Title: Can Mobile Health Improve Depression Treatment Access and Adherence Among Rural Indian Women? A Qualitative Study

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Abstract:

Introduction: Low rates of follow up with mental health treatments, and medication non-adherence are common among patients with Major Depressive Disorder (MDD), more so in low-middle income countries (LMIC). While mobile mental health has the potential to address this problem in resource-poor settings, the feasibility and acceptability of its use in rural women is unknown. We aimed to explore barriers to access and adherence to mental health treatment, and the feasibility of using mobile health to address these barriers among women with MDD in rural south India.

Methods: Six focus groups were conducted among women with MDD (n=69) seeking care at a rural community health center in South India. Discussion centered on barriers to mental health treatment access and adherence and attitudes toward use of technology in addressing these barriers. We transcribed the discussions and analyzed them using qualitative analysis software.

Results: Reasons for non-adherence were: transcultural explanatory model of illness; structural, financial and social barriers to access, and medication side-effects. Women were unenthusiastic about mobile health solutions due to illiteracy, lack of family support, unfamiliarity with use of mobile devices, lack of access to mobile phones and preference for in-person clinical consultation.

Conclusions: This qualitative study examines the acceptability of mobile-mental health as a strategy to address barriers to depression treatment access and adherence among women in a rural setting. There are several barriers to adoption of mobile mental health technology in LMIC. It is important to address these barriers before implementing mobile health based solutions.

Keywords: mobile mental health; depression; non-adherence; global mental health; qualitative study

1. Introduction

Depressive disorders account for a significant proportion of the global burden of disease (Global Burden of Disease Study 2010) (Ferrari et al., 2013; Whiteford & Baxter, 2013). In 2010, depressive disorders were the second-leading cause of disability worldwide and accounted for an additional burden attributable to mortality associated with suicide and cardiovascular disease (Ferrari et al., 2013). About three quarters of the global burden of neuropsychiatric disorders is in countries with low and middle incomes (LMIC), yet the vast majority of patients (76-85%) in these countries receive no treatment (World Health Organization, 2010). In India, according to the National Mental Health Survey (Gururaj et al., 2016) the treatment gap for mental health problems ranges from 70.4% to 86.3% and contributes to the high rates of suicide (Radhakrishnan & Andrade, 2012). Factors that contribute to this treatment gap include workforce deficits (with one psychiatrist for a population of 400000 (Koshy, 2015) with a majority of psychiatrists practicing in urban areas although 2/3rd of the population lives in rural regions), systemic barriers such as poor transportation infrastructure, and patients' unwillingness or inability to seek mental health treatment (Gururaj et al., 2016).

With the goal of bridging the treatment gap and scaling up services, the Disease Control Priorities Network (DCP-3) has recommended packaging interventions across a range of delivery platforms to make care accessible in resource - poor settings in LMICs (V. Patel et al., 2016). This includes information and communication technology packages via mobile phone and the internet to improve outreach and delivery of personalized interventions. Good clinical outcomes require access to and initiation of treatment (access), and adherence to follow up and treatment (adherence). Mobile mental health technology has the potential to address both access and

adherence because of the extent of its reach and availability even in resource-poor settings (DeSouza, Rashmi, Vasanthi, Joseph, & Rodrigues, 2014; Yellowlees & Chan, 2015).

