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Facilitators and barriers in access to mental health services for women with depression in Karachi, Pakistan

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SCHOOL OF PUBLIC HEALTH

Dissertation

FACILITATORS AND BARRIERS IN ACCESS TO MENTAL HEALTH SERVICES FOR WOMEN WITH DEPRESSION IN KARACHI, PAKISTAN

by

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ABSTRACT

BACKGROUND

Women in Pakistan experience a high prevalence of depression; yet make negligible use of mental health services. Information about the barriers and facilitators to mental health services for women is scarce. The present study explored the barriers and facilitators in accessing mental health services and potential strategies to increase the access for women in Karachi.

METHODS

A qualitative study was conducted to identify the barriers and facilitators in accessing mental health services for women. Women and key informants were also asked about their suggestions for reducing the barriers. Women from primary care were screened for depression and thirty in-depth interviews were conducted with those who were not accessing mental health services. Twenty-nine interviews were conducted with women accessing mental health services for depression at mental health clinics. Nineteen Key informant interviews were conducted with various stakeholders. Interviews were transcribed and coded for thematic analysis.

RESULTS

Themes elicited were categorized into family and household, health services, and socio-cultural levels. At family and household level, lack of awareness, normalization of depression, lack of empowerment, burden of looking after children and threats of divorce discouraged women from seeking professional care. Stigma, discouragement to seek mental health care and religious interpretations of depression were reported as broader socio-cultural issues, driving many to visit faith healers instead. Gaps in medical education, general practitioners' case overload, poor quality of health care, gender bias, poor resource allocation and dearth of referral systems were highlighted as barriers at health service level.

For facilitators themes of awareness, concern for children, the severity of the symptoms, family support, receiving a referral, affordability and organizational support were identified as factors that enabled women to access services. Both women and key-informants suggested that providing community-based interventions could be a viable option to increase the access.

CONCLUSION

Study findings suggest that raising awareness, providing mental health services in communities, and reforming medical education through the training of health workers can improve access to mental health services for women. An intervention is proposed to provide mental health services through community based lady health workers in Karachi. This may provide more accessible, and potentially cost effective, mental health services to better address the mental health needs of the population.

TABLE OF CONTENTS

ACKNOWLEDGMENTS iv

ABSTRACT.. v

TABLE OF CONTENTS vii

LIST OF TABLES x

LIST OF FIGURES xi

CHAPTER 1: INTRODUCTION AND BACKGROUND... 1

Depression: Symptoms and Prevalence 2

The Unique Case of Depression in Women.. 3

Impact of Depression 5

Depression in Developing Countries 8

The Challenge for Women 9

Delayed Access to Mental Health Services for Depression......................... 10

Barriers to Accessing Mental Health Services in Developing Countries 11

CHAPTER 2: SIGNIFICANCE OF DEPRESSION IN PAKISTAN........................ 13

Prevalence of Depression... 14

Prevalence in Women 15

Regional Prevalence... 16

Prevalence compared to men 18

Impact on Children's health and wellbeing 19

Mental Health Budget of Pakistan 20

Federal Mental Health Authority 21
Use and Abuse of Psychiatric Medications 23
Summary 24
CHAPTER 3: METHODS 25
CHAPTER 4: RESULTS 42
Demographics 42
Reported Barriers 47
A- Family and household issues: 48
B- Barriers related to Health services 58
C – Socio-cultural 74
Reported Facilitators: 83
A- Family, household level Facilitators 83
B- Health Services level Facilitators: 89
C- Socio-Cultural level Facilitators: 93
Participant's Recommendations 99
Limitations 107
Conclusion 108
CHAPTER 5: RECOMMENDATIONS 111
APPENDIX 130
Appendix 1: KEY INFORMANT INTERVIEW GUIDE 130
Appendix 1A: (Mental Health Care Providers) 130

Appendix 1B: (Primary Health Care Providers) 133

Appendix 1C: (Health department / Working for women's health) 137

Appendix 2: In-depth interview guide- 140

For Women receiving treatment for depression 140

Appendix 3: In-depth interview guide – 145

For Women screened for depression from primary care 145

Appendix 4: List of Resources: 150

BIBLIOGRAPHY 152

CURRICULUM VITAE 165

LIST OF TABLES

Table 1: Changes in rankings for leading causes of YLDs globally between 1990 & 2010……………………………………………………………………………………......2

Table 2: Symptoms of depression…………………………………………………………3

Table 3: Top ten global causes of DALYs for women aged 15–49 years…………...........4

Table 4: Burden of diseases in Pakistan ……………………………………………….. 13

Table 5: Top ten causes of DALYs for Pakistani people aged 15–49…………..……… 14

Table 6: Top ten causes of DALYs for Pakistan women aged 15–49………………..… 17

Table 7: Number of Participants in each study group...……………….…………………30

Table 8: Characteristics of Primary care sites………………………………………... 35

Table 9: Characteristics of Mental health care sites…………………………….…. 37

Table 10: Key informants.……………………………………………..……….…... 39

Table 11: Demographics of women screened positive for depression at the primary care health centers and women with depression, receiving mental health Services……..……45

Table 12: Key informants interviewed for the study………………………………….…… 46

Table 13: Barriers elicited from in-depth interviews of women and key-informant interviews ……..……………………………………………………….........……47

Table 14: Facilitators in accessing mental health services for women in Karachi……………………………………………………………………………...83

Table 15: Participant suggestions for increasing access to mental health services for women in Karachi……………………………………………………..…….. 100

Table 16: Evaluation Indicators and data sources…………………………….....…125

LIST OF FIGURES

Figure 1: A vicious cycle of poverty and mental illness……………………………….…...…. 7

Figure 2: A conceptual framework for the social risk factors for common mental disorders in women……………………………………………………………….... 10

Figure 3: Rate of YLDs in females due to mental and behavioral disorders……………. 18

Figure 4: Portion of mental health budget within the overall health budget……………. 21

Figure 5: Recruitment of women from primary care clinics……………………………..43

Figure 6: Logic model for program……………………………………………….....…122

CHAPTER 1: INTRODUCTION AND BACKGROUND

As the prevalence of non-communicable diseases (NCDs) increases globally, more attention needs to be paid to depression and the barriers to its treatment, especially in developing countries. The burden of disease is shifting from communicable diseases to non-communicable diseases (NCDs) which now contribute to approximately 60% of deaths around the world (1). In the past few years, it has become increasingly evident that non-communicable diseases, including mental illnesses, are placing a significant burden on health (2). Approximately 450 million people suffer from mental and behavioral disorders worldwide (3). Hence, it is necessary to identify mental illnesses and facilitate access to treatment.

Depression is estimated to remain one of the leading causes of disability worldwide (3–5). The Global Burden of Disease study in 2010 ranked depression as the second leading cause of years lost to disability (YLDs) globally since 1990 (see Table 1) (6). Furthermore, depression is predicted to rank second after ischemic heart disease for disability adjusted life years (DALYS)[1] worldwide in 2030, and is said to become the highest ranking cause of disabilities in developing countries (7). Unfortunately, not much work is being done to understand the reasons for the high rates of incidence and prevalence of depression. Identifying depression in developing countries is the first step to provide accessible treatment. This study aims to identify those barriers that make it difficult for women with depression to access required mental health services and those

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[1]Disability Adjusted Life Years: this concept calculates the potential years of life lost due to premature death or equivalent years of life lost due to disability caused by the illness.

factors which can enable them to receive these services.

Table 1: Changes in rankings for leading causes of YLDs globally between 1990 & 2010

1990 Mean rank (95% UI)	2010 Mean rank (95% UI)
1- Low back pain	1- Low back pain
2- Major depressive disorders	2- Major depressive disorders
3- Iron deficiency / Anemia	3- Iron deficiency / Anemia
4- Neck pain	4- Neck pain
5- COPD	5- COPD
6- Other Musculoskeletal	6- Other Musculoskeletal
7- Anxiety disorders	7- Anxiety disorders
8- Migraine	8- Migraine
9- Falls	9- Diabetes
10- Diabetes	10- Falls

Source: Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010), Institute of Health Metrics and Evaluations. Accessed from ***http://www.healthmetricsandevaluation.org/gbd/visualizations/gbd-arrow-diagram***

Depression: Symptoms and Prevalence

According to the Diagnostic and Statistical Manual IV Text Revised (DSM IV TR):

> Depression is diagnosed when five (or more) of the symptoms (see Table 2) have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either depressed mood or loss of

interest or pleasure (8).

Table 2: Symptoms of depression

1.	Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g. feels sad or empty) or observation made by others (e.g. appears tearful). (In children and adolescents, this may be characterized as an irritable mood.)
2.	Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day
3.	Significant weight loss when not dieting or weight gain (e.g. a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day
4.	Insomnia or hypersomnia nearly every day
5.	Psychomotor agitation or retardation nearly every day
6.	Fatigue or loss of energy nearly every day
7.	Feelings of worthlessness or excessive or inappropriate guilt nearly every day
8.	Diminished ability to think or concentrate, or indecisiveness, nearly every day
9.	Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

Source: Diagnostic and Statistical Manual IV Text revised (DSM IV TR)

The Unique Case of Depression in Women

The pervasive nature of depression in women is often downplayed which causes the risk factors of depression in women to be ignored, especially compared to men. Depression is the leading cause of disability among women (4,9). The Global Burden of Disease Study (2010) ranked depression as the second leading cause of disability in

women aged 15–49 years (see Table 3). Furthermore, researchers have consistently reported that women face twice the risk of common mental disorders (10–12), particularly depression, compared to men (9,13,14). Not only is depression more prevalent in women, it is also more persistent in women than in men (15). This points to the need for understanding the unique risk factors for depression in women.

Table 3: Top ten global causes of DALYs for women aged 15–49 years

1990 Mean rank (95% UI)	2010 Mean rank (95% UI)
1- Maternal disorders	1- HIV/AIDS
2- Major depressive disorders	2- Major depressive disorders
3- Low back pain	3- Low back pain
4- TB	4- Maternal disorders
5- Iron deficiency / Anemia	5- Anxiety disorders
6- Self Harm	6- Other Musculoskeletal
7- Anxiety disorders	7- Neck Pain
8- Other Musculoskeletal	8- Road Injury
9- Neck Pain	9- Migraine
10- Road Injury	10- Iron deficiency / Anemia
11- Migraine	11- TB
12- HIV/AIDS	12- Self Harm

Source: Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010), Institute of Health Metrics and Evaluations. Accessed from http://www.healthmetricsandevaluation.org/gbd/visualizations/gbd-arrow-diagram

Several biological and social factors place women at greater risk of depression compared to men. Among the risk factors for depression in women, genetics, and stressful or dysfunctional family environments are well-recognized (16). Depression in women can occur at any age regardless of education, economic background, or social status. The risk of depression in women increases at various reproductive points throughout life. This is partially due to physical and hormonal changes, including the premenstrual period, prenatal period, postnatal period (postpartum), premenopausal, and post-menopausal years (13). Unfortunately, the relationship between women's reproductive and mental health is often ignored (17). Psychological distress related to reproductive issues (i.e. pre-marital or unwanted pregnancies, miscarriages, abortions, lack of control over contraceptive use, surgery, or removal of reproductive organs, sexually transmitted infections, fistula, and infertility) make women more vulnerable to mental illnesses, particularly depression (17). Additionally, social roles and stressors related to puberty, marriage, child birth, increasing responsibility, and gender roles can also increase risk for depression (18). Furthermore, women in all societies are at risk of child sexual abuse and rape. Rates of depression in women who have been sexual abused are much higher than non-victims (19). Women are put at a greater risk of depression as a result of these wide range of unique risk factors.

Impact of Depression

Depression has become an epidemic leading to loss of lives, functionality, and resources. The negative effects of depression on quality of life and functionality are similar to those experienced by heart disease patients. The effects are far worse than

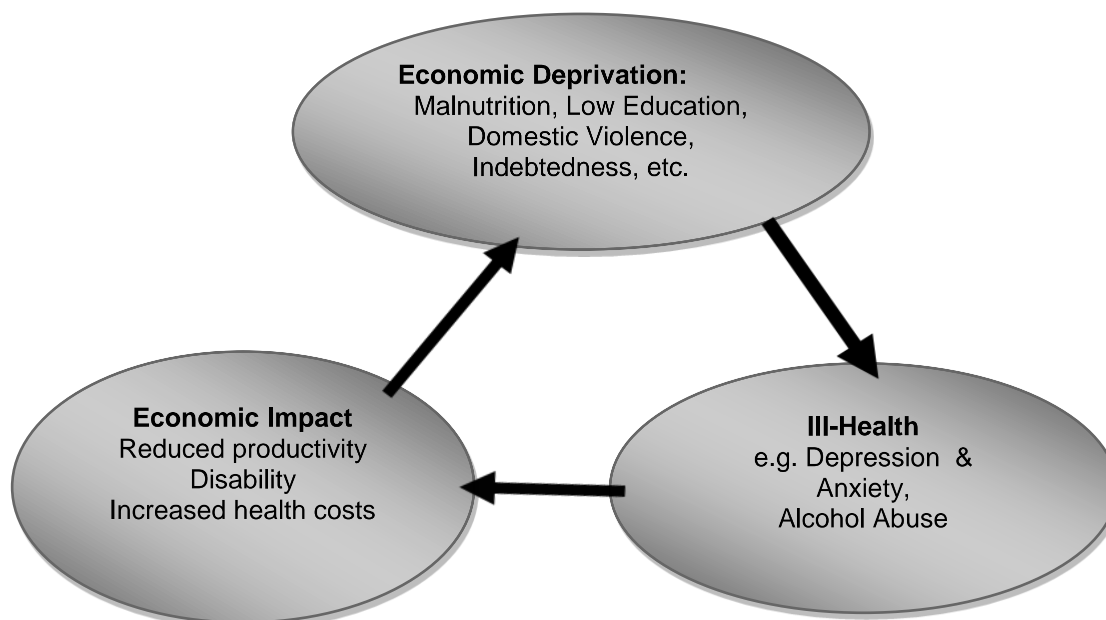
those experienced by diabetes, arthritis, and peptic ulcer patients (20). Depression also leads to several co-morbidities and disabilities. It results in significant human and economic loss, in addition to putting an enormous burden on the health care system (21).

Depression impacts quality of life as a risk factor for other somatic diseases, mental illnesses, and unhealthy behaviors. Depression has been identified as a risk factor for several communicable and non-communicable diseases, e.g. coronary heart disease (22,23), diabetes (24,25), and higher sero-prevalence of HIV (26). A systematic review of 122 studies has also demonstrated a strong association between depression and chronic pelvic pain in women (27). Furthermore, mental illness affects cognitive abilities such as thinking and decision making, causing people to engage in more risk-taking activities such as smoking (28–30), multiple sex partners, refusing to use condoms, and drug abuse, which puts them at greater risk of HIV, hepatitis, cancer, and other illnesses (31). Depression also increases the risk of communicable diseases such as TB and malaria due to reduced immunity and poor adherence to treatment (32–34). Thus, treatment of depression can contribute significantly to improving the quality of life of patients.

Depression has an economic impact as well. If left untreated, mental illness leads to disability, which increases health care costs andeventually drives people into poverty (see Figure 1) (35). Furthermore, research shows that poor people are at a higher risk of mental illnesses (36). The interaction between untreated mental illness and poverty traps people in a vicious cycle of poverty (36,37). In fact, untreated depression increases the cost of non-psychiatric health care through an increase in somatic problems and

emergency visits (38). Therefore, providing access to affordable mental health care is an important pillar in the treatment of depression.

Figure 1: A vicious cycle of poverty and mental illness



Source: Patel V. Is Depression a Disease of Poverty? Regional Health Forum 2001; 5:14–21

Depression in women has a far greater negative impact on a community than has ever been realized. Early diagnosis and treatment of mental illness and depression in women is crucial, not only for the health and wellbeing of women, but for the entire family and community, children in particularIt not only leads to behavioral problems in children but also affects the child's physical health and growth. Studies have consistently demonstrated that depressed mothers are less likely to receive antenatal care and are more likely to partake in risky behaviors, including smoking and improper diet. These actions are injurious to the unborn child, and lead to premature births and low birth weight (39–41). Studies also suggest that depressed mothers provide less stimulation to their children

and expose them to greater family discord compared to non-depressed mothers. Exposure to such adverse events leads to stunting in many children (42–45).

Neglect of depression in women at the global level exacerbates the negative impact of depression. Mental health for women was not mentioned clearly in the Millennium Development Goals (MDGs), although MDGs 3, 4 and 5 promote gender equality and women empowerment, child mortality reduction, and maternal health improvement. This is unfortunate because maternal mental health are closely linked to these goals and can provide insight into a mother's degree of empowerment in society,recognition of her contribution to society, and her independence to make decisions for herself and her children (39,40,46).

Identifying and treating depression brings a number of benefits to the individual and the community. The benefits of treated depression include increased productivity, reduced absenteeism, reduced disability, and reduced burden of care on the family and government. These benefits suggest the need for developing cost-effective treatment options through increased investment in the treatment of mental illness.

Depression in Developing Countries

Developing countries are experiencing a shift in the burden of disease from communicable to non-communicable diseases. However, unlike developed countries, the presence of specific institutional and cultural factors can create complications for depressed pateints. Approximately 80% of deaths from non-communicable diseases are reported from low and middle-income countries, such as Pakistan (1). According to one estimate, 10–44% of people suffer from depression and anxiety disorders in developing

countries (13). These estimates reveal that depression alone creates an enormous burden on the developing world. Of the approximately one million suicides committed every year, 86% occur in low-income and middle-income countries. More than half the suicide victims are between the ages of 15 and 44 years (47,48). However, these figures may be underestimated due to underdeveloped reporting systems in developing countries. In addition, several cultural factors, including shame and guilt suffered by family members, also play a pivotal role in underreporting of suicide (3). Furthermore, death by suicide is reported separately as self-inflicted injury, which prevents the actual impact of depression and mental illness on mortality to be measured (2).

The Challenge for Women

The situation for women in developing countries becomes more precarious. A complex web of sociocultural factors such as domestic violence, lack of decision making power, limited access to education, lack of respect in family and society, humiliation, preference of sons, and heavy workload increase the risk of depression, while simultaneously preventing recourse to professional help (49,50) (see Figure 2). Evidence suggests that gender discrimination and stressful life events increase the incidence of depression and suicide attempts among women (18,51,52).

Figure 2: A conceptual framework for the social risk factors for common mental disorders in women

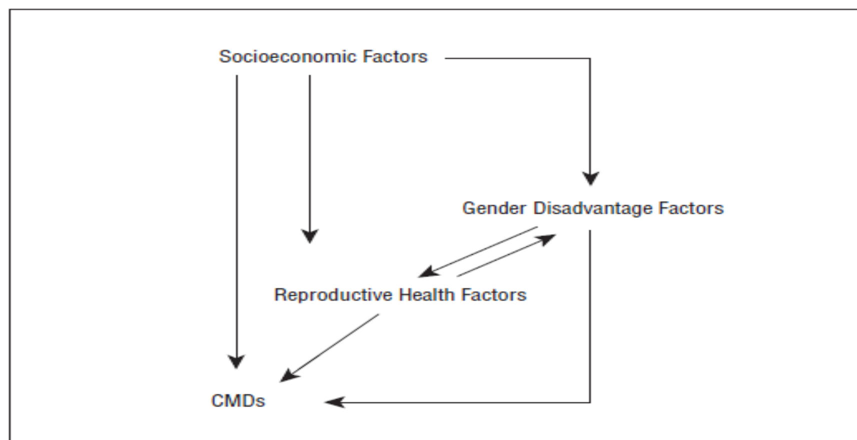


Figure. A conceptual framework for the social risk factors for common mental disorders (CMDs) in women.

Source: Patel, V. et al. (2006) Gender Disadvantage and Reproductive Health Risk Factors for Common Mental Disorders in Women: A Community Survey in India, Arch Gen Psychiatry, 63(4): 404–413. doi: 10.1001/archpsyc.63.4.404

Delayed Access to Mental Health Services for Depression

Although a wide gap exists between the prevalence of mental disorders and their treatment throughout the world (53), people in developing countries take longer to seek mental health services after a mental health problem has been identified. In fact, Lancet's series on mental health reports that whereas approximately two-thirds of people with mental illness in the developed world do not receive treatment (54,55), the percentage of such people in the developing world is 90% (56–60). Similar results were reported by Wang et al. in a study conducted in seven countries where it was found that the proportion of people using mental health services in resource-poor settings was very low (55). More recently, a WHO study investigating the age of onset for various mental illnesses and time to initial access to mental health services in 15 countries, shows that the onset of

depression varies greatly from country to country (unlike other illnesses) showing a wide median age (25–45 years) and an even wider interquartile range (17–65 years) (61). Countries are also found to differ in their first contact with mental health treatment ($p < 0.0001$) (62). Another WHO study reports a gap of 1 to 14 years from the onset of symptoms to accessing mental health services, with a larger gap in developing countries. As a developing country with poor overall health indicators, Pakistan's delay in access to mental health services is similar to other developing countries (62). Hence, identifying and eliminating barriers to affordable mental health care is essential to reduce this gap.

Barriers to Accessing Mental Health Services in Developing Countries

Effective evidence-based treatments for depression are available, yet almost 90% of patients in the developing world do not receive treatment (56–60). Studies examining barriers to accessing mental health services in developing countries are scarce. Moreover, while most studies report delay in seeking mental health services, very few identify and discuss the barriers to accessing mental health services.

In a study to investigate the length of delay from onset to treatment of mental illness, and pathways to care at a hospital and five clinics in Ghana, Appiahpoku et al. (2004) reported that those who visited traditional faith healers or pastors approached mental health clinics sooner. However, the study does not identify the determinants of delay. A multi-country study by Gater et al. (1991) explores delay in accessing mental health treatment in Pakistan. However, the study only analyzes the length of delay and pathways to care without studying its causes (63). Naqvi and Khan (2006), in a single site study in Karachi, reported 3.8 years of delay on average in approaching a mental health

care provider for depression and anxiety treatment (64). Like previous studies, the study also stops short of identifying the causes of delay or barriers.

On the other hand, a study by Nasir et al. (2005) identifies lack of awareness about depression, dearth of appropriate services, rejection of depression diagnosis by patients, excessive workload on healthcare providers, and other social issues as major barriers to depression diagnosis and treatment in Jordan (65). This is one of the very few studies to identify specific barriers to delay.

While this body of literature reflects an increasing effort to identify the length of delay and barriers to treatment in developing countries, studies that offer rich qualitative information about these barriers from the perspective of both patients and providers of varied background have been scarce. In the absence of studies that identify barriers and facilitators to mental health care access in developing countries, appropriate programs and policies to address the need for depression treatment cannot be formulated.

CHAPTER 2: SIGNIFICANCE OF DEPRESSION IN PAKISTAN

Pakistan is the sixth most populous country in the world with an annual growth rate of 3 percent and an estimated current population of over 180 million people. It is a lower, middle-income country with reported per capita GDP at $2900 in 2012 (74, 76). Overall health statistics in Pakistan are among the worst in the developing world (78, 80). Pakistan has not yet overcome the challenges of communicable diseases and the country's health programs are still focused on managing those diseases. In fact, the burden of disease, as measured by disability adjusted life years, shows that the percentage of DALYs lost due to communicable and non-communicable diseases in Pakistan are almost equal at 38.4% and 37.7% respectively (66). The burden of non-communicable diseases would be much greater if the burden of injuries was also included in non-communicable diseases (see Table 4). Pakistan is losing productivity of its working population due to the emerging challenges of non–communicable diseases .

Table 4: Burden of diseases in Pakistan

Burden of disease	Percentage
Communicable disease	38.4 (%)
Non-communicable disease	37.7 (%)
Maternal and prenatal conditions	12.5 (%)
Injuries	11.4 (%)

Prevalence of Depression

Non-communicable diseases (NCDs) are gaining increased importance, and depression is one of the most important NCDs. The Global Burden of Disease Study (2010) shows that disability due to depression has climbed up from the third rank to the second for Pakistani people within the productive age range of 15–49 years (see Table 5).

Table 5: Top ten causes of DALYs for Pakistani people aged 15–49

1990 Mean rank (95% UI)	2010 Mean rank (95% UI)
1- Tuberculosis	1- Tuberculosis
2- Maternal disorders	2- Major depressive disorders
3- Major depressive disorders	3- Road Injury
4- Low back pain	4- Low back pain
5- Road Injury	5- Ischemic heart disease
6- Mechanical forces	6- COPD
7- Diarrheal diseases	7- Maternal disorders
8- COPD	8- Self Harm
9- Iron deficiency / Anemia	9- Migraine
10- Ischemic heart disease	10- Interpersonal violence
11- Migraine	12- Iron deficiency / Anemia
12- Self Harm	14- Diarrheal disease
15- Interpersonal violence	15 Mechanical forces

Source: Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (2010) Institute of Health Metrics and Evaluations. Accessed from http://www.healthmetricsandevaluation.org/gbd/visualizations/gbd-arrow-diagram

Depression is more prevalent among Pakistani people than is usually assumed. In fact, according to the WHO country profile, 10–16% of people in Pakistan suffer from mild to moderate psychiatric illnesses whereas 1% suffer from serious psychiatric problems (67). Although national level or epidemiological data on depression in Pakistan is unavailable, a systematic review of 20 studies by Ilyas Mirza and Rachel Jenkins to examine risk factors, prevalence, and treatment of anxiety and depressive disorders in Pakistan reports a prevalence rate of 34% (29–66% for women and 10–33% for men), much higher than the 11% life-time depression rate in low/middle-income countries (68,69). Another study conducted by Gadit in three major cities of Pakistan finds a 46% overall prevalence rate of depression and a 35.7% prevalence rate in Karachi—the largest city of Pakistan with an estimated population of 20 million—which is consistent with other studies conducted in Pakistan (70).

Prevalence in Women

Depression in Pakistani women demands immediate attention due to its steep rise in recent years. According to a study, depression is the leading cause of disease burden for Pakistani women aged 15–49 years, and has risen from the third to the first ranking between 1990 and 2010 (see Table 6). Studies conducted in different provinces and regions of Pakistan consistently reported a high level of common mental disorders in women. This is perhaps the biggest loss of DALYs for any NCD in women younger than 65 years. Furthermore, in a study conducted in the Punjab province, Atif Rahman et al. report that 25% of women develop depression during the prenatal period and 28% during the postnatal period (45).

