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April 14, 2020

# Mental Illness and Pregnancy among Women in Mysore, India: Health Provider and Women's Perspectives

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An abstract of a thesis submitted to the Faculty of Emory College of Arts and Sciences of Emory University in partial fulfillment of the requirements of the degree of Bachelor of Science with Honors

**Anthropology Department** 

#### Abstract

## Mental Illness and Pregnancy among Women in Mysore, India:

### Health Provider and Women's Perspectives

#### By Ruhika Prasad

Global Mental Health (GMH), a subfield of the broader study in global health, examines how mental health affects populations across the world (WHO 2004). Identification and treatment of mental illness are heavily influenced by factors such as culture and society.

Accounting for this diversity in global mental health requires understanding non-allopathic concepts of wellbeing and distress. To address the global diversity and wide variety of treatments, this study centers around mental illness in India.

As part of a collaboration between the Public Health Research Institute of India (PHRII), University of Oregon, and Emory University, this project studies how women's mental illness was discussed and treated in urban Mysore, Karnataka over a three-month period in the summer of 2019. Researchers focused on the following questions: how do a spectrum of mental health providers in Mysore, South India, perceive and hear the experiences of their female patients' mental illnesses? What terminologies do women use to describe their mental illness symptoms? To what extent does stigma pose a barrier for women to access treatment for mental illness? How do both providers and women perceive mental illnesses that occur during pregnancy, childbirth, and postpartum period?

The research team conducted semi-structured interviews with providers and women who were identified through a combination of PHRII's existing community contacts, online research, and word of mouth. Researchers set up and conducted fifteen informational interviews with community mental health providers including psychiatrists, psychologists, spiritual healers, religious leaders, and NGO workers. Researchers asked providers about the range of pathologies

and descriptions of symptoms they heard from patients. Further, researchers interviewed individual women recruited from focus group discussions to discuss mental illness specifically during pregnancy, childbirth, and the postpartum period. Analysis of transcripts from providers and women used a modified grounded theory approach focused on thematic analysis to identify motifs from interviews (Ryan 2003). Findings include mental health providers treating proportionately high numbers of female patients, and a common pattern of women seeking multiple religious healers and spiritual leaders while seeing psychiatrists or psychologists at the same time.

Words: 345/350

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#### **PREFACE**

"The awareness of mental health is lost, forgotten. People do not know where to go, whom to talk to, or what to do. It is a must, to continue this conversation"- Dr. Shankar, Psychiatrist at JSS Hospital

This undergraduate thesis is one product of two years' worth of team research on the scope of mental health services found in Mysore, Karnataka, India. Dr. Lesley Jo Weaver conducted the first part of this study through a partnership with the Public Health Research Institute of India in the summer of 2018. For the first phase, Dr. Weaver conducted interviews with 35 Mysore-based women speaking about their experiences and perceptions of mental illness. In the summer of 2019, the project expanded to include my component of interviewing providers for their perspectives on mental illness in the populations they serve. While I first interviewed medical doctors, psychologists, and psychiatrists, I wanted to include more community health providers from a broader spectrum.

The care for mental health spans many community members and professions and transcends allopathic notions of mental healthcare with a high prevalence of astrologists, spiritual healers, religious leaders, as well as workers from nongovernmental organizations. I had planned to disseminate this research at the Consortium for Universities in Global Health (CUGH) Spring Conference that has been canceled due to the Covid-19 crisis and have since published an overview of my research in the Emory Undergraduate Research Programs One

Record Series. Dissemination will also occur on site in India, with researchers from the Public Health Research Institute of India speaking with interviewees about access to their resources for mental illness in Mysore city. The conversation about mental illness and how best to deliver it is ongoing. This thesis is an exploration of how Mysore as an urban community functions to serve its people's mental health needs, in an effort to create models and personalized mental healthcare

for those in every socioeconomic status that can best serve them culturally appropriate medically sound care. As a South Indian American woman belonging to the diaspora of India, I was drawn to conducting research on mental health among South Asian women in part because many women in my family have suffered mental illness during pregnancy, causing maternal mortality and morbidity. Though I had originally proposed working on women's health in terms of pregnancy, I started to find connections in my research between mental and maternal health more broadly. Through this connection, my interest in women's mental health during vulnerable times such as pregnancy deepened. It is then that I realized that issues of women's mental health such as postpartum depression cause significant maternal morbidity, but these issues are often overlooked.

Due to the lack of existing literature's focus on women's mental illness in India, this study will focus on the following questions: how do a spectrum of mental health providers in Mysore, South India, perceive and hear the experiences of their female patients' mental illnesses? What terminology do women use? To what extent does stigma pose a barrier for women to access treatment for mental illness? How do both providers and women perceive mental illnesses that occur during pregnancy, childbirth, and postpartum period? To contextualize this research, one must understand the operating definition of mental illness, the burden of mental illness around the world and India specifically, along with factors unique to India that affect mental illness and seeking treatment. The following literature review helps establish the basis for this study. Note, the use of allopathic and biomedical providers is interchangeable because these terms refer to providers that are medically trained. However, other non-allopathic providers were included in this study not only because of the frequency with which they are used but because of their cultural acceptance. These providers, such as astrologists, religious leaders, spiritual healers, are trained in their own skillset and should not be discounted.

#### <u>Definition of Mental Health and Mental Illness</u>

According to the World Health Organization (WHO), mental health is "a state of wellbeing in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community" (WHO, 2005). In the early 1960s, the WHO took on a new initiative called the *Mental Health Program* in which diagnoses and treatments of mental illness were prioritized. Throughout the formation of this program, the International Classification of Disease and Related Health Problems 10th edition (ICD-10) was created to better solidify classifications of

mental illnesses. The ICD-10 remains one of the standards for international mental illness prevention. The ICD-10 identifies the term "mental illness" to mean "the existence of a clinically recognizable set of symptoms or behavior associated in most cases with distress and with interference with personal functions," (WHO 1993). Many of the previous ICD editions use the word "disorder" and "illness" interchangeably, including ICD-10; this study uses the term "illness" because this way of describing conditions was used more frequently at the study site of Mysore, Karnataka, India.

ICD-10 is used as a standard because it acknowledges the wide variations in manifestations and treatments of mental illness across culture, religion and nationality. These variations can make creating a general consensus of health difficult to achieve (Galderisi 2015). Therefore, definitions of health, and particularly mental health, started evolving to include phrases describing mental health as "a dynamic state of internal equilibrium" and "creating a harmonious relationship between body and mind" (Galderisi 2015). These latter definitions open up possibilities of traditional, indigenous medicine as treatment and allow more cultural systems of health to serve as the basis for public health intervention.

#### The Burden of Mental Illness Around the World

Mental illnesses are increasingly becoming a prevalent issue contributing to morbidity and disability-adjusted life years DALYS (Disability Adjusted Life Years Lost) across the world (Murray 2010). The WHO defines a DALY as one lost year of healthy life or a year of deteriorated quality of life. In the realm of public health, DALYs are used as a benchmark for the burden of disease on an individual or population. Overall, the WHO estimates that 7.4% of global DALYS are caused by disorders in the mental and behavioral disorders category. Major depressive disorder composes 2.54% of this value, followed by anxiety disorders with 1.08%, and alcohol and drug use disorders at 0.8% and 0.71% (Murray 2010). Further, the aggregate burden of years lived with disabilities (YLDs) for mental and behavioral disorders encompasses

23% of the global DALYS across conditions not including non-communicable diseases (Becker 2013). This category of disorders continues to be higher than any other disease category, and this trend has continued since the late 1990s (Becker 2013). Therefore, conditions of mental health need to be prioritized in congruence with medical problems, as many times patients can develop mental health needs from preexisting physical ailments or mental health needs can cause physical illnesses.

The burden of mental illness in low and middle-income countries is growing: Low- and middle-income countries are home to more than 80% of the global population but command less than 20% of the share of the mental health resources (Prince 2007). Even more startling for vulnerable populations such as women and adolescents, accurate counting of suicides in India and China have shown that rates are much higher than those reported in routine statistics and that self-inflicted injuries account for a quarter to half of all deaths in young women (Patel 2012).

One notable program targeting mental health issues internationally was sponsored by the World Health Organization, entitled the Mental Health Gap Action Programme (mhGAP). Launched in 2008, the program trained non-M.D. health workers in routine health care settings to identify mental, neurological, and substance use disorders. The goal of the program was to experiment with task shifting and task sharing from doctors to those that were more readily available and could be trained such as nurses or community health workers. In this manner more persons could have access to mental healthcare at a routine doctor's office or clinic. The program was part of a six-year research consortium led by South Africa that included Ethiopia, India, Nepal and Uganda (Patel 2012). Key findings from the program centered on barriers to accessing care that need to be addressed on a country-by-country basis: stigma against those living with mental disorders, lack of community awareness, and the lack of ongoing research targeting the betterment of lives for those affected by mental disorders (Patel 2012). Mental health may

present itself differently depending on social and cultural determinants of health unique to specific regions of the world (Minas 2014). This becomes a key consideration for mental health professionals as it could direct how to conduct therapy.

In some cultures, shame or embarrassment due to cultural and familial views on mental health and the expression of emotions can influence the ability to access treatment. Spirituality and religion may play larger roles in some cultures over others in terms of treatment for mental health (Patel 2012). The awareness and acceptance of illness contribute to the differences in treatment and access to mental healthcare across international borders.

However, some of the lowest rates of uptake and access to allopathic services, such as therapy, medication, or counseling, lie in Africa and Asia, particularly South Asia (Patel 2012). While this may suggest that these communities do not seek care, these communities may have different forms of treatment that may not always align with the allopathic notion of treatment but are culturally applicable. The high burden of mental illness in South Asia directed this research to study and evaluate the treatment and diagnoses of mental illness in South India.

## Mental Illness in India: A Case Study

India is emerging as one of the most populous countries in the world. With 1.35 billion people living in the country as of 2019, over 14% of the population have experienced mental illness including depressive and anxiety symptoms (Sagar 2020). The country, therefore, is grappling with serious mental illnesses and is worth studying (Sagar 2020). A study conducted on maternal mental health in primary care in India reported that rates of depression are affecting over 35% of the population (Baron 2016). However, the study noted that this percentage is much lower than the actual rates of depression in the country due to under reporting of conditions. As doctor and clinical psychologist Dr. Vikram Patel notes, the lack of awareness of mental illness in the nation highly contributes to the lack of uptake of allopathic services for mental illness (Patel 2012).

While Dr. Patel's assessment points to the disparity in awareness of mental illness, the Indian population might be seeking care in *alternative forms* such as astrology, religious healing, and spiritual therapy. Therefore, allopathic-based treatments might be viewed as more of a last resort rather than a primary resource. Other studies have corroborated this notion: patients' explanatory models of mental illness may align more closely with those of traditional or religious practitioners than biomedical models but the parallel use of multiple systems is common (McCabe 2004).

According to the Indian Government's Ministry of Health and Family Welfare, in 2017 197.3 million people had mental illnesses in India, including 45.7 million with depressive disorders and 44.9 million with anxiety disorders (Sagar 2020). Further, researchers from the Government of India found a significant correlation between the presence of depressive disorders and suicide death rate at the state level for females more than for males (Sagar 2020). The contribution of mental illnesses to the total DALYS in India increased from 2.5% to 4.7% from 1990-2017 (Sagar 2020).