Our previous work in a rural mental health clinic in South India (The Maanasi project at the Community Health Training Center, Mugalur), examined the delivery of comprehensive psychiatric care by trained community health workers (CHWs) in collaboration with primary care providers (PCP) and psychiatrists (K. Srinivasan, Isaacs, Villanueva, Lucas, & Raghunath, 2010). In this model, following a monthly visit with a physician at the Primary Health Center (PHC), the CHWs conducted home visits for patients with depression. The CHWs educated the patient and her family about depression and its treatment and encouraged them to visit the rural mental health clinic (co located in the PHC) for further assessment and treatment. Despite this attempt to improve access and care delivery, we found that up to 53% of patients were non-adherent to treatment (Pradeep, Isaacs, Shanbag, Selvan, & Srinivasan, 2014; K. Srinivasan, Isaacs, A.N., Thomas, T., Jayaram, G., 2006). These high rates of non-adherence present a significant hurdle to mental health care delivery and to remission of symptoms. While there is evidence that mobile phone messaging reminders can reduce non-adherence to appointments and treatments (Gurol-Urganci, de Jongh, Vodopivec-Jamsek, Atun, & Car, 2013), the feasibility and acceptability of use of technology to improve adherence among women with Major Depressive Disorder (MDD) in rural areas has not been evaluated. There is a need to understand barriers to access and adherence, and assess the feasibility of using technology such as text-messaging, phone calls and appointment reminder devices to address identified barriers. In particular, we wanted to assess these issues in women, given the higher prevalence of major depression among women (Gururaj et al., 2016) and the fact that factors indicative of gender disadvantage (low

decision making autonomy, reproductive health factors) are risk factors for depression (Vikram Patel et al., 2006).

The aims of the present qualitative study were a) To explore barriers to accessing mental health treatment and evaluate reasons for poor adherence to follow up and medication among women with MDD in the population covered by the Maanasi Project in Mugalur, a rural area of Anekal taluk, Bangalore district, India (b) To assess attitudes towards use of mobile technology to improve mental health treatment access and adherence.

2. Methods

2.1 Setting

We conducted this study among patients enrolled in Maanasi - The Community Rural Mental Health Program of St. John's Medical College and Hospital (SJMCH), Bangalore, India. The Maanasi project, is an ongoing program which has been in operation since 2002. It is coordinated by the Departments of Community Health and Psychiatry at SJMCH, is located in Mugalur, a village situated 30 km from Bangalore city, and is supported by funds provided by the Rotary Foundation. Patients from about 50 villages in this area utilize the services of the project. At the time of the study, psychiatric consultation was available once a month. A PCP is present at the clinic every day, and provides continuing medication management. CHWs conduct home visits for follow up and education.

2.2 Study design

This was a cross sectional, exploratory qualitative study using focus group discussions to collect information on barriers to mental health treatment access and adherence, and attitudes to use of mobile health to address identified barriers. The study was conceived as a process evaluation of the Maanasi project.

2.3 Study participants

Community Health Workers (CHWs) of the clinic approached women (ages 18 – 85 years) who were diagnosed with MDD at the Maanasi clinic for consent to participate in a focus group discussion. We included newly-diagnosed women currently undergoing treatment, those who completed treatment and those who were non-adherent to treatment, to obtain a broad range of perspectives. All participants who expressed interest and were able to provide verbal informed consent were allowed to attend the discussion. We obtained study approval from the Institution Ethics committees of St John's Medical College, India and the Yale University School of Medicine, USA.

2.4 Focus Group Discussion procedures

We developed a FGD guideline for the focus group discussions that included open ended probes specific to the following topic areas: barriers to accessing mental health treatment, reasons for poor treatment adherence, and attitudes towards the use of technology such as text-messaging, phone calls, and appointment reminder devices to improve access and adherence among women

with MDD. RR, BR and 2 CHWs attended all focus groups and GJ attended one. The focus groups were conducted in the local language, Kannada, by the study investigators (RR, BR) and were each of approximately 60 minutes duration. Additionally, two community health workers (CHWs) were also present during the FGD. AB and BR are trained in qualitative methodology. We audio-recorded the focus groups, translated and transcribed the content verbatim. We de-identified focus group participants by not addressing them by their names, and deleting segments of the recording that contained identifying information. At the beginning of each group, we reminded the women that participation was voluntary.

2.5 Analysis

We developed a codebook with definitions and rules for coding, initially including categories based on our interview guide. We derived additional codes by reading the transcripts word by word. (Hsieh & Shannon, 2005). We analyzed the transcripts using qualitative analysis software (www.atlasti.com) and an inductive approach using a modified grounded theory approach (Hsieh & Shannon, 2005). We identified themes and subthemes using constant comparisons within groups and across groups (Corbin & Strauss, 2014).

