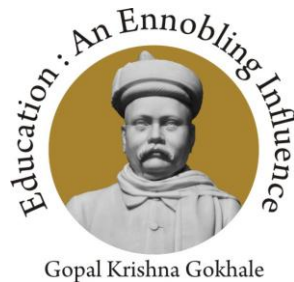


# **Supply and Demand Gap in Mental Health:** A Study of Patients from YMH, Pune

Thesis submitted for the award of the degree of  
Doctor of Philosophy  
in  
Economics

by  
**Anil Vartak**

Under the Supervision of  
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**Gokhale Institute of Politics and Economics**  
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# **Supply and Demand Gap in Mental Health:**

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**DECLARATION**

I hereby affirm that the thesis titled **Supply and Demand Gap in Mental Health: A Study of Patients from YMH, Pune** submitted to the Gokhale Institute of Politics and Economics, Pune, for the award of the Degree of Doctor of Philosophy in Economics, is a record of original and independent research work done by me under the supervision and guidance of Dr. R. Nagarajan, Associate Professor, Gokhale Institute of Politics and Economics, Pune and has not previously formed the basis for the award of any Degree, Diploma, Associateship, Fellowship or other similar title to any candidate of any University.

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**Certificate**

This is to certify that the thesis titled **Supply and Demand Gap in Mental Health: A Study of Patients from YMH, Pune** is a record of original research work done by Mr. Anil Vartak in Economics as a part-time Research Scholar under my guidance and supervision for the award of the Degree of Doctor of Philosophy in Economics. I further certify that this research work has not previously formed the basis for the award of any other Degree or Diploma or Associateship or Fellowship or other similar title to any candidate of this or any other University.

Date: February 24, 2016

**Dr. R. Nagarajan**  
Research Supervisor

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## Abbreviations

BOD	Burden of Disease
CD	Consultation Delay
DALYs	Disability Adjusted Life Years
DD	Duration of discontinuation
GP	General Practitioner
HHs	Households
HIC	High Income Countries
LIC	Low Income Countries
LMIC	Low and Middle Income Countries
MH	Mental Health
MI	Mental Illness
MRD	Months of Recognition Delay
MDD	Duration of discontinuation in months
NPT	Non-Psychiatric Treatment
MNPT	Months of Non-Psychiatric Treatment
OPD	Outpatient Department
OTD	Overall Treatment Delay
PD	Period of Discontinuation
PHC	Primary Health Centre
PMI	Person with Mental Illness
PT	Psychiatric Treatment
RD	Recognition Delay
TD	Treatment Delay
YMH	Yerwada Mental Hospital



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## Chapter I

### Introduction

*“Disabled people are not only the most deprived people in the developing world, they are also the most neglected.”*

*(Sen & Wolfensohn, 2005, p,518)*

Economic development is the ultimate goal of any economy. Economic development includes not only increase in gross domestic product (GDP) or increase in availability of goods and services, but reduction in income inequality, increase in standard of living of masses, increase in the level of education and improvement in health status of the population. For a long time increase in health status was basically understood in terms of increase in life expectancy at birth (LEB) and decrease in infant mortality rates (IMR). In the development literature, it was understood that economic growth leads to a rise in per capita income which enables a population to afford better healthcare services, and provide greater access to improved water and sanitation facilities, all of which have a positive impact on infant and child mortality and life expectancy.

However, health was not considered as an important input influencing economic performance of a country. Research on economic growth was solely focused on the role of physical and financial capital, and labour force. The latter was basically seen in terms of its skill levels and efficiency, which are, no doubt, of extreme importance in the light of rapid changes in technology, especially since the formation of World Trade Organization. However, health status of labour force was hardly given attention as an important input for economic development. However, in the last three decades researchers have noted that improved health leads to an increase in productivity, lesser absenteeism (due to lesser instances of illness) and longer working life for an individual. All these changes have positive influence on economic performance of a country. Hence, for any society

continuous improvement in health status of its population is necessary for ensuring higher rate of growth of the economy.

### **Importance of good health**

Good health is an important asset for individuals. Traditionally, absence of any physical disease was commonly understood as a sign of good health. However, absence of any disease is, of course, necessary for good health, but other dimensions of health like mental and social well-being are equally important. Hence, WHO at the time of its inception in 1948 defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948, p,100). Good health, in all its dimensions, is important for an individual, not only for its own sake, but also for a happy and peaceful life, for developing and maintaining social relationships and for contributing to the production activity of the society. It provides the foundation for stability and growth of individuals, families and societies.

Any departure from good health or instances of ill-health affects all of them negatively: (1) an individual has to bear pain, suffering, loss of work and expenses on treatment; (2) a family has to bear a loss of time, income in caring and expenses on treatment and impoverishment; (3) a society has to experience loss of hours of work and production and other ill-effects arising due to it.

Summing up, any departure from good physical health or good mental health affects individuals, caregivers and society negatively.

### **Mental illness: Popular perception**

Mental illness is as old as the human race itself. Early societies noticed that there were abnormal changes in behaviour and thinking of individuals, which affected their day to day functioning, work and relationship. Moreover, these changes were different from those related to bodily or physical illnesses. However, the traditional societies could not understand the nature, causal mechanism and solution to these problems. Since no systematic and scientific explanation of these illnesses was available, according to the

custom of the time, spiritual and magico- religious explanations were accepted as the cause and solutions to these problems. In tribal societies supernatural visitation and environmental shock are still seen as the causes of mental illness. In India, it is commonly believed that one's karma or actions in a past life determine the success, failure and illness of the present life. Hence, severe (and chronic) illnesses like mental illnesses were perceived as punishment for wrong doing in the past (Khandelwal, Jhingan, Ramesh et. al., 2004).

### **Mental Illness: Modern explanations**

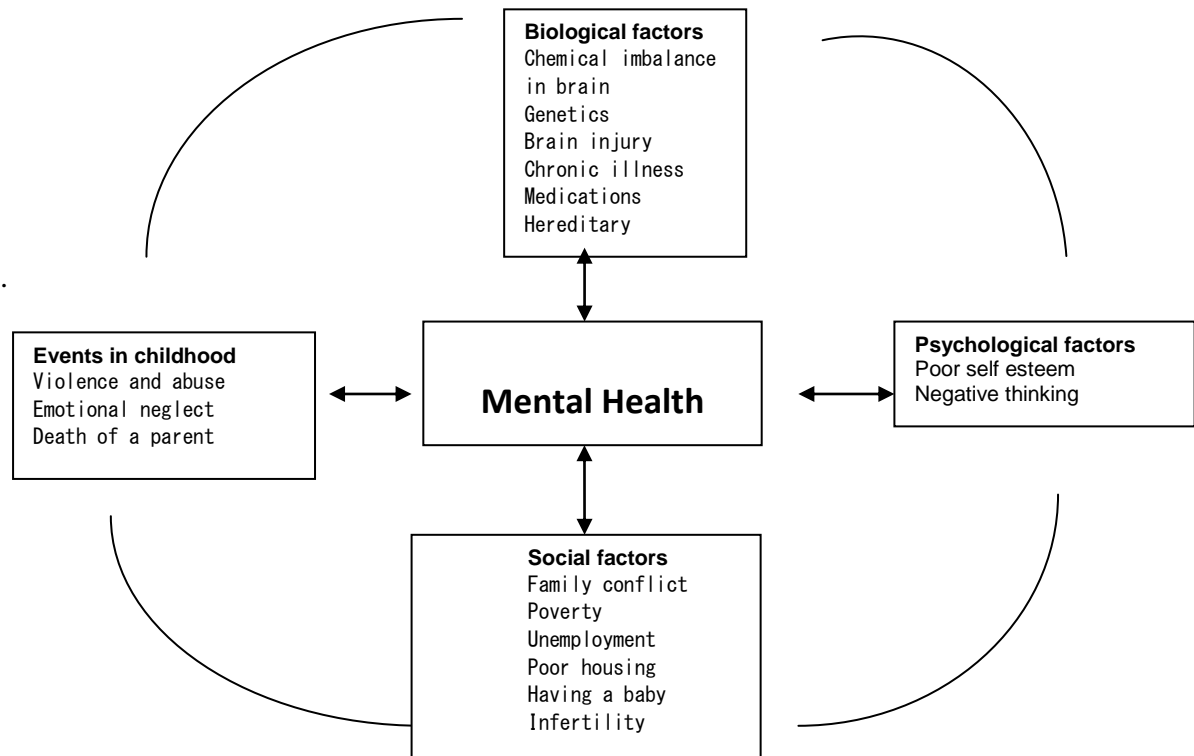
In the last two centuries curiosity, interest and research in mental illnesses have steadily increased. Mental illnesses, which were inexplicable in the earlier centuries, gradually were seen as medical or biological problem in the scientific community. Research in anatomy, understanding, role, functioning and importance of brain facilitated this process. Epidemiological and etiological research helped to understand causal factors and mechanism of mental illness. Now it is well understood by the scientific community that like physical illnesses, mental illness is a biological or medical problem and social, psychological and environmental factors influence its emergence, growth and future course.

Mental and behavioural disorders are understood as clinically significant conditions characterized by alterations in thinking, mood (emotions) or behaviour associated with personality distress and/or impaired functioning (WHO, 2001, p,21). Various factors have been suggested as causal factors. Nature (that is, role of genetic factors) was a dominant theme earlier. Since the fifties, nurture (that is, role of environment) is regarded as an important causal factor. That was the time when argument of nature vs. nurture was debated. However, now it is well accepted that both nature and nurture are equally important (WHO, 2001). National Institute of Mental Health and Neurosciences (NIMHANS, 2009) has given six causal factors for occurrence of mental disorders, viz., changes in the brain, hereditary factors, childhood experience, home atmosphere, social factors and individual factors.



These factors are usually grouped into four broad domains, i.e., biological, psychological and social factors, and childhood events. They interact and decide the nature, extent and type of mental illness. The following figure considers and groups them in to four domains.

**Figure 1.1**  
**Factors causing mental disorders**



Source: (Basic Needs, 2009, p,25).

### **Impact of mental disorders**

Mental disorders have a lasting impact on individuals, families and society. Individuals suffer due to distressing symptoms, loss of work and leisure activities, feeling of shame and guilt, and very stigma and discrimination in society. Families have also to suffer in a variety of ways. They have to bear the cost of treatment, loss of income due to caring, stress of coping with family member's symptoms and often stigma and discrimination owing to disorder in the family. Impact of mental disorders on society is

large and manifold. It includes cost of health care, loss of productivity and several non-health care costs. Knowledge of the size of burden of each one of the diseases is important for the purpose of health policy planning and for deciding allocation of resources among different competing health issues. Impact of mental disorders is measured with the help of burden of disease measures.

### **Burden of a disease (BOD)**

It can be measured with the help of two approaches- epidemiological approach and economic or cost of illness approach. In epidemiological approach, BOD is measured with the help of health status indicators like mortality or morbidity rates – namely, prevalence or incidence and disability rates. These rates reflect spread or severity of a disorder. Economic burden or cost of illness approach measures the total cost of illness calculated in monetary terms for the individual, family, employer and society. Both these approaches look to the problem of burden from different angles and estimate severity accordingly.

### **BOD: Epidemiological Approach**

Traditionally BOD has been measured in terms of prevalence<sup>1</sup> or incidence rate and mortality rate<sup>2</sup> (WHO, 2001; Saxena, Sharan, & Saraceno, 2003a). Prevalence rate is measured in terms of the number of persons having a particular condition either at a point of time or over a period of time. Incidence rate is measured as the number of new cases of a specific disease occurring per 1000 population in a period of one year (Park, 2015,p,60-61). Mortality rate is a measure of the number of deaths, due to either a specific cause or all causes per 1000 population in one year (Park, 2015,p,57).

### **Burden of mental illness**

Due to limited availability of data, incidence rate is not often used as an indicator for measuring BOD. It is the prevalence rate which is often used for understanding the

---

<sup>1</sup> Point prevalence measures the number of persons with a condition at a specific point of time, period prevalence measures the number of persons with a condition over a specific period of time (usually one year) and life time prevalence as the number of persons with a condition during their life span.

<sup>2</sup> This is also called as Crude Death Rate.

severity of illness. Table 1.1 below shows that the aggregate prevalence rate for mental illness is 65 per thousand. Common mental disorders (CMDs) represent a high percentage in the total. It becomes clear that the percentage and number of persons with mental illness are very large. It is not a disorder which is rare or with small percentage and number but it is estimated that as many as twelve crore people are likely to be affected by mental illness is 2015.

<b>Table 1.1 All-India estimates of mental, select neurological and substance use disorders</b>					
Type of mental and behavioural disorder	Prevalence	2001	2005	2010	2015
All-India population (in lakh) <sup>1</sup>		10,280	10,760	11,620	12,450
Major mental/behavioural disorders	65	66,859,671	70,000,710	75,548,395	80,978,755
Schizophrenia	3	3,085,831	3,230,802	3,486,849	3,737,481
Mood disorders	16	16,457,765	17,230,944	18,596,528	19,933,232
Cannabis users	8	8,228,883	8,615,472	9,298,264	9,966,616
Opiate users	2	2,057,221	2,153,868	2,324,566	2,491,654
Mental retardation	1	1,028,610	1,076,934	1,162,283	1,245,827
Child and adolescent disorders	43	25,509,536	26,707,963	28,824,618	30,896,510
Geriatric disorders	3	2,550,954	2,670,796	2,882,462	3,089,651
Dementia	2	1,563,488	1,636,940	1,766,670	1,893,657
Epilepsy	9	9,257,493	9,692,406	10,460,547	11,212,443
Common mental disorders	20	20,572,207	21,538,680	23,245,660	24,916,540
Alcohol users	60	61,716,620	64,616,040	69,736,980	74,749,620
Alcohol dependency <sup>+</sup>	10	10,286,103	10,769,340	11,622,830	12,458,270
* Rate per 1000 population all ages and both sexes. Rates after adjusting to the age distribution. The numbers do not add up as the estimates have been arrived at from individual or pooled or representative studies. See the text for the basis of these estimates.					
<sup>1</sup> This group does not include hazardous alcohol users whose number would be approximately 24 crore.					
This table is reproduced from Gururaj, Girish, & Isaac, 2005.					

Aggregate point prevalence rate for mental disorders is 10 per cent which means that in the year 2010, 700 million persons in the world were suffering from them (Patel &

Saxena, 2013). This number will be 125 million for India. Aggregate life time prevalence for mental disorders is 25 per cent which means that one person in four suffers from mental disorders in their life time (WHO, 2001).

Mortality rates (or premature death) are another important indicator that is used in order to measure the severity of a disease. By using average life expectancy in years and age at the time of death, premature mortality or Years of Life Lost (YLL) due to a disease is calculated. It becomes clear from Table 1.2 below that the share of mental illness in YLL is small while cardio vascular disorders, cancer and AIDS account for a high proportion in YLL or in premature mortality.