Regional Prevalence

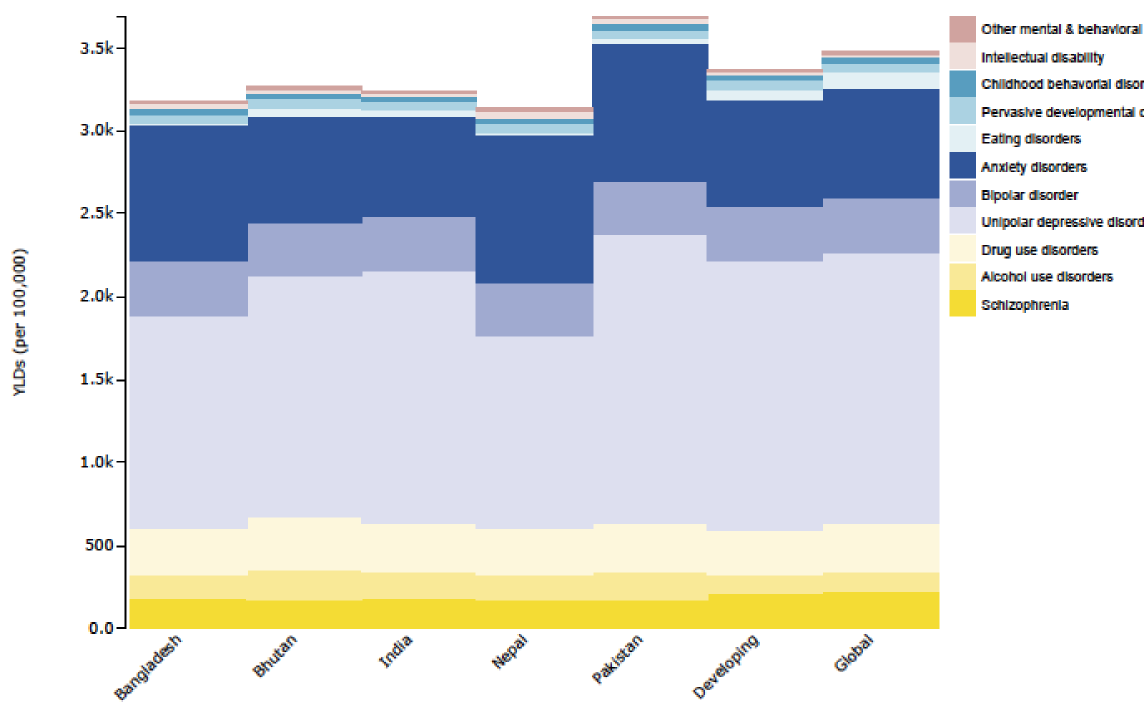
Approximately half the women visiting health centers in the Northern Areas were found to be suffering from depression or anxiety disorders (71). A study conducted in a mountainous village of the Hindu Kush range also reported 46% of women suffering from depression and anxiety disorders (72). The situation is equally discouraging in urban parts of the country. A study conducted in the lower-middle class, semi-urban areas of Karachi found 30% of women reporting symptoms of depression and anxiety (73). Furthermore, 11% of studied pregnant women registered at a prenatal clinic at an urban tertiary care hospital in Karachi had considered suicide whereas 45% of those had attempted it (74). A recent study conducted with Pakistani women in Pakistan suggests that depression during pregnancy is associated with low birth weight in newborns, which in turn leads to behavioural problems (41). The impact of these trends is illustrated in Figure 3 below, which shows that Pakistan has the highest rate of years lost to disability due to depression in women of reproductive age (15–49 years) when compared with neighboring countries, developing countries, and the world overall.

Table 6: Top ten causes of DALYs for Pakistan women aged 15–49

1990 Mean rank (95% UI)	2010 Mean rank (95% UI)
1- Maternal disorders	1- Major depressive disorders
2- Tuberculosis	2- Maternal disorders
3- Major depressive disorders	3- Tuberculosis
4- Iron deficiency / Anemia	4- Low back pain
5- Diarrheal diseases	5- Migraine
6- Low back pain	6- Iron deficiency / Anemia
7- Ischemic heart disease	7- Ischemic heart disease
8- Migraine	8- Anxiety disorders
9- COPD	9- Self harm
10- Anxiety disorders	10- COPD
11- Self harm	11- Diarrheal diseases

Source: Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (2010), Institute of Health Metrics and Evaluations. Accessed from http://www.healthmetricsandevaluation.org/gbd/visualizations/gbd-arrow-diagram

Figure 3: Rate of YLDs in females due to mental and behavioral disorders



Source: Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (2010), Institute of Health Metrics and Evaluations. Accessed from http://www.healthmetricsandevaluation.org/gbd/visualizations/gbd-cause-patterns

Prevalence compared to men

In addition to rising rates of depression among women across the country, there is a higher prevalence of depression among women compared to men. In the Health Indicators of Pakistan, Gateway Paper II, Ilyas Mirza reports that females suffer form anxiety and depressive disorders more than males (approximately 29–66%). A study conducted in a rural village of the Punjab province reports 25.5% prevalence of depressive disorders in males but a staggering 57.5% in females (75). Similar disparity is evident in the tribal areas where depressive symptoms were reported in 45% of males and

60% of females (76). Similar results were found in a study conducted in a rural village in the Sindh province. The study found 54.2% of women suffer from depression and anxiety compared to 28.7% of men (77). The same pattern occurs in cities as well. A study conducted at a hospital in Karachi investigated para-suicide[2] patients over a period of 3.5 years, out of whom married women made up the single largest group (78). Analysis of all non-fatal suicidal cases over a 6.5-year period at the psychiatric department of a Karachi hospital reported a 4:1 ratio of women over men (79). As these studies suggest, it is crucial to make mental health care accessible to women as they constitute the most vulnerable and deprived group of depressed patients in Pakistan.

Impact on Children's health and wellbeing

As in other developing countries, research conducted with Pakistani women reveals damaging impacts of depression on women's personality, health, wellbeing, and the wellbeing of their family and children. Adversities experienced in the early years as a result of depressed mothers can have a deep impact on the wellbeing of children. This was evidenced in a rural community study in Rawalpindi, Pakistan, where it was reported that over 25% of women suffer from depression in the antenatal period and 28% in the postnatal period (39). Whilst postnatal depression affects approximately 10–15% of all mothers in Western societies (19), rates as high as 25% have been reported in Pakistan (41). It follows that women who are prenatally depressed give birth to babies with lower birth weight than normal mothers. At the same time, a prospective cohort study conducted in Rawalpindi suggests poor growth of children in antenatally or postnatally

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[2]**Para suicide:** An attempt at suicide, commonly called a suicidal gesture, in which the aim is not death.

depressed mothers (42). Almost half the children under five years of age suffer from malnutrition in Pakistan, despite food sufficiency (80,81). Infants of depressed mothers have been reported to have high rates of diarrhea and low rates of immunization.

Potential benefits of treatment

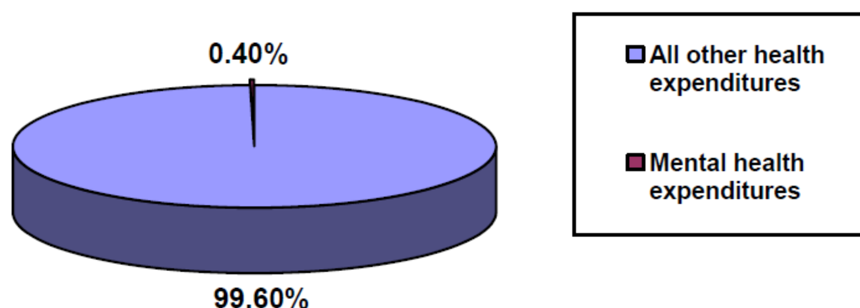
Timely treatment of depression in mothers brings huge dividends for child health. It has been suggested that if maternal depression is eliminated from the population, 30% of infant stunting can be reduced in less than one year (42). According to a study conducted in Pakistan, treating maternal depression can help reduce malnutrition and stunting in children in Asia (42,82). This can be achieved if adequate public and private mental health care services are provided.

Mental Health Budget of Pakistan

Despite the urgent need to provide mental health care to people in Pakistan, women in particular, the measures taken at present are insufficient and inefficient. Pakistan's health budget is less than 1% of GDP, and the mental health budget is only 0.4% of the total health budget (83) (see Figure 4). This is nearly the lowest percentage in the world for health expenditure as a percentage of GDP – much lower than Iran, India, and other neighboring countries. Although the government sector provides free consultation, patients need to buy medication. In addition, health insurance is not provided to government employees and only a few large international organizations reimburse limited medical costs to their employees. Consequently, people have to pay for all or most mental health treatments out of their own pockets (86, 87).

As a result of the inadequacy of public health care, nearly 70% of health care is provided by the private sector. The private sector offers services for a fee and is very costly. A study conducted by Gadit, on the out-of-pocket expenditure for depression among patients attending private community psychiatric clinics in Karachi, reports that often the cost of treatment for individual patients exceeds the financial resources available for the average Karachi resident (84). The study further reports that 65% of the people in the sample were earning only $86 per month whereas the cost of depression treatment was $51.40 per month in 2004 (84). This situation reflects the inefficiency and weakness of public health ministries in Pakistan.

Figure 4: Portion of mental health budget within the overall health budget



Source: WHO (2009) WHO-AIMS report on mental health systems in Pakistan.

Federal Mental Health Authority

The Federal Mental Health Authority (FMHA) was the supreme public body for mental health care in Pakistan until 2010. Formed in 2001, it was assigned the responsibility to advise governments on mental health prevention and promotion, setting up mental health services, and prescribing a code of practice for mental health service

providers. It was also responsible for drafting rules and regulations to help governments enforce mental health laws. Sadly, the 2005 term of the FMHA ended without any significant accomplishments (86). Frustrated by the ineffectiveness of the body, the Pakistan Association of Mental Health (PAMH) filed a case in the Sindh High Court in 2007 for reconstitution of the FMHA, which was ordered in 2008. The FMHA was reconstituted in December 2009 and met in December 2010 after the PAMH initiated a signature drive asking FMHA and the Supreme Court to implement a Mental Health Ordinance (MHO) (86). However, in April 2010 the National Assembly passed the 18th Amendment to give autonomy to the provinces and hence the FMHA and MHO were dissolved. Recently the government has established the Ministry of National Health Services, Regulation and Coordination Division, to consolidate all health departments in the country. This new ministry has been unable to determine its priorities as it is still in a nascent phase and is reviving from the post-devolution fragmentation (89, 90). At present, it cannot be predicted with any certainty whether the new ministry will perform any better than its predecessors. There is a remaining need to remove barriers to affordable and high quality mental health care for women in Pakistan.

State of Mental Health Systems and Services in Pakistan

The resources available for mental health care in Pakistan are appalling, and there is desperate need of expansion and improvement. Pakistan has four public mental hospitals, one of which is in Karachi. The three public teaching and three private teaching hospitals have psychiatric units. A few small private hospitals also operate in Karachi. At present, about 184 psychiatric beds are available in Karachi (85). Karachi has only 44

registered psychiatrists for a population of 21 million (85). The "brain drain" has been instrumental in diminishing the existing services as many psychiatrists have emigrated overseas (89).

An estimated 125 psychiatric nurses, 480 clinical psychologists, and 600 mental health care social workers support the feeble mental health care infrastructure across Pakistan (85). These mental health care providers are concentrated in the major cities. Although Karachi, being the largest city of Pakistan, enjoys the availability of mental health services in government, private, and charitable sectors, access to mental health services for women appears to be a challenge.

Use and Abuse of Psychiatric Medications

The situation for women with depression in Pakistan is made bleaker by the absence of policies and regulations to promote responsible use of psychiatric medication. As a result, many psychiatric medications can be bought over the counter. One study conducted in an out-patient clinic in Karachi reported that 40% of the sample was using psychoactive drugs without any doctor's advice (90). Another study conducted in urban and peri-urban settlements of Karachi reported that the use of benzodiazepines is on the rise, with 14% of the sample (significantly more women) reporting benzodiazepine use (91). Out of the sample, only 3% had seen a psychiatrist and 40% were using it on the prescription of local practitioners. Only 22% of the sample was using it on genuine complaints (depressive disorder). More surprisingly, studies show that general practitioners prescribe these medications without educating the patients about the duration of use and side effects from long-term use (92). Thus, many patients take these

medications for much longer than needed and end up suffering from addiction or substance abuse disorder (92). This risk of abuse highlights the urgency of facilitating access to qualified and responsible mental health care professionals in Pakistan.

Summary

Studies reveal a higher prevalence of mental disorders in Pakistan, especially in Karachi where a study reported depression rates as high as 35.7% (70). Furthermore, depression is reported to be twice as common in women compared to men. Studies have also reported that untreated mental disorders are likely to worsen with associated co-morbid disorders, greater disabilities, and occupational difficulties (93,94). Due to insufficient public mental health care in Pakistan, the population depends almost entirely on out-of-pocket expenses (86, 87) for mental health treatment. The high cost of treatment, poverty, economic dependence, and mobility dependence of women, along with stigma, keeps the utilization of available mental health services low for women and further adds to loss of productivity and misery for them, their families, and society in general (84). Thus, early diagnosis and treatment of mental illness and depression in women is crucial, not only for the health and wellbeing of women, but also for the entire family and community, children in particular.

CHAPTER 3: METHODS

Introduction

This chapter elaborates on the dissertation aims and the methods used for the dissertation. This chapter describes the process used in the in-depth interviews and key informant meetings, and site selections. Subsections include the selection criteria, methodology, and analysis.

Research Goal

The purpose of this study was to explore the barriers and facilitators in access to mental health services for women with depression in Karachi, Pakistan; and thoughts of women and key informants regarding possible strategies to increase the access; and to inform the development of relevant interventions and policies.

Specific Aim(s)

To date, there has been no research to understand why existing services are not used by women with depression in Karachi. In order to achieve the goal of this project the three main specific aims were:

(1) To understand the barriers and facilitators from a patient's perspective

(2) To understand the barriers and facilitators from provider and key informant's perspective

(3) To synthesize information gleaned from this research to inform intervention and policy development in Pakistan.

Knowing and understanding both barriers and facilitators would help in developing future interventions to improve access to mental health services for women. The long-term objective of this study is to provide evidence and input for intervention and policy development to improve access to depression treatment for women in Karachi, and to contribute towards improving women and child health achieving MDG 4 and 5. It is hoped that this study would make a significant contribution to our understanding of existing barriers and facilitators by gathering the thoughts of women and key informants on improving access to services, and through the collection of rich data using qualitative methods through quantitative scales. .

Study Design

A cross sectional qualitative study was conducted using in-depth interviews and key informant interviews in Karachi,Pakistan from August to November 2012.

Sampling Strategy

Selection of Sites within Karachi

The study was conducted at three different primary health care sites of Karachi for women not accessing mental health services, and at three different mental health services sites for women accessing treatment services for depression. Three different sites for both primary health care and mental health care were selected to include the experiences of women accessing services from different public, private, and charitable health facilities from different parts of Karachi. Populations accessing services from different sites are from different socioeconomic backgrounds and potentially have different experiences.

Selection of the samples

Qualitative interviews were conducted with three groups of participants to ensure the inclusion of diverse perspectives on the issue: women seeking primary care, women seeking mental health care, and providers. As typical in qualitative studies, the sample size was driven by saturation, which is the point at which the same stories, themes, issues, and topics emerge. This is when a sufficient sample size has been reached (95,96).

Patient Selection

Adult women within the reproductive age range of 18 to 44 years, who could communicate in Urdu or English, were chosen as participants for the study. Participants younger than 18 years were not included, as they would cater to the factors relevant to children or adolescents. Similarly, women over the age of forty four have a different status and role in Pakistani society than women of reproductive age and could have a different set of barriers and facilitators .

Women seeking primary care

A total of thirty women were interviewed from primary care clinics (refer to the table 7). To recruit thirty women who met the depression criteria, one hundred and five women were screened with the help of the Patient Health Questionnaire (PHQ-9)(97–99). Other studies in Karachi and elsewhere have reported that around 35–40% of patients in primary care clinics have common mental disorders (100–103). A translated version of (PHQ-9) is available in Urdu. PHQ -9 has been reported to give valid and reliable results in screening depression in primary care settings (75,104,105). The score of 15 or higher on PHQ -9 indicates moderately severe depression, and recommends the need for

psychotherapy or medication. This was used as a cutoff point to be eligible to participate in the study. Moderately severe depression means that the patient's functionality and quality of life (i.e. change in appetite, trouble concentrating, or feeling bad or hopeless most of the time) is being affected by the symptoms of depression for at least the last two weeks.

Out of 105 women who were screened, 58 did not meet the criteria, and 17 women who met the depression criteria refused to participate in the study. Ten of the women refused to be interviewed because they were accompanied by someone and did not want to keep them waiting. One young woman was unable to complete the interview because she was accompanied by her father who had to return to work. Seven refused because they were not comfortable with their interview being recorded. The women who refused or could not complete the interview might have different experiences of barriers and facilitators.

Women with depression, who were screened for depression from primary care clinics, were included in the study to investigate what currently impedes their access to services. These women could also add to the knowledge of how they look at their symptoms and problems. However, it was difficult to recruit women from the community, who are depressed, but not accessing mental health services. This is why primary care health centers were selected to recruit women with depression who were not yet accessing mental health services.

Women seeking mental health services

Twenty nine in-depth interviews of women accessing mental health services were conducted (refer to the table 7). Other similar studies have also reached theoretical saturation with this sample size (95,96,106). Women who were currently accessing mental health services were included in the study in order to understand, not only the challenges that they faced before reaching the services, but also the factors that facilitated them to access mental health services. Including both the women who were accessing mental health services and women who were not accessing mental health services can help understand barriers and facilitators from different perspectives.

Provider Selection

Key informants were selected by the investigator who is a clinician in Karachi. She contacted the key informants from leading academic, governmental, and non-governmental organizations based on her knowledge of the stakeholders in mental health and general health. The informants consisted of mental health care providers, general health care providers, government health officials, and people working for health access and health promotion to include the perspective of providers at different levels, program developers, policy makers, and field workers. Key informants were included in the study because their work withdepressed women directly, or through program and policy development and implementation, gives them insight into the issue of accessibility of mental health service for women in Karachi. Key informants included in the study were male and female health care providers at different levels, program and policy developers, and other experts working on women's health issues.

In terms of the key informant interviews, saturation and a variety of perspectives were reached within nineteen key informant interviews (refer to the table 7). Seven key informant interviews were conducted at the beginning of the study, and then in-depth interviews were conducted with the women participants. In the end, the second round of remaining key-informant interviews were conducted with remaining key-informant interviews as a feedback loop. The recommendations in the study were derived from the responses of the participating women and providers when asked to suggest improvements.

Table 7: Number of Participants in each study group

Group 1	Women with depression, receiving mental health services	29
Group 2	Women screened for depression from primary care clinics	30
Group 3	Key informants	19
Total		78

Study Tools

Development and use of a questionnaire to collect data on the issue could limit participant responses and the study could lose vital information pertinent to the culture and experiences of women in Karachi. Therefore, it was decided data would be collected through qualitative methods of in-depth interviews and key informant interviews to gain *Verstehen*; which is attempting to understand people's perspective in a specific time and context in their own words to provide rich information on the relevant issue (107).

Interview guides:

Interview guides with open-ended questions were developed with the help of researchers at Boston University for each group (refer to Appendices). In-depth interviews were designed for participants to tell their stories of how they went through the process of identifying their symptoms and accessing services. And for those who were not accessing mental health services, open-ended questions were developed to explore what they thought of their symptoms and what kind of treatments, if any, they were receiving. Further open-ended questions were included to explore barriers, enablers, situations, circumstances,people that facilitated the process or posed any challenges in obtaining services, and to explore participant perspective on how to design culturally and gender appropriate services. Key informant interviews were designed to explore the observation of the stakeholders about barriers and facilitators that women face (refer to Appendix -1).

An interview is a qualitative interactive tool which can allow us to collect data as participants share their experiences in their social world and express the meaning that they attach to their experiences of depression and access to services in their own words (108). An in-depth interview is a conversational tool that provides the means to re-construct the meaning of participant life experiences through research questions (109) and is helpful in capturing individual participant voices. This is particularly helpful when the conversation is about a sensitive issue, like depression in women, and when confidentiality is important due to the stigma attached to it (107).

Key informant interviews were used to collect data of observations from key informants at broader cultural, community, and health services level. Key-informants included those who have studied these issues within communities and can provide valuable information and data from participants with different backgrounds, observations, and expertise (110). The qualitative methods of in-depth interviews and key-informant interviews were used for this study to provide deeper insight and to advance knowledge about factors that facilitate or impede women's access to depression treatment at various levels.

Compensation:

Patient participants were paid a small stipend in the amount of 500 Pak rupee (US$5.8) and key informants were paid 1000 Pak rupee (US$11.6) for participating in an in-depth interview to cover the costs of travel and/or lost work time. Monetary reimbursement for the interview helps compensate participants for their time and effort. The amount was paid in one lump sum at the conclusion of each interview.

Ethical approval:

IRB approval was obtained from Boston University Medical Center. From Pakistan, letters from local consultants were obtained from professionals in Pakistan to endorse the ethical standards of the study, since there is no central place to obtain IRB approval and recruitment sites were not affiliated with IRB institutes.

Consent Procedure:

Prior to conducting the interview, study participants were given an explanation of the project and verbal informed consent was obtained from study participants for

participation and adio recording of the interview. The investigator emphasized that the study is voluntary and confidential and they may decline to participate without penalty for any reason. Participants were given the opportunity to ask any questions prior to initiating the interview.

Data Collection

The study data was collected from August 2012 to November 2012. The Principal Investigator (PI) was in Karachi for five months to collect the data. The PI contacted the health care providers and administrators of the health centers to gain access to health centers. Initial meetings were arranged with health care providers to explain the study andsupport needed from health centers and health care providers, and to arrange the logistical details (i.e. arranging a private place to conduct the interviews with participants etc.). The PI is from the same city and is familiar with professionals and stakeholders in the city. She recruited key informants by phone, email, and personal meetings.

Women seen in primary care setting:

Women were recruited from three different primary health care sites of Karachi, Pakistan. The government, charitable, and private clinics were selected to include the perspective and experiences of women obtaining health services from different type of health centers. Women visiting government, charitable, and private clinics also belonged to different parts of Karachi and different socioeconomic groups.

Primary Care Site 1: Site 1 was an Out Patient Department (OPD) for women in a provincially funded government hospital situated outside of Karachi. The hospital had separate OPDs for males and females. The OPD was conducted every day from 9 a.m. to

1 p.m. The consultation charges were Rs. 5 (5 cents). Medication was provided at subsidized rates at the hospital pharmacy. Some prescribed medication needed to be bought from an outside pharmacy. Three to four female doctors provided consultations to patients. Patients were called one-by-one on a first-come, first serve basis for consultation. There were long lines and doctors could give less than five minutes per patient.

Primary Care Site 2: Site 2 was OPD at a charitable consultation clinic situated in the center of the city. There was one female for general OPD along with other specialists (i.e. Gynecologist, dentist, physiotherapist etc.). A female doctor conducted OPD from 10 a.m. to 12:30 p.m. daily for women only. Consultation charges were 35 cents; patients who could not afford this fee were given further concession as well. Patients were required to buy medication from a pharmacy. The doctor stored the sample medicine provided to her for free by pharmaceutical representatives and provided it to poor patients.

Primary Care Site 3: Site 3 was situated in an upper middle class educated area of Karachi. A female consultant conducted OPD for females. Consultation charges were Rs. 250 to Rs. 400 (2.5$ to 4$). Prescription for medication was given to patients to purchase it from any pharmacy. OPD was conducted daily from 10:00 a.m. to 1:30 p.m. She gave time to patients, examined them in detail, and offered explanations.

Table 8: Characteristics of Primary care sites

	Site 1	Site 2	Site 3
Consulting charges	5 cents	35 cents, further concession was offered to non affording patients	2.5$ to 4$
Timings	9:00 a.m. to 12:00 p.m.	10:00 a.m. to 12:30 p.m.	Daily 10:00 a.m. to 1:30 p.m.
Health care providers	2–3	1	1
Medicine	provided at subsidized rates at the hospital pharmacy	To be purchased at pharmacy outside. Free medication provided to some non-affording patients	To be purchased at pharmacy outside
Privacy	No privacy, multiple patients in room	Next patients standing at the door	Separate consulting room with privacy
Time given to each patient	3–5 minutes	5 to 10 minutes	10 to 15 minutes

The PI approached women in the primary care clinic's waiting areas, introduced herself and provided brief information about the study and gave them the "Information Sheet for Patients in PHC" sheets (Appendix 3). The women who orally consented to participate were taken to a private area for screening. Informed consent was requested from the women who met the criteria. Interviews were conducted for approximately 90 minutes each.

The women who did not meet the criteria were thanked for their time and support provided to the study through screening. The women who met the eligibility criteria but refused to participate in the study were also thanked for participating in the screening process. All of the women who were screened were offered a list of resources, which included a list of mental health care providers in the study and some online references for

information. Women were interviewed using their own description of their symptoms (i.e. sleep problems, tension, fatigue, feeling sad etc.) rather than using the word depression.

Women seeking mental health services:

The study was conducted at three mental health services sites for women accessing treatment services for depression.

Mental Health Site 1: Site 1 was a mental health consultation clinic in a provincially funded government hospital situated outside of Karachi. The Medical Superintendent of the hospital was a psychiatrist. He was the only mental health care provider in the hospital. The patients were seen in OPD every Friday from 9 a.m. to 1 p.m. The consultation charges were Rs. 5 (5 cents). Medication was provided at subsidized rates at the hospital pharmacy. Often medication was not available there - owever, the psychiatrist used to store the medication received from pharmaceutical companies as samples and provided it to the poor patients. Patients were usually seen privately - however, other staff members at the hospital frequently visited the psychiatrist for administration purposes and sat there during the consultation.

Mental Health Site 2: Site 2 was a mental health department in a federally funded government teaching hospital situated in the middle of the city. The department had many psychiatric residents besides staff psychiatrists. Patients were seen in OPD twice a week from 9 a.m. to 2 p.m. Five psychiatrists with their residents provided consultation to approximately 400 patients per day. This included both new patients and patients visiting for follow-up. There was no privacy for patients. While one patient was seen, other

patients and their family members used to group around the doctor's table. Due to high volume, patients were only seen for few minutes. The consultation charges were Rs. 5 (5 cents). Medication was provided at highly subsidized rates at the hospital.

