9), PTSD (PCL-5), and mania (SPIRIT mania scale) and report medication adherence. In the View Progress module, patients can view a graph of their scores to monitor progress. The Learn More module has information about their condition, about psychiatric medications, tips to manage common side effects, about the Collaborative Care model, and about Behavioral Activation, a psychotherapy available to patients in Collaborative Care. The module also links to stories from people living with PTSD or bipolar disorder on consumer advocacy websites. Frequently Asked Questions explain how the SPIRIT App works and about their data privacy. Patients are prompted to provide feedback through an in-app survey.

Optional features allow patients to customize the SPIRIT App. They can create and view a personal safety

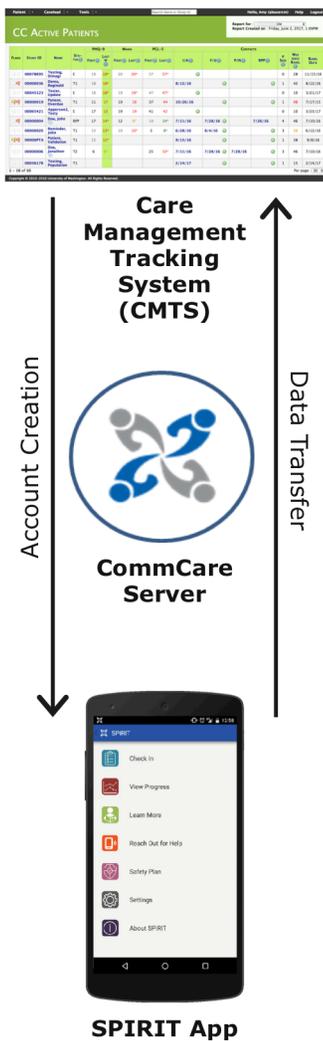


Figure 3. Diagram of the SPIRIT Mobile App System

plan for managing distress and enter contact numbers for supportive friends, family, or care providers. Patients can select the Check In day, the reminder time and message text, and select symptom scales to report on. They can create personalized reminders to take medications or for recurring activities as part of their Behavioral Activation treatment plan. They can also send new contact information to their care manager.

Provider Interface

Care managers use CMTS daily in their Collaborative Care workflow to track patient encounters and view progress. Concurrent with the development of the SPIRIT App, we expanded existing CMTS pages to include data from the SPIRIT App and created several new features. The two major functions that care managers need to accomplish are: 1) registering patients to use the SPIRIT App and, 2) viewing data their patients enter into the SPIRIT App.

We created a registration page in CMTS where the care manager enters the patient's cell phone number to trigger an SMS text message that begins the patient self-registration process by directing the patient to a website to create a username and password for the SPIRIT App. They then link to the Google Play store to download and install CommCare. The CMTS registration page has links to patient handouts and care manager materials about the SPIRIT App (described below).

When care managers log in to CMTS, the first page they see is the Reminders page. We added an alert to this page to indicate when new App data has been imported for any patient on that care manager's caseload. The alert has specific messaging if any patient reports suicidal thoughts on the PHQ-9 (Fig. 4).

From the Reminders page, care managers can access a new CMTS page summarizing all of the SPIRIT App data for any patient on their caseload to quickly identify which patients have new scores. Once they select an individual patient, the Treatment History page displays App scores alongside scores from in-person and telephone encounters (Fig. 4). They can also view individual item scores for each measure in a detailed SPIRIT App Encounter page. Thus, we incorporated App data in multiple CMTS pages at the level of the entire caseload, the individual patient, and the encounter.

Deployment of the SPIRIT App

Our approach to deployment was informed by the recognition that introducing a new, potentially disruptive technology directly impacts providers' task behaviors and requires them to alter routines[11,15]. The complex interaction between the new technology and team dynamics is a key determinant of the success of deployment and may be more important than the features of the technology itself[8]. In SPIRIT, we have 30 clinics from 12 organizations with substantial variability in the qualifications and experience of provider teams, the clinical workflows, and the volume and sociodemographic characteristics of patients. We anticipate that variability in the interaction between the technology and the dynamics of care teams across sites may lead to greater success with deployment in some clinical contexts than others[8].

