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Title: Participatory design of eHealth solutions for women from vulnerable populations with

perinatal depression

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ABSTRACT

Objective: Cultural and health service obstacles affect the quality of pregnancy care that women from vulnerable populations receive. Using a participatory design approach, the SPIRIT group developed specifications for a suite of eHealth applications to improve quality of perinatal mental health care.

Materials and Methods: We established a longitudinal participatory design group consisting of low-income women with a history of antenatal depression, their prenatal providers, mental health specialists, an app developer, and researchers. The group met 20 times over 24 months. Applications were designed using rapid prototyping. Meetings were documented using field notes.

Results and Discussion: The group achieved high levels of continuity and engagement. Three apps were developed by the group: an app to support high-risk women after discharge from hospital, a screening tool for depression, and a patient decision aid for supporting treatment choice.

Conclusion: Longitudinal participatory design groups are a promising, highly feasible approach to developing technology for underserved populations

BACKGROUND

Disorders of mental health are the leading cause of disability globally[1] and remain under-diagnosed and under-treated.[2] Common mental disorders during pregnancy and the year postpartum (perinatal mental disorders PMD; most often depression and anxiety) affect 14-23% of women overall and as many as 50% of those with low income. They increase the risk of both poor maternal and pediatric outcomes.[3,4] Low-income women and those from minority ethnic groups are simultaneously at greater risk for PMD, and less likely to receive care for these disorders.[5,6] These women face a range of both patient and health services related obstacles to care.[7]

The use of patient centered eHealth strategies that accommodate end user needs holds promise to overcome a range of care obstacles for this vulnerable population.[8] Participatory methodologies are used to improve the patient-centeredness of various interventions.[9] Provider engagement with patients is especially valuable when designing computer-based interventions for vulnerable populations.[10] This can help promote bilateral exchange of knowledge, help address bias and disparities in the development of new interventions, and identify and address obstacles and opportunities among patients and their providers.[11-13]

In this paper, we describe an iterative participatory design strategy that resulted in a suite of three eHealth tools geared to the particular support needs of low-income, ethnic/racial minority women at risk for PMD. We briefly discuss the apps that were developed and end with recommendations for using this approach.

METHODS

We initiated a participatory design group in January 2013 to address issues surrounding depression in pregnancy called SPIRIT (Stress in Pregnancy: Improving Results with Interactive

Technology). The work of this group was approved by the IRB of the University of Pennsylvania and focused on the needs of low-income and ethnic minority women in the urban Philadelphia area.

Setting and Participants:

The SPIRIT group met monthly at a large hospital-based outpatient prenatal care center for low income Medicaid-insured women in Philadelphia, PA, USA. The group was comprised of members of the two key stakeholder groups – women with history of depression in pregnancy and their prenatal providers (nurse practitioners, physicians, social workers, care facilitators, psychologists and psychiatrists) – as well as center administrators, mental health services researchers, and an application developer (programmer). The center is part of the University of Pennsylvania Health System and cares for approximately 4,000 pregnant women annually. More than 90% of the patients seen are US born African-Americans with a high rate of low literacy.[14] An initial information session for all frontline clinical, administrative, and support staff was carried out to recruit staff members. This included obstetrics/gynecology physicians, nurse practitioners, nurses, medical assistants, front desk staff, and mental health providers. The session was announced at a staff meeting and through flyers. Key members of the staff seen as potential champions of the project because of interest in perinatal depression were approached in person.

Clinicians from the SPIRIT group were asked to identify potential patient members from their own patient panels with a history of perinatal depression and potential interest in participating. Providers invited their patients to come to a SPIRIT meeting to learn about the group.

Process:

Participatory design meetings occurred monthly in a waiting area of the prenatal center and lasted two hours immediately following the regular work day. Between January and June 2013 participants were compensated with $25 for their time. Patients joined the group in March of 2013. From July 2013 onwards, compensation was increased to $50 due to increased funding for the project. Participants were also provided with a simple dinner. The group collectively wrote a mission statement, which included the objective of improving communication and healthy outcomes in women with emotional distress using easily accessible interactive technology.

SPIRIT group meetings focused on generating ideas and providing feedback on brief pilot studies implemented by providers, clinical administrative staff, health information technology developers, and video producers.   Meetings were facilitated by the research team and involved brainstorming, problem-solving, role playing, and feedback on content. Role playing to review impact of the applications on clinical work flow was particularly effective; members of the group were able to observe proposed work flows and provide immediate responses and suggestions for modifications which could then be discussed for issues such as technical feasibility. Patient participants were critical to identifying favored language, features, and stylistic elements of the "look" of the app that were appropriate to the target population. Input on readability and literacy challenges with language used in the app were particularly targeted by these members of the group. The SPIRIT group took a rapid cycle iterative design approach.[11] At each meeting, the SPIRIT group reviewed progress, provided feedback, tested available pilot software, and formulated specific recommendations for immediate next steps. The tools were then revised for the next meeting. Some examples of changes implemented as a result of this process are shown in Table 1.

