NEW STRATEGIES TO INCREASE ENGAGEMENT AND DECREASE DROPOUT IN mHEALTH INTERVENTIONS

LOG KYA KAHENGE: EXAMINING THE SOCIAL STIGMA SURROUNDING MENTAL HEALTH IN INDIA

A Thesis Prospectus

In STS 4500

Presented to

The Faculty of the

School of Engineering and Applied Science

University of Virginia

In Partial Fulfillment of the Requirements for the Degree

Bachelor of Science in Your Major

By

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November 1, 2021

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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Introduction

Even prior to the COVID-19 pandemic, the prevalence of mental health diseases among the young adult population was increasing. More than 50% of individuals will suffer from a mental illness or disorder at some point in their lives (CDC, 2021), but still, more than two-thirds of them will not receive treatment (Ellis, 2019). With this much of a deficit, it is clear that traditional methods of one-on-one clinical therapy no longer suit the needs of today's individuals, particularly those who face barriers accessing care (WHO, 2020).

Mobile health technologies, most commonly known as digital mental health (DMH) interventions, have shown much potential for allowing for continuous treatment outside of the original clinical settings. These technologies rely on symptom monitoring and self-engagement. Even though there is evidence that these DMH interventions are associated with improved treatment outcomes and greater effectiveness, they have been unable to show their full potential due to high attrition rates and common premature dropouts from the programs.

For our capstone, the team will be working together with the objective to research reasons behind these premature dropouts and design techniques to embed in the DMH interventions to combat this issue. The focus will be on conversational agents as the main DMH intervention, and innovative ways to study these in Mind Trails, an internet-delivered cognitive bias interpretation already established at UVA.

In order to get to this point of DMH interventions, however, there must be a way to ensure eligible individuals get treated to begin with. This thesis will focus on a particularly common barrier experienced by those two-thirds of individuals who refuse to get treatment – stigma – and look specifically at the region of India.

The World Health Organization labelled India as the "most depressed country in the world" (View, 2020) – with over 90 million Indians suffering from some form of mental health

illness (Rathore, 2020). The inability to understand the severity of the situation and necessity to seek treatment due to public and self-stigma has led to a less than 20% treatment rate in the region, and has even gone as far as leading to a shortage in mental health professionals (Bhatia, 2020). Deep-rooted stigma around mental health in India leads to denial and shame, and thus, a lack of treatment. How did the social stigma surrounding mental health in India come about and how have culture and policy contributed to this network of marginalizing those struggling from mental health issues? This paper will strive to answer that question by examining all the actors and actants involved in this actor-network of negativity surrounding mental health in India.

Technical Topic

DMH interventions, conducted via computers, wearables, or mobile devices, have proven to be an appealing alternative to face-to-face and traditionally delivered treatment. Due to the multitude of barriers that in-person treatment options pose, including stigma, cost, lack of insurance coverage, and limited availability of support services such as trained clinicians, many have gravitated towards studying DMH interventions and their ability to surpass most of these barriers, reducing the treatment gap (Proc. ACM Hum.-Comput. Interact, 2020).

However, the effectiveness of these DMH interventions is contingent on participants adhering to the program and reaping the benefits – an issue that mental health professionals have been facing. Dropout rates in internet-delivered treatments for mental health disorders have ranged from 30% to as high as 60% (Proc. ACM Hum.-Comput. Interact, 2020). In addition to the ineffectiveness this issue poses for those looking for treatment, these high dropout rates have limited the generalizability of digital intervention studies and have caused additional expenses as attracting new participants is more expensive than keeping current participants. In order to

combat this issue, it is essential that factors that influence participants attitude and behavior are identified early on within a study.

There have been many studies conducted in the space of conversational agents. One particularly interesting study, conducted at Stanford, studied where conversational agents today fall short. This study focused on the four most utilized conversational agents today, Siri [Apple], Google Now, S Voice [Samsung], and Cortana [Microsoft], and examined their responses to a standardized panel of questions related to mental health, interpersonal violence, and physical health (Miner et al., 2016). The responses were then characterized based on their ability to recognize a crisis, respond with respectful language, and refer to an appropriate helpline or resources. The results of this study proved to be concerning as all the conversational agents responded inconsistently and incompletely. For example, none of the conversational agents referred users to a helpline for depression, showing the necessity to improve conversational agents today.