<b>Table: 1.2 Proportion of YLLs by ten leading causes of total burden in 2010</b>	
	Proportion of total YLLs (95 per cent UI)
Cardiovascular and circulatory diseases	15.9 per cent (15.0-16.8)
Diarrhoea, lower respiratory infections, meningitis and other common infectious diseases	15.4 per cent (14.0-17.1)
Neonatal disorders	11.2 per cent (10.2-12.4)
Cancer	10.7 per cent (10.0-11.4)
Mental and substance use disorders	0.5 per cent (0.4-0.7)
Musculoskeletal disorders	0.2 per cent (0.2-0.3)
HIV/AIDS and tuberculosis	7.0 per cent (6.4-7.5)
Other non-communicable disease	2.4 per cent (2.0-2.8)
Diabetes, urogenital, blood, and endocrine diseases	3.8 per cent (3.4-4.3)
Unintentional injuries other than transport injuries	5.5 per cent (4.9-5.9)
YLLs = Years of life lost.	
Source: ( Whiteford et. al., 2013,p,1578)	

### **Unsuitability of these measures for mental disorders**

In mental disorders (and other chronic disorders too) patients develop their symptoms. But due to the symptoms people do not die early. What is affected is their functionality (disability) or ability to perform their day to day activities or employment

related or other functions. All persons with mental illness do not become dysfunctional or disabled. However, for a significant proportion of persons affected by mental disorders, disability or loss of functionality of varying degree is a major issue as compared with other chronic disorders. Owing to the disability, people may not be able to continue their education or take up and retain a job, have family and social life and contribute economically.

Disability, which is a major issue in mental illnesses, was paid little attention in the traditional measures of BOD. As a result, diseases with low mortality but high disability (like mental illness) ranked at a lower level. Mental disorder was the most prominent case among them.

WHO in its landmark *Mental Health: New Understanding, New Hope, 2001* for the first time emphatically argued that these (traditional) indices are more suitable to acute diseases that either cause death or result in full recovery (WHO, 2001,p,25). However, use of these measures for chronic and disabling diseases poses serious limitations. This is particularly true for mental health disorders which often cause disability rather than death (WHO, 2001,p,25).

### **Defining disability**

The WHO defines disability as any restriction or lack of it (resulting from impairment) of ability to perform in a manner or within the range considered normal for a human being (WHO, 2001; WHO & World bank, 2011; NSSO,2002). In India, the NSSO considered disability as “Any restriction or lack of abilities to perform an activity in the manner or within the range considered normal for human beings” (GOI,2003). According to the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, "Person with disability" means a person suffering from not less than forty per cent of any disability as certified by a medical authority (any hospital or institution, specified for the purposes of this Act by notification by the appropriate Government). As per the Act, disability means (i) blindness; (ii) low vision; (iii) leprosy-cured; (iv) hearing impairment; (v) loco motor disability; (vi) mental retardation; and (vii)

mental illness. In all these definitions, individuals with certain physical, intellectual, psychological and mental conditions (impairment) are regarded as pathologic or abnormal; it is simply the abnormality conditions themselves that are the cause of all restrictions of activities. This is the essence of medical model of disability (Chaudhari, 2006).

Disability is complex, dynamic and multi-dimensional. Recently due to movement of disabled people and research, the role of social and physical barriers in disability has been accepted. This has resulted in the transition from an individual, medical perspective to a structural, social perspective. This is described as the shift from a “medical model” to a “social model” in which people are viewed as being disabled by a society rather than by their bodies (WHO & World bank, 2011,p,4).

The medical model and the social model are often presented as dichotomous. World report on disability (WHO & World bank, 2011) takes a balanced approach and understands disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental. Disability is defined as “Umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (WHO & World Bank, 2011,p,4).

All these definitions highlight reduced ability or functionality as an important outcome of a disease which needs to be accounted whatever may be causal factor/s for it.

### **Global burden of disease project**

In order to overcome this difficulty, in the early 1990s a pioneering project was undertaken at Harvard School of Public Health in collaboration with WHO and World Bank. Global burden of disease project (GBOD) was led by two eminent health economists, Murray and Lopez. They suggested a new matrix, a composite indicator DALY-Disability Adjusted Life Years. The latter includes two indicators, Years of Life Lost (YLL) due to premature death and Years of Life Lived with Disability (YLD). DALYs lost for a disease is the sum of YLL and YLD (Murray & Lopez, 1996). DALYs

provide a representative picture of disease burden. Use of DALY as a new indicator dramatically changed ranking of diseases according to their burden. The disease, which ranked at a lower position on mortality scale but contributed significantly on a disability scale, ranked at a much higher position when the new criterion of DALY is used. Mental disorder is one among such diseases.

<b>Table: 1.3 Proportion of YLDs, YLLs, and DALYs explained by the ten leading causes of total burden in 2010</b>			
Name of the disease	Proportion of total DALYs (95 per cent UI)	Proportion of total YLDs (95 per cent UI)	Proportion of total YLLs (95 per cent UI)
Cardiovascular and circulatory diseases	11.9 per cent (11.0-12.6)	2.8 per cent (2.4-3.4)	15.9 per cent (15.0-16.8)
Diarrhoea, lower respiratory infections, meningitis and other common infectious diseases	11.4 per cent (10.3-12.7)	2.6 per cent (2.0-3.2)	15.4 per cent (14.0-17.1)
Neonatal disorders	8.1 per cent (7.3-9.0)	1.2 per cent (1.0-1.5)	11.2 per cent (10.2-12.4)
Cancer	7.6 per cent (7.0-8.2)	0.6 per cent (0.5-0.7)	10.7 per cent (10.0-11.4)
Mental and substance use disorders	7.4 per cent (6.2-8.6)	22.9 per cent (18.6-27.2)	0.5 per cent (0.4-0.7)
Musculoskeletal disorders	6.8 per cent (5.4-8.2)	21.3 per cent (17.7-24.9)	0.2 per cent (0.2-0.3)
HIV/AIDS and tuberculosis	5.3 per cent (4.8-5.7)	1.4 per cent (1.0-1.9)	7.0 per cent (6.4-7.5)
Other non-communicable disease	5.1 per cent (4.1-6.6)	11.1 per cent (8.2-15.2)	2.4 per cent (2.0-2.8)
Diabetes, urogenital, blood, and endocrine diseases	4.9 per cent (4.4-5.5)	7.3 per cent (6.1-8.7)	3.8 per cent (3.4-4.3)
Unintentional injuries other than transport injuries	4.8 per cent (4.4-5.3)	3.4 per cent (2.5-4.4)	5.5 per cent (4.9-5.9)
Abbreviations are already explained above.			
Source: (Whiteford et. al., 2013,p,1578)			

Table 1.3 shows the share of mental illness in the DALYs lost, in YLL and in YLD of the ten leading diseases at the global level. The share of mental disorder in premature mortality, i.e., YLL is very small at 0.5 per cent. However, the share of mental disorders in

YLD due to all the diseases is the highest at 22.9 per cent. Due to such a high share in YLD, mental disorders account for 7.4 per cent of DALYs lost due to all the diseases which is the fifth highest percentage, preceded by cardio vascular, respiratory, neonatal and cancer.

Table 1.4 below shows shares of various individual mental disorders in the total DALYs, YLDs and YLLs lost. Depression is the single most important cause accounting for more than one-third of the total DALYs lost. Depression and anxiety disorders (which are often ignored by individuals, families and society) account for around half of the DALYs lost due to all mental disorders. Alcohol and substance abuse disorder, schizophrenia and bi-polar disorders also constitute a significant percentage of DALYs lost.

<b>Table: 1.4 Proportion of DALYs, YLDs and YLLs explained by type of mental illness in 2010</b>			
	Proportion of total DALYS (95% UI)	Proportion of total YLDs (95% UI)	Proportion of total YLLs (95% UI)
Depressive disorders	40.5 (31.7-49.2)	42.5 (33.-51.7)	0
Anxiety disorders	14.6 (11.2-18.4)	15.3 (11.7-19.3)	0
Schizophrenia	7.4 (05.0-09.8)	7.4 (04.6-10.8)	7.1 (04.8-10.2)
Bipolar disorder	7.0 (04.4-10.3)	7.4 (04.6-10.8)	0
Eating disorders	1.2 (00.9-01.5)	1.1(00.8-01.5)	2.4 (01.4-03.4)
Childhood behavioural disorders	3.4 (02.2-04.7)	3.5 (02.3-04.9)	0
Pervasive developmental disorders	4.2 (03.2-05.3)	4.4 (03.4-05.6)	0
Idiopathic intellectual disability	0.6 (00.3-00.9)	0.6 (00.4-01.1)	0
Alcohol use disorders	9.6 (07.7-11.8)	7.9 (06.0-10.0)	44.4 (29.1-60.0)
Drug use disorders	10.9 (08.9-13.2)	9.4 (07.3-11.5)	41.7 (27.9-56.9)
Other mental disorders	0.8 (00.5-01.2)	0.6(00.4-00.9)	4.3 (02.40-6.3)
Source: (Whiteford et. al., 2013,p,1578).			



## Burden of Disease Economic Approach

Economic or Cost of Illness approach tries to capture economic impact of diseases. It measures costs that various stakeholders like individual, family, employer and society have to bear due to mental illness. These costs are classified as 1) Direct and indirect costs, 2) Measurable costs and non-measurable or intangible costs, and 3) Core costs and non-health care costs. Direct costs include cost of treatment/cost of medicines, fees of professionals and hospitalization charges, transportation cost for commuting and other costs to various government departments. Indirect costs basically include loss of productivity due to time lost (of patient and caregiver).

Measurable costs include all the costs for which expenditure is made (direct costs) or the costs for which monetary value can be imputed (indirect costs). Non-measurable or intangible costs which basically include psychological and emotional cost that individual and family have to bear. The costs include pain and suffering, hopelessness, guilt, stigma and social exclusion due to mental illness. Though these costs are non-measurable, they pose a significant burden on the individual and family ((WHO, 2001; WHO, 2003). They are much higher for mental disorders when compared with similar costs for physical illnesses (WHO, 2003; WHO, 2013).

<b>Table 1.5 Types of measurable costs</b>		
	Core costs	Other non-health care costs
Direct costs (payments made)	Treatment and service fees/payments	Social welfare administration Public and private criminal justice system Transportation
Indirect costs (resources lost)	Morbidity cost (in terms of value of productivity lost) Mortality costs	Value of family caregivers time
Source: (WHO, 2003. Investing in Mental Health,p,14)		

Core costs are related to availing mental health services and loss of productivity, either due to morbidity or premature mortality. Other non-health care costs include transportation cost and costs that government departments (like social welfare, justice,

etc.,) have to bear. Table 1.5 summarizes measurable costs cross classified into direct and indirect costs and core and other non-health care costs. Table 1.6 provides all economic costs and different stakeholders who have to bear these costs.

<b>Table 1.6 Overall economic burden of mental disorders</b>			
	Care costs	Productivity costs	Other costs (non-measurable)
Sufferers	Treatment and service fee/payments	Work disability; lost earnings	Anguish/suffering, treatment side effects and suicide
Family and friends	Informal care-giving	Time off work	Anguish, isolation, stigma
Employers	Contribution to treatment and care	Reduced productivity	-
Society	Provision of mental health and general health care (taxation and insurance)	Reduced productivity	Loss of lives, untreated illness (unmet needs), social exclusion
Source: (WHO, 2003, Investing in Mental Health, 2003,p,14)			

Estimating the cost of illness (absolute and relative) is important as it gives an idea of the economic impact of illness. Attempts to measure costs of mental illness are of recent origin. All of these studies are from high income countries. There is not a single study from low or middle income countries (including India) which measures the cost of mental illness. it should be noted that some of the costs are difficult to measure (Knapp, 2003). Table 1.7 provides details of these studies along with estimates of their costs.

<b>Table 1.7 Estimates of cost of illness, share of indirect cost and cost as a percentage of GNP by country and study</b>					
Country	Researcher	Year for which cost is estimated	Cost in dollars	Share of indirect cost	Percentage of GNP
USA	Rice et. al., 1990	1985	218.1 Bn (Aggregate Yearly cost)		2.5
USA	Market et. al., 2000	1997	85.3 Bn spending on treatment for mental illness and substance abuse	55	
UK	Patel and Knapp, 1998		32 bn	45	
EU	ILO, 2000		Euro 108 Bn		3-4
Canada	Stephens and Joubert, 2001	1998	14.4 bn		
Nether Lands	Meerding et. al.	1998	23.2 per cent (share of mental health cost out of total health costs)		
World	World Economic Forum	2011	2.5 Tr. (2010) 6.0 Tr. (2030)	67 67	

*Note: Consistent data are not available for all the headings.*  
Source: WHO, 2001; HU, 2006; World Economic Forum, 2011; Rice, Kelman, Miller et.al., 1990; (Meerding, Bonneux, Polder et.al, 1998; Patel & Knapp, 1998; Teh, 2004;

### **Changing scenario of disease burden and growing importance of mental health problems**

Disease burden measured in terms of DALYs lost, absolute and share of each disease in the total, is useful for understanding changing relative importance of disease burden scenario. This burden is changing rapidly in India and the world over due to social,

cultural, demographic, technological and other changes that are taking place. This is particularly true for BOD due to mental disorders. Following are the features of the changing burden of disease scenario.

### *1. Changing composition of disease burden*

Communicable Diseases (CDs) and Non-Communicable Diseases (NCDs) constitute total BOD. CDs imposed higher BOD in the fifties and sixties in the greater part of the world. However, due to increasing immunization and effective control of CDs, its spread and burden has declined substantially. The trend, which started in the High Income Countries (HIC), is now observed in Low Income Countries (LIC). India has shown a marked decline in BOD (DALYs lost) due to CDs. In 2004, DALYs lost due to NCDs were 62 per cent in India, while that due to CDs were 38 per cent (GOI, 2014; World Bank, 2011). This is expected to increase rapidly in the years to come. Another trend is a shift in the disease burden from YLL to YLD (Whiteford, Degenhardt, Rehm et.al. 2013)

### *2. Growing urbanization*

The world over population is gravitating towards cities, which are increasingly overburdened due to continuous flow of people towards them. They are facing an acute shortage of space, congestion on roads, over-crowded localities, rising air and water pollution, and crumbling infrastructure. The world over 54 per cent of the people lived in urban areas in the year 2014 vis-a-vis 43 per cent in the year 1991. This percentage is expected to increase to 66 per cent in 2050. In India 32 per cent of the population lived in urban area in 2014 vis-a-vis 26 per cent in the year 1991. This is expected to increase to 50 per cent in the year 2050 (United Nations, 2014). This pace of urbanization is not only undesirable from the point of view of urban infrastructure, but also imposes negative mental health consequences. It is well documented that MHPs are positively correlated with the degree and nature of urbanization that takes place in a society (Thornicroft & Patel, 2014).

### *3) Increase in Life Expectancy*

Another factor that has a bearing on disease burden in general and MH problems in particular is the rise in life expectancy of the population. This has resulted in a growing proportion of people aged 60+ the world over including India. A rise in aging population will lead to a rise in BOD due to NCDs in general and mental illnesses in particular. Parkinson's disease, Alzheimer's disease, dementia and other geriatric disorders are on the rise. In India life expectancy at birth has increased to 66 years in 2013 from 58 years in 1990.

### *4) Civil wars and chaos*

Civil wars, which erupt in different parts of the world and resultant dislocation of population due to political and economic uncertainty result in increased stress and mental health problems for the affected population (Brundtland, 2000). Many countries in Africa and Asia, which gained independence after the Second World War along with many Latin American countries are facing political, military and economic crises.

### *5) Radical shifts in the society*

Stability in the structure and support of the family and society are prerequisites for good mental health of the population. However, second half of the twentieth century and first decade of the twenty-first century have experienced rapid shifts in the society towards technology, changes in family, societal support, networks and commercialization of existence. This may account for current epidemic of depression and other psychiatric disorders (Brundtland, 2000).