The health care researchers supported the SPIRIT group by organizing and managing the meetings and reviewing literature to gather relevant evidence and content for each of the proposed applications. The researchers also drafted scripts and specifications informed by such considerations as readability and the high rate of limited literacy in the target population.[14] Following lean design principles, the programmer and developer members of the design group were less involved initially until a satisfactory specification was established – after which they developed and presented working prototypes.[11]

Live action videography was carried out on location. Animated "guides" were produced using a commercial software product (Moviestorm, UK). Sound for the animation was taken from the live action video.

RESULTS

Over the course of 24 months, from January 2013 through December 2014, the SPIRIT participatory design team developed three applications: the MyGamePlan suicide prevention mobile app for iPhone, a tablet based screening tool for PMD, and a patient decision aid (PtDA) for supporting treatment decisions for depression in pregnancy by women and their clinicians. The SPIRIT group consisted of a core group of participants (n=17) including patients with history of depression in pregnancy (n=4), prenatal providers (n=2), social workers/care managers (n=2), mental health specialists (n=2), a clinic administrator (n=1), support staff (n=3), research staff (n=2) and a programmer (n=1). Average attendance was 13 (range 5-22). Of the initial 17 SPIRIT members 12 continued for the full development period (71%) while the remaining membership had turnover.

My Game Plan:

The SPIRIT group developed a downloadable suicide prevention smartphone application for iPhone called MyGamePlan. This application was designed for use by patients discharged from an inpatient hospitalization for suicide risk. MyGamePlan includes a set of functionalities to support the transition following hospitalization including: 1) scheduling and reminder features for follow up, 2) standard safety plan support, 3) and connections to local resources which take advantage of geo-location capabilities of the mobile device. The design team was expanded for this application to temporarily include: 1) a discharge planning clinical social worker at an inpatient psychiatric center within the same health system, and 2) the parent of a suicide victim with strong interest in advocacy for discharge support.

Depression screening tool:

The SPIRIT group developed a tablet-based self-report screening tool for risk of PMD using a validated 2-stage process with an initial 2-question screen followed by the PHQ-9.[15-17] The screening tool was designed to allow implementation of efficient universal screening for these conditions. The design process included fitting within existing work flow. A series of role plays were used to work out this process; each step of the screening through risk identification and response by the members of the staff (support staff, prenatal providers, and mental health specialists) was reviewed during SPIRIT meetings with immediate feedback by team members and corrections to design. The final process involved initial identification of eligible patients (following standard recommendations three times over the course of pregnancy and postpartum) during appointment check in. Patient responses are linked to a patient's unique office visit using a visit bar code generated by scheduling software used in the center. Patients take the tablet computer to their seats to complete in privacy before seeing a clinician. The screening includes validated strategies designed to reduce the burden and increases the efficiency of the process.[15] A

provisional diagnosis based on these answers is provided for use by clinicians.[16,17] These results

are immediately transmitted wirelessly through a secure hospital wifi network to the electronic

health record accessible to health care providers for use in that visit. Patients with current self

harm risk are flagged for immediate assessment of risk severity.

TIPS (Technology to Improve Patient Services) tablet-based patient decision aid (PtDA):

The most ambitious of the apps developed by SPIRIT was a patient decision aid (PtDA)

to help women with perinatal depression learn about and discuss different treatment modalities

with their providers.[18] Patient and provider education about available choices is critical to

engagement and monitoring of women at risk for PMD, where choices are strongly influenced by

patient preference. The group's design work was guided by the Ottawa Decision Support

Framework and International Patient Decision Aids Standards (IPDAS; Figure 1): 1) assess

client and practitioner determinants of decisions to identify decision support needs, 2) provide

decision support tailored to client needs, and 3) evaluate the decision making process and

outcomes.[18,19] The group identified a set of key features for the electronic PtDA (Table 2).

Guiding design principles included accommodating patient preferences, clinical usefulness,

cultural appropriateness, and accessibility to women with low-literacy.[19] The group went on to

evaluate depression treatment options for inclusion in the decision aid. Four criteria were

identified by the group and used to select and describe treatment options: evidence of benefit,

evidence of harm, and ease of use, and availability to the patient population. The final set of

treatments are listed in Table 3.

PtDA functionalities:

TIPS is a mobile tablet-based application developed for patient use in the waiting room.

Some examples of the role that the SPIRIT group had in the design of this application are shown

in Table 3. The SPIRIT group selected a tablet as the medium for the PtDA for: 1) ease of use in the waiting room before appointments, 2) patient familiarity with mobile devices, and 3) ability to integrate audio and visual components for low-literacy users. A personified interface "guide" approach was chosen; both a live actor and an animated guide were used to enhance engagement with the application process (see Figure 2). SPIRIT group members felt that the animated option provided an alternative that would be appealing to a substantial portion of users. The actual utilization and preferences of these options will be formally assessed in future evaluation work.