Other studied have taken a deeper dive, examining conversational agents catered towards mental health and their resulting adherence and effectiveness. Shim is a positive psychology-oriented conversational agent that was studied by researchers in Sweden through a pilot randomized controlled trial (Ly et al., 2017). The objectives of this study were to assess the effectiveness of and adherence to the Shim smartphone application, and to explore the participants' views and experiences of interacting with the chatbot. Through this study, the researchers found that the intervention did not differ significantly from the wait-list control group on any of their defined outcome measures, but for those who adhered to the study, there was a significant improvement in terms of psychological well-being and perceived stress. This

shows that this intervention can be highly effective if certain characteristics that would make one drop out earlier on can be pinpointed.

The objective of the technical capstone is to draw upon research similar to the ones discussed above and design our own study to evaluate the acceptability and feasibility of conversational agents among the general anxious population. We are constrained to basing our research on a subset of the population in MindTrails, an internet-delivered cognitive bias interpretation already established in UVA. So far, we have been working on designing our study and will soon begin running the study on our socially-anxious population.

STS Topic

"Log Kya Kahenge?" (Hindi for "What will people say?")

A boy and girl from different castes fall in love and they insist on getting married. Their families disagree: *"Log Kya Kahenge?"*

A depressed IIT student opens up to his parents about his mental health and requests they seek a therapist for him. They disagree*: "Log Kya Kahenge?"*

The Log Kya Kahenge disease has destroyed several millions of lives in India, and has even gone as far as hindering the progression of society. When looking at the last example of mental health, Log Kya Kahenge and both public and self-stigma have stopped so many individuals from seeking treatment. India has the 2nd most depression cases, anxiety cases, and overall mental health cases (McPhillips, 2016) – with over 90 million Indians suffering from some form of mental health illness (Rathore, 2020). The inability to understand the severity of the situation and necessity to seek treatment has led to a less than 20% treatment rate, and has even gone as far as leading to a shortage in mental health professionals (Bhatia, 2020). Deep-

rooted stigma around mental health in India leads to denial and shame, and thus, a lack of treatment. How did the social stigma surrounding mental health in India come about and how have culture and policy contributed to this network of marginalizing those struggling from mental health issues?

The current complicated relationship between mental health and culture can be seen in the production, representation, and reception of mental illness in Indian Hindi cinema (Pathak & Biswal, 2020). With Bollywood being one of the most prolific centers of film production in the world (Maheshwari, 2013), it does have the powerful potential to shape most of the Indian population's thinking. The stigma regarding mental health may be being affirmed by these modern cinemas, allowing for no growth or stray away. In certain examples, it was noticed that psychiatric treatments were shown as modes of punishment or torture, and were overall used by negative characters to create insanity. Additionally, there were several examples that related supernatural elements and magicoreligious beliefs with mental illness. Pathak & Biswal (2020) argued that the problem with these representations is that in order to sustain the interest of the audience, they solidified the existing beliefs on mental illness and provided people with an excuse to alienate patients with mental illness from the community. When promising cinemas with progressive gestures came about, they were often responded to with negative sentiment. Below is an example of this negative or uneducated sentiment.

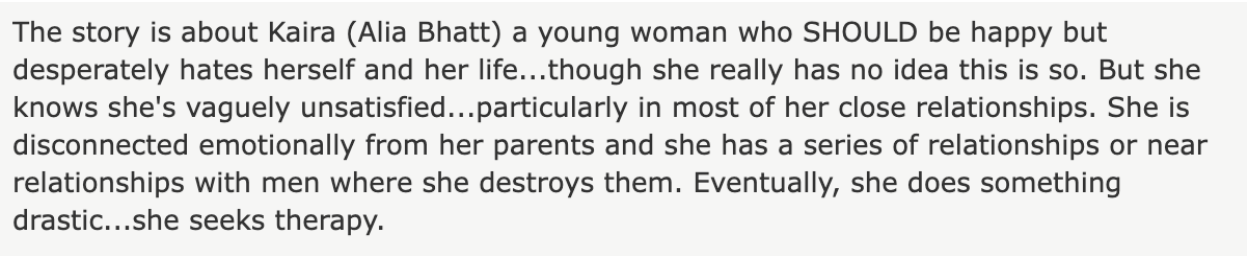

Figure 1. Review for Dear Zindagi from IMDb

These sentiments and inabilities to be receptive are not a shock, considering current official handling of mental health. The Ministry of Health and Family Welfare in India posted the below graphic on their Twitter:

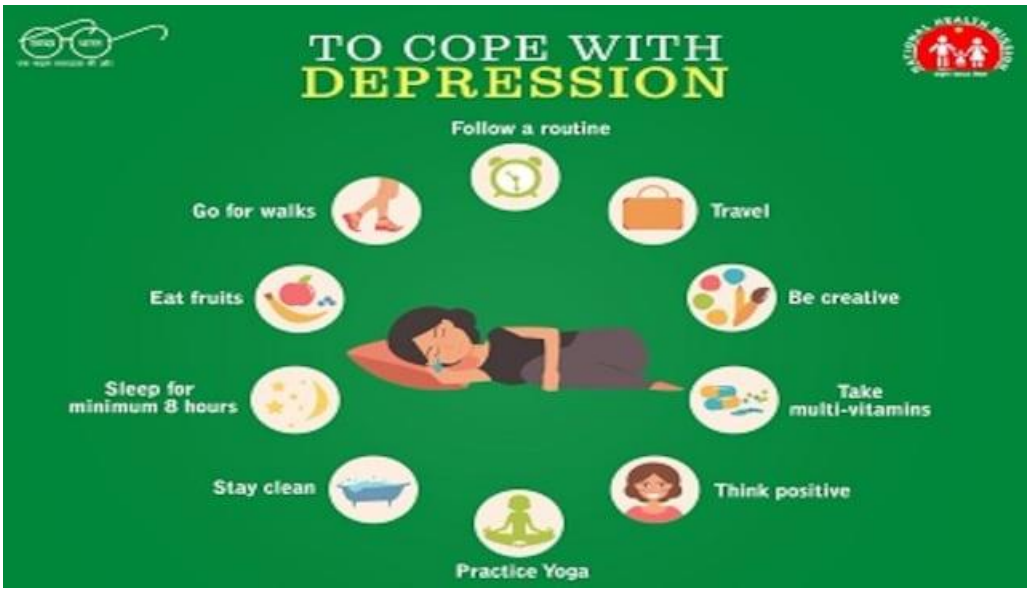

Figure 3. Indian Ministry of Health's Graphic for Depression

Aside from saying insensitive and uneducated statements such as "think positive" or "stay clean", nowhere in the poster does the government mention seeking professional help or therapy. The poster's generalization and oversimplifying of depression to merely being in a bad mood not only shows a lack of regard, but also conveys information that may be harmful. For some cases of depression, yoga is actually not recommended; and there is no evidence that multi-vitamins have any effect on developing depression (Srivastava, 2018).

So, with this sentiment being pushed in Bollywood, the most popularly consumed media in India, and current government handling of the situation, it is no surprise that there is a social stigma surrounding mental health in India. An examination of the marginalized individuals in this network can show just how serious the situation is.

With a grant from the International Reporting Project, Miranda Kennedy (2010) travelled to India to report on a particular case study in the rural part of Tamil Nadu - the temple at Hanumanthapuram. Many travel across India for days and weeks to the temple due to the belief that the faith healers and temple doctors can heal the mentally ill. Kennedy (2020), and Indian social worker Porkodi, focused on one girl, Manimagali, who was diagnosed with schizophrenia but felt more comfortable being treated at the temple rather than being referred to a therapist. Porkodi explained that Manimagali's opinion is not uncommon, "People find it easier to say their children or themselves are affected because of evil magic, because there is so much stigma attached to mental illness". The cultural stigma against mental health is so strong, even individuals who are suffering, like Manimagali, must convince themselves that their condition is not an internal one. Rather, their condition is due to an external force and they themselves are supposed to be completely okay. Thus, they refuse to seek treatment and never fully make a recovery.

However, there are also cases where marginalized individuals in this network themselves are aware of their condition, but fail to find treatment due to disregard from their peers. The Live Love Laugh Foundation (TLLLF) hosted a survey of 3,556 respondents from eight cities across India, and found that 47% could be categorized as being highly judgmental of people perceived as having a mental illness. These respondents were more likely to say that one should keep a safe distance from those who are depressed (Thomas, 2018). If their peers are more likely to stay away from them or downplay their condition, why should they voice themselves? In many cases, individuals are even abandoned by their families. In a story for BBC (2018), Ramaa (name changed) told her story after she experienced this when she was diagnosed with bipolar affective disorder. Her husband promised to return with medicines, but never did so.

This network of mental health in India can be broken into two sub-networks: the network of political and cultural actors involved in maintaining anti-mental health beliefs and the network of actors involved in marginalizing those who are struggling.