Mental Health Site 3: Site 3 was situated in an upper-middle class educated area of Karachi. The psychiatric consultation clinic was within a general consultation clinic of a private hospital. There was one psychiatrist who provided services seven days a week from 9 a.m. to 3 p.m. to approximately 15 patients per day. Consultation charges were Rs. 400 (4$) and patients needed to purchase medications from any pharmacy at full price. The psychiatrist at this site used to give time to patients, listen to them, and would provide explanations in a private consulting room.

Table 9: Characteristics of Mental health care sites

	Site 1	Site 2	Site 3
	Mental health consultation clinic in a hospital managed by provincial government	Mental health department in a federally funded government teaching hospital	Psychiatric consultation clinic was within a general consultation clinic of a private hospital
Consulting charges	5 cents	5 cents	4$
Timings	Once a week from 9:00 a.m. to 12:00 p.m.	2 days a week from 9:00 a.m. to 1:00 p.m.	7 days a week, 9:00 a.m. to 3:00 p.m.
Mental health care providers	1	5–6	1
Patients seen per day (approx.)	30–35	350–400	15
Medicine	Provided at hospital at highly subsidized rates	Provided at hospital at highly subsidized rates	Needed to purchase from any pharmacy at full rates
Privacy	Separate consulting room but people walked in and sat there during consultation	No privacy	Separate consulting room, complete privacy provided

A total of twenty nine women with depression who were receiving mental health services were interviewed. Mental health care providers at above mentioned three sites were approached to recruit women who had been diagnosed with depression by health care providers and were receiving mental health services. Mental health care providers provided brief information about the study and the "Information Sheet form for Women with Depression" to the depressed women patients under their treatment who met inclusion criteria. If they were willing to participate, they were sent to the Principal Investigator (PI) for the interview. The PI explained the study in further detail and took patients' verbal consent before initiating the interview. Interviews were conducted for approximately ninety minutes each.

Key Informants

In total, nineteen key informant interviews were conducted with nine males and ten females. Key informant interviews were conducted with five psychiatrists, three psychologists, five general practitioners, two pharmaceutical representatives, one government health department official, and three NGO professionals working on health and women's issues in Karachi. Some participants were in multiple roles. One GP was also a professor at a government institution, training future GPs, and working in an administrative role as a medical director at a hospital. One GP was involved in the development of an upcoming continuing medical education program for a teaching hospital. The PI conducted approximately 90-minute interviews at a time agreed upon by both the participant and PI. Interviews were conducted in a separate, private area to ensure participant comfort, privacy, and confidentiality.

Table 10: Key informants

	Male	Female	***Total***
Psychiatrist	3	2	**5**
Psychologist	-	3	**3**
General Practitioners	2	3	**5**
Government health official	1	-	**1**
Pharmaceutical representative	2	-	**2**
NGO professionals	1	2	**3**
Total	**9**	**10**	**19**

At the end of the in-depth and key informant interviews, two group meetings were organized to share the preliminary analysis of the interviews with stakeholders. The first meeting was arranged at the mental health department of the federally funded hospital. The participants included the mental health care providers and trainees of the department. Only one of the participants had participated in the study as a key informant.

The second group meeting was held in the waiting area of a primary hospital. The participants of the meeting consisted of psychiatrists, psychologists, primary care providers, health administrators, and patients. Three of the group members were the key informants who also participated in the study. The remaining participants were other health care providers who had not participated in the study.

Data Analysis

Digital recordings of all the in-depth interviews were transcribed verbatim and prepared for analysis. The transcriptions were then coded for key themes and further analysis.

Coding:

The PI read and re-read the transcripts and marked the various topics in the narrative. This resulted in the development of an initial list of codes directly from the interview and memo information. Codes are reoccurring subject areas in which the study participants elaborate. The first drafts of the codebook were developed after five interviews were completed.

Software Nvivo 10 developed by QSR international was used for data management (111). This program allowed for line marking, searching, indexing, collapsing and dividing codes and branches of codes, and other relevant organizational techniques. The investigator conducted the initial labeling and categorizing of the data. The coding was iterative in nature and evolved as new themes emerged and codes were modified, collapsed, or dropped. If new codes emerged, these were incorporated in the code list and also became part of the interview guide. As part of axial coding, the investigator compared predicted patterns with empirically based patterns and engaged in explanation building.

Memoing:

Methodological and theoretical notes were written throughout the process of analytical coding. All sets of notes were included in the textual data sets as memos and were used to begin to seek connections between the various codes. Memos were written for each interview, which in turn provided suggestions for additional data collection. This process continued until the point of saturation was reached.

Thematic Analysis:

Data analysis used the thematic analysis approach. Preliminary searches of codes, salient terms, and emergent themes from the interviews informed probes for the remaining interviews. The thematic analysis involved searching across a data set to find repeated patterns of meaning (themes) (111).

The following chapter reports on the results of the qualitative analysis of all the three groups.

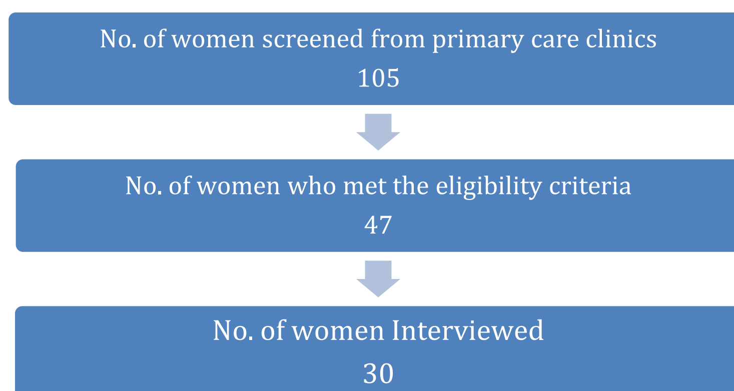
CHAPTER 4: RESULTS

This chapter provides detailed results of the study conducted using the qualitative interviews with three groups of participants that included: (i) women screened positive for depression at primary care clinics; (ii) women accessing mental health services for depression; and (iii) key informants. The following section includes demographics of the three groups followed by reported barriers. The facilitators in accessing mental health services are reported by women accessing mental health services and the key informants. Women and key informants were also asked about their suggestions or recommendation for reducing the barriers in accessing services, which are mentioned in the section of participant recommendation. Results are discussed below in detail as reported by the three groups of participants.

Demographics

The Principal Investigator (PI) screened one hundred and five women from primary care clinics. The Patient Health Questionnaire (PHQ-9) was used to screen women who visited primary care clinics. Of the one hundred and five women screened, 58 did not meet the criteria. Of the forty-seven women who met the criteria, seventeen women refused to participate in the study due to time limitation. The PI conducted thirty in-depth interviews with women who screened positive for depression in primary care clinics and agreed to participate in the study.

Figure 5: Recruitment of women from primary care clinics



The women were screened in the clinic waiting rooms. As soon as they were able to see the doctor, some felt compelled to leave their visit because of concerns regarding their husband or family members waiting to transport them, their children waiting for them at home, and/or meal preparations for their families. Women who were screened but unable to participate might have different barriers.

Table 11 below summarizes the demographic details of the participants' age, marital status and education. Of the women who screened positive for depression, twenty-one (70%) were married; three (10%) were single; three (10%) were engaged; one (3.33%) was a widow; and two (6.67%) were divorced. Twenty participants (66.67%) were housewives; eight (26.67%) were working; and two (6.67%) were students. One participant did not have any education; and the remaining women had an education level ranging from grade one to grade fourteen.

The PI also conducted twenty-nine in-depth interviews with women accessing treatment for depression from mental health care clinics, until the point of saturation. Table I below presents the demographic details of these women. The majority of

depressed women interviewed from mental health clinics were married and housewives (72.41%). Six women (20.69%) were single; one (3.45%) was engaged; and one (3.45%) was divorced. Six women (20%) were working and two (6%) were students. Interviewees had an education level ranging from grade one to grade fourteen, except one who did not have any education.

Ten women from this group refused to participate in the interview mainly due to time limitations (someone from their family would be waiting for their visit to end and/or their children would be waiting at home). Among these women, one was unable to complete the interview because her father asked her to leave in order to return to work. Two young women could not participate as their accompanying parent refused to allow their participation taking issue with the audio recording of interviews. Their parents feared that the audio recording might be played on radio or television and could cause problems for them due to the stigma related to mental health. Seven women refused themselves because they were not comfortable with their interview being recorded. These women might have different barriers and/or facilitators as most of them were either young women accompanied by their parents or guardians, or young mothers worried about the lack of confidentiality and stigma. Other women were also concerned about audio recording and needed reassurance multiple times that their recordings will not be aired on radio or television. Their concerns are reasonable given that there are many television programs in Pakistan that air interviews of people without consent or without informing interviewees that they are being recorded. This media activity has many people

concerned, especially women, because majority of men have negative attitudes towards women on television or radio due to cultural and religious reasons.

Table 11: Demographics of women screened positive for depression at the primary care health centers and women with depression, receiving mental health Services:

Age	Women screened positive for depression at the primary health centers	Women with depression, receiving mental health services
18–20	2 (6.6%)	3 (10%)
21–30	15 (50%)	15 (50%)
31–40	8 (26.6%)	5 (16.6%)
41–44	5 (16.6%)	6 (20%)
Marital Status		
Married	21 (70%)	21 (70%)
Single	3 (10%)	6 (20%)
Engaged	3 (10%)	1 (3.33%)
Widow	1 (3.33%)	1 (3.33%)
Divorce	2 (6.6%)	
Education		
Nil	1 (3.33%)	1 (3.33%)
Can read Quran	0 (0.0%)	1 (3.33%)
1–5th	5 (16.6%)	4 (13.3%)
6th–10th	9 (30%)	14 (13.3%)
11–14	15 (50%)	9 (30%)

A total of twenty-five key-informants were approached for the interviews out of which six refused. Two psychologists were very busy; one was on leave; and one did not respond. One primary health care provider was hesitant and one was too busy. A total of

nineteen key-informant interviews (presented in table 12 below) were conducted with psychiatrists, psychologists, general health practitioners, pharmaceutical representatives, a government health department official, and NGO workers working on women's health issues. There were nine male and ten female key-informants who shared their perspective and experiences regarding barriers and facilitators to accessing mental health treatment for women in Karachi.

Table 12: Key informants interviewed for the study

Key informants	**N (%)**
Psychiatrist	5 (26.3%)
Psychologist	3 (15.7%)
General Practitioners	5 (26.3%)
Government health official	1 (5.2 6%)
Pharmaceutical representative	2 (10.5%)
NGO professionals	3 (15.7%)
Total	**19**

Qualitative interview findings provided an in-depth understanding of the factors that facilitate and impede women's access to depression treatment in Karachi. Each participant had a unique set of factors impacting their access to care. Not every factor became a facilitator or barrier for each woman, but the combination of factors either deterred or helped their access to depression treatment. At the end of the interview, women from primary care clinics were provided with a list of resources, which included a

list of local mental health care providers for consultation and some online references for information.

Reported Barriers

Barriers elicited from interviews were categorized into levels of family, household, health services, and socio-cultural. Themes under these categories are presented in the table 13 below. These barriers are further elaborated with participant quotes from interviews.

Table 13: Barriers elicited from in-depth interviews of women and key-informant interviews

A- Family and household issues
1- Lack of awareness and understanding about depression
2- Normalization of depression
3- Burden of looking after children, households, in-laws
4- Autonomy and agency - ability to make own decisions
5- Threats of divorce and separation
B-Barriers related to health services
6- Doctors don’t ask - No one ever asked about it!
7- Gaps in medical education
8- Perceived lack of concern and attention from health care providers
9- Quality of care and reception
10- Self-medication
11- Financial barriers
12- Lack of referral by health care providers
13- Poor resource allocation and management
14- Discouragement to seek mental health care
15- Gender bias
C – Socio-cultural issues
16-Stigma
17-Misconceptions and discouragement to seek mental health care
18-Religious interpretations of depression

A- Family and household issues:

1- Lack of awareness and understanding about depression:

Interviewees repeatedly mentioned the theme of lack of awareness and understanding about depression leading to myths and misconceptions, or normalization of symptoms; hence the delay in accessing mental health treatment. A housewife shared her inability to recognize depression as a reason for not seeking psychiatric treatment earlier:

> *"I never thought that it was depression, neither did my mother-in-law. So I thought that it was normal. I am visiting here for the first time."* (26-year-old woman with 12 years of education, in mental health treatment)

In some cases, education did not affect the understanding of depression and family members also often ignored the symptoms. A single school teacher shared,

> *"A headache remained for five years and I thought that pain was a usual matter. All my family members are educated, but no one could understand why I cried, why I was tense, why I remained quiet. It was as if there was no problem. I would recover by myself, or I would pretend to."* (21 year old female with 10 years of education, in mental health treatment).

In many cases, patients normalized their illness. A married woman who did stitching work from home, and is now receiving psychiatric treatment, shared that she thought her symptoms were normal since her pregnancy:

> *"I didn't know the reason behind this. ... I did not know that this is an illness. I used to get angry. Everyone at home used to say that she does all this because she doesn't want to work."* (28 year old woman with 12 years of education, in mental health treatment).

This lack of understanding regarding mental health and depression leads people to think that they should only seek mental health treatment if they are totally dysfunctional, or when someone loses contact with reality. A woman from a middle-class educated

family shared that when she told her family that she wanted to see a psychiatrist; they responded saying,

> *"Why are you going to a psychiatrist? You are so good at calculations".* (44 year old women with low education, in mental health treatment).

The tendency to seek mental health services only when the condition gets visibly bad was also reflected in the statement of a housewife:

> *"Even right now when I was sitting outside here [in the waiting area], some people said, and what problem do you have? You look fine. Thank God I am fine, but if I have a mental health problem then it should be considered like we would for cold and flu."* (27 year old graduate woman, in mental health treatment).

Some women reported that they felt they had some mental health related problem and asked their family to take them to see a mental health care provider. However, their family members did not help them receive treatment earlier since they did not understand their illness. Instead, the family members tried to normalize or explain the symptoms from their own perspective. A housewife shared how her family responded:

> "*They said, 'Do not think a lot. You think a lot of past things. Don't think this and don't think that; whatever happened has happened.' They ask us to relax; they don't ask us to get treatment. No one asks to get us treatment."* (27 year old woman with 14 years of education, in mental health treatment).

A housewife was visiting the psychiatric department for the first time. She was visiting a mental health care provider without informing her husband and family members. She explained that they could not understand and did not believe her:

> *"He [her husband] has an idea [of her illness], but he does not believe it. I told him two to three times that I am feeling like this and I should consult a psychiatrist. He said that, 'this is nonsense, you are just thinking like that. If you are feeling angry, bear it. If you feel like crying, try to relax.*

> *You are just making an excuse.'"* (27 year old woman with 14 years of education, in mental health treatment).

Another housewife reported a reason for delayed treatment:

> *"My condition started getting worse, but no one took me to the doctor. It was as if it's not a problem if I am not well and my brain was disturbed."* (26 year old woman with 12 years of education, in mental health treatment).

This lack of awareness, both in women and in their family members, made it difficult for women to access mental health treatment in the early stages of their illness. Treatment was only sought out when the illness could no longer be ignored, when it interfered with responsibilities (doing house chores, taking care of the kids etc.), or once they received information or a referral from a source (as mentioned in the next section of facilitators).

Key-informants frequently mentioned the lack of mental health literacy and awareness about depression in communities, particularly in women, as one of the key barriers. One of the psychiatrists shared his observation:

> "*Awareness is a major problem, someone has to tell the person that they are depressed, and they need to go see a psychologist or a psychiatrist…. Common things like lack of awareness are extremely important, then not knowing where to go."* (Psychiatrist, Head of the department at a large private tertiary care hospital)

Key informants shared that, due to lack of awareness, depressive symptoms in women are often viewed as an "attitude problem", "avoiding house chores", or "being emotional" by her family members, and even health care providers. When depression is dismissed, the woman's problems are further aggravated and she is less likely to seek the required treatment. A psychiatrist said,

> "*They [family members] will say her willpower is weak, someone has cast an evil spell, or she is just making it up. Her family members will believe that if she is a woman and finds it difficult to wake up in the morning and make breakfast, and is unable to do the work, she is just showing attitude.*" (Psychiatrist at a private consulting clinic)

Key informants also shared that people in general, and women in particular, don't know about mental health care providers. A psychiatrist said,

> "*Awareness is not there. People don't know where to go, whom to contact. They don't know where they [mental health practitioners] are [located] and what they treat*." (Psychiatrist practicing at a small private hospital)

A primary care provider also theorized that the limited source of information contributed to the lack of awareness:

> "*We, doctors and family physicians, guide them to our best. I do not think we have any source other than this. There is no source. The TV and media hardly talk about it, our literature and print media talk ... rarely about it"* (Primary care provider, practicing in a personal private clinic in a middle class urban community)

The common perception about psychiatric treatment is that the psychiatric medicines cause lifelong addiction, or that the medications are merely sedatives. Additionally, many patients fear that they will be given Electro Convulsive Therapy (ECT) and their functionality will be worsened. A psychiatrist mentioned the fear of receiving ECT:

> "[The] *impression is that a psychiatrist will give [ECT], so they don't want to go to a psychiatrist*." (Psychiatrist practicing at a small private hospital)

Due to these myths and misconceptions, people around depressed women actively discourage her from accessing treatment or encourage her to stop the treatment. Another psychiatrist talked about these social pressures on women:

> "*In-laws, husbands, sometimes friends also play a very important role, especially with women. They are very negative about psychiatry. [The] general comment is that if [a woman] goes [for treatment], they will give her sleeping pills, she will sleep all the time, then she will develop tremors, and then she will become a drug addict. And once you go [for treatment], you will always go. You will get ECT.*" (Psychiatrist practicing in a personal private clinic)

Due to myths and misconceptions, there are also doubts about the efficacy of the treatment options. One NGO manager stated, "*They are not very sure that [depression] can be treated.*" Usually, people connect their depression with their life problems and expect to recover from depression once their problems are solved. Regarding causes of these misconceptions, a psychiatrist accused the media of fueling misconceptions about depression and mental health:

> "*[The media] highlights the social factors; poverty, unemployment, failures in school exams and so on. They don't see that the majority of suicides are related to mental health problems. They may have the trigger of a life event, but it brings out the mental health problem of which depression is the most common. They don't highlight that. Media has a very important role to play; [electronic media] more so in Pakistan because we have less than 50% literacy. So what they project, and how they project it, is very important.*" (Psychiatrist, Head of the department at a large private tertiary care hospital)

Lack of awareness about depression, and misconceptions about its available treatments, result in fear and hesitation in accessing mental health treatment. This highlights the need to raise awareness and reduce misunderstanding in order to increase access to treatment.

2- Normalization of depression:

The normalization of depression by women and their family members was a re-emerging theme. Women reported that they themselves, and their family members, were unable to

recognize depression. Hence, their family members tried to normalize it by giving general advice to help them cope or ignore it. A divorced housewife reported her mother's response to her depressive symptoms:

> *"My mother asks me to keep my mind free from everything"*. (24 year old woman with 8 years of education, not in mental health treatment)

Another housewife with one child shared her husband's response:

> *"He [her husband] just says don't get disturbed, take God's name, and try to sleep. God will do well."* (28 year old woman with 10 years of education, not in mental health treatment)

A woman, who belonged to upper-middle-class family, was interviewed from a primary care clinic. She complained about experiencing significantly reduced appetite for the past two years. She was losing weight, spending most of her time in bed, not participating in any house chores, and was unable to go anywhere. She said,

> *"I don't have any illness, its just weakness."* (29 year old woman with 12 grade education, not in mental health treatment)

Lack of awareness regarding depression and the normalization of depression keeps women from accessing the mental health care that they need.

3- Burden of looking after children, households, in-laws:

Many of the women felt burdened by their heavy load of work, particularly looking after children and taking care of in-laws. This constant stress of work keeps women from taking care of themselves, taking time for themselves, and accessing health services. Women find it difficult to go out unless some relative, or neighbor, is willing to take care of children. As one woman explained,

> *"Who will look after my children? I have 4 children and they wanted to come with me. But I told them that I am going to the doctor and I will take*

> *them out when I come back."* (23 year old woman with 3 years of education, in mental health treatment)

Most women in nuclear families were concerned about leaving their young children alone or finding someone who could take care of them. If their children are attending school, mothers are concerned about not being able to reach home before their children and not being able to prepare lunch for them on time. One woman gave the following explanation for not visiting a health care provider as needed:

> *"I have come here after taking some time out and I know I have left my children at home, so my mind is there. I will try to come for follow up, but I can't leave my children crying and food uncooked; I can't do this."* (27 year old woman with 15 years of education, in mental health treatment)

Besides taking care of their children and their own home, some women's responsibilities also include taking care of their in-laws, parents, and other relatives when they are sick. One housewife shared:

> *"This time, I had a bit of a gap in follow-up since a doctor had recommended angioplasty for my father."* (27 year old woman with 12 years of education, in mental health treatment)

The majority of women reported difficulty in managing their responsibilities and taking out time to visit health care providers both for initial and follow-up visits. Their husbands are busy at their jobs and are not able to help with daily house chores, or taking care of children.

4- Autonomy and Agency - Ability to make own decisions:

For some women in Pakistan, it does not benefit them to realize that they need mental health care unless their family members also understand and support them. Many of the women seem to lack autonomy and agency. A housewife received a referral from a

doctor at a top private hospital where she was taken for her sleep problems. She shared:

> *"I got mental relief after taking the tablets, I feel much better now. I used to tell my family that I have a mental problem, take me to the mental health doctor. I used to tell them all. I used to say this to everyone and my father as well, but they used to say that you have seven daughters, therefore, you have their tension. I used to tell them that I don't think about that much, but nobody believed me. Some [GPs] told me that I have a blood pressure problem. I could not sleep all night; my heartbeat used to get abrupt. I used to remain awake all night walking upstairs and downstairs at home and spent almost ten years like that."* (44 year old woman with no schooling, in mental health treatment)

Women and their families in conservative communities face this challenge more seriously because their husbands are more controlling and authoritative. This makes it necessary for women to get permission from their husbands and, often, from in-laws for treatment. This can be difficult due to stigma, myths, and misconceptions attached to mental illness, and depression in particular. A housewife expressed this challenge in following words:

> *"Even if woman want to get treatment, everything comes from a man. So many women in our community are psychiatric patients, but they can't get treatment without the permission of a man."* (26 year old woman with 10 years of education, in mental health treatment)

One NGO manager thought that one of the reasons for lack of access to treatment for young women was their dependency on their parents, and lack of mobility as they are not allowed to travel alone even within a city:

> "*Young women have huge mobility issues because of fear of violence and fear of being harassed. A young woman cannot go and see a doctor for her personal issues until she is married. Yes... a cough, flu, and cold, yes... but nothing trickier than that"*. (NGO manager, head of the telehealth department)

Many women do not have a personal phone or have family members that monitor their phone/ expense records. As a result, women are not able to access services over the phone or online support services. An NGO manager, who is in charge of telehealth services, discussed the barriers for utilization of mental health services over the phone:

> *"Over 70% of the callers are males and the ratio of the women is significantly less. And even when they call, it is when they have mobiles, perhaps when they are sharing in the evening, or they call from landlines."* (NGO manager, head of the telehealth department)

This inability to make their own decisions and the lack of resources results in a delay in accessing mental health care. Women are not empowered to make their own decisions and do not even have access to resources, like a personal phone, to avail services from their home.

5- Threats of divorce and separation:

Women not only suffer from the emotional and physical pain of the depression, they also face many other challenges on a personal, family, and social level. Depressed women are often mistreated by their family members, particularly in-laws, who are unable to understand her illness. Often the maltreatment is in response to the woman's inability to do house chores or take care of children. As one patient said:

> *"My in-laws asked me to leave the house. They said, "She does not work". If someone is not well, then how can she work?"* (30 year old woman with 4 years of education, in mental health treatment)

This issue is more complicated for women who live in large joint families because they are responsible for more tasks. If a woman cannot work due to physical illness, families tend to be more accepting and understanding of their inability to work. However,

if a woman is depressed, she often faces taunts and criticism, and is often accused of making excuses to avoid chores. One married woman shared her experience:

> *"My sister-in-law [wife of husband's brother], used to fight with me about house chores. I used to say that I am not well; I want to go to the doctor. They [in-laws] used to get upset. Then my mother took me to her home".* (30 year old woman with 4 years of education, in mental health treatment)

Family members of women with untreated depression also go through a high level of stress. One patient explained that she felt sad and guilty that her mother had a lot of stress about her illness. She stated,

> *"My mother died of stress from the possibility of my husband leaving me".* (30 year old woman with 4 years of education, in mental health treatment)

The survival of a woman's marriage and familial life is dependent on the support of her husband, or a member of his family. Without their support, many women are asked to leave their home and return to their parent's home, and threatened with divorce. Many women try to hide their symptoms and treatment to avoid such consequences. A woman shared the challenges she faced from her in-laws who were interested in getting her divorced:

> *"I am at my home because of my [husband's support], otherwise I could have been in another situation [such as divorce]."* (30 year old woman with 4 years of education, in mental health treatment)

Another woman, who had three daughters, shared that she was afraid her mother-in-law would use her depression as an excuse to arrange a second marriage for her husband if she learned about her depression (even though she lived separate from her mother in law). Her mother-in-law was already trying to convince her son to re-marry because she had not produced a son. In order to save her marriage, she was hiding her

treatment even from her husband by requesting payment slips from another doctor, rather than a psychiatrist. These challenges of stigmatization by family, threats of divorce, or threats of second marriage keep many women from accessing mental health services.

B- <u>Barriers related to Health services</u>

6- Doctors don't ask - No one ever asked about it!