### **Purpose of this study**

All the above factors indicate that the burden of mental illness is going to increase in the times to come. This study has been undertaken with a view to understanding the extent to which this burden is being addressed by individuals, families and society. It goes

further and defines the deficiencies in response of government/society and families as supply and demand gap in mental health respectively. It was undertaken to understand the supply and demand gap for mental health in terms of its size and determinants. Supply gap and its determinants has been widely discussed, but demand gap, its components and determinants have been discussed only to a limited extent. This research effort has been primarily undertaken to fill this gap.

### **Chapter scheme of the thesis**

This thesis is divided into eight chapters. Chapter I presents various estimates of the burden of mental illness and trends in it. Chapter II provides a review of literature of the concepts of supply and demand gap and their determinants. Chapter III presents methodology used for collecting data from the sample households and nature of questionnaire used. Chapter IV discusses the background characteristics of the sample households. In Chapter V findings about the extent of MRD and MNPT are presented. Chapter VI examines the inequality in MRD, MNPT and PD among sample households according to social, demographic, economic, medical and geographic characteristics. The inequality is statistically analysed with Pearson correlation coefficient, OLS regression and Logistic Regression. In Chapter VII measures to reduce supply and demand gap are discussed. Finally, Chapter VIII provides a summary of the findings.

## Chapter II

### Review of literature

*Mental health has been hidden behind a curtain of stigma and discrimination for too long. It is time to bring it out into the open. The magnitude, suffering and burden in terms of disability and costs for individuals, families and societies are staggering. In the last few years, the world has become aware of this enormous burden and the potential for mental health gains. We can make a difference using existing knowledge ready to be applied. We need to enhance our investment in mental health substantially and we need to do it now.*

(WHO, 2003,p,3).

### Huge treatment gap and treatment lag

Even though prevalence, disability and BOD of mental illness are heavy, the use of mental health services is much less. This is so not only in the developing countries but also in the developed countries. This is indicated by two measures: treatment gap and treatment lag. 'Treatment gap' is the percentage of people who need treatment but do not receive it while 'Treatment lag' refers to the period for which no treatment is given since the onset of symptoms.

Treatment gap is very large the world over. For the developed countries, it is 20 to 40 per cent, while in developing countries up to 90 per cent of those with mental illness do not receive any treatment (Movement for Global Mental Health, 2015). The treatment gap is high even when compared with other physical disorders (Saxena, Sharan, & Saraceno, 2003a; Thornicroft & Patel, 2014). It was found in an Australian study that less than 30 per cent of patients with depression received acceptable standard care, while 80 per cent and 90 per cent of patients of arthritis and asthma respectively receive such care (Andrews & Titov, 2007,p,809).

Treatment lag is also high. It varies from few months to several years. Treatment lag is also significant worldwide and varies from few months to several years. It has been found that treatment lag or delay in initiating treatment is higher for developing countries as compared with developed countries and higher for common mental disorders as

compared with major mental disorders (Lahariya, Singhal, Gupta, 2010; Jain, et al., 2012; Thompson, Issakidis & Hunt, 2008).

This condition is dismal. It is the result of two gaps: supply gap and demand gap in mental health services. Supply gap is deficiency in the variety of resources required while providing mental health services. Resources include funding, human resources, hospital beds, other infrastructure, legislation and policy. Demand gap is the time taken to initiate treatment since the onset of symptoms.

### **Need of resources for mental health**

Resources are required to overcome any deviation from good health. These resources may be internal<sup>1</sup> to the affected persons like his/her will power, hope and efforts or they may be external in terms of financial, medical, human resource and other material and infrastructural services. Resources for mental health (external) include mental health policy, plans, legislation, mental health treatment services, infrastructure, community mental health services, human resources and funding. Like any other health sector, mental health sector can perform if adequate resources are made available. Moreover, the resources that are provided have to be used equitably<sup>2</sup> and in an efficient<sup>3</sup> manner. The resources for mental health are discussed below-

#### *1. Policy*

Mental health policy is an official statement of the government regarding areas of actions in order to improve the mental health of a population. It includes organized set of

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<sup>1</sup> Even, in order to raise internal resources, there is a need for external resources. For example, to have enlightened civil society or informed and empowered stakeholders (users of service, family caregivers and professionals) resources are required to educate the stakeholders, make available necessary platforms and initiate required activities. This will include publication of literature, newsletters, books, release of films/documentaries and self-help activities.

<sup>2</sup> Equity refers to the distribution of resources either in terms of rural-urban or province/district wise or distribution by socio-demographic characteristics. Equitable distribution is necessary in order to have equal opportunity in access to health services for the entire population

<sup>3</sup> For any health issue, there may be a variety of health services/treatment services. The principle of efficiency argues that resources need to be allocated in such way that returns are similar per unit of investment/expenditure on the variety of services.



values, principles, objectives and areas of action for promotion of mental health, the prevention of mental disorders and treatment and rehabilitation. It provides vision for the future and enables a model for action. The policy also indicates the degree of priority that a government attaches to mental health in relation to other health and social policies. Generally, the policy is for a long period, e.g., 5 to 10 years (WHO, 2004; WHO, 2011).

Key principles and components remain the same from one country to another even though the content varies according social, demographic and economic conditions (WHO, 2003). Properly designed mental health policy and its implementation ensures adequacy of services and activities, and their effective coordination. Well articulated mental health policy is an essential condition for improving mental health status of the population and reduce burden of disease due to mental illness.

## *2. Plans and programmes*

Mental health plan is a detailed pre-formulated scheme that elaborates the strategies and activities that will be implemented to realize the objective of the policy. It includes important elements like strategies, time frames, resources required, targets to be achieved, indicators and activities. Mental health plan also clarifies role of different stakeholders, while implementing the plan (WHO, 2011).

A mental health programme is an intervention or series of targeted interventions, usually with a short time span for the promotion of mental health, prevention of mental disorders, and treatment and rehabilitation. A programme usually focuses on specific mental health priority and like mental health plans needs to be properly designed, budgeted, monitored and evaluated (WHO, 2011; WHO, 2004).

Mental health policies and plan (and programmes) are essential and powerful tools to coordinate all services and activities related to it. Without a properly designed policy, plans and programmes for mental disorders are likely to be treated in an inefficient and fragmented manner (WHO, 2004) (WHO, 2003).

## *3. Legislation*

Mental health legislation is necessary for protecting the rights of persons with mental disorder who comprise a vulnerable section of the society. It includes a broad range

of issues including admission to a mental facility, quality of mental health care, consent to treatment, freedom from cruel, inhuman and degrading treatment, freedom from discrimination, enjoyment of full range of social, political, cultural and economic rights and provision of legal mechanism to promote and protect human rights. All the issues relevant to mental health, i.e., mental and general health as well as non-health issues may be included in a single document, i.e., in a dedicated mental health legislation (WHO, 2011). The legislation helps to reinforce goals of mental health policies and plans (WHO, 2011).

#### 4. *Human resources*

For provision of a health care service, health professionals are essential along with equipment and technology. However, mental health care relies basically on professionals rather than on equipment and advanced technology. Human resource is the most valuable asset of a mental health service and hence it relies on competence and motivation of its personnel. Mental health professionals include psychiatrists, medical doctors, psychiatric nurses, social workers and occupational therapists. Due to a severe shortage of human resources in the mental health sector, even other non-specialist resources like health workers, trained volunteers, trained service users like family members, and even persons with mental illness are seen and used as a human resource, may be to a limited extent.

#### 5. *Financial resources*

Finance is another important resource for mental health. Other resources, even if, provided adequately do not have any meaning unless backed by adequate financial support from the budgets of the central government, state and local governments. Financial resources enable the government to purchase required human workforce, spend on infrastructure facilities, support education and training facilities, purchase medicines and equipment, and to meet other miscellaneous expenses. The WHO (2003b) asserts that ‘without adequate financing mental health policies and plans remain in the realm of rhetoric and good intentions’

## 6. *Community and family resources*

Community resources that provide mental health care include formally structured bodies like international non-government organizations and indigenous non-government organizations (NGOs), consumer and family associations and informal resources of family, friends and other social network that bear most of the burden of care. (Saxena, Thornicroft, Knapp et.al., 2007; Patel & Thara, 2003). Community resources include traditional healers, alternative health care systems and community-based social and rehabilitation measures. (Saxena, Thornicroft, Knapp et.al., 2007). Each of these resources is essential for improving mental health status of the population.

## 7. *Mental health infrastructure*

Mental health infrastructure is related to all physical structures, gadgets and equipments that are required to provide mental health services. It includes mental health outpatient facilities, treatment facilities, psychiatric wards, residential facilities, mental hospital and community-based treatment and rehabilitation centres. These facilities need to exist in adequate number for a given size of population. Desired ratios of some of these facilities per lakh population have been recommended. (Appendix I)

### **Resources for mental health at the global and Indian levels**

Tables 2.1 and 2.2 take an overview of supply of resources at the global level and in India. Most of the information for Table 2.1 is procured from WHO *Mental Health Atlas* 2011 and 2014 (WHO, 2011; WHO, 2014). However, additional references are quoted wherever they are used. Comparing BOD of mental illness and resources allocated clearly indicates that there exists significant mismatch between BOD of mental illness and resources that are supplied for it. The gap between percentage of BOD of mental illness (in the total health burden) and percentage of resources supplied for mental health (out of resources for all health issues) is huge and rising. Resources are in short supply in all domains ((NHRC and NIMHANS, 2008). However, these shortages vary from one particular type of resource to another, and among both developed and developing countries. National health policy 2015 clearly admits that the gap between service utilisation and needs is widest here (in mental health) (GOI, 2014)

<b>Table 2.1: Resources for mental health at the global level – A report card</b>		
<b>Resources</b>	<b>Current status</b>	<b>Details</b>
Policy	All countries do not have dedicated MH policy.	Sixty per cent countries have dedicated MH policy. However, 76 per cent of them have updated or approved it recently (after 2005). Seventy-seven per cent of the countries report that MH is mentioned in their general health policy.
	Inequality in presence of MH policy	In low and low middle countries, roughly half have approved MH policy. This percentage is high for high income countries at 77 per cent.
Plans and programs	All countries do not have plan for MH	Seventy-two per cent of the countries have mental health plan.
	Inequality in presence of MH plan	Sixty-two per cent among low income countries have MH plan. This percentage rises as one moves from lower income group to higher income group. This per centage is as high as 87 per cent for high income countries.
	Inefficiency in MH plan	Among all the countries that have approved MH plan, 20 per cent do not have timeline for implementation of the plan, 45 per cent do not provide funding, twenty-four per cent do not state shift from Mental hospital to community mental health centres and 12 per do not emphasize integration of mental health with primary care.
Legislation	Small per centages of countries have dedicated MH legislation.	Fifty-nine per cent countries have dedicated mental health policy. However, almost half of them have enacted or revised it after 2005.
	Inequality in MH legislation.	Among low income countries, a small percentage has dedicated MH policy (39 per cent). With increase in income, this percentage rises. For high income countries it is 77 per cent.
Expenditure on mental health in health budget	Low per capita expenditure on mental health and low share of mental health expenditure in health budget	Global median expenditure per capita is \$1.63. Global median of government health budget expenditure dedicated to mental health is 2.8 per cent.
	Inequality in allocation of funds within the countries	Per capita global median expenditure for low income countries is \$ 0.20 which increases to \$44.84 for high income countries. Lower income countries spend 0.53 per cent of their health budget on mental health. This percentage rises as a country moves to higher income group (5.1 percent).
	Inefficiency in use of resources	Large share of mental health budget expenditure is made on mental hospitals. For low income countries this per centage is more than 73per cent. This per centage falls to 54 per cent for high income countries. However, even this percentage is much high considering ideal norms for allocation of resources.

Human resources	Low availability of human resources in mental health.	Global median rate of health workers in mental health is 10.7 per lakh population. However, this rate varies across different specialties of human resources in mental health. This rate is as high as 5.80 for nurses and 0.05 for occupational therapists per lakh of population.
	Inequality in availability of human resources.	Availability of each type of human resources varies across the country income group. In low income countries availability of occupational therapists, psychiatric social workers and psychologists is almost nil or very small. Inequality among low and high income categories is greatest in these specialties. The degree of inequality among low and high income countries is relatively small in the specialties of nurses, psychiatrists and other medical doctors.
	Inefficiency in use of human resources	In significant number of countries, psychiatrists and nurses work exclusively in mental hospitals
Mental health infrastructure	Availability of beds and other facilities is limited	Globally, the number of outpatient facilities, day treatment facilities, community residential facilities and psychiatric beds are very low per lakh of population. However, these facilities are negligible in low income countries and much more for higher income countries.
Community resources and informal resources	Users and family associations are limited	Globally, user and family associations are present in 64 and 62 per cent of the countries respectively.
	Inequality	In high income countries the presence of user and family associations are 83 and 80 per cent respectively while in low income countries, they are 49 and 39 per cent respectively.
	Inefficiency	Participation of these associations in formulation and implementation of mental health policies, plans or legislation at the national or local level is limited.
Insurance	Insurance coverage for mental health is limited	Majority of the countries, particularly low and middle income countries, do not have insurance coverage for mental health. Even in high income countries where insurance coverage is available, several conditions are imposed.
CBR programmes		Availability of day care centres, community-based rehabilitation centres and other forms of rehabilitation facilities are limited and unequally distributed among countries and within countries.

<b>Table 2.2: Resources for mental health in India - Report Card</b>		
<b>Resource</b>	<b>Current status</b>	<b>Details</b>
Policy	National Mental Health Policy was officially approved for the first time recently (October, 2014).	Policy group was formed three years ago and mental health policy was prepared and officially approved. The policy is yet to become functional.
Plan and programmes	Mental health plan and programmes do exist with principles regarding care and treatment	Covers only 123 districts out of 600 districts in India. There are serious arguments against efficient implementation of this programme.
Legislation	Dedicated mental health legislation does exist (MHA,1987)	This act is now more than 25 years old. It needs to be replaced by an act, which enshrines modern principles of care and human rights. Mental health care bill (MHCB, 2013), a new legislation consistent with modern principles and values, has been prepared and submitted to the ministry. However, due to diverse views of ideological groups, the progress of the legislation has been stalled. (The Mental Health Care Bill, 2013)
Share in health budget	Mental health expenditure as a share of total health expenditure is 0.6per cent (WHO, 2011). This figure belongs to central government and excludes figures of state and local governments	Share of health in India's health budget is low at 1 per cent out of which less than 1 per cent is spent on mental health, which ensures low per capita amount on health and abysmally low per capita amount on mental health.
Human resources	There are around 3000 (NHRC and NIMHANS, 2008) psychiatrists, 343 clinical psychologists, 290 psychiatric social workers and 523 psychiatric nurses in India (Goel, 2011).	These numbers of mental health professionals are abysmally low when compared with internationally accepted standards.