The latest data on incidence of mental illness in India are reported by a National Mental Health Survey (NMHS) conducted by National Institute of Mental Health and Neurosciences, NIMHANS, in 2015-16 (Pradeep 2018). The NMH survey reports that "common mental disorders" (including co-morbidities such as substance abuse) are a huge burden, affecting nearly 10 % of the population (Pradeep 2018). This survey defined common mental disorders as including but not limited to bipolar mood disorders, depression, anxiety disorders, panic disorder, obsessive-compulsive disorder, and post-traumatic stress disorder (PTSD). Some individuals and families ignore and neglect these disorders till they become severe (Basu, Das, Misra 2016). Nearly 1.9 % of the population were affected with severe mental disorders in their lifetime and 0.8 % were identified to be currently affected with a severe mental disorder. The prevalence is highest in the age group 30 – 49, and most of the persons who were identified as

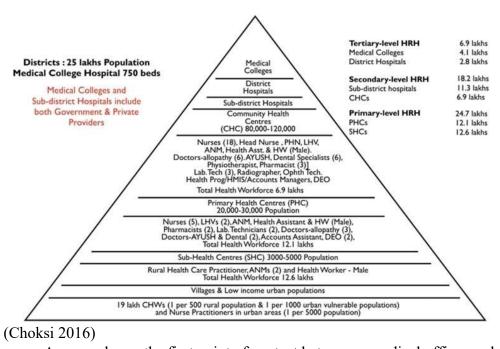
suffering such disorders experienced severe disability and were unable to work for long durations (Pradeep 2018). The most severe outcome from mental health disorders is suicide, and India has one of the highest suicide rates (10.6/100,000 people) in the world (Armstrong 2018; Basu, Das, & Misra 2016; Patel 2012).

In the more recent NMH survey (2016), they also find that the incidence of suicidal ideation is very high at nearly 1% of the population, even though it is not always correlated with other diagnosed mental illnesses (Pradeep 2018). There is a general consensus that while many structural and circumstantial issues lead to suicides, timely and well targeted counseling, treatment, and coverage of external factors exacerbating mental illness such as economic disparities, can adequately address the underlying stress and hopelessness (Mirza 2017). Inefficiencies in the provision of public mental healthcare, thus, have extremely negative effects via the loss of work productivity, earning potential and the quality of life of these individuals and their families, and in the extreme cases loss of life (Mirza 2017).

# Framework of the Public Healthcare System in India.

The majority of India's population utilizes to allopathic healthcare provided by the government, called public healthcare. Therefore, many go to government funded facilities through the public healthcare system to take care of their mental health needs. The structure of this system is as follows.

Figure 5



As seen above, the first point of contact between a medical officer and a patient is a Primary Health Center (PHC), while a Community Health Center is the first level for specialist care. The main towns at the district level generally have a hospital with round-the-clock emergency care, many-bed hospitals for inpatients, and provision of advanced diagnostic and specialist services. The provision of public mental health care in India is a joint responsibility of the center (federal or central) and state governments.

The responsibility of mental health falls under the domain of the central Ministry of Health and Family Welfare (MoHFW). The NMH survey (Pradeep 2018) reports that the treatment gap for almost all mental illness is very high: nearly 80 % of persons suffering from mental disorders had not received any medical treatment despite the presence of illness for more than 12 months (Mirza 2017). However, people may seek treatment from other kinds of practitioners that practice different types of healing.

Given that many PHCs are not composed of practitioners specialized in mental illness, general providers tend to see these cases and refer to the nearest specialist or treat with medications they have in house. The treatment gap was more than 60 % for major mental

illnesses, which the study defines as schizophrenia, neurological illnesses, and mood disorders, and 85.2 % for depressive disorders which was defined as any stage of depression. Only a third of the dozen states surveyed had more than 50 % of the population covered by the public supply of mental health (Mirza 2017). More than 60 % of people who accessed this care did so directly at a district hospital rather than at a local primary health care clinic, and this provision was limited to psychiatric clinics (Patel 2016).

Table 1: Details of requirement and the availability of mental health professionals in India.

Manpower	Requirement	Availability
Psychiatrists	11500	3800
Clinical psychologist	17250	898
Psychiatric social workers	23000	850
Psychiatric nurses	3000	1500

(Kharuna 2016)

Table 1 summarizes the availability of mental healthcare professionals per population of 100,000 people on average in the country, based on the reporting of Khurana and Sharma, as well as the National Mental Health Survey conducted by the Indian Government in 2015-2016 (Murthy 2017). The left column lists WHO recommendations for the country based on population and districts, and the right column lists numbers from the 2015 Indian census. Note, in particular, the greater shortage at lower skill levels, a striking imbalance for a relatively poor country. The number of medical officers at the district level trained to deliver mental health services (per 100,000 people) is very low and highly variable among India's states, varying from 0.1 to 10, which is much greater than the variation in income levels (Khurana 2016). The number of psychiatrists identified in this survey in India is 33% of the recommended or required amount,

and the number of psychologists are only 0.05% of the required number as recommended by WHO standards. The lack of qualified mental health professionals is a challenge that mental healthcare programs face everywhere in the world. In India and other low and middle-income countries, the treatment gap is only increasing and is likely to grow unless there are effective interventions (Kakuma 2011) (Kharuna 2016) (Murthy 2017).

#### Mental Health Policy in India: A Timeline

Health treatment and access is difficult for a significant part of the population because the sheer number of people needing access to care at any given point. In response to growing concerns regarding the lack of access to treatment, the Indian Government Ministry of Health and Family Welfare enacted new legislation and policy initiatives. Below is a timeline of different policy associated with mental health established in India. Note that while more recently global mental health experts call for culturally focused care and policy, India's policy does not focus on this aspect (Table 2).

Table 2: Policy on Mental Illness Prevention in India

Policy	Aims
National Mental Health Program of 1982	Targeted the heavy burden of mental health illnesses and the inadequacy of mental healthcare, particularly for those from low income and low caste groups. The three main objectives of the National Mental Health Program include:  To ensure availability and accessibility of minimum mental health care for all in the foreseeable future, particularly to the most vulnerable and underprivileged of the population;  To encourage application of mental health knowledge in general health care and in social development; and  To promote community participation in mental health services development and to stimulate effort toward self-help in the community.
National Mental Health Program of 1996	Training: imparting short term training to general physicians for diagnosis and treatment of common mental illnesses with limited number of drugs under guidance of specialist. The Health workers are being trained in identifying mentally ill persons.

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The Mental Health Care Bill of 2016	<ul> <li>Recognized that all individuals in the country who are suffering from mental disorders have a right to get treatment, support, and lead a normal life free from discrimination and injustice.</li> <li>Decriminalization of attempted suicide: The bill specifically stated that there is a presumption of severe stress in person with attempted suicide and such person shall not be tried and punished under the said code.</li> <li>Government will be bound not only to provide care, treatment, and rehabilitation of such persons but also to take measures to reduce its recurrence.</li> </ul>
National Health Policy of 2017	<ul> <li>Needed increase in training of specialists through public financing mechanisms that are specifically aimed towards those who are willing to work in public systems after graduation.</li> <li>Training needed for the accredited health workers, ASHAs, to provide community or home-based care for prevention, cure, and rehabilitation from mental illnesses</li> </ul>

(N Wig 2015)

#### **Stigmatization**

Stigmatization of mental health has increasingly been a primary barrier to accessing and using mental healthcare resources in India. Stigma in Indian society and culture particularly influence perceptions of mental health but also influence whether persons seek mental healthcare. Nearly 75% of individuals living with severe mental illnesses in the Central Indian state of Madhya Pradesh revealed that they delayed seeking psychiatric care for their mental health in part due to fear of stigma or being stigmatized in society (Lahariya 2010). Further, in India, people with schizophrenia have reported high rates of perceived stigma and they have primarily felt that discriminatory attitudes come from community (46%) and from family

members (42%) (Mascayano 2015, 200). The presence of stigma acts not solely as a barrier to receiving care but even to talking about symptoms and conditions, especially stigma against visiting biomedical providers. In a recent study by The Live, Laugh, and Love Foundation, researchers in South India found that 62% of participants (both male and female combined) also used derogatory terms like retard (47%) or crazy, mad, stupid (40%) or careless and irresponsible (38%) to describe people with mental illness (TLLF 2018).

Further, one study in South India demonstrated that there are high levels of stigma against discussing mental illness in rural worker populations (Jadhav 2007). This study worked with rural farmers and showed that when prompted about who they speak to about feelings and their mental state, either the farmers did not have these conversations or explained that they were afraid of others' judgement if they did speak on these issues. One in 20 people meets criteria for depression in rural areas of South India (Telangana, Karnataka) but fewer than 15% of these reports seeking treatment (Pradeep 2018). While some studies show populations in rural areas have less awareness of mental illnesses and their prevention than urban areas, other studies cite that distance or proximity to resources has little effect and rather education levels pose a greater barrier and feed stigma (Roberts 2020). Stigma affects individuals to such an extent that some need to meet their mental healthcare providers in locations outside their home or local district in order to avoid being stigmatized by neighbors for their participation in mental health related programs (Kohrt 2018). It is because of this stigma that many studies have noted the use of faith healers and religious leaders as the most commonly sought out primary helping agency for the general public (Lahariya 2010).

#### Alternative Forms of Treatment for Mental Illness

In India, there are a small number of qualified psychiatrists, and these professionals are mostly concentrated in the metropolitan and the urban areas (Gururaj 2016, 25). The tradition associated with faith healers, religious leaders, astrologists, or counselors from NGOs contributes

to the population's continual usage of these treatments either by themselves or simultaneously with allopathic forms of care. Religious leaders might be trained in temples by other monks or priests, while faith healers might be trained in centers called "ashrams". In many situations, family members bring patients to these healers. A study on the treatment of psychiatric disorders in India observed that 80% of the population in both urban and rural areas of South India used indigenous forms of treatments either in congruence with allopathic care or by itself (Roberts 2020). These consisted of Ayurvedic and Unani systems of medicine, religious treatments consisting of prayers, fasting, and so on, as also various witchcrafts and rituals (Lahariya 2010).

Literature clearly cites the use of healers in various capacities in India. In her ethnography, *In Amma's Healing Room* by Joyce Flueckiger writes that the healer she worked with in South India, Amma, frequently classifies the mental illnesses she treats as both somatic and mental illnesses. As Amma treats conditions that are caused by "saitani" or the "impingement of spiritual forces on the physical word", Amma can take the responsibility or fault off of the patient and onto aspects beyond the patient's control, effectively easing their mind and body (Flueckiger 2006, 64). Amma also frequently refers patients to allopathic doctors for illnesses that she identifies as being outside her range of expertise, even recommending these practitioners by name (Flueckiger 2006, 65). Amma's collaboration with allopathic providers demonstrates the intertwined nature of religious healing and allopathic treatment for mental illness that exists and is possible in India.

Anthropologist William Sax echoes these observations, noting that in the state of Uttarakhand ritual healing by religious healers or spiritual leaders is the 'most common option for those with serious behavioral disturbances," (Sax 2014, 829). While Sax notes the therapeutic effectiveness of these techniques, he argues that ritual healing and mainstream "Western" psychiatry might not be compatible. This relationship between allopathic forms of care and religious and spiritual healing, becomes a focus of this current study.

#### Caste Difference

The caste system, a stratification system unique to India, plays a significant role in access to healthcare in terms of discrimination against patients from lower castes. The caste system creates a ranking system for different groups traditionally based on the occupation of the family into which a person was born (Khubchandani 2017). Castes create stratifications that have specific social advantages or disadvantages and create categories for making health treatment in social settings different based on family name. While caste and socioeconomic status are often closely linked, with lower castes often being of lower socioeconomic status, these factors are not the same. The main difference between caste and socioeconomic status is that, while socioeconomic status can be malleable, caste is something one is born with, and therefore cannot change.

Studies have reported that several health measures, including self-rated overall general health, disability, and presence of a chronic disorder, are similar between scheduled tribes, scheduled castes, Brahmins, Kshatriyas, Vaishyas, and Shudras in people aged 18–49 years (Patel 2012). However, people aged 50 years and older in scheduled tribes and castes were reported as having poorer self-rated health and generally higher levels of disability than those in less impoverished groups, which suggests that the longer the exposure to poverty, the greater the effect on the ageing process, possibly more of an effect than the stress included by caste differences and discrimination (Radhamanohar 2015).