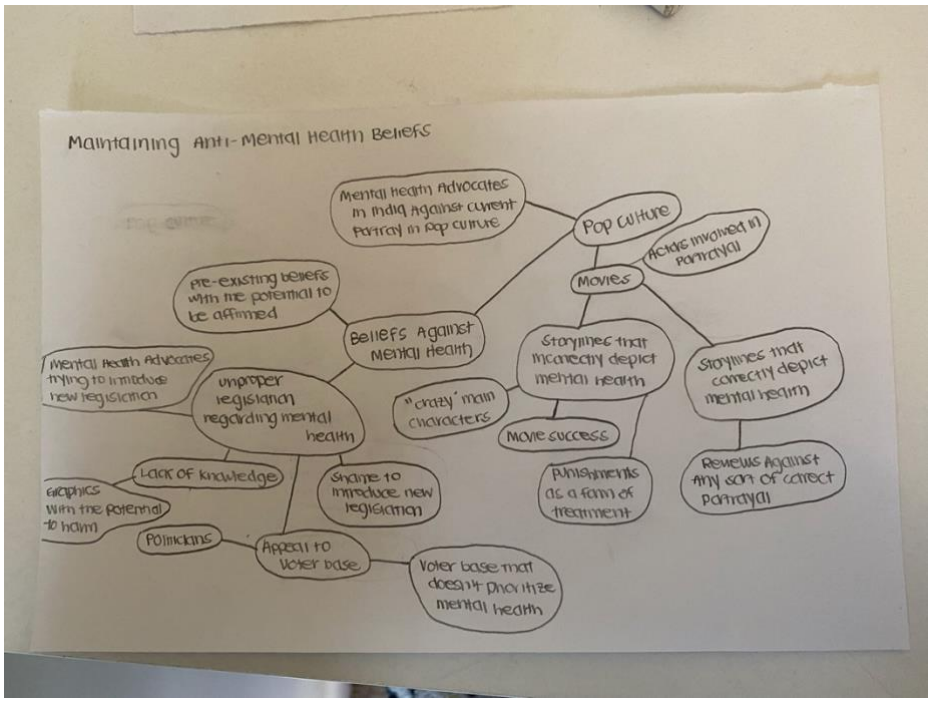

Figure 4. Network 1 of Maintaining Anti-Mental Health Beliefs

Figure 4 diagrams the first network of political and cultural actors involved in maintaining anti-mental health beliefs. On the right side, you see the pop culture element to it, where the discussion on Bollywood movies has been diagramed. Pop culture includes these movies that affirm the pre-existing beliefs against mental health held by the population, by continuously depicting mental health with “crazy” main characters and punishments as a form of treatment or therapy. These movie storylines are also often associated with movie success or a being a hit in the box office. The other side of this, is movies that have storylines correctly depicting mental health. However, these same storylines are often associated with a lot of negativity and poor reviews from the public and the press. On the left side, you see the political side to it. Corrupted politicians, only with the goal of being elected, do not prioritize mental

health as the voter base does not prioritize mental health. Due to this, only improper legislation regarding mental health gets introduced, leading to a lack of knowledge overall and even graphics and statements with the unintended potential to harm. The two sides, cultural and political, work side-by-side to maintain today's anti-mental health beliefs. The different actors and actants involved in this network are the Bollywood movie production staff (actors, directors, producers, writers), the storylines, the press, the box office, social media, movie-watchers, politicians, the government, citizens or the voter base, legislation, incorrect graphics, and advocates working against this belief.