The final design of the TIPS app is shown in Figure 3. Patients screening positive for risk of depression are directed to the PtDA. An introductory video allows navigator selection. Patients are then taken through a series of content and question sections including: psychoeducation introducing patients to depression in pregnancy, and 2) values clarification in which users review preferences regarding features of potential treatments such as safety and efficacy in the context of pregnancy. Results of the depression screening sections determine initial treatment recommendations for patients based on treatment guidelines.[20] The algorithm used to generate this list incorporates severity of depression symptoms, and the presence of thoughts of self harm. All nine of the treatments are available as icons on the screen of the tablet. The navigator describes each treatment, the evidence of benefit and harm, and ease of use.

A patient ultimately selects specific treatment preferences that she wishes to discuss with her prenatal care providers. This information is summarized along with screening results and the values clarification summary for the patient (in paper form) as well as her prenatal provider (electronically through the electronic medical record). Prenatal providers are given additional brief clinical decision support so that they are prepared to discuss and initiate a plan.

In order to balance the need for rapid viewing of videos and potential need for updates of content the TIPS PtDA utilizes a hybrid app design with a web based element but with pre-loaded videos on the tablet devices for viewing. Content will be updated based on new findings as part of the management of the app.

CONCLUSIONS AND RECOMMENDATIONS

Multi stakeholder participatory design groups are an effective way of developing patient centered, eHealth solutions for low income and racial/ethnic minority populations. Since such groups take time to establish we recommend budgeting adequate time and resources to develop applications. Champions from a range of stakeholder groups played a large role in successfully establishing the group. By recruiting patients from the case load of providers already involved in SPIRIT, we ensured that there already was established trust between end users and provider stakeholders.

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Table 1. Examples of changes to design derived from SPIRIT group process – decision aid.

Functionality	Change	Reason for change
Personified Interface: 1. Audio/Video 2. Welcome 3. Guide to application	Addition of animated "guide" to live actor	1. Animation was engaging 2. Opportunity for more diversity in appearance of guide 3. Give patients opportunity to actively participate in application
Video presentation of content	Break videos into small clips of less than 1 minute	1. Allow users greater control of the experience 2. Users will lose interest and exit
Navigation	Allow users to skip sections of application	1. Allow users greater control of the experience 2. Users will lose interest and exit
Content	**Change**	**Reason for change**
Language used	Modification of guide scripts to a more familiar style	Patient team members found initial scripts to be intimidating and unfamiliar
Appearance of guides (live actor and animation)	Physical appearance including skin tone, hair style, clothing, age. Animated guides selected from a range of proposals.	Physical characteristics of the live actor and animation guides were selected based on their appeal to the team members – particularly patients
Selection of treatments	Elimination of some treatment options	Treatment options which were not realistically accessible to the target group were eliminated to save user time

Table 2: Features of TIPS patient decision aid.

Feature
General
Audio-video
Interactive design
Patient Decision Aid*
Psychoeducation
Values clarification
Stratified presentation of options
Review of options
Patient-selected preferences
Clinical needs of center
Screening tool for risk of depression
Clinical summary
Provider decision support
Inclusion in electronic medical record

*IPDAS components[16]

Table 3: Treatments covered in the TIPS PtDA

Treatment
Antidepressant medications
Psychotherapeutic counseling
Watchful waiting
Bright light therapy
Exercise
Behavioral activation
Massage therapy
Relaxation therapy
Music therapy

Figure 1. Ottawa Decision Support Framework.

Figure 1. Ottawa Decision Support Framework.

Decision Needs

- Actions
- Decision Quality
- Values based health outcomes

Decision Support
- Clarify decision & needs
- Provide facts & probabilities
- Clarify values
- Guide in deliberation & communication
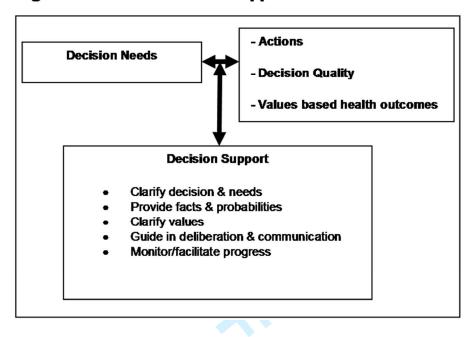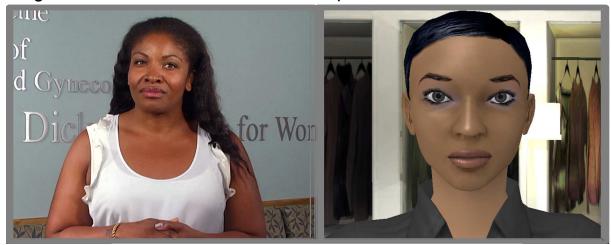- Monitor/facilitate progress

Figure2. Selected characters for TIPS personified interface.

Live Actor   Animation

Figure 3. TIPS App schematic.