Studies indicate that caste-based discrimination continues to persist in modern Indian society, centuries after its establishment (Khubchandani 2017). For example, a study of pregnant women from rural western India belonging to lower castes shows that these women experienced longer wait time and maltreatment in healthcare settings as opposed to women of higher castes (Khubchandani 2017). Further, other studies have noted that the caste system has resulted in an high prevalence of specific autosomal recessive illness in specific lower caste populations such

as mental impairments (schizophrenia, depression, anxiety, mood disorders) (Balgir 2005, 10211026; Bener 2014, 108-114; Shieh 2012, 1236-1241; Pulai 2014, 387-391). Another study conducted in New Delhi found that discrimination based on caste in primary healthcare centers prevented those of lower caste from not only gaining access to treatment but also posed barriers to accessing education on mental illness generally in these clinics (Trani 2015, 8). Therefore, it is important to understand how caste differences and discrimination can infiltrate societal norms and customs and interrupt the "objectivity" of medicine and healthcare delivery systems. Caste, like mental illness, is taboo to talk about openly in many Indian contexts, and many providers may not have felt free to talk about caste in this setting with a researcher they did not know well enough. While caste differences is not the focus of this study, caste differences play a role in access to treatment for mental illness and needs acknowledgement for future studies.

#### Women's Mental Illness in India

Gender is a critical determinant of mental illness around the world. This study's focus is on India, and there are specific systems in India that affect heavily women's' mental illnesses. Girls married at a very young age India are at a higher risk for attempted suicide and self-harm (Malhotra 2015). Low attendance in hospital settings is partly explained by the lack of availability of resources for women in India, and around two-thirds of married women in India were victims of domestic violence in 2015 (Malhotra 2015). Further, specific conditions in India put pressure on and can increase the likelihood of mental illnesses in women, particularly of lowincome status or household income (Baron 2016).

Psychiatric epidemiological data cite a ratio of one woman for every three men attending public health psychiatric outpatients' clinics in urban India (Sood 2008). Indian state officials view this as "under-utilization" by suffering women, attributing it to the greater stigma attached to women's mental illness that restricts help-seeking in public health facilities and/or to the lower importance accorded to women's health generally (Sood 2008). However, it is important to note

that women may be seeking treatment from nonallopathic providers, and this is still considered as service usage for treatment of mental illness. The male: female ratio for the allotment of beds in government mental hospitals with only service was 73%:27% while those with service, research, and training was 66%:34% (Davar 1999). Women's mental illness cannot be considered in isolation from social, political and economic issues (Malhotra 2015). A woman's health must incorporate mental and physical health across the life cycle and should reach beyond the narrow perspective of reproductive and maternal health, which is often the focus of India's policies.

#### Women's Mental and Maternal Needs in India

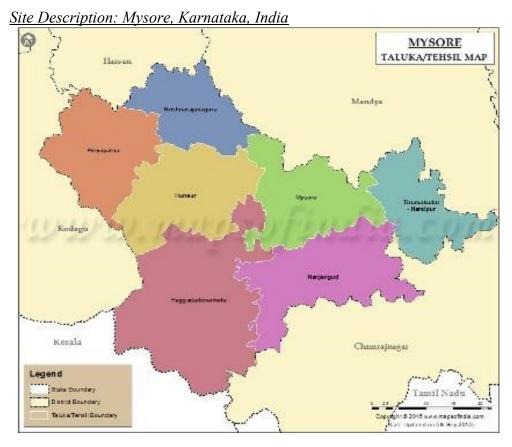
In India, governmental cash and delivery waiver programs have incentivized women below the poverty line to give birth at medical institutions (Murthy 2017). However, these programs only apply to government-operated hospitals. Overcrowded and underfunded, these facilities often do not have enough resources for pregnant women, leading to excessive pain and discomfort due to lack of beds and anesthesia for labor pain (Murthy 2017). Factors such as pain before and during childbirth and the fear of childbirth have exacerbated depressive symptoms in Indian women (Jha 2017). Further, Indian mothers display a high prevalence of postpartum depression (Upadhyay 2017). Though preliminary studies have established a need for developing India's maternal mental health care system, evidence on what practices and screening techniques are used currently and successfully in government facilities is sparse (Upadhyay 2017).

In a cohort study including India, Ethiopia, South Africa, and Uganda, researchers found that in India the rates of depression among women were highest during pregnancy and childbirth at 35.5% (Baron 2016). This value is the second highest in the cohort study, India following Northern Uganda at 35.8%. In India, marriage, pregnancy, and childbirth pose increasing pressure on women to marry into families with higher income statuses. This is because of systematic views towards daughters or girl children as burdens and marrying into families of

higher income statuses can help alleviate the perceived financial "burden" a girl child might pose in a family (Jha 2017). During childbirth, medical issues occurring in the baby are usually attributed to the responsibility of the woman who birthed the child. These pressures contribute to women's mental health, and therefore have crossover with maternal health and sexual or reproductive health (Harsha 2019).

The prevalence of antenatal depression in India is reported to range between 9.2% and 17% (Baron 2016). While this is lower than in other countries included in the sample such as Ethiopia and South Africa, the continuity of depression from antenatal to postnatal period is significant. 65.5% of women with antenatal depression in India continued to suffer from depression 6-12 weeks postpartum (Baron 2016). This period of continuity of symptoms lasted longer than other countries in comparison such as Ethiopia, Nepal, South Africa, and Uganda.

The burden of mental illness in low- and middle-income countries is high, and women in India may be particularly susceptible to mental illness. Further, the perceptions of mental illness during pregnancy, childbirth, and postpartum are high, though research on the manifestations of this in India is limited (Harsha 2019). This study aims to fill these gaps in existing literature and provide a diverse range of views on mental illness from both providers and women's perspectives.



Map of Mysore with its districts (talukas) indicated.

Mysore, Karnataka, India is the site for this field research study. Located in the southern state of Karnataka, Mysore is a small city home to around 890,000 people as of 2011. It is the site of the 2013 Mysore Declaration, a declaration made in response to the treatment of mental illnesses in India. The Mysore Declaration aimed to address marginalized groups affected by mental health and serves as legislative advocacy to protect those from illegal coercion mistreatment. In response to stigmatization discrimination, and marginalization of persons due to mental illness, the government of India's Ministry of Health and Family Welfare started creating policy that is concerned with the following as part of the Mysore Declaration:

- · Rights of the mentally ill (right to care and human rights)
- · Quality of mental health care
- · Use of administrative, and budget control, measures, and

 Consumer participation and involvement in the organization and management of mental health-care services (Gowda 2019)

# The Mysore Declaration states that:

All parties responsible for the care and treatment of mental illness should work towards the elimination of all forms of discrimination, stigmatization, and violence, cruel, inhumane or degrading treatment. We affirm that disproportionate, unsafe or prolonged coercion or violence against persons with mental illness constitutes the violation of the human rights and fundamental freedoms and impairs or nullifies their enjoyment of those rights and freedoms (Gowda 2019)

The declaration and therefore the city of Mysore hold historical importance in the development of policies that declare persons with mental illnesses as viable persons of society and equal receivers of respect and human rights. This was not our research team's primary question, which would require comparative work with other cities and sites. However, the declaration is an interesting backdrop to our research.

Mysore city's proximity to the National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore, Karnataka, also contributes to Mysore's high numbers of biomedical providers. Some biomedical providers work in both Mysore and Bangalore treating patients, and therefore Mysore is a unique setting with high numbers of allopathic providers that are highly trained in their field.

I chose Mysore as a study site because I joined a research team already based there, with Dr. Weaver and the Public Health Research Institute of India, an NGO working on women's health disparities in Mysore. Through a collaboration with PHRI, we recruited participants for interviews and focus group discussions through networking and community engagement and mental health awareness programming. It was a learning experience undergoing participant recruitment and simultaneously getting a tour of Mysore. Mysore is also a small enough city that

one can drive around the perimeter of it in less than an hour. Therefore, we could relatively easily establish connections to people and gain information about providers and places to access care and treatment for mental health.

#### Study overview

This study is a continuation of a study started by Dr. Weaver in the summer of 2018, during which she conducted 35 IDIs with women in the urban Mysore community about their stress and mental health. From these interviews Dr. Weaver compiled a list of common symptom words used for describing mental illness (see Appendix I). In the summer of 2019, I followed up on this research, along with PHRI staff, recruiting participants for 15 individual interviews (IDIs) with community mental health providers, 6 focus group discussions (FGDs) consisting of 4-6 women each, and 6 more individual interviews with participants from the focus group discussions. While I will not be including focus group transcripts in this discussion of themes and prevalent ideas about stressors women face from their perspective, I will be analyzing this data for presentations in the coming months with Dr. Lesley Jo Weaver.

Initially, I planned to use all of the data collected from the summer of 2019 with PHRI in this honor's thesis. However, as I started my data analysis, I realized that the path of exploration and the themes that emerged in provider interviews went in a different direction than did the focus group discussions. As a result, I have decided to focus my analysis on the provider perspectives and use this as my framework for qualitative data analysis and included a separate chapter on pregnancy and postpartum healing from the female patient perspective.

IRB Approval. IRB approval from both Emory University and University of Oregon were received to conduct this study. The IRB process consisted of creating an IRB application and submitting copies of interview guides, patient questionnaires, and surveys for demographic information needed during the research process. An amendment was submitted to the IRB application in the month of June to include provisions for the 6 IDIs with women from the FGDs

to discuss pregnancy, childbirth, and postpartum mental illness. These IDIs were added on after conducting a majority of IDIs with providers. Providers discussed in interviews that these time periods caused a lot of stress in women, and thus became a chapter of this study. The amendment was approved in the beginning of July.

Participant Recruitment. The method for recruiting participants started simply but became more complicated. Initial participants for the 15 IDIs were recruited through connections made with PHRI, and researchers would contact them to schedule interviews. These first few IDIs were with providers PHRI had either worked with in the past or had an established relationship with through working on similar issues in the community. However, PHRI had never worked with the majority of providers whom I and other PHRI researchers interviewed. We located these providers through using the internet, or speaking to neighbors, family, and others in the community about where they go for specific services such as astrology. To be eligible for the study, participants had to be actively providing some sort of treatment or help for mental illness in the urban Mysore community. At the end of the process, I had helped recruit fifteen participants.

For the first five interviews, participants were recruited through convenience sampling as they had had a previously established relationship with PHRI, and I or other researchers could contact them and speak in English to schedule interviews. But afterwards, our methods shifted as we did not know many of the providers beforehand. The method for this consisted of researchers traveling to different parts of Mysore following word of mouth suggestions or online searches for nearby astrologers or therapists.

We then recruited subsequent participants through snowball sampling in which the initial participants suggested providers they knew of who might be interested in participating. A snowball sample was especially beneficial to this study because of how difficult it was to reach this population. It was particularly difficult because some providers do not like to be revealed to

the public because of the fear that people will either not believe in their work for mental health or in their methods of healing. For example, many astrologers practice in temples and can use this easily accessible space to get clients, and sometimes could be less willing to talk to those who are not part of their regular circles.

Consent Process. Throughout the research process, researchers made it clear to participants that their participation was completely voluntary. Before each interview was conducted, I would explain the purpose of the study, the methodology, why the participant was being asked to participate, and that their participation was voluntary. They were also given an IRB approved informal consent form with descriptions of confidentiality, risk and benefits, along with background information about the researchers. Specifically, they were told they were being asked to take part "because you provide some form of mental health or wellbeing support in the Mysore community" (see Appendix III)

Table 2: Individual Interviews with Community Health Provider Demographics

ID	Qualification	Profession	Gender
	Quantication	11010551011	Gender
1	Ph.D. in Psychology	Assistant Professor and Clinical Psychologist/counselor	M
2	Ph.D. in Psychology	Freelance Counseling and Research, Clinical Psychologist	F
3	L.L.B/ M.A.	CEO of Odanadi, social worker	М
4	M.D (Psych), DPM	Psychiatrist and sexologist	M
5	M.S. Ph.D	Counselor/Psychologist	F

6	MSW, M. Phil (P.S.W)	Psychology social worker, Assistant professor of PSW	M
7	MSc. M.Phil (Clinical Psychology-pursuing)	Psychologist/counselor	F
8	MBBS, DPM, DNB	Psychiatrist	F
9	Ph.D.	NGO worker	F
10	10th standard	Therapist and Meditation Spiritual Healer	M
11	Vidwath (Alankar), Kannada Pandit, Hindi Praveena, Yoga PhD, M.A. B.E.D	Astrologist/ Asst. Professor	M
12	Ph.D. in Philosophy	Spiritual Healer	M
13	B.Sc. M.A. M.Phil DLD.	Religious Leader	M
14	N/A	Religious Leader	F
15	N/A	Astrologer	M

Table 2 categorizes participants giving them an ID number and explains their profession and their education levels. Nine of the providers were male and 6 of the providers were female;

we did not locate as many female providers as we did male providers. Note that both patients and the providers themselves seemed to use the terms "psychologists" and "counselors" interchangeably.