3. Results

Participants were 69 women from 5 villages who accessed care at the Maanasi clinic at any time since its inception. Table 1 summarizes demographic information for women participating in the groups. We conducted 6 focus group discussions until we achieved saturation of responses to the

questions raised. We describe themes and subthemes from the focus groups in Table 2, and summarize them below:

3.1 Barriers to accessing mental health care:

3.1.1 Transcultural explanatory models : “What can we do about it, it is our fate”: We found that culture specific explanatory models of mental illness contributed to low rates of seeking mental health care. Women reported physical symptoms more frequently than psychological symptoms, making them question the need to get mental health treatments. Many lived in extended or joint families and reported interpersonal conflicts with their husbands and in laws. Women who reported psychological symptoms attributed the causation and perpetuation of their symptoms to these conflicts. Several women displayed a stoic or fatalistic attitude toward their life situation and attributed depression to their “hane baraha” or fate making them reluctant to initiate or continue mental health treatment.

3.1.2 Financial barriers: “We can’t afford to go to the clinic frequently”: A major impediment to accessing treatment was the cost associated with it – including loss of daily wages, travel times and wait times.

3.1.3 Family level barriers:” “If I ask him (my husband) to take me to the clinic, he says you look fine, why do you need to go?” Lack of support or outright opposition to treatment from the family often contributed to non-adherence. Family members would often criticize women for being “lazy” and refuse to allow them to seek mental health care.

3.1.4 Systemic barriers: “We sometimes travel to other villages for work, and just go the local clinic there instead of coming back to Maanasi”: Participants noted other challenges such as frequent change of psychiatrist and variable quality of providers at the clinic. Though most

women followed up at the Maanasi clinic, some of them sought ad hoc treatment at villages they travelled to for work.

Women who did obtain treatment at the community mental health center were very appreciative of the care they received, from the CHWs, the PCPs and the psychiatrists. They reported that prior to the establishment of this clinic, they had to travel long distances to get to the city for mental health treatment. Respondents were appreciative of the home visits and the education provided by the CHWs.

3.2 Barriers to adherence:

Specific factors contributed to non-adherence to medications once mental health care had been established. Despite the subsidized cost of medications provided by Maanasi project, women said that the financial burden of long-term treatment was high (“We can’t afford the medicine if we have to take it for too long”). The loss of daily wage resulting from traveling to appointments to get refills on medications was an additional consideration. Women expected immediate relief from antidepressants, and when their symptoms did not improve rapidly, they concluded that the medication was ineffective, and discontinued it. They also changed providers frequently in search of rapid relief. Women also discontinued medications due to concerns about side-effects (weight gain, sedation) associated with long-term use. Deference to doctors and the burden of travel prevented them from discussing these side effects with the doctor before discontinuing. Inaccurate information obtained from friends and family about antidepressant side effects like kidney damage, also led to discontinuation. Women often forgot to take the medications.

3.3 Attitudes toward mobile health technology solutions to access and adherence barriers:

Women expressed reservations about the use of text messaging or phone calls to address access or adherence. Many women did not have a personal phone (most families have a single mobile phone which is often with the husband), or could not use text messages because they could not read. They valued face to face interactions more than telephone conversations. Some women reported that their husbands would suspect them of infidelity if they received calls or text messages. In exploring other ways to remind them of an upcoming appointment or to take their medication, they humorously suggested that an announcer (“town crier”) walk through the village for this purpose. They were however, not opposed to reminder devices such as wearable devices with alarms.