	Inequity in the distribution of these human resource professionals.	The problem of inadequacy of human resources is compounded by their inequitable distribution in favour of developed states and urban areas comprising 25 per cent of population which has 75 per cent of psychiatrists. Within urban areas they are more concentrated in metropolitan areas. Distances, stigma and low income makes access further difficult (Gangadhar, 2008).
	Inefficiency in distribution of human resource.	Significant per centage of psychiatrists and other professionals (in public sector) are locked in mental hospitals or institution based care. Limited human resource in the public sector is available for care in the community.
Mental health infrastructure	Available mental health beds are too less as compared with the need.	Available beds for mental health in both public and private sectors are 29,000. However, considering the prevalence, size of population and long term needs of patients, 30 to 35 lakh people need hospitalization at any point of time ((NHRC and NIMHANS, 2008, pp284).
Community resources and informal resources	Limited number of NGOs and their limited participation in policy, planning and legislation (WHO, 2011; (NHRC and NIMHANS, 2008).	There do exist national and international NGOs. Users and family initiatives do exist. NGOs and informal resources provide a variety of activities. However, efforts of most of these initiatives are of recent origin and they are too small considering the size of our country. Their participation in planning, policy and legislation is too limited (WHO, 2011 (NHRC and NIMHANS, 2008).
Insurance	Insurance is not provided for mental health needs.	Mental-neurological and psychiatric disorders are excluded from insurance coverage in India. As a result, there is practically no insurance coverage for MH needs. (Kalyansundaram, 2008). Moreover, persons with mental illness are likely to experience discrimination even in health insurance coverage.
CBR programmes	CBR facilities are limited	CBRs include long term residential facilities, short term residential facilities, day care centre and other facilities are extremely limited. Most of the facilities are in the private sector, which runs on commercial basis and unaffordable to majority of the population (Murali & Tibrewal, 2008)
What is the net outcome of resource lacuna?	Severe shortage of services in all dimensions at all levels	.Huge treatment gap in terms of medication and hospitalization (short term and long term) rehabilitation (day care/occupational, therapy/vocational therapy and other rehabilitation facilities. Huge treatment lag. Violation of human rights. Significant human losses, pain and suffering.

## **Supply gap in burden of mental illness and resources that are available is huge**

High income countries, which have recently increased their allocation for mental health, now, allocate a greater percentage of financial and non-financial resources for mental health. This translates into higher allocation per capita for mental health in them. As one moves down from them towards lower income group of countries, resource allocation drops down sharply (WHO, 2011). Lower and lower middle income countries allocate a small percentage of their already small budgets for mental health (Saxena, Sharan, & Saraceno, 2003a). As a result, the per capita resource allocation for mental health is extremely small in them (Table 1.1). What is applicable for the share of mental health in health budget is observed in the case of other resources like infrastructure, human resources, etc. These countries allocate meagre resources for mental health, leading to gross neglect of mental health services and violation of human rights of persons with mental illness.

### **Barriers to increasing resources**

Various issues are raised (i.e., barriers posed) when the question of greater allocation of resources (investment in mental health) for mental health are raised. Efficacy and cost effectiveness of treatments, and affordability and feasibility of delivery of mental health services through public health system are some of the main issues that are raised. However, many studies have pointed out that these arguments are not tenable.

### **Efficacy**

Often the society in general and policy makers in particular believe that effective treatments are not available for mental ill-health (Thornicroft & Patel, 2015). This belief is the result of limited research on brain and its disorders. Successful treatment on mental health has become available relatively recently. It has been found that even in low income countries older generation medication along with psychotherapy session is effective (Brundtland, 2000; Patel, Jenkin, & Crick, 2012; Patel & Thornicroft, 2009, Patel, Simon, Chowdhary et.al., 2009; Mari, Razzouk, Thara et.al., 2009; Mbuba & Newton, 2009; Benegal, Chand, & Obot, 2009; Flisher, Sorsdahi, Hatherill et.al., 2010; Prince, Acosta, Castro-Costa et.al., 2009). It has also been demonstrated that treatments are available for



mental health problems which are as effective as those of high blood pressure, diabetes or rheumatoid arthritis (Thornicroft & Patel, 2015).

### **Affordability of treatment for mental illness**

Another issue that is raised is about the expenses that are incurred for treating persons with mental illness. It is argued that treatment for mental health is expensive and hence it becomes unaffordable to not only a large number of individuals who avail services from the private sector but also from the public health system. WHO report –*Investing in mental health (2003)* - defines affordability in terms of the cost of treatment in terms of US dollar per person. Treatment is affordable, quite affordable, and less affordable if cost per person is less than \$0.5, \$1.0 and greater than \$1 respectively (WHO, 2013). Several studies (PLOs, WHO) indicate that the treatment for many mental disorders are affordable. Table 2.3 provides information about affordability of different treatments for various mental disorders.

### **Cost effectiveness of treatment for mental illness**

Benefit and cost of treatment for mental illness is another issue that is raised often. Benefit is measured in terms of healthy years gained due to treatment. The cost of obtaining one healthy year from treatment is calculated and it is compared with the average annual income per person. If this cost is smaller than average annual income per person or less than three times of that or greater than three times of per capita annual income, then it is said to be very cost effective, quite cost effective or less cost effective respectively (Table 2.3).

### **Feasibility of delivery of services through public health system**

It is also argued that for lay people to utilize services for mental health, it should be not only affordable but also feasible to deliver in order to reach all sections of the population. WHO has given four aspects in order to fulfil these criteria. One aspect is reach, i.e., capacity of the mental health system to deliver an intervention to the target population; the second is technical complexity, i.e., simplicity or complexity of technologies needed for an intervention; third is the capital intensity needed for an intervention; and, fourth is acceptability (including fairness and human rights) of the

intervention. WHO has produced practical treatment guidelines for use in primary care in low and middle income countries based on the very best evidence that works (Movement for Global Mental Health, 2015). In India since a large percentage of population is poor, public health system is suitable for delivery of mental health service. Various studies show that current available mental health interventions fulfil these criteria and mental health care can be easily integrated into care for general health system in low and middle income countries (Patel, Jenkin, & Crick,2012; Patel & Thornicroft, 2009, Patel, Simon, Chowdhary et.al.,2009; Mari, Razzouk, Thara et.al.,2009; Mbuba & Newton, 2009; Benegal, Chand, & Obot, 2009; Flisher, Sorsdahi, Hatherill et.al., 2010; Prince, Acosta, Castro-Costa et.al., 2009). Training can be given to health staff and workers at the primary health centre with simple steps to provide primary mental health care.

<b>Table 2.3: Identifying interventions that are cost-effective, affordable and feasible</b>				
Health condition	Interventions	Cost-effectiveness (cost per healthy per year of the gained) <sup>a</sup>	Affordability (cost per capita)	Feasibility (logistical or other constrains)
Epilepsy	Treat cases with (first-line) anti-epileptic drugs	+++	+++	Feasible in primary care
Depression	Treat cases with (generic) antidepressant drugs plus brief psychotherapy as required	+++	+++	Feasible in primary care
Harmful alcohol use	Restrict access to retail alcohol	+++	+++	Highly feasible
	Enforce bans on alcohol advertising			
	Raise taxes on alcohol			
Psychosis	Enforce drink-driving laws (breath-testing)	++	++	Feasible in primary care
	Offer counselling to drinkers			
	Treat cases with (older) anti-psychotic drugs plus psycho-social support	++	+	
<b>Cost-effectiveness:</b>				
+++ (Very cost-effective; cost per healthy year of life gained < average income per person)				
++ (Quite cost-effective; cost per healthy year of life gained < 3 times average income per person)				
+ (Less cost-effective; cost per healthy year of life gained > 3 times average income per person)				
<b>Affordability</b>				
+++ (Very affordable; implementation cost < US\$ 0.50 per person)				
++ (Quite affordable; implementation cost < US\$ 1 per person)				
+ (Less affordable; implementation cost > US\$ 1 per person)				
Source: (WHO, 2013,p,30).				

In nutshell, resources for mental health are scarce (considering the burden of the disease) even though effective, cost efficient, affordable and treatment modalities that are implementable through public health system are available. To sum up, it has pointed out by many studies that investment in mental health is a financially prudent decision. Prof. P. Satish Chandra says “Higher investment in mental health care is justifiable because the economic benefits of effective, equitable and accessible care far outweigh cost of disability and loss of livelihood due to mental illness” (Sharma, 2014, p, 1564).

Table 2.3 provide interventions for various mental illnesses along with the applicability of various criteria. Several other arguments are made about additional investment for mental health. These issues/arguments (and potential arguments) may act as barriers in fulfilling the goal of investing in mental health. WHO (2013) report *-Investing*

<b>Table 2.4: Supporting arguments for, and potential barriers against, investment in mental health</b>		
Perspective	Arguments favouring greater investment in public mental health	Potential barriers to greater investment in public mental health
Public health	Mental disorders are a major cause of the overall disease burden; effective strategies exist to reduce this burden.	Mental disorders are not a leading cause of mortality in populations.
Economic welfare	Mental and physical health are core elements of individual welfare.	Other components of welfare are also important (e.g., income, consumption, etc.).
Economic growth and productivity	Mental disorders reduce labour productivity and economic growth.	Impact of mental disorders on economic growth is not well known (and often assumed to be negligible).
Equity	Access to health is a human right; discrimination, neglect and abuse constitute human rights violations.	Persons with a wide range of health conditions currently lack access to appropriate health care.
Socio-cultural Influence	Social support and solidarity are core characteristics of social groupings.	Negative perceptions and attitudes about mental illness (stigma).
Political influence	Government policies should address market failures and health priorities.	Low expressed demand/advocacy for better services.
Source:( WHO, 2013,p,11)		

*in mental health-* gives these arguments which are from different perspectives like

public health, economic welfare, equity, productivity, and social, cultural and political influence. However, studies have refuted these arguments with strong evidence. In fact, these studies argue that investing in mental health is a worthwhile decision or ‘best buy’ for that matter. Table 2.4 gives potential barriers (arguments) to investment and arguments favouring investment in mental health. (See Appendix II)

Taking an overview of resources for mental health, at the global level and in India, it becomes evident that there exists a huge gap in the supply of resources for mental health in a number of dimensions. The severity of this gap and consequent deprivation vary from one dimension of resource to another. The extent of deprivation increases as one moves from countries in higher income group to countries in lower income group. However, the lower income countries are much more in need of greater resources for mental health. They have a greater percentage of poverty, and social and economic inequality. Evidence indicates that poverty, women, minority groups and vulnerable groups have greater mental health needs.

## **Reasons of Supply Gap**

### *1. Low priority given to mental health as compared with physical health*

Many studies point out that the needs of mental health are given a low priority as compared with physical health needs (Jacob, 2001; GOI, 2002;GOI, 2014; Thornicroft & Patel,2015; Saxena, Sharan, & Saraceno, 2003a). Public health importance of mental disorders is not properly understood. Such a low priority to mental health has restrained growth of mental health system (Saxena, Sharan, & Saraceno, 2003a). Jacob(2001) goes further and using Maslow’s ‘Pyramid of needs’ argues that, in future also, it seems that physical health needs will be attended first and then mental health needs.

### *2. Poor advocacy*

For promoting any health issue, advocacy of stakeholders is important. It consists of various actions aimed at changing the major structural and attitudinal barriers to achieving positive mental health outcomes in population (WHO, 2003). It can be of people who are directly involved with the issue or of outsiders. Among the stake holders of

mental health problems, consumers and family organizations are of prime importance. In USA, National Alliance for Mentally Ill (NAMI) is one of the biggest organizations of caregivers of persons with mental illness in terms of coverage, membership, number of advocacy initiatives, and rapport with politicians and policy makers. Through their advocacy efforts, these organizations have helped to maintain the share of mental health at 8 per cent of the national health care budget of the country (Hu, 2003) which is one of the highest mental health budgets in the world.

Sustained efforts of these organizations have led to increased budgetary and other resources. They have forced the government to pass 'parity laws' for bringing parity in insurance coverage for mental health with other physical disorders, improve quality of services and reduce discrimination in the allocation of resources (both public and private) for mental health problems. At the same time, by educating people, family members and users as well as by imparting problem management skills, they ensure early detection, treatment and better care at home.

However, the world over (except in high income countries) family and patient movement is weak or almost absent, especially in low income countries (WHO,2011). Moreover, users and families are not likely to protest or get organised (Saxena, Sharan, & Saraceno, 2003a). There is a need for strong and focused users and family organizations to ensure increased resources and improved quality of care. Very few low and low middle income countries have such organizations. However, with an increase in awareness, aspirations and spread of information among users and family members, these changes are not very far away (Hu, 2003; Department of Health and Human Resources, 1999; Saxena, Thornicroft, Knapp et. al , 2007).

### *3. Lack of evidence based treatment*

Resources that are provided for mental health are extremely limited. One of the reasons is the inability of mental illness to attract and convince donors for releasing more funds. Lack of evidence based treatments is cited as one of reasons for lower resources for mental health. Government and donors (national or international) provide resources where treatments are available with scientific proof. In mental illness, for a long time such evidence base was mostly available only in developed countries, which could not become

directly applicable to developing countries due to cultural, health system, pharmacokinetic, pharmaco-dynamic, local health and drug policy factors. Developing economies need to have their own evidence base (Patel, 2000).

#### *4. Unavailability of successful programmes*

For any disease to receive funding (or for that matter for any social or economic objective), there is a need to have programmes which have proved successful and can be implemented through public health system. It is argued that there is non-availability of such programmes for implementation which makes mental health a less attractive health issue in competition with other health issues.

#### *5. Limited success and research in getting breakthrough in understanding mental health problems and its treatments*

Having a better understanding of any health problem and development of treatments for it is very essential. Significant amount of funding makes it possible to achieve a breakthrough through a clearer understanding of the issue having an impact on the prevention, treatment and recovery. Cancer and cardio-vascular diseases which received condition specific funds achieved such an outcome due to increased funding (Cyhlarova, 2010). For mental health also, even though it is now known that social, biological and environmental factors are responsible for mental illness, science still does not know how the treatment works? It has yet to understand fully the functioning of human brain. However, increased funding can make it happen.

#### *6. Limited research in Economics of mental health and dissemination of it*

For promotion of research in a health issue, it is necessary from the economic point of view to justify the need for additional expenditure on it, comparative advantage of such expenditure vis a vis other health issues and knowledge of the most economical treatment modality within such issue (Hu, 2003). However, very little research is being done on mental health in general and economics of mental health in particular. Moreover, whatever is being done, limited effort has been made to disseminate it.

## *7. Lack of competitiveness of research in mental health vis-a-vis other health issues*

It is also said that competitiveness of research in mental health as compared with other health issues is lower due to several characteristics related to research in mental health (Cyhlarova, 2010). Lack of capacity i.e., availability of few researches in overcoming complex mental health issues like identification and consent of research participants, stigma, lack of condition-specific financing, and pilot and partnership studies lower competitiveness of research in mental health. Cyhlarova (2010) further argues that these characteristics create a cycle ensuring continuous lower investment not allowing the necessary increase in research capacity and skills.

## *9. Shiffman and Smith framework of analysis*

Shiffman and Smith (2007) study the issue of allocation of funds at the global level, i.e., allocation by international health networks and allocations between the governments. They ask why some health issues receive less attention and global funding than other health issues causing a relatively lower burden or mortality. Their study concludes that such an anomaly in the matching between the resources and their burden could be explained with the help of eighteen factors. These factors are grouped into four broad categories. These categories are:

1. Strength of the actors involved in the initiative.
2. Power of the ideas they use to portray the issue.
3. Nature of the political context in which they operate.
4. Characteristics of the issue itself.

To obtain greater funding, it is necessary to act and bring about a change in these factors (Shiffman & Smith, 2007). For generating greater resources, mental health lobby needs to work on all of the above categories. Tomlinson and Lund (2012) provide suggestions using this framework: there is a need for greater mental health community cohesion in order to ensure unified voice, providing evidence-based and scalable interventions in order to create impact on policy makers, innovative strategies for treatment, stigma reduction and a social and human rights approach. Broadly, for generating greater resources, mental health issues have to be positioned and showcased in

such way that policy makers will understand their importance, severity and outcome if they choose to provide more resources.