This was a reoccurring theme. It seemed that primary care doctors almost never asked women about their mental wellbeing. When interviewees screened from primary care settings were asked about the reason of not sharing their depressive symptoms and attempted suicides, women responded that their primary health care providers never asked about their depressive symptoms. A twenty-two year old woman stated:

> *"No one asked me, so I did not tell them. You asked me, I told you."* (22 year old woman with 8 years of education, not in mental health treatment)

Providers are also dealing with an overload of patients and may find it difficult to ask patients about their mental health in the limited time allotted. A forty-four year old woman felt that doctors were too busy to explore other aspects of her illnesses other than physical symptoms. She was and reported her reason for not sharing symptoms of depression:

> *The doctor never asked me. You are asking me this. Doctors never ask. The doctor has no time for it. You are asking in detail."* (44 year old woman with 6 years of education, not in mental health treatment)

Another housewife from primary care setting reiterated the sentiment*:*

> *"None of the doctors ever asked about [my mental health], so I never told them about it"* (28 year old woman with 10 years of education, not in mental health treatment)

Some women thought that it was important to share, but were hesitant since they felt that their doctors were not interested in learning about it. A housewife stated:

> *"This is also important, but generally, no one probes into these matters as you are doing and interviewing about it. No one asks like that."* (38 year old woman with 12 years of education, not in mental health treatment)

Most women were eager to share and desperate to talk about their problems. However, since their health care providers are not asking about their symptoms of depression, their illness remains unidentified, undiagnosed, and untreated. An important opportunity is missed due to lack of screening in a primary care setting.

7- **Gaps in Medical Education:**

Key informants discussed the gap in medical education as a barrier to accessing mental health care within the larger health system. This gap leads to a lack of diagnoses, treatments, or referrals by primary health care providers.. A psychiatrist discussed the gaps in medical education in Pakistan:

> *"There is a big, big lacuna in our medical training…. There is no medical college in Pakistan that examines a student in psychiatry, except [name of college]. If you do not examine students, they will never take a subject seriously. And so they don't attend their sessions, their attachments [indicating they don't have clinical attachments for mental health], they don't study the subject properly, and it is not taught properly. The Pakistan Medical and Dental Counsel (PMDC) that regulates medical education does not make it compulsory for it to be examined. As a result, when they become doctors, they lack the awareness of even the common mental disorders like anxiety and depression. Generations and generations of Pakistani doctors have gone to medical school without any exposure to psychiatry or mental health problems. When they train other junior doctors, they also ignore the same thing. Since juniors learn from their seniors, you have this vicious cycle of training without exposure to any mental health issues. When they become doctors, they have no knowledge of mental health. Patients who see these physicians with things like depression, but presenting with physical symptoms, it never occurs to*

them that this may be a case of depression." (Psychiatrist, Head of the department at a large private tertiary care hospital)

Key informants also mentioned gaps in the training of nurses as well. Another psychiatrist described the attitude of nurses towards mental health:

"We don't have a concept of psychiatric nurses. If you talk to the nurses of [hospital name] and [hospital name] and ask them about psychiatry, they will say that it's the ward of mad people." (Psychiatrist, Head of the department at a government tertiary care hospital)

A general practitioner also shared that a lack of required continued medical education (CME) is one of the reasons. There are no CME requirements for keeping your medical license or continuing practice. Hence, doctors do not have an incentive to update their knowledge or skills. He stated:

"The continued medical education is not required here, this is the basic reason. In developed countries like UK and USA, they have Continuing Medical Education (CME). They have licensing exams, which, when expired, have to be renewed. We do not have such systems here. The person who studied medicine in 1956 is still practicing without being updated. If this won't happen then who is going to identify mental illness?" (Primary health care provider, developing CME program, working in a tertiary care government teaching hospital)

Some mental health care providers were very unhappy with the way cases were managed by GPs due to gaps in the medical education. A psychiatrist stated his observation regarding mismanagement:

"GPs either prescribe lower dosages or do not prescribe them according to proper diagnostic criteria. They [patients] become resistant to psychiatric drugs as well. If you don't diagnose properly, how will you treat properly? For example, if I am diagnosing someone with depression and giving benzodiazepines, it is not going to treat her depression. She will get to sleep, it will help with anxiety symptoms, but it will not help with depressive thoughts. So she will not recover. Her depressive thoughts will only improve when you give proper antidepressants" (Psychiatrist practicing at a small private hospital)

One general practitioner himself admitted that:

> *"GPs have started treating mental illnesses. And he [GP] might not be treating it correctly, perhaps, and aggravating their illness."* (Primary health care provider, working in a personal private clinic)

A psychiatrist mentioned that some GPs are against psychiatric treatment and prohibit patients from accessing mental health care:

> *"Some GPs have an anti-psychiatry element, though they are prescribing benzodiazepines. They say if you go to that doctor [psychiatrist], he is mad himself and will treat crazily as well. I do not know what the problem is. There should be proper studies on them as well; there are some doctors like that."* (Psychiatrist practicing at a small private hospital)

Since health care providers are not properly trained, many don't recognize depression. Some treat (but not appropriately) and some actively oppose the treatment. This shows that gaps in medical education are causing significant delays in access to treatment for patients, not only due to general health care professionals providing inappropriate treatment, but also due to their active discouragement of seeking mental health care treatment.

8- **Perceived lack of concern and attention from health care providers:**

Interviewees mentioned that they were not feeling better in spite of visiting their health care providers, multiple times and taking medicines for their physical symptoms. A twenty-one year old shared her thoughts for not recovering:

> *"If they give more attention to the patients, they would be able to diagnose the disease of the patients better. So, that is the reason I have still not recovered. ...they do not do a thorough checkup and just prescribe medicines and ask to come again the next week. But even when I do, I still feel the same. It is all the same."* (21 year old woman with 4 years of education, not in mental health treatment)

Many women feel that their health care providers are not concerned about them because they do not give them time and do not listen to them. However, they do realize that doctors are overburdened with too many patients in a limited amount of time. The twenty-one year old further elaborated:

> *"They are not as concerned as they should be. There are so many patients there, so they do the checkup in a hurry."* (21 year old woman with 4 years of education, not in mental health treatment)

Many women mentioned that they are not satisfied with brief consultations. A twenty-nine year old housewife, who belonged to an upper middle-class family, complained of a significantly reduced appetite for the last two years. She was losing weight, spending most of her time in bed, not participating in any house chores, and was not able to go anywhere. She was also trying to return to college but was held back by fatigue. She shared:

> *"They just see you for a minute, and that is it. They do not give you the satisfaction of knowing what the illness is or what the problem is, they do not explain."* (29 year old woman with 12 years of education, not in mental health treatment)

Many women shared that they do not share their emotional symptoms because their doctors do not have time to listen. They notice the long waiting lines and how quickly doctors conduct check-ups. Often while doctors are talking to one patient, there are another two patients standing behind that patient, or right at the door waiting for their turn. A forty-four year old married woman stated:

> *"Because there is no time, I just take the medicine and go away…. The doctor has no free time, they just give medicines".* (44 year old woman with 12 years of education, not in mental health treatment)

Some women reported that they wanted to share their emotional symptoms, but doctors do not listen to them. General health care providers might be missing actual cause of their symptoms (i.e. depression in women) due to the overburden and not being able to give proper attention to each woman. A thirty-five year old working woman said:

> *"After coming here, standing in a long waiting line, the doctor does not talk. I came here, but they do not listen; just give medicine, this breaks my heart."* (35 year old woman with 10 years of education, not in mental health treatment)

This shows that women feel even worse when they see that their doctors are not paying attention to them and are not concerned about their illness. This increases their frustration that they are not recovering due to lack of attention from their health care provider.

9- **Quality of Care and Reception:**

Many of the women complained about the quality of care and, particularly, the reception they received in the public hospitals. Some women, mostly at the community charity clinic and a private clinic (where doctors were able to give relatively more time than the government sector hospital), shared their symptoms with their doctors. However, they reported that they still did not get better. A thirty-five years old married woman, when asked to share her depression symptoms, responded,

> *"Yes, I did [share the symptoms]. Actually, tears came into my eyes when I was talking to the doctor. She just said to be patient, get tests done, and we will see; whatever is from God will happen."* (35 year old woman with 10 years of education, not in mental health treatment)

A twenty-one year old single woman from primary care clinic reported:

> *"Yes, I did tell them. But they said that if you take milk, everything will be fine, I would be as good as I used to be. But nothing happened. There is no*

> *difference. I feel these medicines do not work for me."* (21 year old woman with 4 years of education, not in mental health treatment)

Another thirty-five year old married woman visiting a primary care clinic complained:

> *"Nobody is treating it from its roots. This is… I am just trying to pass life."* (35 year old woman with 10 years of education, not in mental health treatment)

An eighteen year old young woman, who was engaged to be married, was repeatedly visiting her primary care doctor at a government hospital. She shared her hopelessness:

> *"Doctors say there is anger, all is due to anger. Sometimes, it is too much, I just weep and pray."* (18 year old woman with 5 years of education, not in mental health treatment)

A forty-four year old married woman, who stopped working two years ago due to her depression, was visiting a private general doctor. She shared her experience:

> *"She gives medicine that I keep taking and that is it. Sometimes I feel like working; sometimes I do not feel like doing anything at all. So I keep lying down. Then I get up and then lay down again. I keep doing that; what else can I do?"* (44 year old woman with no education, not in mental health treatment)

Interviewees reported that their symptoms were not going away and their illness was not treated properly. They either kept visiting the same doctor, or kept changing their health providers. They were not satisfied with the treatment that they were receiving but did not know what else to do. The women in these cases were clearly depressed and had been sharing their dysfunctions and painful life stories for many months or years. But they were not diagnosed, treated, or referred for depression by their doctors in any of the primary care settings. Many women reported that they kept changing their general health

care providers in search for a better treatment. A forty-four year old widow with six children stated:

> *"The medicine she gives me does not benefit me. I have gotten my treatment from several doctors, even from [Dr. ABC] and the doctor who has a clinic in [xxx], Doctor Xyz. She also gave me good medicines, but now my stomach has weakened from too much medication."* (44 year old woman with no education, not in mental health treatment)

When asked about the medicine that women were receiving for their symptoms, most of the women reported that their doctors kept treating them with multivitamins, calcium, and painkillers. Another married woman shared:

> *"Doctors ask me to take the medicine and be patient, and it will be ok. Last time I was given multivitamin, calcium, and I had one surgery before so she gave me painkillers. Since I am here to follow up today, she has given me painkillers and the same medication."* (28 year old woman with 10 years of education, not in mental health treatment)

Some women were treated with quick routine tips and advice only, which were not very helpful in treating their symptoms of depression. However, women appreciated the advice. A thirty-year-old single working woman, who had been through a bomb blast trauma, stated:

> *"The doctor gave me good advice. The doctor advised me to not think a lot, to stay happy, and not to be angry. The doctor gave me good advice."* (30 year old woman with 12 years of education, not in mental health treatment)

Women were not satisfied because they felt unheard, not treated properly, and were not getting any solutions to their problems. Instead, they were managed with multivitamins and general advice that did not help them.

10**- Self-medication:**

The availability of over-the-counter psychiatric medication, particularly benzodiazepines, was mentioned as another challenge causing delay in accessing treatment and further deterioration of a woman's conditions. Key-informants mentioned that many women self-medicate for years before reaching out to any mental health care provider. Women recommend each other to take these medicines to deal with sleep problems and stress, which further worsens their condition and prognosis. One psychiatrist shared how patients are affected by self-medications due to lack of awareness about the illness and hazards of self-medication:

> *"The pink color medicine is very famous, Lexotanil (Bromazepam). It is so famous everyone recommends [it to] everyone for sleep problems. People come to us when they are already taking multiple [doses] of it."* (Psychiatrist practicing at a small private hospital)

A psychologist shared a specific case:

> *"There is one young woman I am seeing; the young woman, around twenty-six years old. She is popping pills like nobody's business. [Pills] like Lexotanil, Xanax, everything. And it is very, very common."* (Psychologist teaching and practicing at a public university)

One GP explained the reason for these practices:

> *"The over-the-counter sale of medicines. ...there is no regulation of [prescriptions] here. Our health system is weak. They don't impose or implement laws or policies."* (Primary health care provider, developing CME program, working in a tertiary care government teaching hospital)

These medications are easily available over-the-counter due to lack of drug prescription regulation. Women usually start taking these medications on the recommendation of their friends or other women in their family. General practitioners also often prescribe these medications without proper counseling, and women continue

taking it for years without further consultation. These women then recommend these medications to other women who share similar symptoms.

11- Financial Barriers:

Key informants shared that many people face financial barriers despite the availability of low-cost services at government and charitable institutions. A psychiatrist stated:

> *"There is the question of affordability; the fact that psychiatrists and psychologists are extremely expensive, most healthcare, 90%, is out of pocket. People have to pay to see a psychiatrist. The minimum charge barring the NGOs or charitable organizations would be at least 600 rupees [$6] and the top of the range is more than 2000 rupees [$20], so it's very expensive."* (Psychiatrist, Head of the department at a large private tertiary care hospital).

The cost of medication is another barrier since medication is required for the long-term treatment of chronic depression. Another psychiatrist commented on the cost of medication:

> *"It is expensive, not only to see the doctor and travel, but also to buy the medication and maintain it. Because some chronically depressed patients need treatment for the rest of their lives. [The] financial thing is a major barrier."* (Psychiatrist practicing in personal clinic)

Most of the patients have to pay the consultation charges out-of-pocket, since most insurance companies do not cover outpatient services. A key informant stated:

> *"Mental health coverage is not good, even by good insurance companies, because most of them don't cover the outpatient. They only cover the inpatient".* (CEO of a national NGO working on health and nutrition)

One of the primary health care providers shared her concern regarding the financial challenges of one of her recent clients:

> *"Naturally, I cannot do as much counseling as a psychologist and she cannot afford a psychologist. "* (A primary care physician working in a community based charitable clinic)

Women who were receiving treatment from public sector hospitals were more worried about the cost of medication. One woman explained the reason she stopped her treatment:

> "*One reason was that the medicines are very expensive. They are out of my budget. We have a fixed income, we have to pay the house rent, we have to pay school fees of our children, and we have to buy general medicine. It gets difficult to spend on extra* expenses". (28 year old female with 12 years of education, in mental health treatment)

The high fees of private consultants, the inability to afford their fees, and the cost of medication and transportation puts a heavy financial burden on patients. This limits the possibility of accessing treatment for many women.

12- Lack of Referral by Health Care Providers:

Women in the primary care setting were asked if any doctor ever recommended they see another specialist or mental health care provider. None of the women in primary care settings had received any such referral or recommendation. A forty-four year old woman, who stopped working two years ago due to her illness, reported:

> *"No, no one ever did [recommend] a mental health provider"* (44 years old woman with no schooling, not in mental health treatment)

A thirty-three year old housewife reiterated:

> *"No. Doctors only asked me to take medicine and be patient and it will be ok"* (33 year old woman with 10 grades of education, not in mental health treatment)

This shows that women visiting primary care clinics continue to suffer from

symptoms of depression due to lack of required treatment and referrals to mental health care providers.

Most of the women who were receiving mental health care had been to their primary care provider before seeking mental health services. Many of the women who were referred to mental health services had primary care providers that took time to talk to their patients and had known their patients for some time before making the referral. However, many women reported they neither received treatment from their general health provider, nor were they referred to a mental health facility. A forty-four year old housewife suffered from insomnia for a decade before her sons took her to a leading private hospital, where doctors conducted multiple physical tests and eventually asked her to see a psychiatrist. She came to see a psychiatrist at the government hospital to avoid high consultation charges at the private hospital. She described her experience:

> *"I am sick since last ten to twelve years…. Initially, they [doctors] said that there is an extreme lack of blood [anemia]. I took treatment from [many places], so much that I did not miss a single hospital.... I tried to commit suicide many times because no one was able to understand my illness"* (44 year old woman with no schooling, in mental health treatment)

Another forty-four year old woman had been suffering from depression for years. She sought treatment from her general health care provider and explained that she felt her illness was brain-related. She was given a referral for mental health services. When asked why she sought treatment so late, she replied,

> *"Because, nobody told me about it! I asked my doctor at [XYZ] Hospital, and he told me that I do not have a mental problem. I only have an issue of sleep".* (44 year old woman with no schooling, not in mental health treatment)

A twenty-one year old school-teacher received many medications for sleep and other somatic problems. Later she was sent for treatment to a neurology department then a psychiatry department:

> *"Those who understand their problem, they reach the right place. Those who do not know, receive their treatment from wrong places like I have been for the past five years. Thank God, my headache is much better now after getting proper treatment."* (21 year old woman with 10 years of education, in mental health treatment)

Due to somatic symptoms and not understanding the reason behind it, most women see their primary health care providers. The primary health care providers are generally unable to detect their depression and keep treating their physical symptoms, instead of depression, or refer them to specialists for their physical complaints. Many specialists, like cardiologists and endocrinologists, receive patients due to somatic complaints or have high co-morbidity of depression and anxiety in their patients. However, women reported that other specialists were unable to diagnose and refer them to psychiatric treatment. One patient explained her experience with specialists:

> *"Ten years! I took medicine from the OPD, got so many tests done, had my other physicals checked. But they just used to give me medicine and nobody said that I needed to go for psychiatric treatment. I used to tell them that my heart remains upset. So they sent me to a cardiologist, where they gave me medicine for two weeks and then said that she does not have a cardiac problem. But did not send me here."* (44 year old woman with no schooling, not in mental health treatment)

Key informants also shared the lack of referral system as a significant barrier resulting from gaps in medical education. Since most of the patients consult their primary care doctors, the lack of a referral system delays their access to needed care. One of the psychiatrists shared:

> *"Patients end up with health practitioners, but they {GPs} are not able to pick up that this person may have mental health problems and because we don't have a proper health system, a proper system of referrals. They don't refer patients." (*Psychiatrist, Head of the department at a large private tertiary care hospital)

Even if some GPs are able to recognize depression, they find it hard to communicate the diagnosis and psychiatric treatment options with their patients. One GP said that,

> *"GPs are the front line people. They must have some strength, some guts, to encourage, to communicate ... If I see you coming with two, three relatives telling me that you have chest pains, and I know that it's just a functional pain, maybe I will give you some major tranquilizer to calm you down. And if I find your family receptive, then only I will tell them that this young woman is all right. She does not have any medical problem, but she has other problems."* (Primary health care provider, working in a personal private clinic)

This lack of communication with patients about their depressive illness and lack of referral prolongs the depression while delays women's access to required mental health services.

13- Poor Resource Allocation and Management:

Key informants also shared their concern regarding the meager allocation of resources to mental health at national and provincial level. When a key informant from a government public health department was asked about the mental health budget he responded with:

> *"hmmm .... I need to check that. Let me check .... No, there is no separate budget."* He further stated: *"Nobody is willing to spend on it, there are no resources."* (Deputy Secretary Health, health department)

He further shared that administrators at government hospitals don't see mental health as a priority,

> *"I think there are no psychiatrists available at the secondary level hospitals. In the case of appointing a psychiatrist, though you don't need much to facilitate him logistically."* (Deputy Secretary Health, health department)

Mental health is not a priority at the government level and hence, mental health care providers are not employed at secondary level hospitals, which limit the availability of low-cost mental health services for women in Karachi.

14- Discouragement to seek mental health care:

A few of the interviewees also reported that their health care providers even discouraged them from seeking mental health care. However, this stands out as an important issue since women take the advice of their health care providers very seriously and tend to follow it. Thirty-three years old housewife from a primary care setting shared what she heard from a doctor about psychiatric treatment:

> *"Dr. XYZ told me that once these medicines (psychiatric medicine) go into your blood; you get used to it for your whole life."* (25 year old woman with 6 years of education, in mental health treatment)

Non-medical team members at mental health care settings also play an important role in encouraging and discouraging patients. A forty-three year old working woman visiting a primary care clinic shared that she was taken by her husband for psychiatric treatment, but she returned without consultation on the receptionist's advice. She shared her experience:

> *"At one time, my husband took me there. A person who was giving his duty at the counter of the hospital for making receipts, etc. normally asked me if I forget things after keeping them somewhere. I replied that it's nothing like that. I only forget things when I am tensed. Then he told my husband that she is not insane. She only gets this way only when tensed; otherwise she has no mental problem…. I became so angry with my husband that he thought that I was mad, that's why he brought me to a mental hospital…. to*

> *a doctor of mad people. It's normal, I can forget things as well, but my husband used to say that I am mad. ... I don't like anything"* (43 year old woman with 4 years of education, not in mental health treatment)

This shows the importance of sensitizing health care providers at all levels and all team members at healthcare setups so that patients do not get discouraged.

15- Gender Bias:

Some key informants thought that physicians are biased against women in recognizing their symptoms as health problems, which results in a further delay in accessing much-needed services. One of the psychiatrists stated:

> *"(A) barrier may be at the physician's level where they may be gender biased in which they see women's problems. For example, a woman with depression complaining of physical symptoms, the physician being a male, might underplay those symptoms, may not take it that seriously. So at all of these levels, women probably have difficulty being taken seriously in accessing services. And even when they reach services there are gender biases that exist in many of the physicians. Both male and female physicians undermine the symptoms, which lead to a delay in recognition. They try to trivialize it by attributing it to the woman that she can control the feelings she has if she wants to."* (Psychiatrist, Head of the department at a large private tertiary care hospital)

Key informants believed that males in Pakistani society often consider females as overly emotional, complaining by nature and hence tend to not to take the symptoms seriously. Rather, their problems are ignored and their complaints are considered as their personality or being women issue. Another psychiatrist shared her disappointment in celebrating mental health day, which focused on depression, but did not discuss depression in women:

> *"Women's depression was supposed to be the key, the theme. Two-thirds of the psychiatric patients are women, and (women are) two to three times or four times more depressed. And they didn't talk about depression in women."* (Psychiatrist practicing at a small private hospital)

Ignoring depression in women patients while talking about depression in conference indicates a blind spot in health care providers, including mental health care providers. This further puts women at risk of not being screened and diagnosed properly just because they are women, who from a male's perspective are considered emotional and tend to display emotional problems.

C – Socio-cultural

16- Stigma

Interviewees reported hesitation in going for treatment, fearing they might be seen at psychiatric setting and stigmatized or labeled as 'mad' or 'crazy' due to various social and cultural factors. A student whose sister underwent treatment for psychosis earlier and now she was under treatment for depression shared her thoughts:

> *"People say that only crazy people go to mental health care providers. People think that only mad people go to psychiatrists. I know that I am not crazy. I know that I need a doctor*." (19 year old woman with 12 years of education in mental health treatment)

A housewife shared her experience of being stigmatized and how it affected her social life:

> *"This is considered unacceptable in our society. If you have a psychiatric problem, they consider you mad, and then the fear is that your life will end. Such people's social life ends."* (27 year old woman with 12 years of education, in mental health treatment)

In addition to their fear of stigmatism, participants hesitate to share their diagnosis and treatment experience, concerned that people might be offended if advised to see a mental health care provider. A married housewife at a psychiatric setting shared such experience:

> *"My husband has guided (referred) many people to get the treatment from here, but people mind it (did not like it), so I asked him to not to refer people."* (44 year old woman with no education, in mental health treatment)

Most of the key informants highlighted stigma as a key barrier preventing women from accessing treatment. The head of the psychiatry department at a government tertiary care hospital stated

> *"Only 5–10% [of] women are coming for treatment, others are not able to come due to stigma."* (Psychiatrist and Head of the psychiatry department at government tertiary care hospital)

Key informants highlighted that Pakistani women often hide depression to avoid disturbing their family lives due to the stigma that surrounds depression and can affect their family life negatively. One GP shared possible effects of stigma on women, resulting in an avoidance of seeking care:

> *"The taboo, they may lose their marriage, they may lose their respect, they may lose their job; all these things come with psychiatric diagnosis or label. One such case involving a married woman was an instance when her family allowed her to seek treatment due to severe depression. However, the moment she recovered, [her in-laws] said, 'she is a nut case. We can't have her for our son." (*Primary health care provider, developing continue medical education program (CME), working in a tertiary care government teaching hospital)

Key informants shared that many women avoid seeking care, and if they do, they request consultation over the phone or request to be seen outside the clinic. One of the psychologists mentioned:

> *"Even educated people don't want to come. They just call and want some help on the phone. If they know somebody they can talk to, they ask for help, otherwise, they keep on trying to sort it out on their own… Another thing they say, when I enter your clinic someone will see me. Why can't you see me privately at your house?*" (Psychologist teaching and practicing at a public university)

The stigma also makes it difficult for GPs to refer clients and communicate with patients about their diagnosis. :

> *"Psychiatry is a taboo and it is difficult for {a} doctor to tell a patient that you need psychiatric consultation." (*Primary health care provider, developing continue medical education program (CME), working in a tertiary care government teaching hospital)

The stigma, not limited to patients, also extends to mental health services and care providers. Key informants mentioned that since other medical professionals have a negative image of mental health care providers, they refrain from referring clients to them. A key informant mentioned, *"If you see our psychiatrists, how much is their practice [indicating low demand]?"*

One psychiatrist shared that their colleagues make fun of them with statements such as "Here comes the doctor of mad people." One primary care doctor also shared similar views about mental health care providers:

> *"The psychiatrist I have seen, they themselves look like they are sick people. They have withdrawn personality, they have out of box thinking or diagnosis you know…they are not following regular tools or diagnostic criteria, and they are jumpy people."* (Primary health care provider, developing continue medical education program (CME), working in a tertiary care government teaching hospital)

Key informants repeatedly mentioned that mental health service for unmarried women is stigmatized in local culture. This is a significant barrier as their family members are reluctant to help them seek treatment, fearing that it will limit their chances of marriage. One psychologist teaching and practicing at a public university stated, *"There is a tendency of married women to come in than the unmarried ones."*

Key informants agreed that females in Karachi have difficulty getting married if

they are known to receive mental health treatment. One psychiatrist also acknowledged that this fear is real:

> *"Parents don't want to bring them here. They say someone will see them and say that she has gone mad; they hide it even from their siblings because she won't get married. They are right though."* (Psychiatrist practicing in a small private hospital)

To avoid the stigma of mental illness, family members often seek alternate treatment options like faith healing, which is culturally acceptable. A primary health care provider observed

> *"Their families take them to faith healers, not doctors because if they will take them to the doctor then people will get to know about it."* (Primary health care provider, working in a community based charitable clinic)

Various fears and concerns caused by stigma lead to avoidance of seeking treatment and a lack of referrals by health care providers, causing a delay in mental health care seeking.