4. Discussion

Reports from LMIC suggest that mobile phones can be used for health information delivery, reminders and communication (Lee et al., 2015; Ramachandran et al., 2015). However the literature on use of mobile health platforms for mental health service delivery in rural areas is sparse (Maulik et al., 2015). There is some indication that it may not be easy to realize the potential of mobile health in rural India for clinical support or as aids to patient adherence (Nahar, Kannuri, Mikkilineni, Murthy, & Phillimore, 2017). In our focus groups among women treated for MDD at a rural community mental health center in Southern India we aimed to understand barriers to mental health treatment access and adherence, and attitudes toward mobile-health technology based support systems.

Barriers to treatment access can have their origins in transcultural explanatory models for psychiatric disorders, and patients' perception of mental health care providers (Kirmayer & Bhugra, 2009). Our findings corroborate those of others (Pereira et al., 2007) in that participating women attributed their symptoms of depression to fate and to psychosocial stressors such as problems with their in-laws and alcohol abuse in their husbands. They presented with physical symptoms rather than psychological symptoms; when they did acknowledge psychological symptoms, they couched their symptoms in cognitive terms such as "thinking too much" rather than in affective terms. This led the women to either not seek help for their symptoms at all, or to seek treatment for physical symptoms from primary care providers. Also important was the family and society's explanatory model. Similar to previous reports (Rodrigues, Patel, Jaswal, & De Souza, 2003), we heard from some women that their husbands and extended family accused them of feigning ill health since they appeared well, and did not support their mental health treatment.

In eastern cultures, patients are often in awe of medical providers as authoritarian figures (Kanabar, 2002), and may be eager to please them and under report side effects experienced with prescribed medications. Women in our focus groups expressed a similar reluctance to discuss side effects with their prescribing provider, and were concerned that the providers would chastise them for discontinuing medications due to side effects. There is a need for repeated, culturally relevant education about mental health disorders and medication side effects. Mobile health technology has the potential to support this education. However, mobile health interventions in these settings should include components that align with local beliefs about symptoms, and local approaches to care, and should involve family members. For example, psychological treatments

that are modified for delivery in different cultures include local practices such as massage and religious therapy and additional educational modules on spirituality (Chowdhary et al., 2014).

Across groups, women reported the cost associated with access to mental health care as a common barrier. Women had to allow for an entire day for a clinic visit due to wait-times at the clinic, commute time, and infrequent and unreliable public transportation. For day laborers, this meant the loss of a day's wages in addition to the direct cost of travel to the clinic. This did not seem to offset the savings from free or extensively subsidized treatments available at the clinic. Services such as mobile clinics and pharmacies can address this barrier of travel time and cost, but are not scale-able (Syed, Gerber, & Sharp, 2013). In considering the role of using mobile phones to provide phone based interventions or medication reminders, our participants reported that mobile phones were not personal devices but a shared resource in the household. They often did not have access to the family mobile phone, and could not receive appointment or medication reminder phone calls. Women were not very enthusiastic about text messages as many of them were not literate. Previous studies from LMIC have reported that although mobile phone possession may be ubiquitous very few of these are smart phones and very few people use text messaging (Nahar et al., 2017), partly due to low literacy levels (Lester et al., 2010). However, another study conducted in urban South India reported that women were comfortable using text messages (P. S. Chandra et al., 2018; Prabha S Chandra, Sowmya, Mehrotra, & Duggal, 2014). This highlights the differences in access barriers among patient populations in rural and urban India, and the need to customize approaches. Potential solutions include using interactive voice response systems instead of text messages and using shared devices in community based locations that women frequently attend such as women's cooperatives or "mahila mandals" that

are held in each village (Vatuk, 2013). In preliminary discussions about innovative solutions such as culturally adapted mobile health devices or wearables for medication reminders, women were receptive to the idea.

4.1 Limitations

It is important to view our findings in the context of the limitations of the study. Firstly, the focus groups were conducted by male moderators who have provided care at Maanasi – introducing the possibility of socially desirable responses. We did not obtain participant feedback on the results of our analysis. However at the end of each focus group we summarized key points/issues to the group, allowing for clarification. We did not have information on the current depression severity of these women who had received treatment at the Maanasi clinic. Although stigma is an important barrier to accessing mental health care across cultures, we did not specifically direct the discussion towards this topic, as this was not a focus of our study, and has been addressed extensively in the literature (Kulesza, Raguram, & Rao, 2014).