Research Procedure. For the 15 IDIs, the participants were met at their place of work and read a description of the study and their participation. After participants agreed to take part, I and other PHRI staff scheduled a day and time that worked best for the participant and came back for the interview. Participants were required to provide both verbal consent and written consent before beginning the interview. The participants separately consented to be audio-recorded for transcription and translation purposes, and each interview lasted an average of 60-70 minutes.

None of the interviewees was compensated. In some cases the participants were photographed for NGO purposes, however those photos are in a locked cabinet to which only Dr. Weaver and Poornima Jay, the president of the NGO, have access.

Data Analysis. After the interviews, I transcribed their audio recordings, and I worked with PHRII staff members Anisa, Ambika, Rashmi, and Naguveni to translate parts of the interviews that were in Kannada into English. I read each interview transcript several times and closely examined it for key details and emerging themes using the software MaxQDA. This software is used for qualitative analysis by coding sections of transcripts to track themes or concepts. Once I identified these themes, I recorded them to serve as the basis for further analysis and organization, and these were coded in the software and color coordinated in MaxQDA.

Using a modified grounded theory approach focused on thematic analysis, I combed through interviews several times to find the most important themes of the transcript (Ryan 2003, 85-109). A grounded theory approach was used because of this study's place in a larger study conducted by researchers in this study and Dr. Weaver. This type of approach includes tagging repeated ideas, concepts, or themes with codes- an identifiable category of elements- in order to sort and group data. I organized quotations from each transcript according to each identified theme in order to efficiently analyze similar subject areas that may have been discussed at

various points in one interview. This way, I was able to track not only the emergence of a theme, but also its growth in the stories providers would tell me.

After this process, I wrote narrative memos for each code I had made based on the organized transcripts to summarize the main themes and important events or stories expressed in each interview. These narrative memos were helpful in distinguishing the various life experiences of the participants and organizing the content of the thesis results section. The narrative memo followed a general structure, starting with a short paragraph outlining the interviews based on commonly discussed themes (Corbin 2007). Next, I organized transcript notes with memos, allowing for a comparison of quotations on a general topic. From this cross transcript analysis, I could easily highlight themes and experiences common to a majority of participants. Participants are represented using pseudonyms.

# Individual Interviews with Community Health Providers

Each of the 15 community health providers in this qualitative case study participated in a one-time qualitative interview conducted at their place of work. These participants had various professions in the realm of treatment for mental illness including astrologists, psychologists, psychologists, psychiatrists, religious healers, and spiritual healers. While the majority of the interviews were conducted in English because I do not speak Kannada, the last two participants were more comfortable in the local language of Kannada, and therefore interviews were conducted in Kannada by another researcher (in my presence) and translated into English. The purpose of the interviews was to identify key issues that providers talked about regarding mental health concerns, and to assess how different providers approach different mental health needs.

Questions asked during the interview range from the provider's demographic population that they serve to asking about specific symptoms heard in the previous summer's IDIs. Interviews with community health providers are broken down as follows.

					TIOUTINI TIO (TOOTE DIOUTING (VII			
Psychologist/ counselor	Psychiatrist	NGO worker	Religious Leader	Spiritual Healer	Astrologist	Social worker		
4	2	2	2	2	2	1		

Table 3: Individual Interviews with Community Health Providers Breakdown

Table 3 describes the breakdown of providers into categories and how many providers within each category were interviewed. Note that the greatest number of providers I interviewed were psychologists. This is because the summer 2018 IDIs highlighted the use of therapy or counseling as treatment for mental illness in women. Therefore, recruitment during the summer of 2019 focused on providers that included counseling as a primary form of treatment such as psychologists. While every provider does a form of counseling, researchers from PHRII in the summer of 2018 found that psychologists tended to see a high number of patients. Using this knowledge, I tried to include more of these providers in my participant sample. With regard to the original research questions, providers varied in their answers. The following are their pseudonyms.

- Dr. Amit- Psychologist/counselor at JSS Hospital (sees mostly children)
- Dr. Rani- Psychologist/counselor at private practice
- Dr. Bhagyalakshmi- Psychologist/counselor at private practice
- · Dr. Vaidehi- Psychologist/counselor at JSS Hospital
- Dr. Shankar- Psychiatrist and Sexologist at JSS Hospital
- Dr. Bhargavi- Psychiatrist at JSS Hospital
- · Mr. Saji- CEO and worker (NGO)
- Dr. Harini- Principal of school for special needs children (NGO)
- · Mr. Aalok- Psychology social worker at JSS Hospital

- · Mr. Naresh- Spiritual healer- Past life therapist, mindfulness and meditation at private practice
- · Ms. Sushila- Spiritual healer- BramhaKumari Counselor (Female-run spiritual group that has counseling services)
- · Father Sebastian- Religious leader, Roman Catholic Priest
- · Mr. Shiva- Religious leader, Rama Krishna Ashrama Priest (monastery for mostly boys and very few girls to study to become monks and ministers that has counseling services)
- · Mr. Suneel- Astrologer at private practice
- Dr. Vikram- Astrologer at private practice

## <u>Individual Interviews with Women from Focus Group Discussions</u>

These six IDIs were based on the focus group discussions we conducted with women in summer 2019. I recruited participants from the FGDs and asked for voluntary participation in these IDIs in the following days. These IDIs were conducted in Kannada by my translator, Gagana, and translated to English using a translated service connected to PHRI. We conducted these interviews in the women's homes and aimed to address specific sources of stress due to childbirth, a theme that came up during both provider IDIs and the previous FGDs with women. While I sat during the interviews and helped direct the process, Gagana conducted the questioning and we communicated either in English or through eye contact to change the question or add something to ask. Individual interviews with women are broken down as follows.

Table 4: Individual Interviews with Female Patients Breakdown

Participant ID	<u>Pseudonym</u>	Age		Number of Children		Level of Education
<u>P1</u>	Rupa		<u>49</u>		<u>1</u>	6th grade
<u>P2</u>	<u>Latha</u>		<u>42</u>		<u>2</u>	10th grade
<u>P3</u>	<u>Sunitha</u>		<u>35</u>		<u>2</u>	5th grade
P4	Shubha		42		2	11th grade (1st year of college)
						1 Ath and (Final
<u>P5</u>	<u>Chandini</u>		<u>25</u>		<u>1</u>	14th grade (Final year of college)
						12th grade (2 <sub>nd</sub>
<u>P6</u>	Sowmya		<u>23</u>		2	year of college)

Table 4 describes the demographic information of the women I interviewed. Note that these women were recruited from two focus group discussions, one with women holding higher than a  $10_{th}$  grade education, and women holding education up to the  $10_{th}$  grade. Women were stratified based on education levels at the recommendation of field experts but was not a focus of this study. The interviews were conducted in Kannada and my translator Gagana did most of the questioning; I added questions when I heard a word about which I wanted to know more or sensed that we needed to ask about something new. The interviews took place either in the women's homes or at PHRII.

### **CHAPTER 3: RESULTS**

## Providers' Perspectives on Kannada Terminology for Mental Illness

Thirteen out of the 15 individual interviews with community health providers were conducted in English. As a discussion of symptoms through language is a key component of counseling and therapy, providers were asked what local language terms they hear their patients using to talk about their mental illness experiences. The research project of the summer 2018 established a set of Kannada words used frequently by women in Table 5 (see below). This question would help highlight any parallels between what women say they experience versus what providers actually hear.

<u>Table 5: List of Common Kannada Words Associated with Mental Illness Based on</u> Previous Interviews with Urban Mysore Women (Summer 2018)

Kannada Word (or English) or Phrase	"Symptoms" of experiencing this condition (as translated by PHRII staff)
"Tension"	Not feeling like not doing any work, as though hands and legs are very weak and it is difficult to wake up, stomachache, tiredness
"Bejaroo"	Hair fall, back pain, gastric, concentration problems; crying, appetite loss
"Bhaiyya"	Fear or nervousness
"Manasika otthada/otthada"	Mental stress, body pain, headache, shivering, palpitations, and blurred vision
"Novu"	Thinking too much, rumination, solution- or self-oriented

<u>Vattada</u> (also known as Ottada). This word, "vattada" or "ottada", directly translates to "pressure" in English, and was a word that came up consistently in interviews with women during summer 2018. Dr. Rani attested to the numerous times female patients came to her with complaints of "manasika vattada" or mental pressure. She explained that her patients that have attended any level of schooling understand "manasika" or the mental aspect of pressure. Others who may be illiterate or less educated simply say "vattada" or "ottada" meaning pressure and do not specify where that pressure is occuring.

Mr. Suneel had a different perspective on the use of "vattada" as heard from his female patients. Mr. Suneel, versed in yoga, meditation, mindfulness, and astrology, tells me that of his patients talk about "vattada," in Kannada or "manasika vattada" interchangeably regardless of their education levels. Women who seek counsel from Mr. Suneel always use this Kannada terminology and can identify these feelings during sessions with him.

Tension. While "tension" is an English word, four of the providers described in depth its integration into the Kannada language because of how often women use it to discuss their feelings. Dr. Shankar, a psychiatrist of JSS Hospital, was one of the first interviewees who explained why so many people use the term "tension." While he heard somatic complaints of aches and pains more often than "tension", he connected these physical symptoms to mental illness. A phrase he heard often amongst the physical complaints, however, is "nanage tension agathaide". This roughly translates to "I am being tensed or feeling tensed," and his theory is that there is no Kannada word that encapsulates this feeling of anxiety, pressure and uneasiness all at the same time; hence his patients use the word "tension."

Mr. Aalok, also of JSS but working in psychology social work, echoed Dr. Shankar's observations that cases of "tension" are frequent. He noticed that women would self-disclose that "nanage tumba tension agathaide yavaglu tension alli irthini" or "I feel too tensed, and I am

always in tension or feeling tension". Mr. Aalok explains that when he hears these complaints from women, they are usually in relation to other issues such as a lack of interest in work and concentration issues.

Dr. Bhargavi from JSS Psychiatry confirmed hearing the word "tension" used in her talks by her patients. However, Dr. Bhargavi observed that women described feeling tension when discussing depression or family issues. A common thread arising from many providers is that they heard physical complaints from women who are connected to mental illness, but sometimes women do not make this connection themselves. "Tension" is a common word that Dr. Bhargavi proposed is used all over India because there is no word that can describe these feelings accurately in Kannada or other Indian languages.

Mr. Naresh, a spiritual healer practicing meditation and mindfulness, expressed different experiences in hearing the term "tension" from women when talking about physical ailments. While women have expressed to him feeling "tensed" or experiencing tension, they do not come directly for tension as a major complaint. Usually there is something else that causes the tension and that is why they seek his treatment. Common ways women present tension to him relate to feeling "pressure in the shoulders caused by tension from work or their boss".