Drawing on Principles of Digital Development, we have approached deployment as a team learning process in which care managers partner with us to explore how the SPIRIT App can improve the care they deliver and their patients' outcomes[7,8]. We seek to minimize burden on care managers as they develop competence

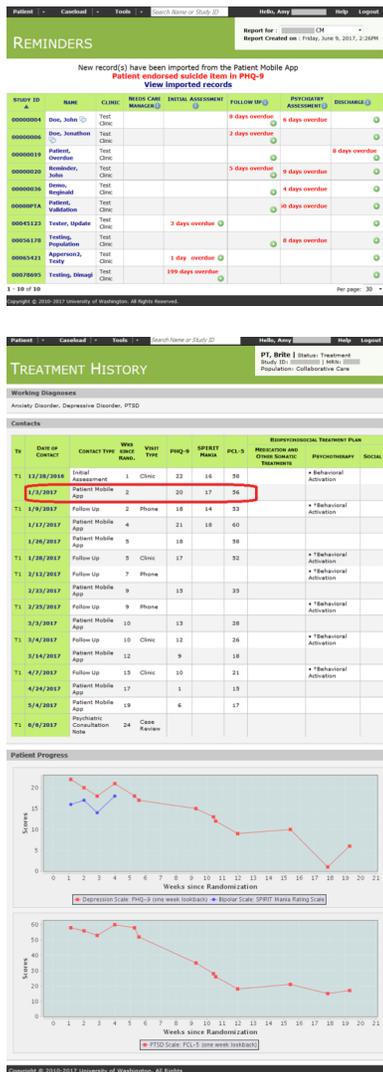


Figure 4. CMTS Provider Views

working with the SPIRIT App and learn how it may affect the relationships they have with patients. We do not expect care managers to be experts in the technical details of the system. However, as the front-line clinicians interacting with patients, they are likely to field questions about the SPIRIT App. Therefore, we sought to equip care managers with materials that would prepare them for conversations with patients.

We created supporting materials that are accessible within CMTS and the SPIRIT project website. A patient brochure provides an overview of the SPIRIT App and a step-by-step installation guide. A Frequently Asked Questions handout addresses questions we anticipate may arise such as reasons to use the App, how it works, and data security. We created brief scripts for care managers to introduce the SPIRIT App to their patients and an overview of how the App may help them as well as their patients. Finally, we augmented the CMTS user guide with detailed information and screenshots of the SPIRIT App CMTS provider interface.

The SPIRIT App launch was announced in routine meetings with study sites, the project newsletter and website, and during care manager training calls. We hosted a live demonstration session by webinar. We will foster peer learning about how to effectively integrate the SPIRIT App into practice in care manager training calls. In all of our messaging, we have invited feedback about how to make improvements in the system and our supporting materials and we created an IT support email account. We anticipate the need to promote the SPIRIT App on an ongoing basis as we onboard new sites and experience provider turnover.

Our early post-launch experience has revealed potential improvements in the deployment process. We conducted extensive quality assurance tests to ensure that the registration process, the App, and the data transfer to CMTS were reliable and robust. Testing focused on technical functions rather than the overall workflow. After launch, we noted that the alert for suicide thoughts on the PHQ-9 does not link directly to the record that triggered the alert. We are updating CMTS to make it easier for care managers to identify the triggering encounter. We also received a request from a care manager to offer the SPIRIT App on a tablet for patients in the waiting room prior to visits. Together these examples suggest that a more comprehensive testing plan would include case-based testing by clinicians with example patient scenarios.