5. Conclusions

This is the first qualitative study, to our knowledge, that examines the acceptability of the use of mobile-mental health as a strategy to address the problem of depression treatment access and adherence in women in a rural setting.

Establishing rural community mental health centers and employing CHWs for home visits, uses task sharing (Vikram Patel et al., 2013) and facilitates delivery of mental health services to a large extent. Mobile health technology has the potential to further improve access, but needs to be tailored to the local context.

We instituted changes at the Maanasi clinic such as the appointment of a psychiatrist for continuity of care, and screens for privacy in the clinic. However factors such as transportation, lack of family support, and poor understanding of mental health disorders and treatments remain as barriers to access and adherence. In examining the feasibility of providing phone reminders or education, we found that many women are illiterate (average literacy rate among women in villages served by the Mugalur project is 60%), do not have access to their own mobile phone device, and prefer not to receive calls or messages on the shared family phone. In this particular situation, although the basic infrastructure for mobile health exists, we may need to modify the mobile health approach before we integrate it into the mental health services delivery system.

The unique cultural and systemic barriers in rural areas call for innovative ways to improve the access to evidence based mental health treatments and to improve medication adherence. Examples include using communication technology within existing social systems such as women's cooperatives to reduce the need for travel to the mental health center, and using modified mobile health solutions to support assessment, education and adherence. There is a need for studies to examine the feasibility and effectiveness of these solutions. Family plays a major role in the access and continuity of mental health treatment of women in rural India

(Jayaram, Goud, & Srinivasan, 2011) and should be included in any solutions proposed.

Although we conducted this study in rural India, the above factors are likely relevant to other resource-poor settings as well.

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Attitudes toward mobile-mental health in rural India: A qualitative study

Table 1. Demographic details of FGD participants

Village	Number of FGDs	Total Number of women	Age (Mean $\pm$ SD)	Age Range
Mugalur (FG 1)	1	12	47.42 $\pm$ 16.54	27yrs-80yrs
Bovipalya (FG 2, FG 3)	2	21	48.52 $\pm$ 15.23	23yrs-70yrs
Kugur (FG 4)	1	15	47.09 $\pm$ 7.91	35yrs-60yrs
Neriga (FG 5)	1	14	45.93 $\pm$ 15.38	25yrs-81yrs
MC Halli (FG 6)	1	7	41.29 $\pm$ 17.83	22yrs-70yrs

FG = Focus Groups

Table 2. Focus group themes and associated subthemes:

THEMES	SUB-THEMES	QUOTES
Barriers to Accessing Care		
Explanatory model of illness	<ul style="list-style-type: none"> Physical symptoms as presenting complaints – headache, body ache, memory problems, vaginal discharge. Expected recovery time - Desire for immediate symptom relief Low salience to psychological symptoms (sadness, decreased sleep, thinking too much) Interpersonal conflict, alcohol use in husband. Stoical attitude and causal attribution of depression to fate “hane baraha” 	<p>“If there are physical problems which cause pain we know that we have to take medicines. But if it’s a mental illness we can’t see any changes or feel any pain in our body” (Participant 3, FG 1)</p> <p>“Like headache medicine, antidepressants should make me feel better quickly” (Participant 4, FG 3)</p> <p>“A doctor who prescribes a pill that makes my symptoms go away fast is a good doctor” (Participant 5, FG 5)</p> <p>“People feel hopeless if they don’t get better right away” (Participant 2, FG 3)</p> <p>“I don’t like being asked about death and dying when I have come to be seen for headaches and body ache” (referring to being questioned about suicidal ideation during psychiatric assessment). (Participant 3 FG 2).</p> <p>“Anyone whose husband drinks alcohol will have problems” (Participant 2 FG 3)</p> <p>“What can we do about it, it is our fate” (referring to depressive symptoms). (Participant 12, FG 5).</p>
Explanatory model of provider	<ul style="list-style-type: none"> Deification of doctors Fear of criticism Doctor shopping 	<p>“We think of doctors as God and do as you tell us to do” (Participant 2, FG 3)</p> <p>“We will listen to doctors more than anyone else” (Participant 2, FG 3)</p> <p>“We think the doctor will scold us if we tell them we stopped the medicine” (Participant 6, FG 2)</p> <p>“If we do not improve quickly we will go to another doctor who gives injections” (Participant 5, FG 1).</p>