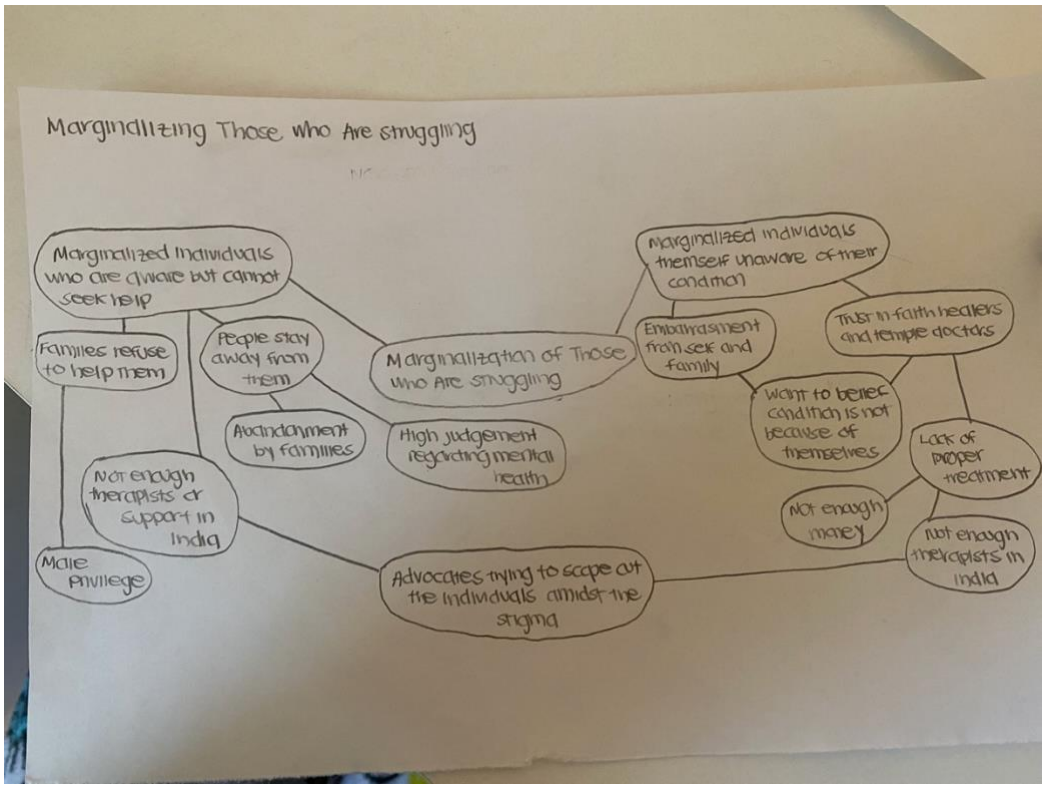

Figure 5. Network 2 of Marginalizing Those Who Are Struggling

The lack of support from the political and cultural actors involved in Figure 4, lead to the network diagrammed in Figure 5: the marginalization of individuals who are struggling from mental health in India. There are two sides to this: marginalized individuals who are themselves

unaware of their condition and marginalized individuals who are aware, but are unable to seek help. For individuals who are unaware of their condition, this may be due to self-embarrassment or embarrassment from family members. As it was seen in the evidence prior, people have a harder time admitting they have a mental health condition than a spiritual condition, which is why they revert to faith healing techniques and temple doctors. This leads to a lack of proper treatment, which is further pushed due to the lack of money in these areas and the lack of therapists in India in general. For individuals who are consciously aware of their condition, they are unable to seek help due to familial refusal to help or familial downplay of emotions, or the belief that you must stay away from those with mental health diseases. This leads to abandonment by friends and families, which is further pushed by the current male privilege in India. On both sides, whether individuals are aware or unaware, we have mental health advocates attempting to scope them out amidst all the stigma. The different actors and actants involved in this network are the marginalized individuals, temple doctors or faith healers, religious texts against mental health, the believed "demons" behind the mental health conditions, the religious treatment methods, families of those struggling, self-embarrassment, those who social-distance from those who are struggling, public judgement, current therapists in India, and advocates of mental health in India.

Overall, there is evidence that there is an actor-network environment in India that contributes to negativity and disregard for mental health in India. Pop culture, particularly Bollywood, and politics have maintained the pre-existing beliefs against mental health, thereby restricting any growth regarding this topic. This lack of growth had led to the marginalization of several individuals in India, both aware and unaware of their condition. More light must be shed onto these interconnected and mutually constituted networks, and an intervention be introduced

into this network that either prohibits further maintenance of these beliefs or gives marginalized individuals an outlet to express their condition.

Next Steps

Technical Capstone Next Steps

Draft and Submit Project Plan to IRB	October 2021 – December 2021
Recruit a Limited Number of Participants	December 2021 – January 2022
Complete Study Activities	January 2022 – February 2022
Complete Thematic Analysis and Quantitative Analysis	February 2022 – March 2022

STS Topic Next Steps

Research Other Studies in this Domain	October 15, 2021 – October 22, 2021
Pull Other Pieces of Evidence (Literature, Pop Culture, etc.)	October 22, 2021 – October 29, 2021
Finish Final Prospectus	November 1, 2021
Set Up Future Research Goals for the Spring Semester	November 1, 2021 – December 7, 2021
Potentially Design a Study or an App to Research	December 2021 – January 2022
Reach Out to Supportive Organizations in India to Learn	January 2022 – February 2022
Meet All Future Deadlines and Assignments	February 2022 – May 2022

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