### **Demand gap**

Demand gap refers to delay in initiating treatment since the onset of symptoms. This is called Overall Treatment Delay (OTD). It can be classified into various components, i.e., recognition delay, consultation delay and treatment delay. Treatment delay varies from few weeks to years. Developed countries with well organised mental health care system also show demand gap. Researchers have found that treatment delay is smaller for major mental illnesses where symptoms are severe, visible and patient is likely to become troublesome to him/herself and others (Jain, et al., 2012).

In India and many other countries, the demand gap is a regular characteristic of mental health scenario. Various factors related to attitude and belief system of a society, affordability and convenience of treatment are responsible for it. Discussions on these factors help us to understand the barriers and solutions to get over them.

### **Reasons of demand gap**

Researchers have identified various factors that reduce the demand for mental health services.

#### *1. Myths and beliefs*

Mental disorders and issues of mental health are a part of human history. Mankind has addressed them according to the perceptions prevailing at different points of time and dominant ways of understanding the world. Many of them and explanatory models have survived even today. In India even now a large number of people hold beliefs and explanations which are not consistent with modern explanations. Murthy (2012) elaborates about a variety of beliefs, attitudes and practices people hold about the nature, causation and treatment of mental disorders. They often result in a stigma (Kermode, Bowen, Arole et.al., 2009; Abramovitz, 2008; Jacob, 2001)



## 2. *Level of mental health literacy*

Knowledge of a disorder – its nature, symptoms, causes and sources of help is essential for an early recognition, intervention, treatment and prevention of a disorder. In major physical illnesses, many people have knowledge of appropriate sources of available professional help, some of the medical and complementary treatments they might receive and their likely benefits (Jorm, 2011). However, mental disorder poses contrasting a scenario. Many members of the public are ignorant about what they can do for its prevention. They commonly delay or avoid seeking treatment and view the recommended treatment with suspicion. They are unsure about how to assist others with mental disorders (Jorm, 2011; Murthy, 2012). Erritty & Wydell (2013) observes that lay people are not good at recognising symptoms of schizophrenia. The participants in their study perceived positive symptoms as more indicative of mental illness than negative symptoms. Prabhau (1984) observes...

*Information held by the general public is un-crystallised and diffused. The lay public, including the educated urban youths, are largely uninformed about the various aspects of mental health and the information possessed by them remains un-crystallised. The mentally ill are perceived as aggressive, violent and dangerous. There is a lack of desirable degree of awareness about available facilities to treat the mentally ill and a pervasive defeatism exists about possible outcome after therapy. A tendency to maintain social distance from the mentally ill and reject them makes its existence felt.*

Lack of information about mental illness and difficulties in understanding or recognising symptoms coupled with not knowing where to go for help leads to delay in treatment (Pavitra KS, 2013; Tanskanen, Morant, Hinton et.al.,2011). Lack of awareness about burden of mental illness at the level of individual, family and society coupled with thinking that ‘nothing much can be done’ is the main reason for neglect of mental illness (Patel & Saxena, 2013).

### 3. *Social stigma*

Social stigma is another serious barrier to treatment. It is a mark of disgrace that the society holds towards mental illness and persons with mental illness. There exist a number of beliefs, attitudes and practices regarding mental illness which have developed over a period of time (Jacob, 2001; Kermode, Bowen, Arole et.al., 2009). Often they result in a stigma towards mental illness. Stigma may cause neighbors or community to have negative opinion about the individual and hence such individuals and families do not want others to find out about the illness. Feelings of blame and shame also contribute to inhibition in seeking help for mental disorders (Saxena et.al., 2007).

Due to stigma and consequent discrimination in employment and otherwise, people hide their illness and delay initiating treatment (Saxena et.al., 2007; Pavitra KS, 2013; Jacob, 2001; Tanskanen, Morant et.al., 2011; Abramovitz, 2008; Shidhaye & Kermode, 2013; (Corrigan, 2004; Jorm, 2000; Ustun, 2000; Murthy, 2012; Thornicroft, 2007). Stigma delays not only treatment but also acts as a barrier in taking the right and treatment, continuous treatment, finding alternatives or complementary treatments and leading to discriminatory allocation of resources (Ustun, 2000). Social stigma exists not only around mental illness, but it occupies the entire surrounding around mental illness, i.e., patient, caregiver, treatment and professionals (Murthy, 2012).

Stigma and discrimination are the most important factors in the reluctance of many people worldwide to seek help or even to accept that their difficulties relate to mental illness (Saxena, Thornicroft, Knapp et.al., 2007). Mental illnesses are more stigmatised than physical illnesses and have been referred to as 'Ultimate stigma' (Saxena, Thornicroft, Knapp et.al., 2007). Very often people with mental illness internalise social stigma which is usually in an exaggerated stage. This stigma i.e. self-stigma prevents people from taking treatment (Srinivasan, 2015; Corrigan, 2004).

### 4. *Lack of laboratory test*

Another probable reason may be that detection or confirmation of mental illness is not based on any laboratory test. Diagnosis is made solely on the basis of verbal interaction between the patient and mental health professional. Lack of laboratory tests means absence of any medical report or record which makes patients (and caregivers)

difficult to understand the illness and problematic for the professional to convince the patient (and caregiver) about the presence of such a mental health condition and need for adherence to the treatment (Andrews & Titov, 2007).

5. *Common mental disorders like anxiety, depression and others are not considered as an illness*

Depression, anxiety and unexplained somatic symptoms are not considered as mental illnesses in many societies (Jacob, 2001). Beliefs about causation of psychiatric disorder determine help seeking behaviour (Zafar, Syed, & Tehseen, 2008). The varying cultural models of illnesses (Kleinman, 1980) attribute such conditions to life event, fate, supernatural causes and physical diseases, and therefore reduce the demand for mental health care (Jilani & Trivedi, 2011). Jain (2012) points out that patients of obsessive compulsory disorder and depression do not realise that they are suffering from an illness for a long time and present themselves only when they are too much distressed. People think that these conditions arise due to stress and strain.

**Other reasons**

It has been found in several studies that greater cohesion between family members, increased community tolerance and simple ways of life lead to easier accommodation of the patients without treatment for several years. (Murthy, 2004; Thara, Padmavati, & Nagaswami, 1993)

**Impact of deficiency in demand**

Jacob (2001) points out the significant impact of deficiency of demand on the commitment of mental health professionals and mental health system. Such a deficiency leads to the absence of urgency to tackle the problems and a consequent lack of translation of plans into action-oriented programmes (Agarwal, 1991). Jacob (2001) further argues that such a deficiency along with lack of consumer movement has a major impact on the supply of services (and resources). It leads to lack of political and administrative will of the government.

<b>Table 2.5: Steps taken to improve mental health services at the global level.</b>			
Publication/Report	Year	Highlights /recommendations	Impact on resource allocations for mental health
Global burden of disease report (Murray & Lopez, 1996)	1993	Developed a new health matrix-DALY. It is a comprehensive measure which includes premature mortality and disability due to a disease.	With this new measure, mental disorders became a disease with one of the highest burdens. The report helped to highlight the burden of mental disorders which became a basis for highlighting deprivation of resources for mental health vis-a-vis burden due to it.
Mental health –A report of the Surgeon-General(USA)	1999	Comprehensive report covering all aspects of prevention, treatment, rehabilitation, science, resources, financing, human rights and action of a caring society.	The report by providing most scientific and evidenced based information helped to change the attitude of all the stakeholders that influence the flow of resources.
World Health Report (WHO)	2001	<b>Gave ten recommendations:</b> Provide mental health treatment in primary care centre, make psychotropic medicines available. give care in the community. educate the public, involve communities, families and consumers, establish national policies, programmes and legislation, develop human resources, link with other sectors, monitor community mental health and support more research.	This report, using GBOD methodology, gave a clear, comprehensive and authentic picture of plight of mental health in the public and private domain and provided evidence based recommendations for improvement in mental health services. With this report, WHO, as a steward for nations, created a favourable platform for changing attitude of the nations. The report became a basis for advocacy groups for demanding higher amount of resources.
Mental Health Atlas (WHO)	1999 2005 and 2011 2014	Collected and published a report based data about mental health services, resources and infrastructure for mental health. This data is further classified according to WHO regions and World Bank income groups	These reports by providing data on various dimensions of resources, enabled comparison of resources by regions and income groups. It became a basis for advocacy groups – domestic and international, for improving quantity and quality of services and resources.
Reports on Investment in Mental Health (WHO)	2003 & 2013	The report does not stop simply by saying that there is mismatch between the burden due to mental illness and resources for it, but shows that the treatment for it is cost effective and efficient from the economic point view.	By making scientific and convincing arguments, the report shows that making investment in mental health is a worthwhile decision.

		Moreover, it also shows that the care for mental health can be distributed through public health system.	
Dollars, dalys and decisions (WHO, 2006)	2006	Highlight the need for and relevance of an economic dimension to decision-making and to summaries results from existing mental health economic analyses.	Greater resources for mental health are expected.
Macroeconomics and health (WHO,2007)	2007	Highlighted importance of health in general and mental health in particular as an important input.	
Lancet publications (special issues on mental health)	2007 and 2011	These special issues, with the help of research, draw attention to several aspects of mental health like neglect of mental health in resources, human resources, human rights, vicious circle of poverty and mental health, etc.	The articles in this special issue make arguments based on scientific research. Politicians, policy makers and opinion makers are influenced by such arguments.
Movement for Global Mental Health (Patel, et al., 2011; Prince M. , 2008))	2011	Network of individuals and institutions.	Through large membership and their networking, knowledge sharing, initiating and experimenting with new ideas, it helps to disseminate information, create conducive attitude and indirectly influences greater resources for mental health.
WISH report (Patel, Saxena, De Silva et.al., 2013)	2013	Took overview of burden and resources for mental health, especially in low and middle income countries and gave concrete suggestions to change the scenario.	This report gives multiple suggestions for overcoming current deprivation in mental health. Moreover, it point us to innovative and evidence based solutions that have been experimented in different countries. Moreover, by emphasizing that these innovations are efficient and cost effective, the report helps to influence attitudes of policy makers and administrators.
Comprehensive Mental Health Action Plan (WHO, 2013)	2013	Calls action to change attitude, stigma and discrimination and expansion of services	Government and international donors are expected to increase flow of resources.
Sustainable development goals (Basic Needs, 2016;United Nations, 2016)	2016	Inclusion of mental health as a target in sustainable development goals.	Flow of resources for mental health from international donors is likely to increase.

**Table 2.6: Steps taken in India to improve mental health services**

	Area of focus	Suggestions/recommendations	Suggestions/impact related to resources
Bhore Committee (1946)	Comprehensive	Creations of mental health organization, Improvement of mental hospital training of medical and non-medical personal, establishment of department of mental health in the proposed All-India Institute.	Recognized that mental health has received a low priority. All the recommendations will need greater resources.
Mudliar Committee (1961)		Setting up preventive mental health services, expansion and improvement of curative institutions, providing training to medical and non-medical personnel, Greater research in various dimensions.	Each one of the recommendations will need greater resources.
National Mental Health Programme (1982) and District mental health programme(1996)		<b>Objectives:</b> To ensure availability and accessibility of minimum mental health care, to encourage mental health knowledge and skills in general health care, to promote community participation	Each of the recommendations will need greater amount of resources.
National Health policy (2002) (GOI, 2002)		Setting up of network of decentralized mental health institutions to address common mental disorders, upgrading of physical infrastructure of mental health institutions.(NHP, 2002. Section 4.13)	Formal acceptance that mental disorders are much more prevalent than as understood and even though they do not contribute significantly to mortality, they influence the quality of life. Acceptance that there is a serious shortage of institutions, trained manpower. (GOI, 2002). Section 2.13)
National Human Rights Commission report (NHRC & NIMHANS, 2008)	1999 2008	Mental health services should be accessible, equitable and affordable. Government should downsize large mental hospitals. HR for mental health must be systematically enhanced. Creation of data base for mental health services and resources, state and central governments should follow a stepped care approach.	All the recommendations, if implemented, will need greater amount of resources.

		After care rehabilitation and integration within the society, convergence of mental health with social, education, labour and legal sectors, periodic law review and reform, limitations in insurance coverage should be rectified, mental health care of vulnerable groups should receive priority.	
First National Mental Health Policy (2014) (GOI, 2014)	All the issues related to mental health.	Suggestions provided are comprehensive covering all stakeholders and all related issues, effective governance, increase in human resources and training facilities to achieve it, universal mental health care facilities, prevention, promotion and treatment, increased infrastructure, increase in awareness, greater participation of stakeholders and Rights based approach.	Compliance of any or all the recommendations will require greater amount of resources. The policy also calls specifically for increase in financial allocation in a progressive manner.
National Health Policy, 2015 (Proposed) (GOI, 2014)		Action on several fronts is required for improvement mental health, increase in creation of specialists and those who are willing to work in public systems, to limit emigration, integration with the primary care, use of tele-medicine linkages, supplementing primary level facilities with counsellors and psychologists in various programmes, de-stigmatising the psychological disabilities and movement away from institutional care.	Policy unequivocally accepts the sad state of neglect of mental health. Further points out that the gap between service availability and needs (resources) is widest here. All the recommendations, if implemented, will need greater resources.

Table 2.5 and table 2.6 take an overview of steps taken by various committees/ reports and its impact on resource allocation for mental health at the global level as well as in India. The recommendations of these committees and reports (Table 2.5 & 2.6) have certainly made an impact in improving on resource allocation for mental health. But, most of the major improvements and reforms in mental health have come whenever there was any serious violation of human rights of persons with mental illness (basically in mental hospitals) or some disaster (like Yerwadi event) and media covered it extensively, or

whenever there was any judicial inquiry, the Government has paid attention to it and provided more resources. There is a need to address mental health issues from the economic point of view.

### **Summary**

Treatment gap and treatment lag is huge for mental health which is basically due to supply and demand gap in mental health. This study was conducted to understand the nature, extent and determinants of supply and demand gap. It addresses issues regarding supply gap with the help of secondary data and issues regarding demand gap using the primary data. A good number of studies have been done to find the extent of supply gap and its determinants. However, very few studies have been conducted in India to find out the extent of demand gap and its determinants. Moreover, all of them focus from the point of view of 'pathways to care' and address the variables related to it. Although some of these studies address treatment delay, they fail to take cognisance of its components and determinants of it from the point of view of demographic, social, economic, medical and geographic characteristics of the sample households.

Another limitation of earlier studies is that they do not try to find out the extent of NPT or extent of duration of discontinuation (DD) and its determinants. NPT is only seen as an age old practice and it is assumed that it is a major factor for treatment delay. It is hardly tested whether the period of NPT is the cause of treatment delay or some other factors are responsible. This study tries to fill these research gaps by finding out the period of treatment delay, NPT and DD and determinants of it. In India, demand gap is significant. However, focus of most of the research and policy is on ways of reducing the supply gap. Hence, this study can be considered as a step towards understanding this relatively neglected area.



## **Chapter III**

### **Methodology**

This is an exploratory study. This Chapter explains the methodology of the survey that was conducted in order to explore the nature, extent and causal factors/mechanism of demand factors in mental health at the level of individual households.

As mentioned in Chapter I, there exists ‘Supply gap’ or inadequacy of resources for mental health at the macro level which leads to inadequacy of mental health services. The consequences of such a supply gap are huge ‘treatment gap’ and ‘treatment lag’. The former refers to the percentage of people who need treatment but do not receive it and the latter alludes to the delay in receiving treatment since the onset of symptoms. ‘Supply gap’ or inadequacy of resources for mental health is one of the factors for huge treatment gap and treatment lag. The other factor is ‘demand side factors’. Individual households may delay seeking treatment for various reasons.