		<p>“They go from one clinic to the other, looking for an instant cure – getting injections, taking painkillers, then they go to the temple” (Participant 4, FG 3)</p>
Financial barriers	<ul style="list-style-type: none"> • Loss of daily wages 	<p>“We can’t afford to go to the clinic frequently” (Participant 6, FG 4).</p>
Family level barriers	<ul style="list-style-type: none"> • Lack of access to transport: Women are dependent on family for transportation to the clinic • Family’s lack of knowledge about mental illness 	<p>“If I ask him (my husband) to take me to the clinic, he says you look fine, why do you need to go?” (Participant 5, FG 2)</p> <p>“Family members do not understand mental illness. Farmers have a lot of work – if we stay in bed complaining of sadness and headache, our family blames us for not getting the work done”.(Participant 3, FG 4)</p> <p>“the doctor should explain about mental illness to the family, not just the patient” (Participant 7, FG 3)</p>
Systemic barriers	<ul style="list-style-type: none"> • Appreciation for the community mental health center which improved access to a large extent by avoiding the need to travel to the city • Lack of regular public transportation services. • Long wait times at the clinic • Clinic hours, lack of consistent providers, variable expertise of providers, lack of privacy in clinic 	<p>“Coming to Maanasi is easier than going all the way to Bengaluru” (Participant 2, FG 3)</p> <p>“After we come to the clinic, there is no bus to take back home in the afternoon and it takes us 3 hours to walk home” (Participant 7, FG 2)</p> <p>“We sometimes travel to other villages for work, and just go the local clinic there instead of coming back to Maanasi” (Participant 4, FG 2)</p>
Barriers to Adherence		
	<ul style="list-style-type: none"> • Financial burden associated with long-term treatment 	<p>“We can’t afford the medicine if we have to take it for too long” (Participant 5, FG 5)</p>

	<ul style="list-style-type: none"> • Medication discontinued with improvement, or because of lack of rapid relief of symptoms • Concern about side effects – damage to kidney and uterus • Forget to take medications 	<p>“I heard that if you take this medicine for long it will damage your kidney” (Participant 6, FG 3) (humorously) “Send a village announcer through the village reminding people to take their pills”(Participant 8, FG 4) (humorously) “give them medicines to help improve their memory so they remember to take their antidepressants” (Participant 3, FG 1)</p>
Attitude towards mobile health		
Reminders / Attitude to technology	<ul style="list-style-type: none"> • Lack of access to personal cell phone • Unsupportive or suspicious husband • Inability to read text messages • In person assessments and frequent follow ups are highly valued. 	<p>“the phone is with my husband and he is out all day – he will forget to give me the message when he comes back” (Participant 2, FG 2)</p> <p>“My husband will think I may have complained about him to the doctor and will get angry or suspicious” (if they receive a phone call from the clinic) (Participant 5, FG 3)</p> <p>“sometimes if the husband is drinking too much alcohol he becomes suspicious of other people calling his wife” (Participant 1, FG 4)</p> <p>“I am a ‘big thumb’” (referring to the use of the thumb impression as a signature by illiterate people) – I cannot read text messages on the phone”(Participant 3, FG 4)</p> <p>“phone calls won’t help - we need to see the health worker or the doctor – start a clinic in our village also” (Participant 2, FG 1)</p> <p>“It does not matter if we have to wait, it is better if we see the doctor in person” (Participant 4, FG 6)</p>