17- Misconceptions and Discouragement to Seek Mental Health Care

Many people who have misconceptions regarding depression and mental health treatment often discourage patients who are planning to seek treatment or currently receiving treatment. Actively discouraging people from seeking treatment is considered socially acceptable. A housewife shared her reason for her delay due to such concerns:

> *"Some people told me that the psychiatric hospital is not good. Do not go there. They will give you injections for sleep and you will keep sleeping all the time, so I was frightened."* (44 year old woman with 12 years of education, not in mental health treatment)

A twenty-six year old married housewife with five children reiterated:

> *"[People around] say that [psychiatrists] will give you tablets and you will temporary benefit. After your treatment, you will be in the same*

> *condition again. It is like addiction treatment; it will soothe you temporarily. You will have this problem again*." (26 year old woman with 12 years of education, in mental health treatment)

An 18-year-old school teacher was constantly asked to stop her psychiatric treatment *as* people told her

> *"They say medicine is useless and it causes more harm. There is a teacher in my school who stops others from taking medicine."* (18 year old woman with 10 years of education, in mental health treatment)

Many women are discouraged to seek mental health care by health care providers and people around them even after receiving a diagnosis. A 25 years old housewife with 6 years of education who had a relapse shared her reason for discontinuing her treatment on the advice of a general health care provider who told her to instead tolerate her problem so that she would not be required to take medicine her whole life. She recently relapsed and is undergoing treatment again.

This clearly shows the great need for education for health care providers so that they are able to correctly identify, diagnose and refer people with depression rather than discouraging them from psychiatric treatment.

18- *Religious interpretations of depression*

Many interviewees mentioned that they seek the help of God to deal with their illness as they were not getting better with treatment and could not understand why. A housewife with four children, interviewed at a primary care clinic said:

> *"I turn to Allah more and… I offer prayers, fast, and ask him for everything; my problems are [usually] solved, but I do not know why health is going down. Walking around is very hard for me. I feel stress in my feet. What can [doctors] do? The problems are with life and God solves it... Ask Allah for help. I think it is right to turn to Allah. He listens so thank him when tensions are overcome; tensions and being examined is*

> *part of this world."* (44 year old woman with 12 years of education, not in mental health treatment)

Lack of awareness led many women to believe they had no other option except to seek help through prayer. A 43-year-old working widow from a primary care center said:

> *"I think we can only pray. There is no helper other than Allah."* (43 year old woman with 8 years of education, not in mental health treatment)

Those women receiving care cited religious interpretations as barriers. Another twenty-four years old single woman not accessing care said:

> *"I leave it to Allah. It's just that if I have a long life then I'll live. That is why I leave it on Allah."* (24 year old woman with 10 years of education, not in mental health treatment)

Others also interpreted their depressive symptoms as an indication of distance from religion, blaming themselves for not trusting God.

> *"It depends on us. God has told us to offer prayers for five times do this and do this; if we don't do that, then we will become patients ourselves. If we need peace, we need to pray. It will help in relieving stress and better sleep and things will look better. Time changes; people change so one should wait for a good time. God gives better time; he listens to us, but it's just that it takes some time."* (28 year old woman with 10 years of education, not in mental health treatment)

While talking about other women, she further said:

> *"They should not take tension; they should leave this on God and offer prayers five times a day. We don't remember our God. That's why we remain upset. God is taking care of everyone. May he relieve everyone from his or her problem"* (28 year old woman with 10 years of education, not in mental health treatment)

On one hand, getting help from religion and trusting God helps women feel that they have some support, hence feeling better. However, only relying on faith kept many women from thinking about other causes and solutions to their problem and prolonged

their suffering.

Many women also considered their illness as their destiny. Many women in mental health treatment interpreted events in their lives as fate and accepted it as God's will, stating things such as

> *"Whatever is in their fate, they get it."* (33 year old woman with 6 years of education, in mental health treatment)

A twenty-five-year-old, married housewife stated:

> *"Our health is from God. If God wishes, there will be no depression."* (25 year old woman with 6 years of education, in mental health treatment)

25-year-old housewife at a primary care clinic felt that her sisters also needed treatment, but she could not convince them to get the treatment due to their religious interpretation of the illness.

> *"My sisters are very careless, they say that my God takes care of me and they should not bother to go for treatment."* (25 year old woman with 10 years of education, not in mental health treatment)

Interviewees reported that if someone looks disturbed, unhappy or upset, people often interpret these behaviors as having an evil eye[3] or, spirit infestation. So instead they consult faith healers or religious scholars for their treatment. Faith healers heal people with spiritual methods and rituals to ward off the effect of spirit and the evil eye. A housewife shared her experience of visiting a faith healer before getting a psychiatric referral from her husband's colleague:

> *"I went to a religious person. I thought there might be some evil eye. Out of the three sisters, I used to be the happiest one, but these prayers and amulet didn't help"* (42 year old woman with 10 years of education, in mental health treatment)

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[3]A look or stare believed to cause injury or misfortune to others

Most women admitted that they go to mental health care providers after visiting a faith healer, but not benefiting from it. Another reason why they resort to health care providers is because faith healers demand a lot of money. A housewife stated:

> *"My husband took me there and gave him Rs. 8,000 ($80) so I told him that I should have had recovered, but I did not, and I had to come to the doctor, so do not spend money there… I think at least 50% of people do not take treatment because they think it is the job of the faith healer's/shaman's voodoo, etc. and all these are not good people. Some people just do that to collect money."* (44 year old woman with 14 years of education, in mental health treatment)

Some women considered that being content with their illness meant being religious. Other women considered it lack of understanding of Islam and illness, as Islam asks people to get the required treatment and taking care of oneself in all kinds of illnesses. Most women interpret their symptoms as God's will or visit the faith healers.

Summary:

The women interviewed in primary care did not share their emotional symptoms with the health care providers due to lack of awareness about depression as an illness. They also believed that their doctors are not interested in their emotional problems because of their lack of questions about those symptoms. Few health care providers also negatively view mental health treatment. Women reported that they did not receive any referrals.

The women who did not feel better with the treatment they were receiving from primary care either blamed their health care providers for their lack of concern or blamed themselves for not recovering. Others looked towards religion to seek the meaning of their illness.

Women accessing mental health care also reported suffering for long periods before reaching mental health services, usually after the depression becomes severe, function becomes impaired, or the symptoms become visible.

Key informants mentioned similar barriers to the women. However, they went a little further and talked about issues within the medical, educational and health care systems. Lack of awareness about depression, including not knowing when and where to get the treatment, adds considerable delay in accessing mental health services and produces misconceptions, fueling the stigma in society. As a result, women turn to self-medication and faith healers to find solace. Key informants also highlighted the existing gaps in the medical education system that do not equip health professionals with the knowledge and skills needed to diagnose patients with depression.

Gender bias towards women within the health care community further affects the diagnosis of depression in women. Very few doctors refer women to the appropriate services they need.

Karachi does not have mental health care providers at primary and secondary care levels. Key informants identified that women either need to travel far from home to access mental health treatment and wait in long queues in the government sector or consult with private health care providers, putting a financial burden on them. These findings can inform possible policy changes as they highlight the need for changing medical education, recruiting mental health care providers at the primary and secondary care, and providing community-based services through community health workers. There is a need to organize and support women with depression to come forward and be

advocates for their rights. Stigma reduction activities can help depressed women engage actively in supporting other depressed women through referrals.

Reported Facilitators:

Depressed women receiving mental health services and Key informants also shared facilitators that eventually helped women access the mental health services after facing barriers that caused a delay of varied duration.

Themes elicited for facilitators are also grouped in the Family, household level facilitators, Health Service level, and Socio-Cultural level facilitators. Table 4 presents the themes under these categories.

Table 14: Facilitators in accessing mental health services for women in Karachi

Facilitators
A- Family, household level Facilitators:
1-Family and Social Support
2-Concern for Children
3-Referrals Other than Health Care Providers
B-Health Services level Facilitators:
4-Referral by Health Care Provider
5-Affordability and Low Consultation Charges
C-Socio-Cultural level Facilitators:
6-Awareness
7- Education in women
8-Severity of Illness
9-Organization and employers support

A- Family, household level Facilitators

The women mentioned that receiving a referral from any source whether from health care provider or non-health care providers encouraged them to access mental health services. Awareness within family and friends, the severity of depression, which made symptoms visible or impossible to carry on life, and affordable health care options,

enabled them to access mental health services. Below is the detailed description of these facilitators that eventually helped women with depression seek mental health services.

1- Family and Social Support

The theme of family and social support emerged from the majority of the interviews. Most respondents are housewives whose lives revolve around their families. In some cases, women were hesitant to see a mental health care provider, but their family members encouraged and reassured them. A housewife who belonged to a poor, but supportive family visited the hospital's psychiatric department for the first time with her mother. She shared how her mother brought her in for treatment:

> *"My mother yesterday asked me to come along with her. I said it is usual, I will get better, but mother said, 'let's go and see a doctor and spend some time outside.' She might have felt the need, seeing my condition. My mother said that [I was] not looking fine, [I] seem to be very different from earlier so come with [her]".* (26 year old woman with 12 years of education, in mental health treatment)

In many cases, family members supported women to seek treatment by accompanying them and giving them an acceptable reason for consultation. A twenty-five-year-old housewife visiting for mental health care shared,

> *"My aunt* said that at [the hospital], they gave *treatment for a headache. My aunt brought me here once and then I kept coming myself."* (25 year old woman with 6 years of education, in mental health treatment)

Some women also had supportive husbands who encouraged them to seek treatment. A forty-two-year-old married housewife with four children shared how her husband encouraged her to seek psychiatric treatment despite her fears and concerns:

> *"My husband is very caring; he took me to all the places [for treatment]. My husband asked me to go and convinced me by saying that he wants*

> *everything to be fine at home. If women are not fine, then families break up. I told him that I was afraid, but he said that I didn't need to be afraid; everything will be fine."* (42 year old woman with 10 years of education, in mental health treatment)

This shows that the support and understanding of family members who play a pivotal role for women with depression accessing treatment. With family and social support, they are able to handle the various barriers, including misconceptions and fear of stigma.

Key informants highlighted that educated families who accept that depression is an illness are better able to recognize if women in their families are depressed. They continue to support them in actively seeking mental health services. A psychiatrist shared:

> *"Family members who recognize that the female is under stress and needs help, someone, take a more proactive role in making contact with a health professional, they find out who is where and what their expertise is. I think one of the important things in facilitating their help seeking is the support system and the people around them."* (Psychiatrist, Head of the department at a large private tertiary care hospital)

Family support is identified not only as a facilitator in initial access to services, but also mentioned as a pivotal factor for follow-up and prognosis. A psychologist mentioned that:

> *"The basic thing is the social support they get from the family, especially when the husband's support. We have seen that there is a marked difference. When the husband accepts, he doesn't take it as a flaw in his wife or a sign of weakness, just takes it as something unfortunate that happened and something that needs to be overcome. In cases where the woman is unmarried, lives with her parents and the parents are still supportive; there is a mark difference... Social support is very, very important; I would say one of the most important things." (*Psychologist teaching in a private university and practicing in a consulting clinic)

Another woman getting psychiatric treatment shared how mother in law supports her in following words:

> *"My [mother-in-law] takes care of me. When she feels that I am going to start crying or I am getting irritable, she takes care of my kids and she tries to make me go to sleep so when I wake up, I feel fresh. She sends me somewhere outside or she calls her son [telling him I'm] not feeling well and to take me somewhere outside"* (26 year old woman with 12 years of education, in mental health treatment)

Women also need support in babysitting while they go for a consultation. Family support in this regard is very important when kids are small. Women accessing mental health services mentioned who was helping them. One 28-year-old woman with 12 years of education shared*, "I have two kids. My parents support me. Whenever I come to the hospital, my parents keep my kids."*

2- Concern for Children

Women are more concerned about their children than themselves or anyone else. The women are motivated to get treatment so that their illness does not affect their children. One 27-year-old woman shared that her reason for getting psychiatric treatment was her realization that her mood was affecting her children:

> *"We have to look after our children; if… we scold them for no reason, they won't understand that their mother has a headache or she is angry and feeling annoyed. [My children] love me and I am being rude to them! I beat them! They won't understand this and it will affect their personalities. Understanding all this, I decided to come here for treatment.*" (27 year old woman with 15 years of education, in mental health treatment)

The disability and dysfunction caused by depression concern women who worry about their children and feel guilty. Their concern for children and sense of responsibility

also motivates them to seek treatment. Another woman in mental health treatment shared:

> *"We see our children, we have to bring up our children, and we have to look after them. We have devoted our whole lives to them; if we will be fine, then we will be able to look after them. When I feel tense, I get confused. Why is it happening to me? Why am I unable to look after my children? Why am I unable to cook food for my children? Why I am unable to give them things, why can't I give them a shower? Why am I unable to provide them everything on time? Then I think that if I will be fine then maybe I am able to look after them."* (26 year old woman with 10 years of education, in mental health treatment)

A primary health care provider practicing in a community based charitable clinic also shared a similar thought that women try harder to better themselves if they have kids:

> *"They want to get better soon, especially those who have 2, 3 small kids. They want to get better soon so they can look after their children and home."* (Primary health care provider practicing in a community based charitable clinic)

Key informants also shared that women comply with instructions and adhere to medication more than men. This is because women seek solutions to their problems and want to take care of their responsibilities, particularly related to their children.

3- Referrals (Other than Health Care Providers)

Knowing someone within the family with depression or mental illness became a facilitator for many women when accessing the appropriate services in a timely fashion. These women found it easier to get access to treatment since the family members were already sensitized to mental health issues and knew where to get treatment. Women coming from such families where someone else was using mental health services did not face and talk about barriers for themselves. One single woman started receiving psychiatric treatment as soon as her symptoms started because her brother was able to

understand her illness since he had been through depression as well. The 33-year-old shared, "

> *"My brother was there, who is also a [depression] patient for the last 10-12 years."* (33 year old woman with 6 years of education, in mental health treatment)

Some women received a referral through other female family members, neighbors or friends. A divorced woman who received a referral from her family mentioned:

> *"My aunt told me. Her daughter had the same problem*". (25 year old woman with 10 years of education, in mental health treatment)

A housewife who was married to a primary care doctor received psychiatric treatment, mentioned:

> *"People will start taking treatment seeing us; two young woman among our relatives are also getting treatment now. People will seek treatment by looking at others like us. My sister-in-law is getting treatment after I told her that her brother also started it. It is like if I have a problem and I tell others, people will go for it."* (26 year old woman with 10 years of education, in mental health treatment)

She further shared that some husbands also encourage their wives to receive treatment when they see someone benefiting from treatment. She added:

> *"This doctor also treated my younger brother-in-law. He is very good with medicine, so my husband said, 'you also get treatment from him,' Therefore, I started getting treatment." (*26 year old woman with 10 years of education, in mental health treatment)

Women had the least delay in accessing treatment when coming from families where someone was already accessing treatment. This highlights the importance of recognizing depression symptoms and treatment options at the community and family levels. Awareness can reduce barriers in accessing mental health treatment for women with depression.

Key informants repeatedly mentioned that getting a referral from another patient helps women the most in reaching mental health care. One psychiatrist said:

> *"Perhaps patient referral is the most effective thing."* (Psychiatrist practicing at a small private hospital)

Another psychologist reiterated*,*

> *"Referrals from different patients who have been treated successfully are one of the significant sources."* (Psychologist teaching in a private university and practicing at a consulting clinic)

Another psychiatrist shared:

> *Sixty percent of my referrals are from people I've treated who go back and refer someone... I have been working for the last seventeen years, so past patients bring new patients. This is how the chain continues. This is what mostly happens if you help recover one patient; you will become famous in their family, their neighbors because we have close knitted families and people interact with each other so people share. People do take an interest in other's affairs; whether they intend to help or not, they keep an eye on when people are going for treatment. What are they doing? Which faith healer or doctor are they going to? So this is how your rapport with community develops and if you practice for five or six years then your name gets established in the community. (*Psychiatrist practicing at a small private hospital)

Referral of patients is instrumental in reaching required services. Peer counseling or interventions based on existing users of the services can be helpful in increasing the use of mental health services for women with depression.

B- <u>Health Services level Facilitators:</u>

4- Referral by Health Care Provider:

Women reported referrals from their general health care providers as the most helpful facilitator in reaching mental health services. Most of the women were happy and thankful to their health care providers for giving them an understandable diagnosis of

depression and for the referral. A thirty-year-old married housewife described how important it was, for her to receive a referral:

> *"The mental problem started eight to ten months ago. Then Dr. ABC referred me here. She told me, 'don't think that you are mad and that's why I am sending you. Your problem is that your mind is getting weak because you have taken many medicines or due to some other reason you might have some infection.' I came here because my family doctor told me the root cause of my condition. That's why I got treatment otherwise I would be roaming around with the problem. My family doctor is really nice".* (30 year old woman with 4 years of education, in mental health treatment)

Many patients who visited the outpatient department (OPD) of a tertiary care hospital with underlying psychiatric problems were referred to the psychiatric department. Health providers in the OPD of tertiary care hospitals referred many of the interviewees suspected of underlying depression. Having mental health services within the same facility helped women get a referral and consultation from psychiatry department. A housewife shared that she visited the OPD in the tertiary care hospital for her somatic problems, but was then referred to the psychiatric department. She shared her experience:

> *"In OPD, I told them that I am feeling pain and they asked me to consult Dr. ABC [in the psychiatric department] who would find some solution. So I came here and told him about the situation and he diagnosed me with depression."* (25 year old women with 6 years of education, in mental health treatment)

Health care providers quickly referred those women to mental health care providers who complained of symptoms relating to the brain. Women also perceived it less stigmatizing when their problems were related to the brain (physiological part of the head rather than psychological). A housewife mentioned her symptoms while talking

about receiving a referral from her primary care doctor:

> *"There is a doctor near my house. He told me to visit here. I told him that I have a problem in my brain. I was worried about it. I had doubts that I have some brain issue".* (44 year old women with 10 years of education, in mental health treatment)

Women reported visiting faith healers for treatment of psychological and non-psychological problems. Some religious scholars and faith healers also referred a few of the interviewees to mental health care providers. A nineteen-year-old student mentioned:

> *"I took spiritual treatment and he said that it's a little bit of spiritual problem and it will get resolved. He also asked me to take medicine. He is not like general faith healers who give amulet, etc. He only treats with Quran and he asked me to visit a psychiatrist as well."* (19 year old women with 12 years of education, in mental health treatment)

Since people believe and follow their health care providers and faith healers, getting referrals and recommendations from them to seek mental health services enabled patients to seek the necessary mental services.

Key informants also mentioned that referrals from general, and other health care providers became significant facilitators for many patients. A psychologist shared the source of her clientele:

> *"Hospitals, people who know me, psychiatrists, and different consultants refer. Years back, I was on the panel of [the hospital]. I was teaching there; a lot of referrals come from there so it is through contacts."* (Psychologist teaching in a private university and practicing in a consulting clinic)

She further added that she gets referrals from different health care providers:

> *"There are other clinicians in the field, consultants like gynecologists, neurologists or other consultants... The Diabetes specialist would refer and the Endocrinologists because they see that some patients with underlying cause are something else."* (Psychologist teaching in a private university and practicing in a consulting clinic)

This shows that understanding and awareness of mental health issues in health care providers along with the referral system play significant roles in increasing access to mental health treatment. The healthcare providers who lack knowledge and referrals become a barrier and cause a delay in accessing appropriate mental health treatment. Women are able to access the treatment when they reach to health care providers who are able to provide referrals. This shows the importance of increasing awareness of mental health issues in health care providers and development of a referral system.

5- Affordability, Low, and flexible Consultation Charges:

Women who visit the private clinic did not mention any financial challenges, even when specifically asked if they had any financial problem. This is because the majority of them were from upper-middle or higher income groups. A married woman who worked from home responded while talking about the cost of treatment:

> *"Thank* God there is no financial issue. My husband is really nice. He gives me money.*"* (44 year old women with no schooling, in mental health treatment)

The women who faced financial difficulties, mostly visited government-funded facilities where a consultation fee was only Rs. 5 (5 cents). Low charges at government hospitals made it possible for these women to receive treatment. A nineteen-year-old woman at a government mental health care site said,

> *"The doctors are specialists here* and [there are] no fees as well.*"*(19 year old woman with 7 years of education, in mental health treatment)

Women were happy about the availability of subsidized services and traveled far to receive such services, which included low consultation charges for specialized services and low cost or free medicine. Twenty-five years old, housewife described her reason for

visiting the psychiatric department of government hospital from a suburb of the city:

> *"Here it takes only Rs. 5 and travel cost. Doctors also gave medicine to patients if it is available. My village doctor charges Rs. 50 and he prescribes medication to be purchased from a store. It cost Rs. 400 to 500. Isn't it better to buy something else in Rs. 500?"* (25 year old women with 6 years of education, in mental health treatment)

This clearly shows that women would not be able to access the services if it created a financial burden. The key informant also shared the effort they themselves and their institutes are making to ensure availability for all socioeconomic classes. One key informant shared:

> *"We have two or three different payment systems at work here. One is people who pay out of the pocket, the full fees. Then we have a tiered system for people who cannot afford the full fees and can pay a discounted fee. Then we have a welfare system, which the institution gives the subsidized care through 2 avenues: One is the welfare society and one is the zakat (charity) funds. So these are all the different ways people can access services here right from paying the full fees to not paying anything at all. And then we also have certain clinics at… an off-campus site with very reduced fees".* (Psychiatrist, head of the department at a private tertiary care teaching hospital)

Women and key informants both highlighted the importance of increasing such low-cost services, which increases affordability for everyone so that more women are able to access the treatment within their communities.

C- <u>Socio-Cultural level Facilitators:</u>

6- Awareness:

Women repeatedly mentioned that learning about their illness and where they can find treatment were important and helpful in accessing treatment. A housewife who went through depression for some time shared her decision to seek services after she

accompanied someone to the hospital (as women usually accompany their neighbors, friends, and relatives as women prefer not to travel alone) and read the name of the psychiatrist on a poster that explained symptoms of illnesses he treated. She reported,

> *"I read [the psychiatrist's] name. I read the things on board so it came to my mind that I should consult here."* (27 year old woman with 14 years of education, in mental health treatment)

Majority of the key informants believe that mental health literacy has increased in the past few years, but there is still a dire need to raise awareness of depression in women. The media has contributed to raising awareness through various health and general discussion programs. Mostly housewives tend to watch TV programs, so those who watch such awareness programs now understand their illness as depression. This encourages them to seek mental health care providers for treatment. A psychiatrist stated:

> *"Females have started to come out more compared to 18 years ago when I started my practice. Probably because there is some increase in awareness through media."* (Psychiatrist practicing at a small private hospital)

Pharmaceutical representatives highlighted the important role of their companies to raise awareness through marketing campaigns for drug sales. This is done through posters, health camps, and advertisements. Pharmaceutical representatives mentioned that the market share of psychiatric drugs is increasing due to an increase in awareness:

> *"We don't have the exact figure, but it seems that they know that they have depression, so they go to the doctor. Awareness is increasing. Media is involved. Pharmaceutical companies are involved. And the market is increasing day by day."* (Pharmaceutical sales representative)

Though awareness is spreading, so is the population of Karachi. Knowledge about the prevalence of depression and other common mental health issues can be increased

through culturally accepted means such as local media and easily accessible community health camps. Awareness needs to be further increased at all the levels as it is helping women to access the required services.

7- Education in women

The Majority of health care providers, especially mental health care providers in private practices, mentioned that women who have a higher education are reaching out more and earlier for treatment compared to women with less education. As one psychiatrist mentioned:

> *"I do get a lot of educated women. They have more awareness. They see media; they use the Internet so they consult more compared to women with low education who would come only one or two out of ten. But if someone has done masters, four or five out of ten depressed women will come for treatment. So that is the difference*". (Psychiatrist practicing at a small private hospital)

An NGO manager believed that education helps women understand their illness and its treatment hence helping them seek care from mental health professionals rather than going to faith healers. The CEO of a national NGO stated:

> *"Educated people, they already know most of the time that this is [a] mental health issue and can be treated. But in an illiterate's case, they are superstitious and go to some spiritual person or shrines".* (CEO of a national NGO working on health and nutrition)

One woman from primary care setting also agreed that education in women makes a difference when it comes to health awareness. She stated:

> *"Those who are educated, they know about it, and those who are not don't know."* (43 year old woman with 10 years of education, not in mental health treatment)

Another woman reiterated:

> *"If a woman is educated, she takes care of herself; uneducated women are not able to take care of themselves. Education makes a lot of difference. Education affects your whole life"* (32 year old woman with 10 years of education, not in mental health treatment)

Education in women increases their ability to understand their symptoms and illness, helping them reaches necessary mental health services.

8- Severity of Illness

Many women reported getting treatment when their severity of depression reached dangerous levels and their daily functioning was significantly impaired. In such cases, they were unable to perform their daily responsibilities, their depressive symptoms were too obvious to ignore, or their illness started bothering people around them. A married woman, who received psychiatric treatment after more than two years of suffering, narrated her experience of receiving treatment:

> *"What I became like, I didn't care if I am cooking or not, if I am seeing my kids or not. I used to be absent minded. Then my husband took me to [the] hospital. I was under treatment there".* (28 year old woman with 12 years of education, in mental health treatment)

One housewife who lived in a large joint family shared her ordeal of going through depression, reaching a severe level and finally receiving psychiatric treatment. She shared her life situations before receiving treatment:

> *"I could not take care of my children; they were very upset. [My in-laws] were angry with me. I remained in bed for three months. I could not move. I did not have the energy. I did not feel hungry. I did not care for my daughters; it all remained for three months. Then my elder brother came and he took me to XYZ hospital. They gave me an injection and medicine."* (44 year old woman with 10 years of education, in mental health treatment)

Many women and their family members had no idea of depression and it's effects;

they suffered for a long time before seeking mental health services. However, in cases with severe symptoms, families could not ignore it and actively searched for the right treatment. In one such case, a married housewife mentioned that:

> *"My brother was so much concerned for me that he took me to all these doctors within eight days ... he took me to many places till we were satisfied."* (33 year old woman with 6 years of education, in mental health treatment)

This shows how one of the key determinants of getting treatment, though not ideal, is the severity level of depression. Many women reported that they were only able to access the treatment when it was bad enough to impair their personal and social lives, when they were unable to take care of their responsibilities and started to affect people around them, particularly their family.