Bejaru. Many providers I spoke to mentioned that women frequently use the word "bejaru" to talk about sadness, depression, loss of interest in work, and helplessness. Translated as "sadness" in English, this word means much more than just sadness in the Kannada context. One provider, Dr. Bhargavi. brought up the word "kinathe," which technically directly translates to depression; however, the word is not used colloquially. So even if there is a Kannada word for a particular condition, if it is not regularly used then it is not as useful as words such as "bejaru". Dr. Shankar reported that he hears "nanage bejaru aguthae" almost on a daily basis from women. This directly translates to "I am feeling sad," however Dr. Vaidehi explained that

"bejaru" is an umbrella term to mean lack of interest in things or sadness or a mixture of both. At this time in a consultation, Dr. Vaidehi described having to differentiate between words such as "dhukha" meaning painful sadness or "bejaru" which is a mixture of sadness and lack of interest.

Dr. Vaidehi observed that one word in the Kannada language can represent a multitude of symptoms ranging from deep sadness to a lack of interest in work. Therefore, it is important for providers to understand what patients are inferring, even if they do not say feelings they are grappling with in a direct manner. The word "bejaru" not only is an umbrella term, but it can direct completely different forms of treatment depending on whether the patient experiences loss of interest in work or depression, or both. In order to find out exactly what a patient is suffering from, Dr. Vaidehi has to ask more questions such as "how long have you been feeling this way" and "when did you first notice these feelings?" Typically, patients will describe the feelings of sadness being conflated with other feelings in order to use "bejaru" as an accurate description. While the aspect of ambiguous meanings for words is not unique to Kannada, women's use of the word "bejaru" could help direct treatment for mental illness because it could signify many different conditions. Dr. Bhargavi also acknowledged the frequency with which she hears "bejaru" is high however, she asserted that women will only use "bejaru" when they are able to identify their depression and sadness as internal feelings. Otherwise, they express their symptoms as body aches.

Bhaiyya. All of the providers mentioned women expressed facing fear or experiencing fear, which in Kannada is directly translated into the word, "bhaiyya". "Bhaiyya" represents anxiety or uncertainty, but because there is no direct translation between both of these feelings in one word in English, in Kannada this word is used for a variety of settings. For example, Dr. Vikram heard "bhaiya" in the context of women coming to him in fear of getting married if they

are of age to be married. Further, he also heard from women about fears of having children and of being able to balance raising children with working.

Father Sebastian heard from women coming to him for counseling express fear of financial hardship and less about mental or physical ailments. Father Sebastian saw women even outside the Catholic faith coming with complaints of "bhaiyya" because of "money problems" or financial trouble.

Mr. Saji, an NGO worker who works with victims of domestic or sexual abuse, talked about patients' "bhaiyya" of integrating back into life after experiencing trauma. He told me that mostly women use this word and they use it to describe feeling scared about their trauma or abuse. The term "bhaiyya" includes all of these meanings, and providers only can tell which, if any, a patient is feeling with further questioning.

Novu. "Novu" is directly translated in English as pain, however it is used in many contexts to refer to different types of pain. Phrases that include "novu" include:

- "Tale novu": headache
- "Maikai novu": back pain
- "Kaikal novu": legs and feet pain

Fourteen out of fifteen providers reported hearing "novu" in some form; however, which types of "novu" they heard more frequently depended on what kind of healing they practiced. Dr. Rani heard the word "novu" when she asks women what other treatments they have tried before coming to her practice. Her patients told her when they first experienced something wrong in their mental state, they went to healers and astrologists, but then they go to a medical doctor when they start to feel physical pain--novu. When women described having a migraine or something physically painful, she says she can immediately identify that they are suffering from a psychosomatic disorder having both physical and mental manifestations.

Dr. Shankar observed that at least 90% of his patients come with a complaint of "novu" every day. Every day brings a different kind of pain, however, as this word is used in a diverse range of situations. He reported that women say the word "novu" in consultations frequently. Female patients came with complaints of aches and pains in describing what he identified as depressive ideas.

Dr. Shankar's colleague at JSS Hospital, Mr. Aalok, reported women using the English word "pain" while describing symptoms in Kannada. He heard phrases such as "body tumba pain agthaide" meaning "the body is in too much pain". Mr. Aalok now sees patients solely from the JSS Hospital, but in his previous work treating women from other districts he heard them use "novu". Dr. Vaidehi said that sometimes providers like herself will hear "novu" and start referring to it in English as pain. When I asked her why she switches to English, she said that since providers such as herself study in English, she has to start asking technical questions in English. However, her patients will purposefully use "novu" because of their comfort with the Kannada term. The word "novu" exemplifies one of the main challenges that providers mention that they encounter their work: the use of a Kannada language term that has a specific definition but that women use colloquially to describe a range of symptoms.

### Symptoms of Mental Illness Experienced by Women from the Providers' Perspective

Regarding symptoms of mental illness for which women seek treatment, providers had varied experiences. However, all providers discussed common themes such as stress caused by marriage and familial problems, depression, and anxiety.

Stress Caused by Marriage and Familial Problems. Dr. Amit, a psychologist from the JSS Hospital, saw women of adolescent to married ages (Dr. Amit cited approximately 18-35 years old) with complaints of stress from entering a new marriage or from problems with their new inlaws. Patients expressed to him feeling "pain in the feet, headaches, loss of sleep, and loss of appetite" and after asking more about their mental state he can decipher that they are

experiencing stress. A different psychologist, Dr. Rani, also noticed that adult women came to her for family disputes and misunderstandings with spouses or in-laws, like splitting up the workload with the husband or having issues with the mother in law. Further, Dr. Rani talked about the value of counseling to help mitigate some stress women feel during marriage. Dr. Rani said,

For a girl that is about to get married she may not be aware of the problems she might have in the future so if she is counseled before she's married, she can adjust better.

Instead of getting married and then getting problems and then seeing a psychologist if she sees one before I think she may be able to adjust better and be more prepared for it and then step into it (Dr. Rani 2019).

Providers such as Mr. Suneel, an astrologist, told me how women who come to them feel they have so many responsibilities put on them, especially after marriage, and that causes them stress. Because women are expected to be in charge of dealing with family, children, and work whether that is a job or housework, these tasks together can feel very daunting (Mr. Suneel 2019). Dr. Amit and Dr. Rani discussed how the addition of these responsibilities along with the component of marriage itself and adjusting to a partner and in-laws can exacerbate mental illness.

Mr. Naresh, a secular spiritual healer, also brought up insight on how stress from marriage can contribute to mental illness. His work is primarily in meditation, mindfulness, and past life therapy. While Mr. Naresh does not associate with a particular religion, his work in past life therapy is based in Hindu and Buddhist concepts of reincarnation. Past life therapy involves exploring the impact of a trauma from a previous life in the current one through meditation and mindfulness. The women Mr. Naresh treated often describe symptoms of stress and cite marriage or spousal issues as the primary instigator. Mr. Naresh discussed common ways in which women present their symptoms to him, with descriptions such as, "the wife said her new husband takes

her for granted or is insensitive and treats her matter of fact" (Mr. Naresh 2019). These issues last longer than the first few years of marriage, according to Mr. Naresh. Women who have had children and have been married for years also brought complaints of "[having] to do more than the man and [having] to work in and outside of the house and take care of the kids while working too" (Mr. Naresh 2019).

Dr. Amit, Dr. Rani, and Mr. Naresh all heard symptoms of stress accompanied by stories about marriage or problems within laws from women. These included most commonly loss of sleep, loss of appetite, body pain, and headaches. In contrast, Mr. Saji, CEO of an NGO that helps rehabilitate women experiencing sexual assault or domestic violence, discussed different symptoms due to stress from marriage and family unlike previous providers. The women he counsels, likely due to the specificity in issues of violence they face, cite fewer physical manifestations of stress but rather mental manifestations. He lists primarily issues of "nightmares, intrusive thoughts, and suicidal ideations" caused by stress from particularly abusive marriages and family members.

Depression, Sadness, Helplessness, and Loneliness. Many providers explained that patients often do not use the word depression and instead use sadness, helpless, loneliness, and loss of interest in work to describe their symptoms. Mr. Shiva, the monk responsible for counseling at the Rama Krishna Ashram, explained that he classifies women who come to him bringing complaints of "[having] no motivation to do tasks they previously described as enjoyable, feeling empty or sad, and lonely" as having symptoms of depression (Mr. Shiva 2019). While causes of depression among the women he sees were varied--some women discussed issues with family while others had financial trouble--they all discussed these common symptoms when talking about their feelings. Dr. Rani also reported that she hears common complaints of women expressing frustration and sadness over their married life and being a mother and a wife at the same time as working (either in or out of the house). Similar to Mr.

Shiva, she also heard "money troubles" as another reason why women came to her "feeling deeply sad or lonely" (Dr. Rani 2019).

In contrast, Dr. Shankar, a psychiatrist from the government funded JSS Hospital in Mysore, said he saw more cases of depression in women caused by loneliness than marriage or financial troubles. Dr. Shankar explained that, "most of the women who come with symptoms of depression such as helplessness, irritability, or decreased energy tell me first that they are lonely," (Dr. Shankar 2019). Dr. Shankar also talked about how loneliness, sadness, and helplessness were used interchangeably with his female patients when discussing their feelings. For example, some women he treats might have originally discussed feeling lonely, but in the next session they include sadness instead of loneliness or sadness and helplessness together.

Ms. Susheela, a counselor from the Bramha Kumari Ashram, discussed similar language being used interchangeably by the mostly adolescent women she counsels. Whether caused by "negative results on exams, problems with siblings, or financial issues," she heard young women saying they felt alone, helpless, and sad at the same time (Ms. Susheela 2019). While she never heard the word depression from any woman, she was able to identify it as the condition they were suffering from because she heard this language specifically.

Anxiety. When both providers and patients talk about anxiety, it is often in the context of fear. Fear and anxiety are equated in this situation such that when people talk about their fear it is assumed that they are mentioning things that make them anxious or they observe this behavior in others. Mr. Suneel, one of the two astrologers I interviewed who also teaches yoga and meditation, tells me that most of the cases of fear or anxiety that he sees are in women, and this is manifested when they have discontentment with their training or they have a lack of focus on their technique in yoga students. Further, he tells me about his observations with phobia or fear in females who are studying mindfulness that is demonstrated through their inability to focus

during meditation sessions. This suggests that within the context of fear and anxiety there is a component of loss of focus as a symptom of anxiety.

On the other hand, Dr. Rani narrated stories she has heard in the past about women having anxiety over their newborn babies and how to raise them. The gender of the newborn baby may provoke anxiety in the mother because elders in the family might have wanted a male baby, but a girl was born, and the mother is usually blamed for this (Dr. Rani 2019). Dr. Shankar also cited reasons for anxiety or fear in his female patients as having to do with being a new mother, but he added the component of marriage and living with in laws. Some of the women who come to Dr. Shankar also are working and reported feeling anxious about balancing this with living in a new family (Dr. Shankar 2019). Dr. Shankar heard complaints of fear when women discussed experiencing "trouble adjusting to their new life with a husband and in laws" and to him these feelings, if not addressed, contribute to anxieties of being a new mother (Dr. Shankar 2019).

Dr. Bhagyalakshmi brought a different perspective because she discussed seeing anxiety more frequently in female adolescents than older age groups of women. Dr. Bhagyalakshmi defines adolescents as 15-20 years of age. Whether because of big exams, pressure from their parents, or getting ready for marriage, she noted that more adolescent females, rather than young mothers, were coming to her expressing fear or anxiety (Dr. Bhagyalakshmi 2019). She also noticed among women who came to her that there was a pattern of issues or disagreements between the bride or bride to be and the in-laws, specifically the mother-in-law.