Chapter I take an overview of BOD of mental illness in the world in general and in India in particular. Chapter II discusses the various concepts, estimates of supply gap and different barriers that lead to under provisioning of resources by the government. However, what is relatively less researched is the nature and extent of ‘demand gap’ or actual utilisation of mental health services at the level of individual households. For initiating timely and adequate treatment, not only should the supply of resources be adequate, that is, sufficient number of mental health facilities and infrastructure should be available and well distributed over a geographical area, but people should also need to demand and utilise such treatment adequately and in a timely manner.

Very often demand side factors are taken as granted and it is assumed that supply or availability of services will automatically lead to utilisation of services. However, due to various barriers individual households do not utilise the existing services. Unavailability of services is one of the reasons but ‘demand gap’ or lack of demand due to ignorance, lack of information, myths, belief system, stigma and other barriers are the other important

reasons. These reasons are particularly important for the mental health sector (Trivedi & Jilani, 2011).

This research is conducted with a view to filling this gap. The study aims to explore the nature, extent, characteristics and causal factors/mechanism of ‘demand gap’ for mental health at the level of individual households. This gap is measured with the help of treatment delay. The focus of this chapter is to explain the methodology of the study that was conducted in order to obtain the results for this research. It aims to investigate the following research questions.

### **Research questions**

1. Does a person with a mental illness experience demand gap or treatment delay?
2. Does such a person experience discontinuations in treatment?
3. Does demand gap or treatment delay vary across socio-demographic groups?
4. Is there inequity in treatment delay for mental health services?

### **Specific objectives of this study**

1. To understand the extent of demand gap or treatment delay and the number and the period of discontinuations for a mental illness by the households according to socio-demographic characteristics.
2. To understand the average period for which NPT (Full term) is used and its relation with the treatment delay.
3. To analyse inequity in the demand gap or treatment delay, NPT and in the discontinuations in the treatment.
4. To find out the reasons for or barriers to the treatment delay.

### **Conceptual Framework**

Burden of mental illness is huge as well as its treatment gap and treatment lag. Supply gap or inadequate supply of resources which leads to under provisioning of

services for mental health is usually highlighted as the most important factor. This study finds that in India the shortage of resources is high in each type of resources. Apart from inadequacy of resources, this study examines two other dimensions of supply of resources, namely, inequity and inefficiency.

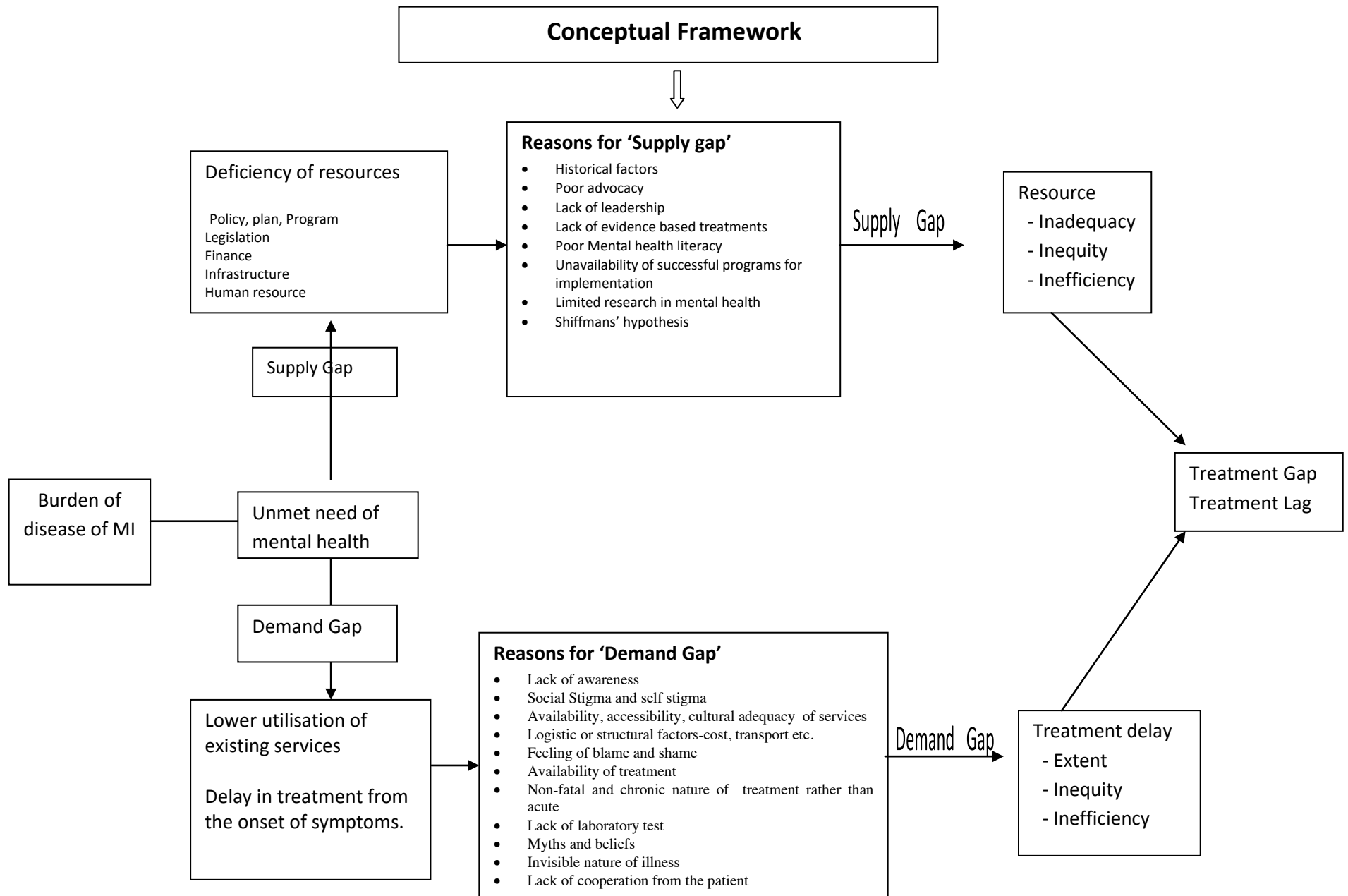
There is supply gap' or inadequate supply of resources and hence supply of services is important. But finally the utilisation of services (and hence the extent of treatment gap and lag) depends upon demand for such services by the individual households. Demand considerations play a dominant role in the mental health sector (Trivedi & Jilani, 2011). It is argued that demand consideration plays a major role in mental health as compared with physical disorders. Some studies point out the evidence to show that the demand for mental health services is lower as compared with the demand for physical health (Andrews, 2006; Andrews & Titov, 2007).

This study is conceptualised around the demand factors of mental health services. For actual utilisation of mental health services people need to demand such services. In other words, they need to understand the emergence of the symptoms of mental illness, acknowledge them and take action in order to seek mental health services. Thus, early detection and consultation with a professional person and appropriate action is necessary in order to receive timely treatment. Several barriers may inhibit an individual household's desire to go in for treatment. These barriers get reflected in treatment delay for mental illness. Hence, Treatment Delay (TD) is considered as a variable that measures demand gap.

Like the supply of resources, three attributes of the demand factors or treatment delay (which reflects aspects of demand) are considered here, viz., extent or period of treatment delay, inequity and inefficiency in treatment delay.

This study is conceptualized around these three facets of demand gap (Figure 3.1). Inadequacy, inequity and inefficiency have different connotations in the context of supply gap (macro level) and demand gap (micro level). In supply gap inadequacy in resources refers to deficiency of resources that are required according to the standard norms (in terms

**Figure 3.1**



of share in budget, number of professionals or beds per lakh of population, etc.) as compared with the actual availability of resources. Inequity in the availability of resources refers to an unequal distribution of resources within a specific socio-demographic characteristic of the population. Inefficiency in the use of resources means to the misallocation of resources across different treatment modalities or treatment options. A detailed overview of these three facets of resource allocation at macro level is taken up in Chapter I.

At the micro level, the demand gap is measured with the help of treatment delay. Like supply gap, it has three facets, i.e., inadequacy, inequity and inefficiency. Inadequacy refers to the extent of treatment delay in terms of weeks or months. Inequity means variations in demand gap or average treatment delay within various social, demographic, economic, medical and geographic groups. Inefficiency refers to inappropriate choices or demand for various mental health services.

### **Treatment delay**

For any illness, timely treatment from a medical professional is necessary. Symptoms of an illness indicate some abnormality in the physical and mental condition of the individual. However, sometimes symptoms may be visible or obvious to the patient or to family members, while at other times they may not be visible. Recognising symptoms of an illness is an important step for taking a patient to a medical doctor. Consulting a medical professional and then actually initiating treatment are the following stages. There may be delay at every stage of initiating treatment. This delay may occur for physical illness as well as mental illness. Extent of treatment delay in initiating treatment for the first time is considered as a measure of demand gap. In this study, treatment delay was calculated in terms of the number of months.

There are three steps in initiating treatment- recognition, consultation and treatment. Hence, overall treatment delay may be due to recognition delay, consultation delay and treatment delay. These four variables are defined as follows: Recognition Delay (RD) is defined as the time taken from initial onset of symptoms to their recognition as

mental illness. Consultation Delay (CD) is defined as the time taken from recognition of symptoms to actual consultation with the medical practitioner of psychiatry. Treatment Delay (TD) is the time taken from consultation to medical practitioner of psychiatry to actual beginning of treatment. Overall Treatment Delay (OTD) means the total time taken from initial onset of symptoms to the beginning of psychiatric treatment.

In the case of mental illness, a trained professional<sup>1</sup> is a psychiatrist and the treatment that he/she gives is psychiatric treatment which is generally medicines<sup>2</sup> or occasionally hospitalisation to start with. This treatment is assumed to be important for the patients diagnosed with mental illness. Psychiatric treatment is defined as treatment in which (allopathic) psychiatric medicine is administered. Such treatment may be given by a specialist or general practitioner either at a primary health centre, specialist clinic or hospital. All other treatments, which include plethora of other interventions, are termed as Non-Psychiatric Treatment (NPT) in this study. It includes all interventions/treatments/services other than psychiatric treatment like services of faith healers, spiritual leaders, temple healing, AYUSH (Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy) and other traditional medical systems.

### **Study area and selection of Yerawada Mental Hospital (YMH), Pune**

For the purpose of this study, Pune city was selected. Obtaining patients and their caregivers from the private clinic of a psychiatrist or private hospital is difficult due to confidentiality maintained and stigma attached to mental illness. For this reason, most of the studies in India have collected data from mental health institutions and that too mostly from government mental hospitals ((Lahariya, Singhal, Gupta, & Mishra, 2010; Jain, et. al., 2012; Naik, et. al., 2012). This study required collecting data from a large number of caregivers of patients in order to cover social, economic and demographic diversities.

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<sup>1</sup> Even graduate doctors from other medical systems like AYUSH can recommend medicines.

<sup>2</sup> Psychiatrists may have other options like counselling, ECT or other rehabilitation therapies. However, usually treatment starts with medicines.

YMH is the biggest mental hospital in Asia. Hence, it was decided to collect data from it from where a large number of respondents could be obtained.

### **Collection of data from caregivers of persons with mental illness**

In this study the information was collected not from persons with mental illness but from their caregivers, who accompanied them. This was done for two reasons. Firstly, patients do not necessarily visit YMH on each OPD visit for collection of medicines. It is primarily the caregivers who visit it and collect medicines all the times. Long distance from their residence, travelling expenses of one more person and inconvenience in taking a patient to YMH accounted for it. The second reason was that the patients might not know or remember some of the details in the development of his/her illness, or some of the patients, due to advanced stage of their illness, were not in a position to talk and give details at the time of interview. However, we made sure that the patients were present at the time of the interview and on some occasions they supplemented information given by the caregivers.

### **Use of mixed sequential method**

For this study, data was basically collected by quantitative method. However, it was realised in the pilot stage itself that considering several difficulties, collection of data on all the aspects of this study may not be possible from the questionnaire. It was thought that collection of additional qualitative data was necessary to support, supplement and strengthen some of the informational gaps. Therefore, it was decided to use qualitative method of Key Informants Interview (KII) once quantitative data had been collected. Therefore, it was decided to use mixed sequential method.

### **Collection of data by Quantitative method**

In order to collect quantitative data, a semi structured interview schedule was prepared (Appendix VII). It was divided into two parts. In Part A, information about social, demographic, economic, medical and geographic characteristics of patients and caregivers

was collected. In Part B questions which dealt with the history of illness and treatment were asked like the time of commencement of the symptoms, their nature, use of NPT and other alternative treatments, psychiatric treatment, any delay in use of psychiatric treatment and reasons for that, discontinuations in treatment, etc. Overall there were 78 questions divided into nine sections.

YMH is one of the biggest hospitals of its kind in Asia in terms of bed capacity. It provides residential facility to more than 2,000 patients. They come not only from Pune and other districts in Maharashtra, but also from outside the state. Most of them either come from very low income group or their condition is chronic and the family cannot afford to put them in a private hospital.

YMH also has a large OPD in which 100 to 150 patients and their family members visit every day for consultation and collect their monthly quota of free medicines. Collecting free medicines is one of the reasons for visiting YMH. Another reason is for most of the caregivers is that patients admitted in the recent past are discharged on a temporary basis for a period of six months or so. Monthly or bimonthly follow-up is essential if in the future patients need readmission. Hence, caregivers continue to visit the OPD of YMH (Addlakha, 1999).

### **Collection of data by Qualitative method**

Data collected by quantitative method is supplemented and strengthened by KII of caregivers and staff at YMH. In order to facilitate KII, an interview guide was prepared. Focus of these interviews was to understand how households take decisions regarding treatment for mental and other disorders, who in the family is involved in decision making process, what is his/her role, what is the decision making process, what is its importance, what are the pathways of this process, what is the role of NPT, what are the different services in mental health and how do they avail them, how much time is taken to avail them, what barriers did they face while taking decision, how do social-economic-cultural factors and other family specific factors influence decision making process?



Information on these lines was collected basically for mental disorders and to some extent physical disorders.

### Sample scheme for this study

Nature of inquiry	Nature of analysis	Sample size	Aspects to be examined	Method	Tools used
Survey	Quantitative interview	249	Inadequacy Inequity Inefficiency	Primary data and quantitative	Semi-structured questionnaire
KII	Qualitative interview	6 (YMH staff 3 and caregivers 3)	Inadequacy Inequity Inefficiency	Qualitative	Semi-structured interview

Marathi is the local language and mother tongue of most of the respondents. As they were more comfortable answering in it, the interviews were taken in it. The transcript of these interviews is available with the researcher. The interviews were translated by the researcher in English. For the purpose of uniformity, only English translations have been referred to.

### Selection of respondents and duration of interview

Data were collected with the help of a semi-structured interview over a period of three months from June 15 to September 30, 2014. Some qualitative information was also collected. Trained students assisted the researcher in the collection of data. Each interview took around 40 minutes. Interviews were conducted on all days during the above period except for official holidays in YMH or absence of researcher to be present for some reason or the other. The first respondent selected was the one who was first sighted and who gave consent for the interview. Next selected respondent was in the queue for collection of medicines and about to leave. If the chosen respondent refused to give interview, the next person in the queue was approached. Before the beginning of the interview, it was ensured that the accompanying caregiver knew the history of illness and other related matters and was willing to reveal them to the interviewer.