9- Organizational/Employer Support

Key informants also highlighted and appreciated the role of foreign multinational companies that provide psychological services for their employees and their family members. A psychologist on the team, sessions conducted for stress management, and the availability of mental health services within the organization allowed employees to consider getting treatment for women in their families. One psychologist teaching in a private university and practicing in a consulting clinic mentioned:

> *"The employee assistance program is becoming popular. You have a psychologist in the house because sometimes you have a bad day and you just want to talk about it or had a row with a spouse or a bad meeting with your boss… There are a lot of management consultations that help them make decisions, and refer those employees having serious productivity issues."* (Psychologist teaching in a private university and practicing in a consulting clinic)

Some large international corporate organizations arrange mental health professionals for counseling and recruitment. This availability of services to the depressed woman's family members through their organizations also helps women get the appropriate treatment. The psychologist continued, "

> *"I do some work in the corporate sector. Their employees and their relatives, by the word of mouth*, bring *their family members."* (Psychologist teaching in a private university and practicing in a consulting clinic)

Key informants mentioned that some people even bring their personal drivers or home cleaners, noticing a change in their behaviors. They not only bring them in for treatment, they also take care of their treatment expenses. One of the psychiatrists stated:

> *"Some people are so nice they help their servants and workers. Otherwise, the poor employees cannot afford."* (Psychiatrist practicing at a small private hospital)

Few people are fortunate enough to have that opportunity to work at a good multinational company or for aware and kind employee.

Summary

Those women who were facilitated by various family and sociocultural factors were able to receive treatment. They were more likely to do so if they were aware about the illness and treatment availability, could afford treatment, had family support, or received a referral from health care providers and acquaintances. At times, their symptoms became visibly severe, causing extreme disability and family disruption. Women reported that those families who understand depression tend to be more supportive than those not familiar with the illness; similarly those health care providers who are able to diagnose and understand the depression are better able to provide

treatment or referral.

Key informants also shared the facilitating factors that help women in accessing services that include women's education and mental health literacy. These findings highlight the need to raise awareness within communities and health care providers and develop a referral system to increase the access to mental health services for women with depression. Referrals help women, whether they receive one from health care providers or non-health care providers. Key informants also mentioned that referrals from other depressed patients are an effective facilitator. Stigma reduction activities help depressed women actively support other depressed women by providing referrals.

Participant's Recommendations

All the participants, women and key informants, were asked their opinions regarding potential solutions to reduce barriers or improve mental health by increasing access to mental health services for women with depression. Table 15 shows themes were identified from their suggestions.

Table 15: Participant suggestions for increasing access to mental health services for women in Karachi

1- Awareness Raising
2- Training of Primary health care providers
3- Women Empowerment
4- Community based interventions

Awareness Raising

Majority of the women suggested increasing awareness of depression, including how to recognize the sign and symptoms and what can they do about it through various mediums. The women highlighted that raising awareness in women alone might not be helpful unless their family members, particularly males, were also aware. A woman in mental health treatment shared:

> *"Awareness is very important. TV and mass media can be helpful. These days, people watch TV with a lot of interest and some program should be on it, some program for both men and women. The program should address males because if they will not support women, they cannot do anything. If a man does not allow, she cannot go out. We need to approach both of them. There is more need to make [men] understand. If males understand it, women would automatically go for treatment."*(44 year old woman with 14 years of education, in mental health treatment)

But there are families who do not have TV at their homes for religious reasons. In these cases, religious gatherings were suggested to raise awareness. She further shared:

> *"In our area, people give importance to religion and attend religious meetings and gatherings. If you give information there, it will be useful because the families who do not watch TV attend these gatherings"* (44 year old woman with 14 years of education, in mental health treatment)

Some women thought that educational settings are the best option for reaching women. One woman gave her suggestion in following words:

> *"Awareness programs should be conducted in schools and colleges for young women, as they will become mothers. So for them, the programs should be conducted in colleges and schools. Usually, these are not conducted there. The general public and women will take interest and follow it if someone guides them to take care of their health".* (44 year old woman with 10 years of education, in mental health treatment)

Another woman also shared that they do not care for themselves, but if something is required by the school of their children, then they would. So schools could be a good

platform to raise awareness for women. A 29-year-old woman t shared:

> *"If there is a program in school, children keep telling their moms [to go]. If there is any function, then I want to see my children's future and I would go; parents have to go. Otherwise, we won't go for ourselves."* (29 year old woman with 14 years of education, not in mental health treatment)

According to the majority of the participants, raising awareness was recommended, but with caveats in various awareness raising mediums. It appears that various mediums of awareness raising need to be utilized to reach different segments of the society (e.g. those who watch TV vs. those who do not watch TV, those who attend religious gatherings vs. those who do not attend gatherings, parents of children in education vs. those who do not get an education). The translation of awareness into accessing mental health services is another challenge due to barriers such as women not making decisions for themselves.

Training of Primary and Specialist health care providers

Female participants felt that they could feel better if their primary care providers prescribed them their needed medicine, anti-depressants.

> *"Write effective medicine so I get better, this is what I want."* (35 year old woman with 10 years of education, not in mental health treatment).

Key Informants also considered GPs as key players in providing mental health treatment.

> *"GPs are likely to get the mental health patients so they need to be trained and motivated to treat these kinds of patients."* (CEO of a national NGO working on health and nutrition)

One of the key informants who is also director of primary care services at a government hospital agreed that GPs need to be trained though he still thought that not all

women even reach there.

> *"The first step should be with women who are contacting the primary care physicians. We should train primary care physicians so that they are able to identify the issue, treat the basics, and refer those cases that are complicated. It would be great if they are able to do this. It means that we have to basically address the primary care physicians. It might be difficult to address primary care physicians, but not impossible. Right now, it is difficult to bring the population out of the home. So I think that it would be a great service."* (Primary health care provider and director Primary health care in a government teaching hospital)

One of the psychiatrists also recommended that primary care physicians not only be trained to provide treatment, but also to reduce myths and misconceptions. :

> *"[We need to] train all doctors in recognizing, treating, knowing when to refer and intervene–also how and what to educate the patient because [doctors] give wrong messages, propagate and reinforce myths that are nothing. They widely prescribe benzodiazepines (e.g. Laxotanil) instead of anti-depressants."* (Psychiatrist practicing in a consultant setting)

Some Key informants thought that nurses could also play a role in identifying and helping women with depression. :

> *"It is necessary that not only medical students, but also nurses are educated in mental health because nurses are more in contact with the patient than doctors. They even observe more than doctors. If we educate them, then this will be a big service at least for in-house facilities. The basic mental illnesses shall be addressed more."* (Primary health care provider and director Primary health care in a government teaching hospital)

Training primary health care providers and nurses could help women who approach their primary health care providers to share their symptoms and follow up as required. However, women who do not reach to the primary care services need to be approached and served by different options. This approach also needs to be considered with the challenge of time limitation of primary care providers mentioned as a barrier by

both key informants and participating women.

Women Empowerment:

Women and key informants thought that access to services cannot be increased until women are empowered through education and given the right to make their own life decisions. One woman shared,

> *"Every woman should be educated; if she is educated, she will win everywhere; [she will be able to solve her problems]."* (30 year old woman with 5 years of education, in mental health treatment)

Some of the women thought that many women were depressed due to early marriages and their inability to deal with challenges that may come with it. These women recommended stopping early marriages. As one woman in mental health treatment said:

> *"Parents should not get their daughters married at the early stage."* (40 year old woman with 6 years of education, in mental health treatment)

Another woman reiterated,

> *"[Women] should not be married after 10th grade."* (19 year old woman with 13 years of education, in mental health treatment)

Key informants also agreed that there is a dire need to change social and cultural practices of how women are treated in the society. A psychiatrist frustrated with dealing with frequent relapses shared:

> *"How much fluoxetine can you give? Or how frequently can you conduct psychotherapy sessions? It's not going to work unless there is some change in them. The situation that they are living in… that's why there are frequent relapses."* (Psychiatrist practicing in a consultant setting)

Another key informant also agreed that women empowerment could be the solution:

"This won't work until and unless the woman herself comes to you and demands treatment–that moment is your success. That also comes when the change begins from inside. This will only happen when the education and literacy rate increases so much that people come by themselves for the right treatment." (Deputy Secretary Health, health department)

Overall, most of the participants considered women empowerment key to increase access for mental health services. They felt that women will not be able to access the services even if they have awareness and if the health care providers are trained. This is because they may not be making decisions for themselves and are financially dependent. Many participants realized that though this would be ideal to bring change in the culture, but is difficult for a society where overall literacy ratio is low and old customs and traditions are highly valued.

Community Based Interventions

Majority of the women viewed community-based interventions as the best option to raise awareness and provide treatment. One of the women stated:

"I suggest that some senior good doctor should come to our village and treat the poor people there. Treatment is important." (25 year old woman with 6 years of education, in mental health treatment)

Another woman reiterated the need for home visits for raising awareness:

"We should start some organization or something in every area for the door-to-door campaign and a group of people should visit homes and spread awareness." (20 year old woman with 12 years of education, not in mental health treatment)

Another woman mentioned her observation the high prevalence of depression in the women of her area who were not accessing treatment:

"We have so many problems with depression in our area. If you come there, you will find that 50 out of 100 women have depression; if you talk

> *to them you will find that many women are psycho patients."* (26 year old woman with 10 years of education, in mental health treatment)

She insisted that the interviewer should visit her area and talk to them.

One woman at a primary care center suggested using camps in areas to raise awareness and provide services to women in their own areas.

> *"You people should put up some camps where you can deal with such women. This way knowledge could be spread. If one woman visits, she would tell the other two women as well… The way government puts up camps for other things, it should start putting up camps for health as well because only then our women will stay healthy".* (30 year old woman with 12 years of education, not in mental health treatment)

Key informants also agreed with the women and thought that community based-interventions are the best option in the local context.

> *"Women may not access these services even if you have a good primary health care system where they are trained in mental health issues. And for that, you probably need something like a lady health care visitor program to go from door to door to look after children's and women's health. So you can piggyback a mental health program onto the lady health care visitor or you can develop a cadre of mental health visitors who can go from door to door and screen people... You make the referral to primary care physicians who assess them and then they can refer to the specialist depending on the case. But these have to be government funded."* (Psychiatrist, Head of the department at a large private tertiary care hospital)

One primary care provider stated:

> "*Conduct a community seminar to [warn] us about [early] symptoms and what can they turn into. The patients themselves will come forward and tell you about their symptoms."* (Primary health care provider practicing at a community based charitable clinic)

A CEO of a national NGO working on health and nutrition suggested using the community health workers to deal with the lack of trained mental health professionals:

> *"I think it will take more than a hundred years to train more psychiatrists in this country. We should really replicate this model of community and we have lady health workers available–more than 90,000 lady health workers. They can get basic training, at know how to screen, and be able to treat the basic issues of mental health and refer to a mental health specialist after motivating her. That level of the program can be very helpful."* (CEO of a national NGO working on health and nutrition)

He further discussed the need and reasons for utilizing community health workers for mental health services:

> *"I mean you cannot isolate; you have to go with a holistic approach. It's what we talk about with lady health workers. She has to treat the whole lady or the whole community at the same time. If we take the vertical approach, then we get more stigmas. If the worker is treating a mother and child's physical health and she also provides mental health services, then there will not be a stigma with this... What I suggest all the time is that it should not go vertically".* (CEO of a national NGO working on health and nutrition)

A primary health care provider developing CME and working in a tertiary care government teaching hospital also shared the same thoughts:

> *"You will have to develop community psychiatry, nurses or others… like lady health visitors. You can train certain people who can visit the home and can screen out cases and establish relationships like the vaccinators. They go to every home to vaccinate the child despite plenty of advertisements, which don't help, so they have to go. They have to walk miles through rough terrains to find a child for vaccination. So in psychiatry, since it's a taboo, the LHV or the community nurse, should be trained to go; so you have to develop the multi-person… multi-stratum strategy to increase access."* (Primary health care provider, developing continue medical education program (CME), working in a tertiary care government teaching hospital)

The psychiatrist realized that raising awareness does not always work in the health sector. Another psychiatrist also endorsed the recommendations of women and other key informants:

> *"Community-based intervention–one of the studies showed that it worked for seven out of nine patients. We need more community mobilization in terms of that they do get help... Some sort of community interventions where they can participate like a self-help group. I think arranging a group for depressed women [would help] provide them with opportunities to socialize, express themselves, share, and learn*" (Psychiatrist practicing in a consultant setting)

According to both the participating women and key informants' opinions, community-based intervention can be one of the preferred approaches for providing services at the doorsteps of women.

Limitations

There were several limitations to the study. Since this was a qualitative study, the sample is not representative and results cannot be generalized. One limitation is that it only included women screened for depression who were receiving health services from primary care.

Further studies need to be conducted with women from communities that are not accessing any kind of treatment in order to investigate their experiences of accessing depression treatment. Interviewing caregivers of women with depression can also help identify barriers and facilitators from a caregiver's perspective. So far, there has been no effort to measure the duration of untreated depression in women in Pakistan. A study to measure the length of untreated depression in women in Karachi prior to any intervention can help assess the result of interventions on the reduction of delay as well as depressive symptoms.

This study only reflects the perspective of a few selected key informants. Other key informants, such as nurses, community health workers, gynecologists and

obstetricians who deal with women's health issues, might have a different perspective.

Conclusion

Three groups of participants mentioned similar and different barriers and facilitators. Women accessing mental health services and key informants identified that lack of awareness, myths and misconceptions about depression are the major barriers to accessing mental health services. Women accessing general health services from primary care reported that they did not share their emotional symptoms with their health care providers thinking that their symptoms were not worth reporting or their health care providers would not be interested.

Referrals are one of the most helpful facilitators for women going through depression, as many women did not realize what they were going through and know where to seek help. Women recruited from primary care services were not yet receiving mental health services and had not received any referral from any source. They were asked if they received any referral since they were not feeling better with their symptomatic treatment. The referrals they received, if any, were only related to their symptomatic presentation (e.g. Heart specialist for chest pain).

On a socio-cultural level, women reported that religious interpretation of depression and acceptance of visiting faith healers for illnesses as barriers. Women reported taking the support of religion to seek the meaning of their illness and considered it as God's will, test, or their destiny. Key informants highlighted stigma in their communities and within the health sector playing a major role at the socio-cultural level.

While talking about facilitators, key informants from different backgrounds and

women with depression mentioned similar facilitators that helped women reach mental health services. Facilitators included women's education, mental health literacy, support of family members, and referrals from health care providers or other patients. Key informants from different professions also mentioned that some women who are educated are able to understand what they are going through and refer themselves, especially if they have an awareness about depression to understand what they were going through and where to go for the treatment.

Key informants also mentioned that a referral from other depressed patients is an effective facilitator. Stigma reduction activities can help depressed women engage actively to support other depressed women by providing referrals. Training women as peer educators or community workers can enable others to understand their illness and access treatment. Alternatively, those women who are already working in the community can also be trained to screen, identify, provide basic counseling, and refer the most severe cases.

Female participants and key informants were also asked for suggestions on how to reduce the above-mentioned barriers. Both women and key informants thought that awareness is an important element in increasing demand and access to services. They also recommended training primary health care providers where women mostly go for their somatic and general problems. However, women and key informants also thought that despite the awareness and training of primary care, women might not be able to avail in the services until they are empowered enough to make their own decisions. They should be able to go to a health care provider for any kind of treatment while financially

independent. Both women and key informants agreed that providing community-based interventions, such as maternal and child health services provided through Lady Health Workers (LHWs), could be the best option in the given scenario. The next chapter will elaborate on recommended programs based on participants and key informants results and responses.

CHAPTER 5: RECOMMENDATIONS

This thesis attempts to explore the factors that lead to a lack of access to mental health treatment for women with depression as an issue of public health significance. It is an endeavor to give voice to the women who suffer quietly from the agony, sadness, and hopelessness of depression in Karachi. Investigators from Boston University School of Public Health conducted a qualitative study employing in-depth interviews and key informant interviews to identify the barriers and facilitators in access to mental health services, which could help women with depression access mental health services in Karachi. Along with identifying barriers and facilitators, we asked women for suggestions on how to improve access to services. Program and policy recommendations in this chapter are developed on the basis of the results of the study.

Background:

Pakistan is already lagging behind in Sustainable Development Goals (SDGs) 3 and 5, which relate to maternal health and gender empowerment. Karachi is the largest city of Pakistan with a population of over 22 million. The rates of depression in Pakistani women are higher than the general population. Depression is known to cause disability and suffering for women, and has negative consequences for their family. Lack of access to mental health services can result in increased disability, impacting the health of women, children, families, and the nation.

The analysis presented indicates that there is a need for mental health awareness and training of primary care health professionals. However, the lack of empowerment of women and the workload of the primary care physicians may act a barrier in addressing

this need. Educating and empowering women would be ideal but would require a cultural shift over a long period of time. Considering the limitation of these strategies, study results indicate that it could be helpful if community workers visit homes for identification and management of mental health issues, just as they visit for the vaccination of children and other maternal and reproductive health services. It is a viable option in the current scenario considering the dearth of mental health professionals and other barriers that women face in accessing mental health services.

Pakistan should train allied health care professionals like primary health care providers, nurses and lady health workers to identify and treat (where appropriate) common mental disorders like depression. This can include evidence-based treatment options such as cognitive behavior therapy and problem-solving therapy, which can be administered in patients' homes. This will reduce the barriers to visiting mental health care providers including travel time and cost, the need for permission from family members, and concerns about childcare and finishing house chores.

The concept of task sharing was coined to deal with the human resource crisis for health, particularly in the developing countries. Task sharing refers to assigning the tasks of qualified health care workers, to the more available, but comparatively less qualified community or health workers. With training and supervision these workers can provide some important services. One of the possible alternative strategies to attain MDGs / SDGs is to involve Community Health Workers (CHWs), not only in community mobilization, but also in delivering health interventions (112). CHWs have not only substituted for health professionals in many areas but have also played a key role in

working with “hard to reach” population and areas (113,114). This task sharing was particularly effective in response to the high demands placed in the face of increased need for treatment of HIV/AIDS (115–118).

CHWs can play a significant role in increasing access to mental health services, and can contribute to improving mental health outcomes in low-resource countries. CHWs have been trained in different areas of mental health. Cochrane systematic review reported positive outcomes of intervention delivered by non-specialist health workers in reducing depressive symptoms (119). A meta-analysis found psychosocial interventions by non-specialist health workers for perinatal mental health in low-income countries to be better than treatment as usual (120). Another systematic review reported psychosocial interventions delivered by non-specialist health care providers in low-income countries as feasible (121). Local health workers and volunteers were also identified as a useful community resource for scaling up mental health services in rural Ethiopia through a rigorous community mapping exercise (122).

Considering the financial challenges of providing mental health services, Evans-Lacko also recommended utilizing the task sharing approach of utilizing community health workers to provide mental health services in low-income settings (123). Community health workers training on mental health (124) and village health workers training on clinical depression (125) conducted in India reported improvement in health worker’s knowledge, and attitude. Another qualitative study reported that mental health intervention delivered through peers in Goa-India, and Rawalpindi-Pakistan demonstrated acceptability of interventions delivered by community members (126)

Rahman et al have also demonstrated the feasibility and acceptability of community health workers in delivering cognitive therapy based intervention for depression in Pakistan (127). The results of a recently completed cluster randomized control trial in one of the Karachi towns reported that psychosocial intervention delivered by trained community health workers (CHWs) could benefit women with depression. Focus groups conducted with CHWs reported that such training improves their knowledge about psychosocial interventions and help in increasing access to mental health services (128). Increasing competencies in mental health across non-specialist health disciplines in primary care can lead to more accessible, efficient, and potentially cost effective health care and can better address the mental health needs of women in a low-resource setting.

In Pakistan, a low-income country with 32.6% of the population living below the national poverty line, health inequalities are the result of economic polarization (129). Lady Health Workers Program (LHWP) was an initiative to improve access to primary health care as private sector hospitals were only accessible to a limited population of Pakistan. The LHW program had trained 93000 LHWs by the end of 2006 and they covered 60–70% of the rural population, where each LHW is responsible for 200 families (130).

The results of a community-based study demonstrated that intervention delivered by trained LHWs led to a decreased rate of stillbirth and neonatal mortality as well as increased care seeking behaviors (131,132). Considering the association between maternal depression and stunted growth in children (Rahman, 2004), the Thinking

Healthy Program was developed based on cognitive behavior therapy (133). This intervention was conducted with trained LHWs and led to lower depression scores for mothers and improved outcomes for children, like fewer diarrheal episodes and better vaccination rates (127). The effectiveness of a community based program was also tested through trained LHWs in rural areas of Pakistan and showed significant improvement in mothers (134).

Proposed project:

In light of the study findings presented in the previous chapter and the evidence supporting the utilization of community health workers for mental health interventions, an intervention program, named “Zindagi” (meaning *life*), is proposed to provide mental health services through community-based lady health workers to all 18 towns of Karachi, This will increase access to mental health services efficiently and cost effectively to better address the mental health needs of the population. The lady health workers program will be approached with the offer of training and supervision of LHW supervisors and health officers. The principal investigator has been working on a feasibility study in a town of Karachi with lady health workers who are already working for an NGO. The proposal can be expanded from the NGO or academic institution to offer the same training and supervision to all community health workers of Karachi.

The LHW program in Pakistan was developed in 1994. The program was successfully implemented and replicated across the country. The LHWs' access to homes, interaction with local women, and their high level of acceptability, has made them appropriate and reliable Maternal, Neonatal and Child Health (MNCH) care providers at

the grass root level. The effectiveness of this program is demonstrated by the ease with which LHWs perform their regular household visits and deliver preventive and simple, but essential, health care services with greater focus on maternal and child health; and by their ability to provide confidential counseling to married women on reproductive health and family planning. Additional roles carried out by LHWs include conducting antenatal care during home visits; promoting and monitoring the use of skilled birth attendants and encouraging families and communities to timely access available referral Emergency Obstetric and Neonatal Care (EmONC) services. The large-scale community acceptability of the LHWs' role and their proven capacity to absorb additional skills and integrate these into their standardized regular service package, make them indispensable team members for the effective delivery of key national interventions.

These workers, who are residents of the community in which they work, are each responsible for an average of 1000 people. Each lady health worker is attached to a government health facility, from which they receive training, a small allowance and medical supplies. Candidates are recommended by the community and meet a set of criteria, including having a minimum of eight years of education. They are trained for 15 months in the prevention and treatment of common illnesses; 3 months in the classroom, followed by 12 months of practical on-the-job training. After training, provincial and district coordinators monitor and supervise the LHWs in the field.

We intend to use the existing model of the LHW program for improving the mental health of women because of its successful implementation of this broad range of services. The integration of this Zindagi program with the already existing LHW program

at the city level can provide access to women all over Karachi, particularly, the most at risk women with low health resources (women in rural areas). We can develop a regular supervision program, based on the evaluations of the LHW programs, along with refresher trainings to keep them engaged, motivated and refreshed with skills and information to be able to perform their duties.

This project is designed for a low resource setting. Only those activities will be included that can be integrated into the existing community and primary health care services, and that will be sustainable after the intervention is finished. The programme can be carried out by a variety of non-specialist staff (e.g., health workers, day care workers, lay home visitors) after appropriate training. The program can be delivered in a variety of formats with individual woman or groups of women. Evaluation of the intervention will provide local evidence that the development of competencies in mental health across non-specialist health disciplines in communities and primary care can lead to more accessible, efficient, and potentially cost effective health care to better address the mental health needs of the Pakistani and low – income population.

The overall aim of the program is to contribute to the reduction of the depression epidemic in Pakistan by containing its spread among women through task sharing, building the capacity of health staff, and promoting referral practices. The program is comprised of three strategies mentioned below:

Strategy 1: To provide community-based mental health intervention through LHWs

Goal	To reduce depression in women through existing government lady health workers program
Activities	Advocacy and MOU with Lady health worker program Advocacy with local and city health officials and other stakeholders Advocacy with existing health center teams Training of Lady Health workers in identifying depression and other common mental health problems

The LHW's assist with immunization, registration of births and deaths, and other maternal and child health care services. These health workers are attached to the basic health unit of the area for further support and needed supplies. The health system in Pakistan is integrated yet complex. The health system is divided into three tiers. At a local level, basic health units and rural health units provide health services to a population of around 10,000 to 15,000, and conduct outreach activities through lady health workers. These basic and rural centers are supported by the second level of health care provided by district / tehsil health hospitals, which are supported by the tertiary, care hospitals. Basic health units send referrals to secondary health care units (established in the district headquarters) and tertiary health units (established in most populated districts) according to the severity of the illness. Community health workers will identify and counsel women with depression in communities and refer women with severe depression to the level of referral they need.

Sindh has 23,000 lady health workers who provide door-to-door health services to women under the supervision of 1000 lady health supervisors. Supervisors in each district will be trained by district health officers. The supervisors will impart the training to their supervisees in their regular meetings and training sessions teaching them to screen and counsel women during their home visits. They will counsel women for depression, while visiting them for other maternal and child health issues, and will provide referrals to women and their family members to nearby health centers and mental health experts if needed. This program will attempt to provide counseling and information to women at their doorstep. This is highly important for women in Karachi, particularly in the peri-urban and low-income areas where women's movement is restricted due to cultural and financial barriers, such as poor transport system and potential violence.

This program will utilize the existing infrastructure of the LHW program within the provincial health system and will seek to integrate their basic counseling and other referral services with the partnership of the Sindh health department. Existing basic, secondary, tertiary health care units will be selected for referrals based on consultations with the health department and the need of the community.

Strategy 2: Development of referral network

Goal	To increase access to mental health services through referrals in case of severity (if and when needed)
Activities	Development of referral directory Referral to other services (assessment, counseling, medication prescription, and management) Advocacy meetings with local health care providers and mental health care providers for referrals

Karachi, being a widespread geographic area, has a large population of women in rural areas away from urban centers in need of medication and / or services from mental health experts. A referral directory will be developed and given to LHWs and health care providers at health centers so they can guide women to the nearest and the most feasible mental health care provider.

Strategy 3: Behavior change communication program to increase awareness in women and their family members

Goal	To increase awareness regarding depression and mental health in women, their families, and communities
Activities	Training of district health officers Training of peer educators Training of lady health workers' supervisors Supervision of peer educators Printing of pictorial IEC material Distribution of IEC material

Behavior change communication activities will be conducted at an individual and community level targeting women and community members in Karachi. A peer education program will be launched in all 18 towns of Karachi. Town health education officers will be trained as master trainers. These master trainers will then train members from the participating clinics/centers in a peer education program. These members will identify, train, and supervise formerly depressed women and other women who are willing to work as peer educators. Peer educators will be from the same communities to ensure they have an established trust and connection with the population. They can be instrumental in raising awareness regarding depression and other mental health issues in women. Peer educators will also be able to raise awareness in community members and refer them for further consultation and treatment to mental health providers if necessary.