Dr. Vaidehi and Dr. Bhargavi similarly mentioned that women who come to them with fears or anxiety also bring body pains. She noted that "while patients might be coming in to talk about their physical pain, often times there is a psychosomatic connection," (Dr. Vaidehi 2019). Dr. Bhargavi, the only female psychiatrist at JSS Hospital I interviewed, saw women on a daily basis experiencing symptoms of fear and anxiety and often these complaints came with physical

pain. The most common causes of anxiety she hears from women included "marriage, childbirth, money troubles, and increases in workload either at an occupation or at home," but these complaints are paired with physical pain such as "shoulder pain and headaches," (Dr. Bhargavi 2019). The process of becoming a wife, taking care of a child, and dealing with work issues can cause anxiety and therefore physical pain for women, though women do not often make the connection that their physical and mental pain contribute to each other (Dr. Bhargavi 2019). *Taboo or Stigma and its Role in Accessing Treatment* 

Providers unanimously brought up stigma as the primary reason why people in general in India are hesitant to access treatment for mental illness. While this is not unique to women in India, stigma was heavily discussed by each provider in reference to women seeking treatment at later stages of their conditions. Dr. Amit talked about how women are worried that if people see them seeking treatment from him, a psychologist, it will affect their reputation in their community (Dr. Amit 2019). He said, "people are worried of being called 'huccha' or 'mad'" which means they are afraid of being negatively stigmatized against or thought of as "going mad" (Dr. Amit 2019). Dr. Rani similarly reported that patients are often afraid to come to see her for fear that neighbors will see them walking to her house. Instead, more recently she has been getting phone calls on Whatsapp or over the landline and she gives consultations this way. Many of the women who seek counseling from her think that "only patients that are severely mentally ill should go to clinical psychologists or seek mental health help" (Dr. Rani 2019).

Mr. Saji, when asked about stigma acting as a barrier for treatment, said women before coming to him would think it is "beneath their dignity or standard and they think they would get socially stigmatized [if they come]" (Mr. Saji 2019). He reported that women would come to seek treatment from him only when their family members, namely their mother or sister, would bring them against their own request. Dr. Bhagyalakshmi expressed similar sentiments about her patients' fears of ostracization and thus the delay in seeking treatment. Women she saw would

talk to her about how they tried to delay their visit because they feel they will be "branded as mentally not okay and this frightens them" (Dr. Bhagyalakshmi 2019). Frequently, she saw women being brought to her for counseling by their mothers, sisters, and husbands even though the women themselves expressed that they were not suffering from mental illness.

In contrast, Mr. Aalok, the psychology social worker from JSS Hospital, saw that most of his female patients were unaccompanied by family. He attributed this to family members' worries or worries of the women themselves of being stigmatized against (Mr. Aalok 2019). Mr. Aalok said that "if the women are unmarried they do not want anyone to know that they are consulting a psychologist or psychiatrist because they do not want this to hurt their chances of getting married," (Mr. Aalok 2019). Dr. Bhargavi, a psychiatrist at JSS Hospital, concurred with the idea of stigma posing barriers to accessing to mental health illness treatment for women. She reported that some of her female patients are brought against their will by family because women themselves say they don't want everyone "thinking they are going mad and [are] incapable of being a wife or mother," (Dr. Bhargavi 2019).

Mr. Suneel, Dr. Vikram, and Dr. Harini, the CEO of a school for special needs children, talk about fears of stigma parents and family members have that contribute to female family members refusing to seek care for their mental health challenges. Dr. Harini mentioned that women have told her "family members might insult them (women) or ostracize them, or force them to move out of their family home," and therefore women would come to her long after the onset of their mental illness, even though these women acknowledge that their symptoms have been occurring for long periods of time.

In contrast, Dr. Vikram and Mr. Suneel, the two astrologers I interviewed, discussed how women do not necessarily have fears of stigma to come to them. Both providers presupposed that this was because people visit astrologers frequently and it is not therefore questioned in Indian society (Mr. Suneel 2019). Women often come to both of these providers to discuss feelings of

stress, sadness, or problems with the marriage or childbirth and this is not looked down upon, according to both Dr. Vikram and Mr. Suneel.

# CHAPTER 4: PREGNANCY, CHILDBIRTH, AND POSTPARTUM MENTAL ILLNESS FROM PROVIDER AND PATIENT PERSPECTIVES

In this chapter, I introduce both providers' perspectives on their patients' experiences of pregnancy, childbirth, and postpartum as well as women's own perspectives. Women were recruited from focus group discussions and asked questions about their pregnancy, childbirth, postpartum healing process (see Appendix III). Note that there is not a specific section on childbirth from the provider or female patient perspective. This is due to the issues of childbirth being intertwined in the discussion of postpartum for both providers and women. Any discussion on childbirth with either a provider or woman was in the context of the postpartum period.

## Pregnancy from the Provider Perspective

Seven out of the 15 providers I interviewed reported seeing pregnant women who for mental illnesses that were either preexisting or occurring during pregnancy. Dr. Shankar said that many of the women coming to him during pregnancy experienced symptoms of depression and stress. Dr. Shankar said that these conditions are "very common and need admission and active treatment because of the risks they pose to both the mother and baby's life," (Dr. Shankar 2019). Dr. Bhagyalakshmi also has heard symptoms of depression and stress from pregnant women that see her, but she also hears complaints of anxiety or fear. While depression is the common issue she heard, soon-to-be mothers also tell her "they are worried they can't or won't be able to do everything they used to do before pregnancy and feel anxious," (Dr. Bhagyalakshmi 2019). She heard fear or anxiety in anticipation of being a new mother almost as commonly as depression or sadness (Dr. Bhagyalakshmi 2019). Mr. Naresh, a spiritual healer, also saw pregnant women commonly complained of "severe migraines and feeling lonely, sad or feeling nervous about the childbirth process," (Mr. Naresh 2019).

Contrastingly, Dr. Vaidehi and Dr. Bhargavi explained that they hear complaints of preexisting mental illnesses from pregnant women. Women come to Dr. Vaidehi with "problems

such as mood swings and obsessive-compulsive disorder that they know about and are restricted because they cannot take too many medications during pregnancy" (Dr. Vaidehi 2019). Instead of hearing from women about issues occurring due to their pregnancy, Dr. Vaidehi hears from women about their preexisting mental illnesses being exacerbated by the pregnancy. Dr. Bhargavi also discussed how she sees women with preexisting conditions such as bipolar mood disorder or epilepsy that have become exacerbated during pregnancy much more frequently than women coming with new conditions that have developed during pregnancy (Dr. Bhargavi 2019). Mr. Suneel and Dr. Vikram, the astrologers, heard different complaints from pregnant women than those other providers heard. Mr. Suneel said that the pregnant women who come to see him are stressed and in need of counseling on "having an easy delivery, and they want guidance to raise a healthy child, or they want to know the sex of the child," (Mr. Suneel 2019). Dr. Vikram also noted that many pregnant women will come to him to know the sex of their unborn child and describe feeling anxiety or stress if the sex of the child is not desirable by their family members (Dr. Vikram 2019). Sex determination of the baby is illegal in India and while it is likely women would not go to a hospital to try to learn this information, the sex of the baby still might create anxiety in the mother.

### Childbirth and Postpartum Experiences from the Provider Perspective

Mr. Saji was the only provider to discuss childbirth experiences on its own instead of in conjunction with postpartum like other providers. The women who come to Mr. Saji have suffered abuse and many of these women have had stressful pregnancies for two reasons. Mr. Saji explained that, "either the birth itself was done at home and there was pain and stress due to this, or the pregnancy had come about from abuse and the childbirth process was painful physically but also emotionally because of the reminder of abuse it brings to the woman," (Mr. Saji 2019). More frequently, Mr. Saji saw that the problems from the childbirth process itself

were not what made women come to him but rather the reason was the emotional turmoil from abuse that brought forth the pregnancy.

Mr. Naresh explained that he saw mothers with postpartum anxiety on a daily basis. Whether it is anxiety about being a mother or taking care of children while balancing their work, anxiety is the most common issue he has treated in postpartum women (Mr. Naresh 2019). He also discussed how many times women immediately after giving birth go to their mother's homes. He said, "if women have gone to their maternal homes for childbirth, when they move back into their in laws house, they often feel unsupported and alone," (Mr. Naresh 2019). Mr. Naresh has frequently heard new mothers use words such as "bejaru", meaning the mothers feel sadness and loss of interest in work due to the new birth. However, he noted that he rarely saw postpartum women coming to him with issues of stress, anxiety, or anxiety due to the actual childbirth process. Like Mr. Naresh, Dr. Vikram saw women who have recently given birth for issues of postpartum stress or anxiety. Some women express worry over the gender of the child, as family members were expecting a male and a female is born. The responsibility for anything going "wrong" or not according to standards set by family are placed on the wife or mother and there is often a lack of a support network for her after birth (Dr. Vikram 2019).

In clinical settings, Dr. Shankar acknowledged there is a very high chance that women after pregnancy will get depressed or experience mental illness. Dr. Vaidehi also discussed seeing many women come to her for issues of postpartum depression specifically. The women who come to her often cited feeling lonely or sad, and helpless without support from their family once they move back into their in-laws home. Dr. Vaidehi emphasized that many of her patients' husbands do not help their wives take care of the baby even though the wives would prefer them participating actively in the parenting process, and this adds to the chances of the new mother experiencing depression (Dr. Vaidehi 2019).

On the other hand, Dr. Harini, the CEO of a school for special needs children, has seen parents come to her with their child and the mother is suffering from postpartum depression. In her experiences, while the father of the child might be ready to help her seek care, usually the mother herself is not ready. In these cases, the father or husband has to push his wife to go to a psychologist in order to get her adequate treatment.

While Dr. Amit does not work directly with women who are postpartum, he conducted a project with postpartum women in collaboration PHRI this past year. The most typical problem he saw in this population was postpartum depression and almost a quarter of the women he talked to this study had this condition. Dr. Amit said that results from his study suggest that the most significant factors causing postpartum depression is the husband's level of education, among other factors such as socioeconomic status, the woman's level of education, or caste. In Dr. Amit's experience, if the husband of the new mother is well educated, he may either recognize signs of sadness and loneliness, or he will help take care of the baby and ease stress off of the new mother. He also mentioned that he has never seen this condition being treated, at JSS or in any clinical setting he has worked in previously, While he asked his study subjects suffering from depression to see the local clinical psychologist at JSS for their conditions, he doubted that many women will follow through with his suggestion.

### Pregnancy from the Female Patient Perspective

News of Pregnancy. Each of the six women I spoke to about pregnancy cited being happy about the news of pregnancy, even if the pregnancy itself was unplanned. Rupa, for example, said that her first pregnancy was a surprise to her, yet she was happy about the news and her family members were as well. Rupa attributed her happiness about the pregnancy to the experience of her aunt's daughter having given birth (at a much younger age). Rupa "used this experience as hope that [she] and [her] baby would be fine in the future," (Rupa 2019). When asked about stress she may have felt about being a new mother, she explained that while she had

not necessarily prepared to be a mother, she felt ready and whenever she felt worried she would talk to her husband, mother, and other family members and they would console her.

Latha, Shubha, Chandini, and Sowmya echoed these sentiments, also saying that while their pregnancies were unplanned, they were all happy about the news of both their first and second pregnancy (if they had more than one child) and did not feel stress due to the pregnancy. Like Rupa, Shubha discussed talking to other family members such as her sister and sister-in-law about their pregnancies once she found out that she was pregnant, and this helped her ease any stress she did feel initially.

While Sunitha was happy about her news of pregnancy for her first child, when it came to her second child, she explained that she did feel stressed because of complications that had arisen from her previous pregnancy. She discussed how "the pain from [her] first operation got [her] worried that the second pregnancy would also be like that and [she] felt less happy," (Sunitha 2019).

Later Stages of Pregnancy. All of the women expressed that their first signs of stress, anxiety, or sadness appeared towards the later phases of pregnancy or soon before childbirth. These complaints mirror what providers heard from women who are pregnant. For Sunitha, while she had initial trepidation about her pregnancy, support from her mother and father helped her become less stressed until the later stages of pregnancy, when she became fearful that her second delivery would be just as painful as her first (Sunitha 2019). When asked about why they felt stressed during later stages of pregnancy, several women described feeling pressure and said, for the first pregnancy, they had not expected the pain they felt during the pregnancy itself and they were worried about complications.