### **Determination of diagnosis of patient**

Patients are thoroughly screened at the time of their first visit to YMH. Psychiatrists use screening tools developed by Indian Psychiatric Society to determine the diagnosis of the patients. Usually, a patient is observed for three months and then his diagnosis is confirmed and recorded in his case paper. The researcher has taken the diagnosis of a patient on the basis of his/her case paper.

### **Deciding beginning of symptoms**

Caregivers were asked questions regarding history of illness of their patients. One of the questions was ‘when did you notice a change in the behaviour or abnormality in his/her behaviour for the first time?’ Most of the caregivers were in position to tell the year and month of such beginnings. Probing techniques were used in order to ascertain the exact month and year.

### **First treatment**

The first treatment was defined in terms of the month and year when the patient was first taken to a psychiatrist or general practitioner in the clinic, private hospital/ government hospital. In India due to lack of training and convention, general practitioners rarely diagnose and treat psychiatric patients. Hence, the first treatment is basically the treatment initiated by psychiatrists.

### **Reliability check**

Care was taken to ensure that reliable data was collected from the respondents. Since mental disorder is a sensitive area and caregivers are generally reluctant to get interviewed, it was thought that individuals may not provide accurate information when they think that their or other family members’ decision has gone wrong. In order to

minimise this, care was taken to ask check questions at crucial stages in the development of this disorder.

### **Informed consent**

Since this issue is sensitive, Informed Consent ( Appendix VII) was obtained from all the respondents. The purpose of the interview and research objectives was explained to them. The consent was obtained orally and participants were explicitly assured that the information revealed by them would not be shared with others and if used, it will be used in the aggregate form only.

### **Ethical guidelines**

The purpose of the ethical guidelines was to ensure that the respondents were not harmed emotionally or psychologically due to being asked questions. Before interviewing individual caregivers, a set of ethical guidelines was prepared and shared with the Directorate of Health Services, Maharashtra at Mumbai and with Superintendent, YMH, Pune. They permitted the researcher to contact both the caregivers and patients. Prior approval of the Ethics Committee of the GIPE, where the researcher has registered himself as a PhD student, was taken. All the ethical guidelines were explained to the interviewees before asking questions and consent of the respondents was taken.

For the analysis of data, SPSS version 20 was used. Eighteen variables were divided into five groups – demographic, social, economic, medical and geographic. Bivariate tables were cross classified into these variables and months of recognition delay (MRD), months of non psychiatric treatment (MNPT) and duration of discontinuation in months (MDD) were made. Statistical tools such as correlation coefficients, OLS regression and logistic regression were used for analysing the data. For OLS regression, five models of regressions were run. The study started with variables in the demographic group as independent variables and MRD as dependent variable. Then each time variables from the next group were added to assess the effect of each group on OLS parameters.

## **Pre-testing of the structured questionnaire**

Considering sensitive nature of the problem of pre-testing of the interview schedule for caregivers was planned. Five interviews were taken in the beginning and the schedule was modified suitably. Fifteen more interviews were taken to find out the suitability of the questionnaire for caregivers with varying socio-demographic backgrounds. The data generated were converted into appropriate tables and possibility of statistical analysis was evaluated. After suitable modifications in the schedule, 249 caregivers were interviewed.

## **Limitations of this study**

The results of the study need to be interpreted with caution as the study has following limitations: (a) Caregivers who visited YMH were not necessarily primary caregivers of the patients and in few cases there is likely to be a deviation in the information given by primary caregivers and the interviewee caregivers. In such cases, interviews were conducted only after confirming that the accompanying caregiver knows the facts about history of symptoms and treatments; (b) Information for this study was collected from caregivers of person with mental illness who visited YMH (OPD) during the survey period. Most of the patients were previously hospitalised at YMH for psychotic problems. Hence, this study is a representative study for patients visiting OPD section of YMH, but not for all the patients in the society; (c) Caregivers from YMH represents people from the lowest socio-economic strata of the society. Hence, the study covers this section of the population alone and cannot be considered as a representative study of the entire society; and (d) Reliability of the information collected in this study depends upon willingness of the participating caregivers. No scale was used to measure the reliability of information given by family members.

## **Chapter IV**

### **Background Characteristics of Study Population**

This study collected data from 249 caregivers/respondents who visited YMH along with their patients. YMH is one of the oldest government mental hospitals in India which was established in 1915. It has a bed capacity of 2,400. It also provides outpatient department services (OPD) and 100 to 150 patients and caregivers visit it every day in order to consult psychiatrists and collect medicines. These services are offered free of cost. A nominal amount of Rs. 20/- has to be paid in order to collect the case papers. Medicines, if purchased from the open market, cost in the range of Rs. 1,000 to 3,000. This is the main reason why patients and caregivers use OPD services at YMH covering long distances and travelling time from their place of residence.

#### **Section I**

##### **Background Characteristics of Caregivers**

A total of 249 caregivers participated in this study. Their background characteristics are presented in Table 4.1. Out of the total caregivers, 73.1 per cent were male and 26.9 per cent female. Hinduism was their most common religion with 87.95 per cent respondents, followed by Buddhists (7.63 per cent), Muslims (3.61 per cent), and Christians (0.80 per cent). In terms of caste, respondents from the open category were 48.59 per cent, 23.29 per cent from SC, 8.84 per cent from NT, 17.67 per cent from OBC and 0.8 per cent from ST. Among caregivers, 47.79 per cent respondents had joint families, while 52.21 per cent had nuclear families. The mean age and education of the caregivers were 43.97 and 9.10 years respectively. Among the respondents, 62.10 per cent were direct relatives of patients, while 37.90 per cent represented other relatives.

Out of the total caregivers, 73.1 per cent were male and 26.9 per cent female. This reflects predominance of male caregivers over female caregivers accompanying a patient to YMH. However, primary caregiver at home, i.e., one that spends more time in looking after treatment and formal and informal care may be a different caregiver. This also reflects traditional division of responsibilities among men and women. Long distance of YMH from

caregivers' residence may be another reason. Our data show that most of women caregivers came from Pune city itself. Very few women caregivers came from districts other than Pune district, especially from Marathwada from where they have to make an overnight journey to reach YMH. Greater responsibility on men as caregivers may be acting as a barrier in taking early treatment or visiting YMH on a regular basis as they have to keep away from their work during day/s of their visit to YMH.

Hinduism was the most common religion of caregivers with 87.95 per cent Hindu respondents, followed by Buddhists (7.63 per cent), Muslims (3.61 per cent), and Christians (0.80 per cent). Under-representation of Muslim population may be because social and economic conditions are not favourable among them and visiting a dargah for relief when symptoms are observed is a common practice among them. Buddhist population seems to be slightly over-represented in our survey considering their population in India. However, considering that in Maharashtra the percentage of Buddhist population is much larger (7 per cent) it was adequately represented in our study.

In caste-wise classification of caregivers, SC population was slightly over-represented with 23 per cent of the total respondents. This may be because of higher education and awareness among it as compared with other castes on the one hand and their higher percentage of population living in urban areas. There was only one caregiver belonging to ST indicating that patients among them did not even reach YMH.

Mean age of caregivers was 44 years and caregivers in the age group 36 to 60 were the most dominant group, i.e., 48.2 per cent of the total caregivers. As we move towards younger age group of 16 to 25 or 26 to 35, the number of caregivers declined to 22.9 per cent and 12.5 per cent respectively. Similarly, with an increase in the age of caregivers (60+ group), the number of caregivers declined to 16.5 per cent.

Mean education of caregivers was 9.1 years. Caregivers with the secondary level education were the most dominant group having 39 per cent of the total caregivers. Caregivers with no education or only up to primary level education constituted 12.9 per cent and 6.4 per cent respectively.

<b>Table 4.1 Number and percentage of Caregivers by background characteristics</b>		
	Number	Per cent
<b>Religion</b>		
Hindu	219	88.0
Muslim	9	3.6
Christen	2	0.8
Buddhist/Neo Buddhist	19	7.6
<b>Caste</b>		
SC	58	23.3
ST	1	0.4
NT	22	8.8
OBC	44	17.7
Open	121	48.6
Others	3	1.2
<b>Gender</b>		
Male	182	73.1
Female	67	26.9
<b>Type Of Family</b>		
Joint	119	47.8
Nuclear	130	52.2
<b>Place Of Residence</b>		
Rural	142	57.0
Urban	107	43.0
<b>Relation of Caregiver with the patient</b>		
Father	61	24.5
Mother	32	12.9
Brother	57	22.9
Sister	4	1.6
Son	33	13.3
Husband	13	5.2
Wife	22	8.8
Others	27	10.8
<b>Education of Caregiver</b>		
Illiterate	32	12.9
1 to 4	16	6.4
5 to 10	97	39.0
11 to 12	48	19.3
13 to 15	40	16.1
16 & above	16	6.4
Mean education		9.1
<b>Age of Caregiver (years)</b>		
16 to 25	31	12.5
26 to 35	57	22.9
36 to 60	120	48.2
61 & above	41	16.5
Mean Age		44.0
<b>Marital status</b>		
Married	203	81.1
Unmarried	36	14.1
Widow	10	4.0

...Table contd.

	Number	Per cent
<b>Occupation</b>		
Not employed	3	1.2
Cultivator (large farmer)	5	2.0
Cultivator (small farmer)	38	15.3
Agricultural labourer	21	8.4
Non-agricultural labourer	15	6.0
Government service	18	7.2
Private Service	64	25.7
Business	27	10.8
Self-employed	18	7.2
Pensioner	15	6.0
Home maker	16	6.4
Student	3	1.2
<b>Monthly income of the Caregivers (Rs)</b>		
No income	23	9.2
1 to 5000	53	21.2
5001 to 10000	66	26.5
10001 to 15000	46	18.4
15001 to 20000	30	12.0
20001+	30	12.0
<b>Total</b>	<b>249</b>	<b>100.0</b>

Caregivers with junior college, senior college and education above graduation level were substantial, i.e., 9.3 per cent, 16.1 per cent, 6.4 per cent respectively. A large number of caregivers were educated above junior college which reflects potential of educating and developing awareness about mental illness in this group.

About relation of caregivers with the patients, 75.2 per cent of the caregivers were blood relatives of patients. This reflects importance of family in being caregiver for person with mental illness. A similar observation has been reported by some studies that have found that for a majority of patients primary caregivers were their blood relatives. Among blood



relatives parents formed 38 per cent of the total caregivers. This reflects important role of parents in India in looking after their children even in their old age. This also shows the kind of family atmosphere which patients have in spite of the chronic nature of their illness. This is helpful for the recovery of patients or for reducing their disability. Patients in India, unlike patients from developed economies, have an advantage in this respect. However, in the light of delayed, irregular treatment and almost absence of any support from the government, this also reflects the enormous burden that families have to bear.

In occupational classification of caregivers, those unemployed were negligible, i.e., only 1.2 per cent of the total respondents. The number of large farmers was small in our survey with 2.0 per cent of the respondents. This may be because large farmers with greater income may be approaching private mental health service providers rather than going to the government hospital which is considered to be providing service to people from the lower income strata. Caregivers belonging to the categories of small farmers, agricultural labourers, non- agricultural labourers and private servants, who basically come from very low income group, collectively formed 55 per cent of the total caregivers. Several studies show an association between indicators of poverty and the risk of mental disorders (Patel & Kleinman, 2003). Pensioners and caregivers in government service were around 13 per cent.

## **Section II**

### **Background Characteristics of Patients**

Among 249 patients, 68.3 per cent were males and 31.7 per cent female (Table 4.2). The mean education of the patients was 7.69 years, while the mean age at the beginning of symptoms and the current age were 24.68 and 37.75 years respectively. Among them, 55.82 per cent were employed while 44.17 per cent unemployed. Schizophrenia was the main diagnosis of the patients which afflicted 74.44 per cent, Psychosis 8 per cent, Bipolar affective disorder 7.48 per cent, and others 9.69 per cent. Predominance of patients with Schizophrenia or major mental disorders is also reported by other studies (Lahariya, Gautum, & Jain, 2010; Jain, et al., 2012).

Predominance of male patients over female patients reflects a gender bias in terms of taking patients to mental hospital for treatment. It is said that mental illness is most

democratic, i.e., its prevalence is uniform across sex and other characteristics. Hence, if prevalence of mental illness among women is not less than among men, then a significantly higher number of male patients over female patients at YMH is a clear reflection of gender bias. Males receive preference over females in taking them to YMH for treatment. Similar observations are recorded by (Lahariya, Singhal, Gupta, & Mishra, 2010). He argues that illness of male patients is taken more seriously than that of female patients. That results in a greater utilisation of psychiatric hospital services by male patients.

Mean education of the patients was 7.7 years, lower than that of caregivers. Onset of symptoms very often occurred at a relatively young age (WHO, 2001; WHO, 2003), which is an important period for continuing of their education. Emergence of symptoms brings disturbance in their education and very often on a permanent basis in the case of major mental illnesses. This was the reason for the very less number of patients with education above secondary level in our studied population. Patients in the secondary education group (5 to 10 years) were in a majority with 53.4 per cent of the total.

Mean current age of the patients was 38.8 years. However, patients in the age group of 36 to 60 and 26 to 35 years were predominant at 44.2 per cent and 36.0 per cent respectively. Together they made 80 per cent of the total number of patients. Age group of 25 to 60 years is the most productive age group and patients in this age group who develop chronicity of disorder may not be able to perform even their day to day activities or contribute economically. That is the reason for contribution of mental illness is the highest in terms of DALYs lost among all disabilities.

Many patients develop symptoms of mental illness from 16 to 25 years of age. This is the prime time in the life of an individual. During this period of life, adolescent and late adolescent individuals learn new skills and develop relationships which are important for growth and stability in their future life. In our sample, 60 per cent patients developed their illness during this period. Since mental illness strikes in early age and people have yet to live many more years, it has the highest share in the total disability due to all disorders (WHO, 2001).

Out of the total patients, 74.4 per cent has schizophrenia, 7.5 per cent BAD, 8.4 per cent psychotic and 9.7 per cent others. All these illnesses come under what is called as major

<b>Table 4.2. Number and percentage of patients by background characteristics</b>		
	Number	Per cent
<b>Gender</b>		
Male	170	68.3
Female	79	31.7
<b>Current Age of the patient (years)</b>		
<25	37	14.9
26-35	91	36.0
36-60	110	44.2
61+	11	4.4
Mean age		37.8
<b>Age at the beginning of symptoms (years)</b>		
<25	150	60.2
26-35	64	25.7
36-60	32	12.9
61+	3	1.2
Mean age		24.7
<b>Education of the patient in completed years</b>		
No education	39	15.7
1--4 years	18	7.3
5--10 years	133	53.4
11--12 years	36	14.5
12--15 years	19	7.6
16 years & above	4	1.6
Mean education		7.7
<b>Type of illness</b>		
Schizophrenia	169	74.4
BAD	17	7.5
Psychosis	19	8.4
Others	22	9.7
<b>Marital status</b>		
Married	145	58.2
Unmarried	82	32.9
Widow/Widower	12	4.8
Divorcee	10	4.0
<b>Employment status</b>		
Unemployed	110	44.2
Employed	139	55.8
<b>Occupation</b>		
Not employed	110	44.2
Cultivator (large farmer)	4	1.6
Cultivator (small farmer)	25	10.0
Agricultural labourer	11	4.4
Non-agricultural labourer	4	1.6
Government service	7	2.8
Private service	20	8.0
Business	11	4.4
Self-employed	10	4.0
Pensioner	1	.4
Home maker	41	16.5
Others	4	1.6
Student	1	.4

Table contd..