Implementation and management:

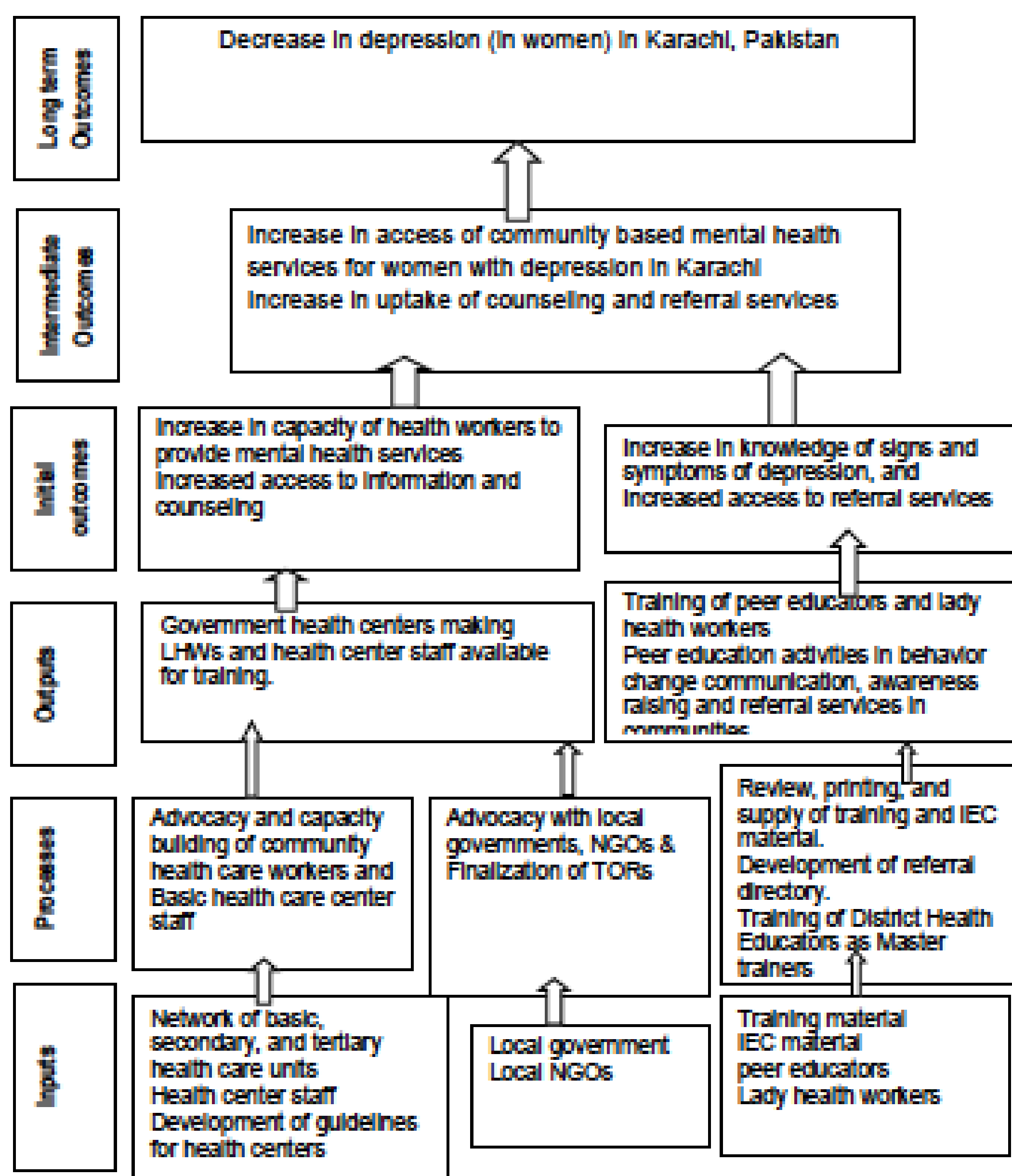
The provincial health department, in collaboration with the lady health worker program and the city health department, will implement this program. A program officer will be recruited to ensure the timely initiation and smooth implementation of the program, to coordinate with all national and local agencies, and to prepare the required documentation.

Monitoring and evaluation plan

Monitoring and evaluation will be an integral part of the overall program. It will be established from the beginning to ensure that the program components are suitable for the target population (formative evaluation) and the program is being implemented as designed (process evaluation). It will also help assess whether the program impacted the

community's knowledge, attitude, and practices (short-term outcome) around mental health, and whether the program led to a reduction in depression among women (long-term outcome). The logic model of the program presented below will guide the development of the evaluation plan.

Figure 6: Logic model for program Zindagi



Formative evaluation

For the last few years, NGOs have been working to increase awareness about depression and have also produced Information, Education and Communication (IEC) materials, as well as other training and peer education material. Rather than re-inventing the wheel, existing IEC, training, and peer education materials will be reviewed by technical experts and community members (women who have had depression) for applicability, language comprehensibility, cultural appropriateness, and acceptability to various socioeconomic and regional groups. Consultative meetings will be held with various stakeholders, including community members and health workers, to ensure the suitability of the program and training material in all areas.

Process evaluation:

Process evaluation will ensure that all the activities of the project (i.e. material development, dissemination, training of health workers and peer educators, regular screening of depression and counseling, etc.) are implemented as planned on a timely basis. This will include the development of detailed project work plans for each strategy and monthly review to ensure: all the inputs and resources are utilized appropriately, activities are conducted as planned, and outputs are delivered as planned. This process will ensure the project runs smoothly and will allow us to document challenges that require modification of the project. The program logic model will help inform the evaluation process.

Impact evaluation

For outcome and impact evaluation, a third party will be recruited to ensure the objectivity of the findings. Following is a tentative evaluation plan that will be revised upon approval of the project with the recruited evaluation agency.

This is a large, city-level project, which includes changes in knowledge, attitude, and practices (KAP) of community health workers. Baseline and post-program evaluation will be conducted in consultation and coordination with the national and provincial health department and the LHW program to evaluate changes in the knowledge, attitude, and practices of community health workers, as well as any reduction of depression in women and increase in access to community-based mental health services.

Evaluation will also have a very strong qualitative component. In-depth interviews will be held with women and their family members. Individuals will be informed about the qualitative element of the evaluation and will be asked for their consent to conduct a qualitative interview. A purposeful sampling strategy will be used to identify potential participants. Within this purposeful strategy, maximum variation sampling techniques will be used so patients of different socioeconomic background, gender, and age are invited for the interview. Participants will be sampled across 18 towns. We anticipate needing to interview up to 30 people in order to achieve data saturation.

We will invite a sample of lady health workers, their supervisors, local stakeholders, and referring clinicians to be interviewed until saturation. Topic guides will be developed by the qualitative research team through discussion and in reference to the

published literature. Semi structured interviews will be used to elicit views on the perceived effectiveness and sustainability of the program in the identification, counseling, and referral of women who have depression. Semi-structured interviews offer opportunities to cover, in-depth, a range of topics relevant to the research questions, while allowing for exploration and probing of issues raised during the interview. Analysis will be conducted by the evaluation team and will be iterative as data collection progresses, using the principles of constant comparison, until category saturation is achieved.

Table 16: Evaluation indicators and data sources

Evaluation stage	**Indicators**	**Data Source**
Formative evaluation	# Consultation meetings with local communities, lady health program Director, health officials MOU signed # of training material reviewed # of IEC material developed / reviewed and finalized	▪ Meeting minutes ▪ MOUs signed with Lady health worker programs, Health services directors / provincial health govt., local health bodies, and NGOs ▪ IEC material records and reports
Process evaluation	# advocacy meeting with health center staff # of IEC material printed and distributed # of training manuals and calendars printed	▪ Meeting minutes ▪ IEC material records ▪ Training reports ▪ Pre-post evaluation of training participants Focus groups and in-depth

	# of community health workers trained # of district health educators trained # of peer educators trained	interviews of the participants / health workers
Output evaluation	# awareness sessions conducted # of women received counseling # of IEC material distributed to peer educators, lady health worker and other vendors	▪ Inventory - List of IEC material distributed ▪ Awareness session reports ▪ Counseling records ▪ Referral records
Initial Outcomes	# of women received counseling # of women referred for further consultation # spouses / family members counseled / received Psychoeducation	▪ Inventory control records ▪ Counseling records ▪ Referral records ▪ Reports of psychoeducation and awareness activities
Intermediate outcome	# of women with improved mood / reduced symptoms of depression as measured by the Hamilton depression scale	▪ Counseling records ▪ Depression assessment scores after receiving the counseling (three months after the intervention)
Outcome Evaluation	# of women with sustained improved mood / reduced symptoms of depression as measured by the Hamilton depression scale and anxiety as measured by GAD-7 over a period of one year # of referrals received from women receiving counseling KAP survey of communities and	▪ KAP Survey ▪ Depression assessment scores after 6 months and 12 months of intervention Qualitative interviews of women, health workers, family members and community members

	health workers at the end of the intervention / three years Feedback received from families, communities, health workers and their supervisors	

Strengths and Limitations

There are several strengths and limitations of the proposed program. The overall objective of the study and the proposed program is to reduce depression among women, reduce overall morbidity, and increase quality of life. In low-income countries, there is a huge treatment gap. Results from the study provide a strong foundation to translate research into action. There can be other, wide-ranging positive outcomes including increased awareness, improvements in relationships, and greater employment. It is suggested that counseling based therapies, such as cognitive behavioral therapy and problem solving (which enhance self-efficacy), may also reduce relapse and recurrence rates of many mental disorders, including depression and anxiety.

The Zindagi program could also face some challenges. LHWs might get overburdened with additional responsibilities, which could lead to burn out. Also government policy regarding the lady health worker program can also change over time. We face a diverse array of challenges such as paying LHWs an adequate stipend in a timely manner. There is a lack of continued medical education and a lack of sustained motivation. This could be improved with incentives such as increase in wages, timely contract renewals and promotions, and reevaluation of goals.

The partnership model will reduce costs by utilizing existing facilities and human resources, and by building the capacity of health care providers. It will also provide long-term sustainability of services with the support of existing systems and partnerships.

In the end, I would like to reiterate that we are facing financial challenges. However, we cannot afford to deal with the financial and human losses caused by depression in women that affect our future generations and nation overall.

Conclusion:

Depressed women can have a better prognosis and recovery if identified and treated earlier (135,136). The longer the duration of untreated depression, the poorer the prognosis, the higher the chances of recurrence, and the higher the burden of disability (137,138). Treating depression in women can have many positive outcomes including increased productivity, reduced disability, and lower burden of care on family and government. There is no single or easy solution for increasing access to mental health services for women with depression in Karachi. Nevertheless, community-based programs using community workers have been identified as a potential intervention that recruits individuals, communities, and the health system to improve access. Pathways to mental health care services can be impacted by both medical and nonmedical factors, and personal circumstances for women with depression. Public private partnership of NGOs and the government sector can make this possible.

The results of a PI's study (B. Fatima et al. in process of write up) conducted in a town of Karachi from Dec 2013 to Nov 2015 has provided preliminary local evidence that the development of competencies in mental health across non-specialist health

disciplines in primary care can lead to more accessible, efficient, and potentially cost effective health care that better addresses the mental health needs of women. A portfolio of user-defined, evidence-based, participatory intervention; and a training program for possible use across health services in Pakistan is now available. The findings of this study will be helpful in advocating community-based, local health care provider initiated, health services for mothers and children in low-resource settings. We now plan to scale up the intervention. Donors have shown their interest in further funding this project for expansion. The support and collaboration of the government is necessary in order to sustain the project by scaling up, integrating health systems, and providing training programs for health care providers.

Understanding what prevents or delays women with depression from accessing mental health treatment and what facilitates them can help develop interventions and policies that can contribute to the reduction of depression in women. Most of the delays at an individual, social and healthcare level seem to be stemming from lack of awareness. Families who understand depression tend to be more supportive. Similarly, healthcare providers who are able to diagnose and understand depression are better able to provide treatment or referral. Education and women empowerment can also enable women to understand their own illness and look for treatment options. There has been an effort to engage and train community health workers(127); but there is a need to scale up such efforts and other pilot projects which have proven to be effective (139,140).

APPENDIX

Appendix 1: KEY INFORMANT INTERVIEW GUIDE

Appendix 1A: (Mental Health Care Providers)

Salam. My name is Batool Fatima and I would like to interview you. The interview will take approximately 60–90 minutes and at any time you need a break, please feel free to say so and I will stop. The reason for this interview today is for me to hear about your experiences regarding your patients suffering from depression. Your name or any identifying information will not be on the tape. After the session, the tape will be typed up into a transcript, and the original tape will be erased. If you happen to refer to a name during the session, the name will be disguised in the transcript. The only people who will see this transcript are involved in this project.
Any time you want to stop the interview or have me turn off the tape, you can tell me and we will stop. I will begin with a few demographic questions:

Demographics:

Gender: M / F	Age:
Education:	Occupation:
Years of experience:	Organization (optional):
Years of service at the organization:	

(Turn on the tape)
Section 1:
1.1 On average, how many patients do you see per month?
1.2 On average, how many patients with depression do you see in your practice every month?
1.3 What is the ratio of male vs. female patients with depression that you see?
1.4 What do you think is the reason behind this difference?
(If reported equal) Prevalence of depression is much higher in females as compared to males, why do think that the number of female patients is not higher than males?
2. Average delay:
2.1 On average, how chronic (delayed) are these cases of depression when they reach you?
2.2 Do you see any difference in the delay / chronicity in men and women with depression when they reach you?

2.3 What do you think are the reasons for this *difference* in length of delay in women and men?

3. Pathways:

3.1 How do patients usually reach to you? (Further explore on ratio of self appointment vs. referrals)
3.2 From where do you get referrals of women suffering from depression?
3.3 On average how many other service providers / help providers; women have usually seen for these symptoms before reaching you?
3.4 What kind of help providers / health care providers are those?
i.e. faith healers, religious scholars, primary health care provider? Any other specialist?
3.5 What is the usual pathway / route of seeking help in women with depression? Whom do they visit first and then second and so on?

4. Barriers and enablers in accessing treatment:

4.1 What do you think are the challenges/barriers that women in Karachi face in visiting you and other mental health care providers in accessing treatment for depression?
4.2 Can you elaborate on these challenges? (Discuss each challenge mentioned and how it affects the patient's access to mental health services)
4.3 What do you think are the most important barriers amongst it?
4.4 The women who reach early as compared to others, what do you think are the factors that help them in getting early treatment?

5. Barriers and enablers in following treatment:

5.1 Once they reach you, get the diagnosis, and recommended treatment; do they follow your advice on? (ask below mentioned factors one by one)
5.1.1 Medical prescription (adherence)?
5.1.2 Regular / required follow ups?
5.1.3 Other recommendations (changing life style, exercise, going for psychotherapy etc)?
5.1.4 Any other …

5.2 What do you think are the reasons that women do not follow medical prescription?
5.3 What do you think are the reasons that women do not visit for regular / required follow ups?
5.4 What do you think are the reasons that women do not follow other recommendations / advices?
5.5 Those who follow the recommendations (prescription/follow up/other advices), what are the factors that help them in following these?

6. Cost of treatment

6.1 How much are the consultation charges per visit here?
6.2 Do you accept company or any other insurance?
If yes, how many of your patients have any kind of insurance?
6.3 Are all other patients paying out of pocket or there are any other means?

7. Recommendations:

7.1 In your opinion, what can make it easier for women to access treatment for depression?

7. 2 What recommendations would you make or what changes would you like to see in the existing health system to increase access treatment for depression for women?

7.3 Could primary health care providers have a role in identification and treatment of common mental problems?

What challenges do you see in training and practice of primary care providers?

7.4 Could nurses have a role in identification and treatment of common mental problems?

What challenges do you see in training and practice of primary care nurses?

7.5 Could health care providers related to women health issues (Gynecologist/obstetrician/ antenatal and postnatal health care providers/ child vaccinators/ pediatricians)? have any role in identification and treatment of common mental problems

7.6 What do you think about health awareness campaign on depression and common mental illnesses?

7.7 What do you think about adding emotional health curriculum in schools or colleges for teaching emotion management, communication skills, identifying common mental illness, and when and from where to seek help?

7.8 Could religious scholars play any role in raising awareness, reducing misconceptions, and encouraging families to bring women for treatment?

7.9 Could media play any role in raising awareness, reducing misconceptions? (If yes, what do you think how can we involve them?)

7.10 Could your organization play any role in reducing those barriers / increasing enablers? Or are there any future plans?

If yes, what challenges do you / your organization face and foresee?

We have reached the end of this interview, Thanks for your time and valuable input. Everything you have said will be kept confidential.

Comments/Observations about interview:

KEY INFORMANT INTERVIEW GUIDE

Appendix 1B: (Primary Health Care Providers)

Salam. My name is Batool Fatima and I would like to interview you. The interview will take approximately 90 minutes and at any time you need a break, please feel free to say so and I will stop. The reason for this interview today is for me to hear about your experiences regarding your patients suffering from depression. Your name will not be on the tape. After the session, the tape will be typed up into a transcript, and the original tape will be erased. If you happen to refer to a name during the session, the name will be disguised in the transcript. The only people who will see this transcript are involved in this project.
Any time you want to stop the interview or have me turn off the tape, you can tell me and we will stop. I will begin with a few demographic questions:

Demographics:

Gender: M / F	Age / Date of Birth:
Education:	Occupation:
Years of experience:	Organization (optional):
Years of service at the organization:	

(Turn on the tape)

1.1. On average how many patients do you see per month?
1.2. On average how many patients do you see that present with depression or depression like symptoms?
1.3. What kind of symptoms do they present with?
1.4. Do you see any difference in the symptoms in men and women in this regard?
1.5. How many of them do you think, can be diagnosed with depression?
1.6. What is the ratio of male vs. female patients with depression that you see?
   1.6.1. What do you think is the reason behind this difference?
   1.6.2. (If reported equal) Prevalence of depression is much higher in females as compared to males, why do think that number of female patients is not higher than males?
1.7. How do you treat them (What do you prescribe them)?
1.8. Do you recommend them something else?

2. Referral Information/Contacts:

2.1. Do you ever refer them to any mental health care professional?
2.2. If yes, how often and when do you refer them to mental health care providers?
   2.2.1. What do you tell them while referring to mental health care provider?

2.3. Whom do you usually refer? Who else do you refer?

2.4. How many of the patients that you refer, actually go see that mental health care provider?
2.5. Do patients ever mention any difficulty in seeing that mental health care provider?
2.6. Can you tell me the ratio of males vs. female patients that you have referred for mental health care?
2.7. What do you think is the reason for this difference?
2.8. What do you think is the ratio of male vs. female patients who actually consulted the mental health care provider?
2.9. What do you think is the reason for this difference?

3. Reaction on diagnosis / referral (If diagnosis / referral provided):

3.1. How do patient react when you tell them that he/she is suffering from depression?
3.2. How do person accompanying the patient react when you tell the patient that he/she is suffering from depression?
3.3. Do you find any difference in the reaction of male and female patients?
3.3.1. If yes, Why do you think is that difference?
3.4. How do patient react when you tell them that they need to see mental health care provider?
3.5. How do person accompanying the patient react when you tell the patient that he/she needs to see mental health care provider?
3.6. Do you find any difference in the reaction of the person accompanying male and female patients?
3.7. Do you find any difference in the reaction of the person accompanying patients due to other factors?
3.7.1. Relationship with the person accompanying (Mother/ Mother-in law/sister/husband)
3.7.2. Age of the patient (young/old)
3.7.3. Marital Status of the patient
3.8. If married (Women with / without children specifically son)
3.8.1. Gender of the person accompanying patient

4. Capacity of primary health care providers to treat depression:

4.1. Was treatment of mental illness included in your medical school curriculum?
4.2. Did you ever receive any kind of training for identifying and treating mental illness?
4.3. Would you like to receive further training on common mental disorder’s identification and management?
4.4. Do you think other primary care providers would like to get further training?

5. **Average delay:**
    5.1. On average, how chronic (delayed) are these cases of depression you diagnose/ treat / refer them?
    5.2. Do you see any difference in the delay / chronicity in men and women with depression when they reach you?
    5.3. What do you think are the reasons for this *difference* in length of delay in women and men?

6. **Pathways:**
    6.1. In your experience, on average how many other health care providers/ service providers / help providers' women usually see for depression before getting required treatment?
    6.2. What kind of help providers / health care providers are those?
        6.2.1. i.e. faith healers, religious scholars, primary health care provider? Any other specialist?
    6.3. In your opinion, what is the usual pathway / route of seeking help in women with depression? Whom do they visit first and then second and so on?

5. Barriers and enablers in accessing treatment:
5.1. What do you think are the challenges/barriers that women in Karachi face in accessing appropriate treatment for depression?
5.2. Can you elaborate on these challenges? (Discuss each challenge mentioned and how it affects the patient's access to mental health services)
5.3. What do you think are the most important barriers amongst it?
5.4. The women who get treatment early as compared to others, what do you think are the factors that help them in getting early treatment?

6. **Barriers and enablers in following treatment:**
6.1. Once they get the diagnosis, and recommended treatment; do they follow advice on? (ask below mentioned factors one by one)
6.1.1. Medical prescription (adherence)?
6.1.2. Regular / required follow ups?
6.1.3. Other recommendations (changing life style, exercise, going for psychotherapy etc)?
6.1.4. Any other …

6.2. What do you think are the reasons that women do not follow medical prescription?
6.3. What do you think are the reasons that women do not visit for regular / required follow ups?
6.4. What do you think are the reasons that women do not follow other recommendations / advices?
6.5. Those who follow the recommendations (prescription/follow up/other advices), what are the factors that help them in following these?

7. **<u>Cost of treatment</u>** (ask only if primary health care provider is providing treatment /referral for depression)

7.1. How much are the consultation charges per visit here?

7.2. Do you accept company or any other insurance?

7.2.1. If yes, how many of your patients have any kind of insurance?

7.3. Are all other patients paying out of pocket or there are any other means?

8. **<u>Recommendations:</u>**

8.1. In your opinion, what can make it easier for women to access treatment for depression?

8.2. What recommendations would you make or what changes would you like to see in the existing health system to increase access treatment for depression for women?

8.3. Could primary health care providers have a role in identification and treatment of common mental problems?
What challenges do you see in training and practice of primary care providers?

8.4. Could nurses have a role in identification and treatment of common mental problems?

8.4.1. What challenges do you see in training and practice of primary care nurses?

8.5. Could health care providers related to women health issues (Gynecologist/obstetrician/ antenatal and postnatal health care providers/ child vaccinators/ pediatricians)? have any role in identification and treatment of common mental problems

8.6. What do you think about health awareness campaign on depression and common mental illnesses?

8.7. What do you think about think adding emotional health curriculum in schools or colleges for teaching emotion management, communication skills, identifying common mental illness, and when and from where to seek help?

8.8. Could religious scholars play any role in raising awareness, reducing misconceptions, and encouraging families to bring women for treatment?

8.9. Could media play any role in raising awareness, reducing misconceptions? (If yes, what do you think how can we involve them?)

8.10. Could your organization play any role in reducing those barriers / increasing enablers? Or are there any future plans?

8.10.1. If yes, what challenges do you / your organization face and foresee?

We have reached the end of this interview, Thanks for your time and valuable input. Everything you have said will be kept confidential.
Comments/Observations about interview:

KEY INFORMANT INTERVIEW GUIDE

Appendix 1C: (Health department / Working for women's health)

Salam. My name is Batool Fatima and I would like to interview you. The interview will take approximately 90 minutes and at any time you need a break, please feel free to say so and I will stop. The reason for this interview today is for me to hear about your opinion and experiences on depression in women and health services available for them. Your name will not be on the tape. After the session, the tape will be typed up into a transcript, and the original tape will be erased. If you happen to refer to a name during the session, the name will be disguised in the transcript. The only people who will see this transcript are involved in this project.
Any time you want to stop the interview or have me turn off the tape, you can tell me and we will stop. I will begin with a few demographic questions:

Demographics:

Gender: M / F	Age / Date of Birth:
Education:	Occupation:
Years of experience:	Type of Organization: Government / NGO / Service providing
Name of organization (optional):	Years of service at the organization:

(Turn on the tape)

What are the major health problems women face?

- *If depression/common mental disorders not mentioned, do you think that women in Karachi suffer from depression.*

What do you think is the prevalence of depression in women in Karachi?
How do you think it depression affects women's lives?
What are the treatment options for women suffering from depression in Karachi?

Pathways:

In your opinion, where do women prefer to go for treatment of depression?
What are the reasons for it?
Do you think it works? (i.e. going to faith healers, primary health care providers, talking to friends)
What happens when they visit them?
In your opinion, where do they go next?

Barriers and enablers in accessing treatment:

What do you think is the ratio of women getting treatment for depression?
In your opinion what are the reasons that remaining women are not getting required treatment for depression?
Can you elaborate on these challenges? (Discuss each challenge mentioned and how it affects the patient's access to mental health services)
What do you think are the most important barriers amongst it?
In your opinion the women who are seeking treatment, what helps them in getting treatment?

Barriers and enablers in following treatment:

In your opinion, once women get the diagnosis, and recommended treatment; do they follow the recommended treatment? (Ask below mentioned factors one by one)

1- Medical prescription (adherence)?
2- Regular / required follow ups?
3- Other recommendations (changing life style, exercise, going for psychotherapy etc)?
4- Any other …

What do you think are the reasons that women do not follow medical prescription?
What do you think are the reasons that women do not visit for regular / required follow ups?
What do you think are the reasons that women do not follow other recommendations / advices?
In your opinion, those who follow the recommendations (prescription/follow up/other advices), what are the factors that help them in following these?

Cost of treatment

How much are the consultation charges for treatment of depression?
For treatment of depression and common mental disorders do companies provide insurance?
How many of the patients have access to any kind of insurance?
Are all other patients paying out of pocket or there are any other means?

Recommendations:

In your opinion, what can make it easier for women to access treatment for depression?
What recommendations would you make or what changes would you like to see in the existing health system to increase access treatment for depression for women?
Could primary health care providers have a role in identification and treatment of common mental problems?

What challenges do you see in training and practice of primary care providers?
Could nurses have a role in identification and treatment of common mental problems?
What challenges do you see in training and practice of primary care nurses?
Could health care providers related to women health issues (Gynecologist/obstetrician/ antenatal and postnatal health care providers/ child vaccinators/ pediatricians)? have any role in identification and treatment of common mental problems
What do you think about health awareness campaign on depression and common mental illnesses?
What do you think about think adding emotional health curriculum in schools or colleges for teaching emotion management, communication skills, identifying common mental illness, and when and from where to seek help?
Could religious scholars play any role in raising awareness, reducing misconceptions, and encouraging families to bring women for treatment?
Could media play any role in raising awareness, reducing misconceptions? (If yes, what do you think how can we involve them?)
Could your organization play any role in reducing those barriers / increasing enablers? Or are there any future plans?
If yes, what challenges do you / your organization face and foresee?