Sowmya attributed her stress and loneliness to the doctors' communication with her and her family. She got scared because the doctors at the government hospital told her that the baby

was "rolling around in her intestines" and therefore she became concerned that something would go wrong. She prayed that her baby would be born normally because she was worried something bad would happen during the birth. The attending doctors did not communicate stages of pregnancy to her, according to Sowmya. Every hospital she visited to hear more about the baby's condition said that it had "migrated in her stomach" and would reset on its own, but no one could assure her of a normal pregnancy. It was only when she went to the last governmental hospital that the doctors were able to tell her she could have a normal delivery. Sowmya said that she felt ""bejaru" because she did not know what was going to happen with her pregnancy and the uncertainty made her feel helpless," (Sowmya 2019).

Latha, in contrast, emphasized that pressure from her family to have children caused her more stress as she approached her delivery date. She described how her family members put pressure on her to have children after she had failed to get pregnant within the first two years of marriage. Latha explained that "[her] aunt was telling [her] to a doctor to get the fixed" and described her feelings as deep sadness or "bejaru," (Latha 2019). Therefore, during her pregnancy, she was stressed and worried that there would be complications.

## Childbirth and Postpartum Experiences from the Female Patient Perspective

Type of Delivery. Every woman expressed wanting to have a "normal" or vaginal delivery instead of a cesarean operation for all of their births. However, five out of the six women ended up having a cesarean delivery for at least one of their children. In India, according to the District Level Household Survey 3, the cesarean section rate or percentages of births conducted through the C-section operation is 28.1% in the private sector and 12% in the public sector hospitals and facilities (DLHS-3 2017). While cesarean operations are not as prevalent at vaginal deliveries, the decision to have a C-section caused women some anxiety. Rupa discussed how she had been hoping for a normal delivery for her child, but "after seeing the condition of

[her] baby being so small, [she] became stressed" and she decided to deliver with the cesarean operation (Rupa 2019).

Similarly, Latha had a normal delivery for her first child, but for her second child she had to undergo a cesarean operation due to complications and this had made her anxious. Latha said that her contractions became abnormal three days before her third trimester was complete, and when she went to the hospital doctors had said that "they had to operate to take the baby out right then or either the mother or baby would not survive and this made [her] panic," (Latha 2019). After she made her decision to undergo the operation, Latha emphasized that she was "sad and stressed because [she] was expecting a normal delivery," (Latha 2019). Sunitha had a similar experience to Latha, in which complications and pain during the delivery of her second child resulted in a cesarean. Like Latha, Sunitha said this decision caused her pain because the operation itself was painful but also she had thought that a normal delivery was the best way to have her child (Sunitha 2019).

Shubha also opted for a caesarian after experiencing pain and complications but, unlike Rupa, Latha, and Sunitha, she did not have any stress about her decision. However, her family members, namely her mother in-law, had put pressure on her to not have a cesarean leading up to the delivery date. Shubha said her mother in law told her that " if a C-section happens then in the future it would be very painful and there would be lifelong back pain," but Shubha said her pain was too much to bear and she noted being happier once she chose to have a cesarean (Shubha 2019).

Chandini expressed similar initial pressure to have a normal delivery but had intense complications and had to deliver by cesarean. However, unlike many of the other women, Chandini had so many complications during her birth that mid-procedure she had to be shifted to the cesarean operation hall. According to Chandini, "the stress and fear had taken over her so much that she lost consciousness" and awoke later to see the operation had been done and she

had given birth (Chandini 2019). Sowmya was the only woman I talked to who had not had a cesarean.

Pain during Childbirth. Every woman detailed the experience of pain they felt during the childbirth process, but they also talked about how the pain caused them more anxiety. Rupa's complications and need for the cesarean operation made her anxious, while Shubha and Chandini lost consciousness during the delivery because the pain and anxiety about their pain became unbearable (Shubha 2019) (Chandini 2019). While Sowmya had a normal delivery, she too experienced pain and anxiety because her baby was "stuck" or not moving while she tried to push it out (Sowmya 2019). Latha and Sunitha, on the other hand, experienced sadness and pain during the delivery because they felt "helpless during the complications and delivery," (Latha 2019) (Sunitha 2019).

Postpartum Healing. Further, all of the women, when asked if providers inquired about their mental state after pregnancy, answered that medical doctors did not ask them about their feelings, and neither did nurses. Family members were mostly the people who asked them about how they were feeling mentally and emotionally after their delivery. But every woman I talked to spoke about feeling some kind of depression, sadness, anxiety, or stress about the baby and being a new mother. Shubha for example felt that "taking care of [her] child is too much of a stressful situation for [her]" and balancing her work and taking care of her baby caused her "depression, and [she] used to share [her] unhappiness with my friends and family," (Shubha 2019).

Chandani said that she "was good for few days after delivery and then was abnormal for a month. [She] wasn't taking care of [her] baby. [She] wasn't interested in it. [She] wasn't feeding it milk either," (Chandani 2019). Chandani said that she felt helpless, lost interest in taking care of the baby, and became sad soon after delivering. Sowmya and Sunitha mentioned feeling deeply sad after their first birth and stressed about their new responsibilities as a mother.

Sowmya recalled when her sister in law gave birth in a government hospital and "the nurses were

yelling at the pregnant women in the maternity ward," (Sowmya 2019). This gave her stress during her second delivery because she remembered how she too had been "scolded by nurses during her first birth at a government hospital and fell into long term sadness afterwards because of it," (Sowmya 2019).

While every participant noted that their family members such as their husbands, aunts and uncles, and in laws visited them in the hospital after the birth, only their mother and/or father stayed with them in the hospital. Many women noted they wished more family had been around them more often during this time. The husband was present in the hospital during the delivery itself for all of the participants, but only Latha and Sunitha talked about having their husbands with them in the delivery room. All the participants said they would have felt less alone if their husbands had been more active in their pregnancy.

Four out of the six participants reported staying at their mother's house for three to five months after giving birth; Sowmya was the only participant to talk about her mother in law also taking care of her and the baby post birth. The other five women said that only their mother supported them, or a sister if they had one.

### **CHAPTER 5: DISCUSSION**

While existing literature demonstrated the high burden of mental illness in women of India, previous studies did not include a diverse range of providers and address both mental and maternal health needs of women (Jha 2017) (Baron 2016). Therefore, in this study, I sought out to understand three ideas: how community health providers perceived and heard symptoms of mental illness from women who sought treatment from them, to what extent stigma poses a barrier for women's access to treatment for mental illness, and how mental illnesses that occur during pregnancy and postpartum period were discussed by both providers and women.

This study has demonstrated that in Mysore, certain words in Kannada and English had meanings that were adapted to mean a physical or mental state such that female patients were able to use this language to acknowledge symptoms to their provider. Even though women may not have known that the problems they described had to do with mental illness, these words served as strong indications to providers that a patient had symptoms of mental illness, and often its physical manifestations. Kannada words such as "bejaru", "novu", "bhaiyya", and English words such as "tension" have specific connotations so that when providers hear them, they know to ask more about these conditions. Providers such as Mr. Naresh, Dr. Vaidehi, Dr. Vikram, and Mr. Shiva, though different in their mode of practice, all rely on language to treat the women who seek treatment from them. It is useful, therefore, to understand the range of definitions of words with implications for symptoms of mental illness to streamline the course of treatment from provider to patient.

However, it is also important to note the diversity of providers and their implications included in this study. While providers heard many of the same words to describe symptoms, it became clear in interviews that every provider heard these words in different contexts and interpreted these words in different ways and different treatments. For example, if a patient came to Dr. Vikram, an astrologist, with complaints of "bhaiyya" he might have diagnosed that this

patient has been cast with the "evil eye" or negative spirits and prescribed them with an amulet or certain foods to eat. In this manner, Dr. Vikram took the responsibility off of the patient themselves and onto an external force. In contrast, Dr. Bhargavi, a psychiatrist from the JSS Hospital, might have diagnosed this condition as a form of anxiety and prescribe a form of medication. Both kinds of healing are forms of treatment that are utilized in Mysore and neither form of treatment should be discounted.

Most commonly, providers said women who came to them were experiencing stress from marriage and family problems, depression, and anxiety, but it is important to note that not every provider uses these specific terms to describe conditions. For example, Ms. Sushila, a spiritual healer from the Bramha Kumari ashram, might have heard women describe feeling stressed through their descriptions of physical pains. Normally she has treated women who come to her complaining of these physical pains with mindfulness exercises. However, she may not ever hear the word "stress" or use it herself in consultations. While she distinguished that pains in certain parts of the body might indicate specific conditions, the concept of "stress" is discussed differently than a biomedical provider such as Dr. Shankar even if these two providers seem to be talking about the same condition. Dr. Shankar might have had a higher likelihood of using the word "stress" in his diagnosis and his treatment might include forms of therapy specific to stress management.

Many providers I spoke to mentioned seeing many women suffering from stress, sadness, and fear or anxiety, no matter if the provider was an astrologist, religious leader, spiritual healer, psychologist, or psychiatrist, though they categorized these conditions differently. These providers discussed how these manifested differently in different women. For example, stress caused by marriage, work, financial trouble, or family problems might cause headaches in one patient but loss of appetite in another. Many providers cited the complicated nature of mental illness paired with language used to describe symptoms in Kannada as factors that make

diagnosis more challenging. Therefore, when providers hear women talk about marriage, feelings of sadness, helplessness, or fear, or variations of these words, they said that they pay more attention to or ask more questions about these symptoms in particular.

Stigma plays a role in people to delay seeking treatment for mental illness or to decide not to seek treatment at all. While thirteen out of the fifteen providers reported women being worried about stigma against them for seeking treatment for mental illness, not all providers discussed stigma against their forms of treatment. In fact, many providers noted that there are higher levels of stigma against seeking treatment from biomedical than non-allopathic providers. Mr. Aalok, from JSS Hospital, stated that biomedical providers are the last resort for patients. Whether the fear of stigma was imposed by family members or something women themselves were afraid of, stigma operated as both a barrier and a cause of delay in accessing this type of treatment for mental illness in women of Mysore. Some providers, such as Dr. Shankar from JSS Hospital and Mr. Shiva from the Rama Krishna ashram noted that women might be seeking treatment from multiple providers simultaneously.

Providers noted pregnant women coming to them for conditions that were either new during this time period or were getting exacerbated due to the pregnancy. Often, providers saw women complaining of stress and anxiety due to the pregnancy, family, or balancing the pregnancy and their workload. Further, anxieties of being a new mother and stress over the gender of the baby were heard by providers ranging from spiritual healers to psychologists, demonstrating the range of providers women were seeking during pregnancy. While many providers did not have experiences with hearing complaints about childbirth, twelve out of the fifteen providers saw patients complaining of issues postpartum such as anxiety, stress, and sadness. The causes of these symptoms that providers heard were diverse, such as familial pressure to have children, the gender of the baby, and fears about being a new mother. However, some biomedical providers described what they heard from postpartum women most frequently

as symptoms inducing stress, anxiety, sadness or a combination of all three. Further, many of these providers attributed these conditions to changing hormone levels in the new mother.

Non-allopathic providers described these conditions with different technical language than biomedical providers. Mr. Naresh for example heard conditions of anxiety in postpartum women through their descriptions of pain in the shoulders. When he heard this condition, he knew that this patient may be experiencing a form of "bhaiyya" and may attribute this symptom to a trauma in a past life that now is affecting the present and pregnancy.

For many women, while the news of pregnancy was positive, later stages of pregnancy brought more stress, anxiety, and sadness presumably as the delivery date became sooner and more complications in the pregnancy arose. Whether it was from familial pressure or the woman's own desire, every woman wanted a vaginal pregnancy, while the majority of women ended up having at least one cesarean. Women highlighted pain, stress, and anxiety as primary feelings during childbirth, but in the early postpartum phase they all expressed their happiness or relief with having given birth to a baby either through normal or cesarean delivery. Note that women may or may not have used the words of stress and anxiety to discuss their conditions but biomedical providers might have diagnosed these conditions as such due to the context of the symptoms. Non-allopathic providers might have diagnosed these conditions instead as spiritual forces impinging on the physical world (Flueckiger 2006).