We will evaluate patients' experience using the SPIRIT App with an in-app survey of usability, acceptability and satisfaction that includes free-text comments. Patients complete independent research interviews at 6 and 12 months post-baseline that include questions about the impact of the SPIRIT App and potential burden. We also ask reasons non-users did not use the SPIRIT App. We will solicit feedback from care managers through regularly scheduled meetings and training calls and track feedback we receive through the SPIRIT IT email account. We will revise our evaluation plans as needed to capture and generate knowledge that best informs the use of mobile technologies in the care of rural patients with bipolar disorder and/or PTSD.

Early Lessons

The technology to build mHealth apps to manage mental disorders is increasingly commonplace, yet their integration into clinical care has lagged. There are

tremendous challenges to deploying mHealth technology into routine practice settings that include mapping the technology onto the clinical workflow, educating providers and patients, and developing robust support systems. We have identified lessons from each stage of design, development, and deployment that can inform mobile designers and clinical researchers seeking to advance mHealth integration into clinical care.

During the development phase, we found that patients in rural settings who own smartphones face additional barriers to their use. Cellular coverage can be sparse and patients may be unable to afford a data plan. In outlying areas, patients may lack electricity to charge phones regularly. Clinics may also have limited network access. During usability testing, we found that the download and installation time could be unacceptably long in such settings. To address this unanticipated challenge, we reduced the multimedia content.

We approached quality assurance testing from a technical perspective and focused on ensuring specific functions of the SPIRIT App and CMTS linkages were reliable. Our testing did not emulate the typical Collaborative Care workflow in which a provider manages a panel of patients. For future deployments, we recommend expanding the scope of testing to mirror practice with case-based testing scenarios and employing clinicians as testers prior to deployment.

As we launched the system, the care managers were learning new clinical skills to carry out their role functions. Because the SPIRIT App is an optional tool, we promoted and encouraged its use gradually, as they mastered basic care management competencies. Care

managers in this project vary widely in their prior experience and comfort with behavioral health and with technology. Even for care managers with significant experience with complex psychiatric conditions, using mHealth to support care is new. As a result, they need to gain skills in talking with patients about the SPIRIT App and how it fits into their care. For some care managers, this also means using the App themselves as a test patient to gain confidence and familiarity. Technology-supported care is new for patients and is not intuitive. We have observed that patients need help understanding how the App fits into the ecosystem of their care. Patients may make inaccurate assumptions about how the App works based on experience with other consumer apps and thus, may need reminders over time about what the app does and does not do.

In deploying the SPIRIT App, we have found a flexible approach to be helpful. We envisioned the SPIRIT App for patients' use in the community, but one of the care managers envisions using it on a tablet in the waiting room. Responding to this provider need represents an important opportunity for team learning about how mHealth can facilitate effective, evidence-based care.

Care managers have expressed enthusiasm for using mHealth to increase efficiency and reduce documentation. However, the practice change required to learn a new system is difficult, especially if the system is used infrequently. Having champions at the care manager level and providing opportunities for peer learning may facilitate uptake. Similarly, these initial hurdles may be overcome more readily if providers believe that the new technology will benefit a majority of their patients. Care managers with a 'critical mass' of eligible patients may be more likely to try a new

technology. This may present a challenge in small rural clinics in SPIRIT serving a handful of patients with PTSD and/or bipolar disorder. It also suggests that integration of mHealth into clinical practice may be more successful when one system can support care for multiple chronic illnesses rather than having separate apps for each condition. Tools that support multi-condition management are likewise more patient-centered. For adoption to be successful, the system must offer concrete value to patients and to providers.

Conclusion

Our approach to the design and deployment of a mHealth system to support care for patients with complex psychiatric conditions in rural health centers may serve as a model for other clinical researchers and technology developers. We encountered technical and training challenges, as well as enthusiasm among CAB members, providers, and patients for integrating patient mobile tools in the care of complex psychiatric conditions. We anticipate the need for ongoing efforts to support and promote use of the SPIRIT App in settings with low volume or provider turnover. We hope our lessons will be informative to workshop attendees and stimulate discussion about how best to integrate mobile technology into rural practice settings.

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