We have reached the end of this interview, Thanks for your time and valuable input. Everything you have said will be kept confidential.

Comments/Observations about interview:

Appendix 2: In-depth interview guide-

For Women receiving treatment for depression

Salam. Thank you for taking the time to meet with me about this research study. My name is Batool Fatima and if you agree I would like to interview you today. The reason for this interview today is for me to hear about your experiences with depression, the process of identifying it and getting treatment for it. The interview will take approximately 90 minutes and at any time you need a break, please feel free to say so and I will stop. Also you can decide to not to further participate or not to answer any question, if you feel uncomfortable at any point during the interview I will be tape-recording this session. Your name or any identifying information will not be on the tape. After the session, the tape will be typed up into a transcript, and the original tape will be erased. If you happen to refer to a name during the session, the name will be disguised in the transcript. The only people who will see this transcript are involved in this project. Let me know if you have any question.

Any time you want to stop the interview or have me turn off the tape, you can tell me and we will stop.

(Turn on the tape)

Demographics:

Age:

Marital Status:	Number of children (M/F)
Education:	Occupation:
Years of experience (if working):	Organization (optional):

1. **<u>Pathways:</u>**

1.1 Can you tell me what did you feel in the beginning of your illness?

1.2 What was going on in your life at the time when you first began wondering about your mental health?

1.3 From whom and where did you first seek help for those symptoms?
- *1.3.1 How did you find it?*
- *1.3.2 Then whom did you see? How did you find it (repeat until the existing health care provider?)*

1.4 How about the time that you first received the diagnosis for depression?

1.5 How do you feel about your diagnosis?

1.6 What do you think caused you depression?

1.6.1 What do you think are the cause's depression in general to other women?

1.7 How did you feel when you were first given the diagnosis?

1.8 Tell me about how your feelings have changed over time about depression?

2. <u>Barriers and enablers in accessing treatment:</u>

2.1 What kind of difficulties did you face in getting appropriate treatment for depression?

2.2 Can you elaborate on these challenges? *(Discuss each challenge mentioned and how it affects the patient's access to mental health services)*

2.3 What do you think are the most challenging amongst it?

2.4 What were the factors that were helpful in getting the treatment?

2.5 Would it make any difference in your treatment if your health care provider is male/female?

2.6 Do you think it would have been easier for you to get the treatment if you were a male? Why?

2.7 Some people tell me that they like it when a doctor explains things in detail to them.

2.7.1 Describe for me a time when your doctor explained things well to you?

2.7.2 Describe for me a time when your doctor didn't explain things well to you?

2.7.2.1 What would you have liked to have happened instead?

2.7.2.2 Did you ever ask the doctor to explain things in more detail?

2.8 What examples can you give me of things you have brought up to the doctor?

2.9 Some people have told me that they do not trust what the doctors tell them.

2.9.1 Describe for me a time when you did not believe what your doctor told you about your health?

2.10 What do you think makes women not to go the doctor?
2.11 What do you think makes women go?
2.12 How is it different for men and women?
2.13 How is it for you?

3. <u>Barriers and enablers in following treatment:</u>

3.1 How do you find it to follow the recommended treatment prescription of the … (existing health care provider)?

3.1.1 Prescription
3.1.2 Seeking other consultation (psychotherapy)
3.1.3. Making life changes

3.2 Are you able to make the follow up visits as recommended by the … (existing health care provider)?

3.2 What can help you in following the recommendations (prescription/follow up/other advices)?

4. <u>Treatment:</u>

4.1 What kind of treatment are you currently receiving?

4.2 If receiving medicine: Which medication are you taking right now? (note name and dosage)

4.2.1 Since how long are you taking this medication?
4.2.2 Did you receive any other medication before?
4.2.3 How do you feel about taking these medications?

4.3 If receiving psychotherapy/counseling:

4.3.1 Since how long are you receiving psychotherapy/counseling?
4.3.2 How many sessions per wk/per month are you taking?
4.3.3 Has frequency of sessions changed over time?
4.3.4 How do you feel about the sessions?

5. <u>Social Support:</u>

5.1 Thinking about when you felt about your wellbeing what did you do first?
(Talk to family members, friends)

5.2 How did people in your life react when you were first given this diagnosis?

5.3 How do people in your life react to you now in terms of your diagnosis?
5.3.1 Who knows about this diagnosis?

5.3.2 Who doesn't know?

5.4 Who usually comes with you to your appointments?

6. ***<u>Socio-economic Factors:</u>***

6.1. Can you describe for me your current income status?
6.2. What is the highest grade that you went to in school?

6.3. Can you describe for me your current job? *(If not currently working asking about the most recent job they held and tasks regularly done at home)*
6.3.1. (If they are working) Can you describe for me what it is like to take time out of work to go to the doctors
6.3.2. (If not working) ask about responsibilities at home and what it is like to take out time to go to the doctor

6.4. Do you have any kind of health insurance?
6.5. Does your health insurance cover this treatment?
6.6. If not, how do you pay / who pays for your treatment?
6.6.1. How do you feel about this?

6.7. How far is your house from here?

6.8. How do you get to here for your appointments?

7. <u>Recommendations:</u>

7.1. What can make it easier for you and other women to access treatment for depression?

7.2. What recommendations would you make or what changes would you like to see in the existing health system to increase access to treatment for depression for women?

7.3. Would you like to get treatment from your primary care provider, if she/he is trained in treatment of depression?
7.3.1. Can you elaborate on the reason for it?

7.4. Would you like to get treatment from your nurse, if she/he is trained in treatment of depression?
7.4.1. Can you elaborate on the reason for it?

7.5. Would you like to get treatment from your Gynecologist/obstetrician/ antenatal and postnatal health care providers/ child vaccinators/ pediatricians?

7.5.1. Can you elaborate on the reason for it?

7.6. What do you think about health awareness campaign on depression and common mental illnesses?

7.7. What do you think adding emotional health curriculum in schools or colleges emotion management, communication skills and identifying common mental illness with when and how to seek the help?

7.8. Could religious scholar have any role in raising awareness, reducing misconceptions, and encouraging families to bring women for treatment?

7.9. Could media play some role in raising awareness, reducing misconceptions? (if yes, what do you think how can we involve them?)

We have reached the end of this interview, Thanks for your time and valuable input. Everything you have said will be kept confidential.

Comments/Observations about interview:

Appendix 3: In-depth interview guide –

For Women screened for depression from primary care

Salam. Thank you for taking time to meet with me about this research study. My name is Batool Fatima and if you agree I would like to interview you today. The reason for this interview today is for me to hear about your experiences with your current illness and symptoms, and getting treatment for it. The interview will take approximately 60–90 minutes and at any time you need a break, please feel free to say so and I will stop. Also you can decide not to participate or not to answer any questions, if you feel uncomfortable at any point during the interview. I will be tape-recording this session. Your name or any identifying information will not be on the tape. After the session, the tape will be typed up into a transcript, and the original tape will be erased. If you happen to refer to a name during the session, the name will be disguised in the transcript. The only people who will see this transcript are involved in this project. Let me know if you have any question
Any time you want to stop the interview or have me turn off the tape, you can tell me and we will stop.

(Turn on the tape)

Demographics:

Age:

Marital Status:	Number of children (M/F)
Education:	Occupation:
Years of experience (if working):	Organization (optional):

1. **Pathways:**

1.1. How are you doing today?

1.2. Can you tell me for what symptoms and illnesses are you here to seek consultation?

1.3. What did doctor tell you about these symptoms? (explore about current and previous diagnosis)

1.4. How do you feel about it?

1.5. Since when are you having these symptoms?

1.6. Can you tell me what did you feel in the beginning of your illness?

1.7. From whom and where did you first seek help for those symptoms?
1.7.1. How did you find it? (explore regarding any diagnosis given)
1.7.2. What were you prescribed and advised?
1.7.3. Then whom did you see? How did you find it (repeat until the existing health care provider?)

Ask theses only if the participant has received the diagnoses of depression from existing primary health care provider or past service providers visited:
1.8 How about the time that you first received the diagnosis for depression?
1.9 What do you think are the causes of depression?
What do you think caused you depression?
1.10 How did you feel when you were first given the diagnosis?
Tell me about your feelings about it?

2. <u>Barriers and enablers in accessing treatment:</u>

2.1 What kind of difficulties are you facing due to these symptoms?

2.2 Are you finding any difficulty in getting treatment for it?

2.3 Can you elaborate on these challenges? *(Discuss each challenge mentioned and how it affects the patient's access to mental health services)*

2.4 What do you think are the most challenging amongst it?

2.5 What were the factors that were helpful in getting the treatment?

2.6 Would it make any difference in your treatment if your health care provider is male/female?

2.7 Do you think it would have been easier for you to get the treatment if you were a male? Why?

2.8 Some people tell me that they like it when a doctor explains things in detail to them.
2.8.1 Describe for me a time when your doctor explained things well to you?

2.8.2 Describe for me a time when your doctor didn't explain things well to you?
What would you have liked to have happened instead?
Did you ever ask the doctor to explain things in more detail?

2.9 Some people have told me that they do not trust what the doctors tell them.
2.9.1 Describe for me a time when you did not believe what your doctor told you about your health?
2.10 What do you think makes women not to go the doctor?
2.11 *What do you think makes women go?*
2.12 *How is it different for men and women?*
2.13 *How is it for you?*

3. <u>Barriers and enablers in following treatment:</u>

3.1 How do you find it to follow the prescription of your health care provider)?
3.2 How do you find it to follow the other advice and recommendations (changing life style, exercise, going for other consultations etc) given by the existing health care provider?
3.3 Are you able to make the follow up visits as recommended by the … (existing health care provider)?
3.4 What can help you in following the recommendations (prescription/follow up/other advices)?

4. <u>Treatment:</u>

4.1 What kind of treatment are you currently receiving?

4.2 If receiving medicine: Which medication are you taking right now? (note name and dosage)
4.2.1 Since how long are you taking this medication?
4.2.2 Did you receive any other medication before?
4.2.3 How do you feel about taking these medications?

4.3 If receiving psychotherapy/counseling or any other treatment:
4.3.1 Since how long are you receiving psychotherapy/counseling?
4.3.2 How many sessions per wk/per month are you taking?
4.3.3 Has frequency of sessions changed over time?
4.3.4 How do you feel about the sessions?

5. <u>Social Support:</u>

4.1 Thinking about when you felt about your wellbeing what did you do first?

(Talk to family members, friends)
4.2 What do people around you (your family, friends, and neighbors think about these symptoms)
4.2.1 How did people in your life react when you were first started having these symptoms?
4.3 How do people in your life react to you now in terms of your illness/diagnosis?
4.3.1 Who knows about this diagnosis?
4.3.2 Who doesn't know?
4.3 Who usually comes with you to your appointments?

6. *Socio-economic Factors:*

5.1 Can you describe for me your current income status?
5.2 What is the highest grade that you went to in school?
5.3 Can you describe for me your current job? *(If not currently working asking about the most recent job they held and tasks regularly done at home)*
(If they are working) Can you describe for me what it is like to take time out of work to go to the doctors
5.5 Do you have any kind of health insurance?
5.5.1 Does your health insurance cover this treatment?
If not, how do you pay / who pays for your treatment?
5.5.2 How do you feel about this?
5.4 How far is your house from here?
5.5 How do you get to here for your appointments?

7. Recommendations:

6.1 What can make it easier for you and other women to access treatment for such problems?

6.2 What recommendations would you make or what changes would you like to see in the existing health system to increase access for women to treatment for depression?

6.3 Depression is increasing in our society particularly amongst women, we have some women here who have depression or depression like symptoms, and what do you think they should do for treatment?

6.4 What do you think women would feel like it if primary care providers provide treatment for depression?

6.5 What do you think women would feel it if they get treatment from their nurse, if she/he is trained in treatment of depression?

6.6 What do you think Do you think women would feel it if their Gynecologist/obstetrician/ antenatal and postnatal health care providers/ child vaccinators/ pediatricians provide treatment for depression?

6.7 What do you think about health awareness campaign on depression and common mental illnesses?

6.7 What do you about adding emotional health curriculum in schools or colleges for teaching emotion management, communication skills and identifying common mental illness with when and how to seek the help?

6.8 Could religious scholars have any role in raising awareness, reducing misconceptions, and encouraging families to bring women for treatment?

6.9 Could media can play some role in raising awareness, reducing misconceptions? (If yes, what do you think how can we involve them?)

We have reached the end of this interview, Thanks for your time and valuable input. Everything you have said will be kept confidential.

Comments/Observations about interview:

Appendix 4: List of Resources:

Karwan-e-Hayat
KPT and Karwan-e-Hayat 'Psychiatric Care and Rehabilitation Center' (PCRC),
Neart KPT Hospital,
Keamari, Karachi
Ph: 2856879-80, 2856774-75
Email : info@keh.org.pk, kehpcrc@hotmail.com
Web: http://www.keh.org.pk/

Jinnah Post Graduate Medical center Hospital
Ward no. 20
Psychiatry department J
PMC Karachi

Aga Khan Hospital
Stadium road, Karachi
Psychologists: Dr. Saiqa Khan and Dr. Nargis Asad
Psychiatrist: Dr. Murad Musa Khan

Dr. Ayesha Muquim Quraishy
Liaquat National Hospital Karachi
111-456-456
009221 34939612-4
9 am to 2 pm
OMI Hospital (Tuesdays 1:30 to 4:30 pm)

Institute of Clinical Psychology
Ph: 34613584, 34614944 Fax: 34615369
Email: icp@uok.edu.pk

Institute of Professional Psychology
Bahria University Karachi Campus
13 National Stadium Road
Karachi Pakistan
Ph: +92-21-99240013, 99240014

Pakistan Institute of Learning and Living
D-9, Block I, North Nazimabad,
Karachi -Pakistan. 74700.
+92 - 21 -36703712
info@pill.org.pk

AK Centre Bahadurabad
Psychologist – Dr. Rabia Riaz , Mrs. Qudsia

Specialist Care Clinic,
Psychologist - Saima Ali
Specialist Care Clinic,
MA Jinnah Road, Near Taj Medical complex

Psychiatrist - Dr. Hanif Mesia
1st Floor Glass Tower
Clifton, Karachi

The Youth Help Line (YHL) is a resource centre working on the emotional and reproductive health of young people. A toll free telephone counseling service those operates 7 days a week from 10am to 8pm 'Accessible from all over the Pakistan also from mobile (with regular landline charges). Call 0800-22444

Resources on Internet in Urdu:
http://www.camh.net/About_Addiction_Mental_Health/Multilingual_Resources/urdu_about_mentalhealth.pdf

http://www.rcpsych.ac.uk/mentalhealthinfoforall/translations/urdu.aspx

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Manchester Assessment of Caregiver-Infant Interaction (MACI)	Pakistan Institute of learning and Living, Sharja UAE	23rd –24th Feb, 2015
Programme Management Development (New Steps in Result-Based Management & Organisation Development)	Management for Development Foundation Kathmandu, Nepal	29 Oct – 9 Nov 12
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Behaviour change communication Planning	International Centre for Development Communication Kasetsart University Bangkok, Thailand	8–25 Mar 2005
Inter-country workshop on Voluntary Counselling and testing for HIV/AIDS Training for trainers	Bangkok, Thailand	26 Mar– 8 April 05

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Nov 2005 – Apr 2007	Aga Khan Health Service, Pakistan Behavior Change Communication Specialist
Nov 2003 – Nov 2005	Marie Stopes Society (HIV/AIDS Program) Clinical Psychologist / Manager Counseling Services.
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Clinical Experience:

Dec 2005 – March 2007	Center for Counseling Services at Medilink Co-Director and Consultant Clinical Psychologist, (Part Time)
Dec 2002 – Jan 2009	Specialist Care Clinic, Near Taj Medical Complex Consultant Clinical Psychologist
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Consulting Experience:

Assessment of the Impact of Psychosocial Tools Developed by UNICEF, April– July 2009
Client: UNICEF Punjab, Pakistan
Assignment: Assessment of the Impact of Psychosocial Tools for HIV/AIDS infected and affected children developed by UNICEF Punjab and implemented by Pak plus society, Revision of tools and programmatic Recommendations

Communicating with HIV positive people: 29th July 2008
Client: UNICEF& SINDH AIDS Control Program, Pakistan
Assignment: Conducting Voluntary Counseling and testing part of the Care and Support training

Voluntary Counseling and Testing for HIV/AIDS
Client: Family Health International, Pakistan. 4–12 July, 2008
Assignment: Training Partner NGOs of Family Health International on Voluntary Counseling and Testing

Communicating with HIV positive people: May–July 2008
Client: UNICEF& National AIDS Control Program, Pakistan
Assignment: Develop curricula for communicating with HIV positive clients (Presentation, guidance notes and reference material), conduct training and update the material as per the participant's feedback.

Project Proposal Development
Client: Mustashaar / WISES
Assignment: Proposal developed for Tackling HIV/AIDS Stigma and Discrimination, 2008.

Client: United Registrar Systems
Assignment: Technical Audit of NGO- Church World Service, Pakistan Afghanistan. Jan, 2008

Facilitation Skills for utilization of videos in community
Client: **CONCERN**
Assignment: Trained team members and partners of CONCERN for raising awareness on HIV/AIDS with the use of video "Choti se Ghalti". Dec 07

Training: PPTCT (Preventing Parent to Child Transmission of HIV
Client: UNICEF
Assignment: Conducted Two days Training in **PPTCT (Preventing Parent to Child Transmission of HIV -training** for National AIDS Control Program and UNICEF partner NGOs Dec, 07

Training workshop: Voluntary Counseling and Testing for HIV/AIDS
Client: Family Health International – FHI
Assignment: Co – facilitated **"Voluntary Counseling and Testing"** workshop with Kathleen Casey (Regional senior technical person for VCT- FHI). 14–21st June, 07 for Family Health International – FHI and National AIDS Control Program Pakistan

Training workshop: Counseling for HIV/AIDS
Client: Family Health International
Assignment: Conducted training on **"Counseling for HIV/AIDS"** for partner NGOs of Family Health International at Crown Plaza, Lahore. May 12–16, 2006

Training workshop Voluntary Counseling and Testing for HIV/AIDS
Client: Marie Stopes Society
Assignment: Conducted Training on **Voluntary Counseling and Testing for HIV/AIDS,** for Psychologists of the Behtar Kal Program Marie Stopes Society. 20 Feb–1st Mar 2006

Client: Spectrum Communications
Assignment: Technical support in Project Proposal development on **BCC Campaign** for optimal Birth Spacing on Family Planning Motivational Campaign, Oct–Nov, 05 for Green Star Social Marketing **by** Spectrum Communications

Training Workshop Counseling for HIV/AIDS
Client: Church World Service Pakistan and Afghanistan
Assignment: "Counseling on HIV/AIDS", on 23–24 Mar 04 at Ratanabad, Mirpur Khas, Consultancy for Church World Service Pakistan and Afghanistan

Publications

Emotional intelligence: A key factor for self-esteem and neurotic behavior among adolescence of Karachi, Pakistan**.** ZH Khan, K Ilyas, **B Fatima** - Indian Journal of Positive Psychology, 6(2) 2015, page 171–174

A brief psychological intervention after self-harm: An RCT from a low-income country. Nusrat Husain, Salahuddin Afsar, Jamal Ara, Hina Fayyaz, Raza Ur Rahman, Barbara Tomenson, Munir Hamirani, Nasim Chaudhry, **Batool Fatima**, Meher Husain, Farooq Naeem, Imran B Chaudhry. The British journal of psychiatry: the journal of mental science. 03/2014; DOI:10.1192/bjp.bp.113.138370

Mental health and adaptation of young Liberians in post conflict Liberia: a key informant's perspective. Dominguez S, Borba C, **Fatima B,** Deborah A. Graya, Stinehart C, Murphy G, Wang E, Harris B and Henderson D. International Journal of Culture and Mental Health, 2012 . DOI:10.1080/17542863.2012.683158

Husain N, Chaudhry N, **Fatima B,** et al. Antidepressant and group psychosocial treatment for depression: a rater blind exploratory RCT from a low income country. **Behav Cogn Psychother. 2014 Nov;** 42 (6):693–705.

Fatima B, Munawar N**.** Type A behaviour and Road Accidents, Pakistan Journal of Social and Clinical Psychology. Vol. 4, No. 1–2, June, 2006

Manuscripts under review:

Husain, N., Zulqernain, F., Carter, L., **Fatima, B.,** et al. Treatment of maternal depression in urban slums of Karachi, Pakistan: A randomized controlled trial (RCT) of an integrated maternal psychological and early child development intervention.

Chaudhry, N., Kiran, T., Fayyaz, H., **Fatima, B.,** Furber, C., Lunat, F., Husain, M., Naeem, F., **Husain, N**. Maternal depression and the role of psychosocial intervention: Perception of community health workers in Pakistan.

Published Abstracts:

1) Batool Z, **Fatima B**, Zadeh Z. Feasibility randomized controlled clinical trial of mindfulness and acceptance based therapy for females with social anxiety in Karachi, Pakistan. European Psychiatry. 2016;(33):S391.
2) Husain M, Tayyeba K, Husain M, **Fatima B**, Ansari SUH, Rahman R, et al. Depression and quality of life in hospitalized patients with congestive heart failure (CHF): A cross-sectional study from Karachi, Pakistan. European Psychiatry. 2016 Mar;33, Supplement:S390.
3) Karbhari A, Chaudhry N, Kiran T, Fayyaz H, **Fatima B**, Furber C, et al. Maternal depression and the role of psychosocial intervention: Perception of community health workers in Pakistan. European Psychiatry. 2016;(33):S224–S225.
4) Tauseef B, Zadeh Z, **Fatima B**. Feasibility of the stress and anger management program on children with high functioning autism spectrum disorder in a sample population from Karachi. European Psychiatry. 2016 Mar;33, Supplement:S360.

5) Nusrat H, Zehra N, Amir B, Nasim C, tayyeba K, Shehla Z, et al. Group interpersonal psychotherapy for maternal depression an exploratory randomized control trial. European Psychiatry. 2016 Mar;33, Supplement:S413–4.
6) Nusrat H, **Batool F**, Tayyeba K, Farah N, Ann M. Change your life with seven sheets of paper: A pilot randomized controlled trial for postnatal depression (CREATOR). European Psychiatry. 2016 Mar;33, Supplement:S414.
7) Husain N, Kiran T, **Fatima B**, Chaudhry IB, Saeed Q, Masood SN, et al. Development and assessment of a mobile phone-based intervention to reduce maternal depression and improve child health. European Psychiatry. 2016 Mar;33, Supplement:S608–9.
8) Husain N, Fayyaz H, Kiran T, **B. Fatima,** Lunat F, Hamirani M, Chaudhry IB, et al. Psychosocial Correlates of Self Harm: Perspectives from Pakistan. Journal of Psychosomatic Research. 2016 Jun 1;85:68.
9) Nobody told me about it! A qualitative study of barriers and facilitators in access to mental health services in women with depression in Karachi, Pakistan**.** **Batool Fatima**, Ulrike Boehmer, Frank Feeley, Susan Foster. Journal of Psychosomatic Research. 06/2015; 78(6).
10) EPV07 -e-Poster 07: Cultural Psychiatry Key Informant's Perspective On Barriers and Facilitators in Access to Mental Health Services for Women with Depression in Urban Area of a Low-income Country **B Fatima** · B Ulrike · S Foster · F G Feeley. European Psychiatry 03/2015; 30(1):1290. DOI:10.1016/S0924-9338(15)31009-9
11) Group Interpersonal Psychotherapy For Maternal Depression: An Exploratory RCT**.** Husain N, Naqvi Z, Chaudhry N , Khoso A , Kiran, T Naeem S, **Batool F,** Naeem F. *Journal of Pakistan Psychiatric Society. 12(1),75. March 2015*
12) No one ever asked about it! barriers in access to mental health services for women accessing treatment from primary care in Karachi. **Fatima B,** Boehmer U, Frank F, Foster S. European Psychiatry. 2014; 29, Supplement 1:1
13) Antidepressants and group psychosocial treatment for depression: an RCT from a low income country**.** N. Husain, N. Chaudhry, **B. Fatima,** M. Husain, R. Amin, I.B. Chaudhry, R.U. Rahman, S.U. Haq, F. Jaffery and F. Creed. European Psychiatry, Volume 25, Supplement 1, 2010, Page 1393.
14) Batool Fatima. Depression in women and Mental Health Services in Karachi, Pakistan - Do we need to address the gap? Presented in American Public Health Association's 138th annual meeting and expo 9th Nov, 2010
15) Batool Fatima. Challenges in the Implementation of Mental Health Law in Pakistan & its implications on the quality of life and human rights, Presented in American Public Health Association's 138th annual meeting and expo 9th Nov, 2010.
16) Ethical Challenges in the implementation of Voluntary Counseling and Testing (VCT) Program Pakistan and Strategies adopted, Indian Journal of Medical Ethics, Vol II 2005 Supplement.
17) Innovative approaches to reduce myths and increase acceptability of interventions in a conservative society, Ghauri AK, Bilgrami M, Siddiqui H, **Fatima B,** Arain I, Iqbal K, Jafri SI; International Conference on AIDS (15th: 2004: Bangkok, Thailand).

Reports / Training Material:

- Provided technical, cultural review and input in the development of HIV Counselling Trainer's manual for Asia Pacific

- Developed curricula for communicating with HIV positive clients (Presentation, guidance notes and reference material), conduct training and update the material as per the participant's feedback, July, 08

Grants:

- **Lead-applicant: 2013–2015:** (Lead investigator Batool Fatima) **Grand Challenges Canada, Global Mental Health Seed Grant (Ca$ 249,000)**. Participatory intervention to reduce maternal depression and under five child morbidity– A cluster-randomized controlled trial.
- **McNamara Memorial Fund Educational Grant** – 2011 (USD 12,000)

Awards:

- **Fulbright Scholarship** – 2009
- **Fellow NFP** - Netherlands Fellowship Programme (NFP), funded by the Netherlands Government. 2008
- **Fellow LDM Pakistan** (Leadership Development for Mobilizing Reproductive Health - International Institute of Education) 2004