Female support for women in delivery and postpartum is built in by traditional customs of women returning to their maternal homes to give birth and to stay there after birth. However, according to the six women I interviewed, family support was lacking when the woman comes back to the in laws house and could have contributed negatively to their mental state. Paralleled with providers' experiences, women discussed feelings of sadness, fear or anxiety, and stress in the postpartum period. While medical staff did not ask about the mental state of the women after giving birth, these women had agency in discussing their mental state with those around them.

By confiding in family or friends around them such as their mother and sister, and in some cases husbands, these women created a different network of support to serve their needs for mental illness. Women may or may not have been aware that their feelings that they talked to family members about were issues of mental illness, however they are openly discussing these issues with those they trust the most (Malhotra 2015). Family members, after hearing women in their family discuss these feelings, may have brought them to a provider for more treatment, providing a form of screening for maternal and mental health.

Increasing priority should be placed on mental illness and its prevalence because of its increasing burden in the world, particularly in low- and middle-income countries (Patel 2012). In India, women are disproportionately affected by mental illness, both generally, and specifically during the pregnancy, childbirth, and postpartum period (Malhotra 2015). While biomedical providers and allopathic providers might have had similar forms of counseling or questioning, these providers differed not only in their diagnoses but also in the way they interpreted their patients' symptoms. The diversity of providers created a vast set of resources for a woman undergoing forms of mental illness, and while this may be especially the case in Mysore, women were actively seeking treatment and forms of care from multiple types of providers. Women also took agency in creating support networks among themselves when this either did not exist or women did not feel as comfortable sharing information in a medical setting during the pregnancy, childbirth, and postpartum periods. This study demonstrated the depth of knowledge regarding resources women had while seeking care for mental illness in Mysore, but also their capacity to actively seek treatment either by themselves or with other female members. Even if women do not know there are suffering from mental illness in Mysore, they exhibit care-seeking behavior and service uptake from a diverse set of providers practicing various forms of healing.

In India, different factors such as cultural acceptance and stigma contribute to why a woman might be more likely to see astrologist or religious healer rather than a psychologist as her first source of treatment. However, I speculate that women also might be more willing to go to non-allopathic providers because they might take the responsibility off of the woman and instead attribute mental illness to external factors such as spirits, the environment, or negative forces. This may help her cope with her mental illness against the pressure of family and the stigma of seeking care for mental illness. Future research could be directed at stigma and how it perpetuates lack of mental health service usage.

Family support, or the lack thereof, was a recurring theme I heard from both providers and the women I interviewed. While some studies have found that family involvement can increase stigma if family members do not support the person getting treatment, they haven't looked how these family views are developed (Jha 2017). If we can understand how families arrive at the beliefs they do, and whether the neighborhood in the city where women live or their level of education, amongst other factors, contribute to this, we can have a better perspective of how to support women undergoing treatment or suffering from mental illness.

More collaboration between different types of providers could be useful to streamline treatment for women seeking care for mental illness. Astrologists, for example, could send patients to JSS Hospital and the patients might be more willing to go because such a provider has already referred them. It is important to prioritize further research and intervention efforts on blending allopathic and culturally sensitive care because this research and other studies have highlighted the myriad of providers for mental illness that exist in India. Further, one of the many ways stigma against seeking allopathic care in India could be dismantled is by linking cultural and allopathic providers. In the future, biomedical and other kinds of healers working together

could help increase education or awareness of mental illness, lower stigma, and encourage positive family involvement in pregnancy, childbirth, and postpartum.

With childbirth and pregnancy, Dr. Amit noted in his own study that the level of education of the husband determined whether a woman was open to seeking care for mental illness postpartum. No other studies have examined this relationship and I wonder how it affects women and their future children, as well as decision making. There is a dearth of research on the intersection of maternal and mental health in Indian women; this research should be prioritized due to the high proportion of women affected by these conditions, as demonstrated in this study.

This research is particularly important because of its diversity of providers and types of interviews included. The input of both biomedical and non-allopathic providers brought holistic perspectives to the discussion of mental illness in South India. Further, viewpoints on pregnancy, childbirth, and postpartum from both providers and women offered a comparison of attitudes towards mental illness during these specific time periods. Together, these factors contribute to this study's unique addition to existing literature surrounding mental illness in women generally and during crucial time points in women's lives.

This study highlights the need to include both biomedical and non-allopathic providers as givers of care for mental illness because both are used in India, often simultaneously by women. Therefore, focus should be placed on both biomedical and non-allopathic providers because both types of healing are prevalent in Indian culture (Mirza 2017). Women in Mysore, according to many providers I spoke to, access a balance of biomedical and non-allopathic providers. Henceforth, even if minimally, communication between biomedical and non-allopathic providers should be increased because it expands the network of provider support available to a woman in Mysore undergoing mental illness.

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# APPENDIX I: INTERVIEW GUIDE FOR INDIVIDUAL INTERVIEWS WITH COMMUNITY HEALTH PROVIDERS

- 1. What is the demographic composition of the people you see? Are they mostly men or women?
- 2. What ages? Religions? Languages? Castes? Socioeconomic status? Location?
- 3. What are the most common complaints that bring people to you for help?
- 4. What kinds of words or phrases do people use to describe their problems to you? For instance, we have heard many people talk about "mental torture" and "tension" a lot. Are there other specific kinds of terms like this that you frequently hear?
- 5. What do you think are the most common mental health problems in Mysore more generally the Kannada speaking population you have served?
- 6. How does a person know when it is time to come to you for help?
- 7. What, if any, remedies or resources do people seek before they come to you?
- 8. Do you perceive that people have trouble of any kind accessing the help you provide? When people come to you for help, do they report having experienced any challenges [trouble] before coming to you? If so, please explain.
- 9. After people come to see you, do they report back to you with any challenges [trouble] in following your recommendations? If so, please explain some of these.
- 10. Are there certain groups of people that could benefit from the services you provide, but whom you never see in your office/temple? Why do you think these certain groups do not visit you?
- 11. What kinds of issues are you unable to address? When that happens, where do you send people for further help? [What kinds of mental health issues are you unable to address?]
- 12. What resources are missing in Mysore locally for supporting people's wellbeing?
- 13. Do you see/treat women who are pregnant or have recently given birth?" And if so, "what is their typical problem?" And "how is it treated?"

# APPENDIX II: INTERVIEW GUIDE FOR FOLLOW UP INTERVIEWS FROM FOCUS GROUP DISCUSSION PARTICIPANTS

- 1. In this interview, I am interested in learning about women's experiences of stress. Please tell me about something that happened to you recently that was stressful. a. What happened?
  - b. How did you feel? Why?
  - c. Has it resolved?
  - d. If so, how did you resolve it?
- 2. How stressed are you, in general? Why? Please list the major causes of stress in your life.
  - a. Probe for more causes of stress if people mention only one or two.
- 3. When you feel stressed, what makes you feel better?
  - a. Probe: "Anything else?"

Now I want to ask you some questions specifically about pregnancy, since this can be a difficult time in a woman's life.

- 4. Please tell me about your first pregnancy.
  - a. How old were you when you got pregnant? How many years after marriage? Did you have any difficulties getting pregnant? Any difficulties during pregnancy? Did you understand what was happening to your body? Had any woman your age given birth while you were living in the house? How did you feel during it? Did you experience any tension or stress?
- 5. Please tell me about your first birth.
  - a. Where did it occur? Who was with you? how long was your labor? did you have a lot of pain? did anyone give you medicine for the pain? How did you feel during it? How did you feel afterwards?
- 6. Did you have any problems breast-feeding? if so, who did you go to and how did they help?
- 7. What are the customs in your family for a new mother?
  - a. Were you fed special foods? Did you have to stay separate from the rest of the family for a certain number of days? When did you first go out of the house? Did you feel any sadness or tension or stress after the birth? Did you know how to take care of your baby? Was there one particular relative who helped you

with the baby? What feelings were you experiencing after your first birth? Did you ever visit a doctor to address these feelings? How long did these feelings persist?

- 8. Where did your other births occur? Who was with you?
- 9. How did you 2nd or following births differ from your first birth? Were you more ready for what was about to happen? Did you feel any sadness or tension? Did you feel these feelings again after your other births?
- 10. Did anyone ask you about these feelings? If so, who did? Where did they ask you? (hospital, home, etc.)
- 11. Did you seek out anyone else to talk to about these feelings? If so, who and how do you know them?
- 12. How would you advise a new mother about what is about to happen, and what she can expect to feel, etc.?

#### APPENDIX III: CONSENT FORM

# Recruitment statement for participating in informational interviews

Title: Women's Stress in South India: Year Two

<u>Principal Investigator</u>: Dr. Lesley Jo Weaver <u>Funding Source(s)</u>:

University of Oregon Introduction:

You are being asked to be in a research study. The overall purpose of this project is to investigate how women in South India experience and talk about stress in their lives. You are being asked to participate in this study because you provide some form of mental health or wellbeing support in the Mysore community. Your involvement in this study will begin when you agree to participate and will continue only until the interview. It is entirely your choice to participate or not. If you decide to take part, you can change your mind later on and withdraw.

#### Procedures:

We are conducting a series of informational interviews with people in Mysore who provide various kinds of help and support for people's mental wellbeing. You do not need to have any special personal experience with stress to participate in the study, and you will not be required to discuss your personal experiences with stress unless you want to do so. Instead, interviews will ask you to describe generally the kinds of people who come to you for help, and your expert opinion about what forms of support are lacking in the Mysore community. The interview should take about 1 hour, and it will be voice recorded for later translation into English (if relevant) and transcription.

### Risks and Benefits:

We do not foresee any significant risks to taking part in this study. Taking part in this study may not benefit you personally, but we may learn new things to improve the way we treat and manage stress.

### Confidentiality:

No personally identifying information will be recorded with your responses during the interview, and pseudonyms will be used. People who look at the results of this study will not be able to identify you personally. Your name and other facts that may identify you will not appear when we present this study or publish its results. Personally identifying information will be kept locked in a password-protected computer file on a password-protected computer in a locked office, and only the principal investigator will have access to it.

### Costs and Compensation:

You will not be compensated for your participation in the informational interview. The only cost to you for participating will be your time. <u>Voluntary Participation and Withdrawal</u>:

Taking part in the interview is completely up to you. You have the right to leave a study at any time without penalty. This decision will not affect in any way your current or future care/services or any other benefits to which you are otherwise entitled.

### **Contact information:**

If you have any questions about this study or you have been harmed from being in this study call Dr. Lesley Jo Weaver at +1 2058865339.

If you have questions about your rights as a research participant, or wish to obtain information, ask questions or discuss any concerns about this study with someone other than the researcher(s), please contact Mrs. Poornima Jayakrishna, Member Secretary, PHRII Institutional Review Board, Phone: 821 425 955 or via email: poornima.phrii07@gmail.com

We will give you a copy of this information form to keep. Nothing in this form can make you give up any legal rights.

### Informed Consent statement for participating in informational interview



### **Consent for participation**

[To be attached to the recruitment statement]

By signing this document, you are agreeing to be in the study. You will be given a copy of this document for your records and one copy will be kept with the study records. Be sure that questions you have about the study have been answered and that you understand what you are being asked to do. You may contact the researcher if you think of a question later.

#### **Subject Consent**

I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I agree to participate in this study. I have received (or will receive) a signed copy of this form for my records and future reference.

As part of my consent, I agree to be audio-taped a	nd photographed.
Subject Name (Printed by Subject)	
Signature or thumbprint of Subject	 Date

Name of Witness  Person Obtaining Consent	Signature of Witness
I have read this form to the subject and/or the subject with a signed copy of this consent form. questions from the subject were solicited and ansigudgment, the subject has demonstrated comprehsubject adequate opportunity to read the consent	An explanation of the research was given and swered to the subject's satisfaction. In my tension of the information. I have given the
Name and Title (Print)	
Signature of Person Obtaining Consent	 Date