	Number	Per cent
<b>Monthly income of the patients (Rs)</b>		
No income	180	72.2
1 to 5000	27	10.8
5001 to 10000	19	7.6
10001 to 15000	6	2.4
15001+	7	2.8
<b>Total</b>	<b>249</b>	<b>100.0</b>

mental disorders. In this study ‘Others’ include only 5 patients who had a common mental disorder (CMD). In India the prevalence of CMD is four to five times greater in number as compared with that of major mental disorders (Gururaj, 2005). However, in our study their number is negligible. It means that a majority of the patients with common mental disorders are not brought to YMH.

Considering that there are hardly alternative facilities for treatment of common mental disorders, either at primary health centres or district hospitals, our conclusion is that very few such patients receive any treatment. Patients with schizophrenia over-represent in this study. This may be because their symptoms are and they become troublesome to other members in the family.

Similar findings have been reported by others (Lahariya, Gautum, & Jain, 2010). They argue that very poor turnover of patients with CMD in a mental hospital is because there is a myth among caregivers that psychiatric hospitals are basically for psychotic patients, i.e., patients with severe mental illnesses. There is a need to remove this myth in the minds of the public so that persons with CMD will also avail services at mental hospitals. Jain, et al. (2012) argues that often patients with depression do not realise for long that they suffer from an illness and realize it only when symptoms become severe, while psychotic patients disturb peace of the family and hence early consultation is sought from the nearest possible source. Being unemployed is the single largest category among patients with 44.2 per cent of the total patients, followed by home maker which is 16.5 per cent. In all 61 per cent of the patients in this study were not in the labour market.

This study collected data from 249 caregivers from OPD section of YMH. Out of the total caregivers, a majority of them were male, which reflects predominance of male

caregivers over female caregivers. Hindu and SC population was slightly over-represented in their respective categories. The mean age and education of the caregivers were 43.97 and 9.10 years respectively. The most frequently found relation of caregiver with the patient was the parent or some other family member.

Among 249 patients, a majority were males, which reflects neglect of the female population in taking them even to a mental hospital. Majority of them had experienced the onset of symptoms at an early age, i.e., before attaining 25 years. The mean education of the patients was 7.69 years. Most of the patients (as many as 74.44 per cent of the total patients) were diagnosed with schizophrenia, while patients with CMD were negligible in number. Around 50 per cent of the total patients came from Pune district alone. Around 25 per cent of the total patients came from districts adjoining Pune and around the same number came from far-off areas like Marathwada and Vidarbha, and patients had to travel 300 to 500 kilometres one way alone to reach YMH.

## Chapter V

### Treatment delay for mental illness: A micro analysis

*In addressing the significant problem of public mental health the focus is on developing better treatments. However, better treatment will not benefit the public if the public is not accessing them. We need to better understand the factors that delay initial help seeking.*  
-- (Thompson et.al,2008,p,72)

As discussed earlier, like any other illness, timely treatment is necessary for mental illness. However, due to several barriers, people with mental illness and their families demand mental health services with a considerable time lag. This failure to demand mental health services or 'demand gap' is important from the point of view of the patient, family and society. It is called 'treatment lag' or 'treatment delay'.

#### Importance of treatment delay

Understanding the extent of demand gap or treatment delay and its socio-demographic determinants is very important. Treatment delay indicates choices made by individuals and families towards a particular health problem. Studying treatment delay is important as it leads to pain and suffering to the patient and family members, high socio-economic costs and poor prognosis (Black, Peters, Rui et.al., 2001; Drake, Haley, Akhtar et.al., 2000; Jilani & Trivedi, 2011) of the course of the disease associated with delay. Hence, greater delay is detrimental from the point of view of the individual, family and society. Jilani & Trivedi,2011 and Garg, Sidana, & Chavan, 2011 calls treatment delay (or duration of untreated mental illness-DUMI) as the single most important modifiable factor (Compton, Chien, Leiner et.al., 2008) predicting prognosis of psychiatric disorder. Understanding the extent of treatment delay in mental illness and its socio-economic and demographic determinants is important both from theoretical perspective as well as policy perspective. This chapter analyses the problem from this perspective.

## **Types of treatment delay**

Overall Treatment Delay (OTD) is the delay that people make in initiating the treatment since the beginning of symptoms. However, people may make delay at various stages. In their study regarding delays in untreated psychosis, Brunet, Birchwood & Lester (2007) argue that it<sup>1</sup> is not a unitary variable but is composed of distinct intervals. Their study divides it into three components, 1) delays in help seeking, 2) delays in referral pathways, and 3) delays in mental health services. Thompson, Issakidis, & Hunt (2008) divided total delay into two components, 1) recognition delay and 2) delay between problem recognition and actual treatment. In India the prevalence of stigma is extensive which may deter people to consult a mental health professional even after its recognition. Moreover, it due to several other barriers like myths, misconceptions and financial problem, people may not initiate treatment even if they consult a mental health professional. Hence, it was decided to divide OTD into three types, i. e., Recognition Delay, Consultation Delay and Treatment Delay. Recognition Delay (RD) is the time taken in recognising changes in behaviour as a result of mental illness. Consultation Delay (CD) is the time taken to consult a mental health professional after recognising mental illness and Treatment Delay (TD) is the time taken to initiate treatment after consulting a mental health professional. It was decided to use these three variables as the factors that influence these variables are different. RD has more to do with individual, psychological, social and cultural factors while the other two have more to do with economic and logistic factors

## **Extent of OTD**

Out of the sample population, OTD was found in 84.3 per cent of the sample respondents (Table 5.1 and Figure 5.1). All of them, i.e., 210 households had RD. While three per cent of the total had either CD or TD or both along with RD. The latter is the most important component with mean of 35.8 months. CD and TD are few in terms of the numbers of sample respondents and have mean delay of one month and 0.2 months respectively.

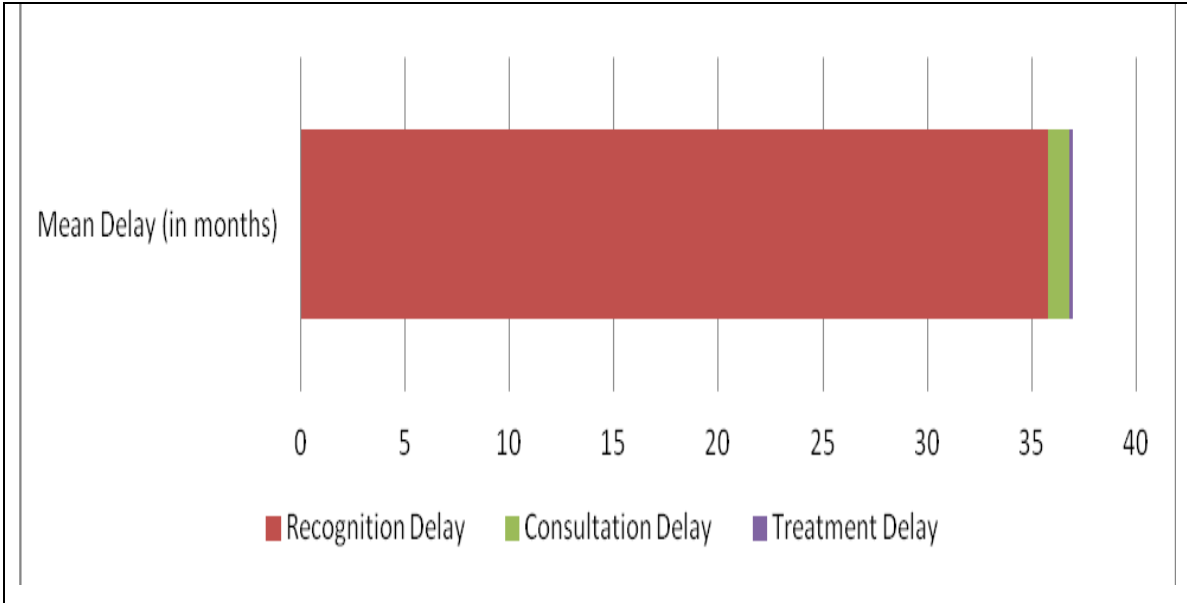
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<sup>1</sup> They used the term as 'duration of untreated psychosis' or DUP

<b>Table 5.1 Number, percentage and mean delay of patients by type of delay</b>			
Type of delay	Number	Per cent	Mean delay (in months)
Recognition Delay	210	84.3	35.8
Consultation Delay	8	3.2	1.0
Treatment Delay	3	1.2	0.2
Overall delay	210	84.3	36.9

Since RD is the most important component and other components of OTD are insignificant in terms of number and their contribution to OTD, it will be appropriate to consider RD and its determinants alone. However, CD and TD may become important over time as RD is reduced through increase in awareness.

**Figure 5.1 Components of treatment delay**



**Extent of RD**

Respondents delayed recognising changes in the behaviour of a patient as mental illness since the onset of symptoms (and hence in initiating treatment). The average RD from onset of symptoms to recognition of illness is 35.8 months, i.e., around three years



(Table 5.1). It is high considering the pain and suffering caused to patient and family members, social-economic costs and poor prognosis of the course of the disease. Some delay is unavoidable since the symptoms of mental illness, like most physical illnesses, are not visible immediately (Appendix IV for difference between physical illness and mental illness). Moreover, people have poor mental health literacy and symptoms of mental illness get mixed up with stages of life or life events or normal deviations, which are found in all people. Moreover, this period of treatment delay is likely to be underestimated. Respondents (who have very little exposure to information about mental illness, have lower level of education and occupied in daily earning activities) are likely to suspect symptoms only when they become glaring.

**Table 5.2 Percentage of total sample households that avail NPT, show RD and their mean MNPT and mean MRD**

Total size of sample	Per cent availing NPT	Mean MNPT	Per cent showing RD	Mean MRD
249	67.9	23.0	84.3	35.8

In their study of patients with anxiety and mood disorders in an Australian clinical sample, Thompson, Issakidis, & Hunt (2008) found that the average time taken to recognise the problem accounted for a majority of the total delay to seek help. Out of total delay (help seeking) of 8.2 years, delay to recognise the problem accounted for 6.9 years and 1.3 years was accounted by help seeking delay. Predominance of recognition delay was observed across all the mental disorders. However, their study did not report the percentage of people that have RD alone or otherwise.

There are few studies in India or developing countries which estimate TD or RD. Jain, et al. (2012) report mean delay of untreated illness (treatment delay) as 36.7 months and also observe that TD delay in India and other developing countries is much higher than in developed countries. Lahariya, Gautum & Jain (2010) in their study of Gwalior Mansik Arogyashala found the mean treatment delay of 10.5 months.

### **Period-wise variations in RD**

Out of the total patients (249) in this study, 84 per cent of the respondents had RD. However, there is substantial variation of it among respondents (Table 5.3). Those with no

RD were 15.7 per cent, those with RD of one to six months 20.1 per cent, those with RD of 7-12 months 14.5 per cent, those with RD of 13-60 months 34.9 per cent and those RD of 61 months and above 14.9 per cent. It is seen that the number and percentage of respondents rises along with a rise in period of (RD). It reaches a peak of 13 to 60 months with 34.9 per cent respondents and falls thereafter. One-third of the total respondents had RD of 13 to 60 months with mean value of 34.2 months.

<b>Table 5.3 Number, percentage of respondents and mean MRD of patients by months of RD</b>			
Months of RD	Number	Percent	Mean
No delay	39	15.7	0
1 to 6 months	50	20.1	3.7
7 to 12 months	36	14.5	11.5
13 to 60 months	87	34.9	34.2
60+ months	37	14.9	144.0
<b>Total</b>	<b>249</b>	<b>100.0</b>	<b>35.8</b>

The table indicates that a majority of the sample households have some or other RD. Perhaps, over time people do get information or symptoms become visible and they recognise changes in the behaviour as mental illness. However, in case of one-third of the sample households, RD is significant, i.e., in the range of 13 to 60 months. This may be because of lack of information or silent progress of the illness or several other barriers which delay recognition and treatment. Around 15 per cent respondents had MRD of 61 months and more. They indicate presence of the severity of barriers –economic, familial or logistic.

The above table indicates four groups: no delay, short delay (one to 6 months), shorter delay (seven to 12 months) and long delay (13 to 60 months). The following table give the results.

<b>Table 5.4 Distribution of patients by months of RD , mean and median delays</b>			
Months of RD	Number	Per cent	Mean
No delay	39	15.7	0.0
Shorter delay (up to 12 months)	86	34.6	7.0
13 to 60 months	87	34.9	34.2
Extreme delay (>60 months)	37	14.9	144.0
Total	249	100.0	35.8

Table 5.4 indicates the percentage-wise importance of the three groups- patients with longer delay, patients with shorter delay and patients with extreme values (i.e. patient with no delay plus patients with extreme values). Patients with shorter and longer RD are numerically a dominant group and indicate significant deprivation or neglect. From the policy perspective, this group is amenable to measures to shorten or eliminate the delay. Hence, socio-economic determinants of RD of this group are important from policy perspective.

### **Distribution of patients by type of diagnosis**

Most of the patients included in this study had major mental illnesses (Table 5.5). Persons with schizophrenia dominated with 74.4 per cent of the total patients followed by BAD with 7.5 per cent and psychosis with 8.4 per cent. A very small percentage of patients (4 per cent) had any form of common mental disorder (CMD) which includes anxiety, depression, phobia, epilepsy and panic.

In their study conducted at government run facility at Jaipur, Jain et. al., (2012) found that a majority of patients were with psychotic illness and depressive illness while their variants were less common. They argue that this may be because tertiary level facility receives more severely ill patients as compared with patients received at other facilities.

In this study, patients with schizophrenia, which make the largest group, have the highest average RD. Patients with BAD or Psychosis have slightly lower mean RD, while patients with other psychiatric illnesses are very few cases and hence are not comparable for the analysis. Patients with MR stand out among all illnesses due to their longest mean RD of 87 months. This means that cases with mental retardation are brought for treatment at a much later stage and probably that too for the purpose of certification. Similar observation has been recorded by (Jain, et al., 2012) in his study in the mental hospital in Jaipur.

This data lead to two important conclusions. One, total dominance of patients with diagnosis of major mental illnesses (including schizophrenia) at OPD of YMH and their

almost marginal presence with CMD. This means that a majority of patients that avail OPD services have major mental illnesses. Two reasons may be responsible for this. One, patients with major mental illnesses who experience severe symptoms and become troublesome to others are brought to YMH. The other reason may be that for caregivers, YMH may be a safety net to put patients whenever any psychiatric emergency arises (Addlakha, 1999). That may be the reason for these patients for availing services at OPD section of YMH.

The second observation is that persons with CMD do not turn to YMH for help. This looks surprising considering that the prevalence rate for CMD is around 4 to 5 per cent in India, which is four to five times that of major mental illnesses. (Gururaj, Girish & Isaac, 2005). Two possibilities may account for these results. One is that medicines for CMD are available at primary health centres (PHCs) or district hospitals and people avail services from these centres which are closer to them as compared with YMH. The other possibility is that people with CMD do not take treatment at all.

<b>Table 5.5 Number, percentage, mean MRD and MNPT of patients by psychiatric disorder</b>				
Name of psychiatric disorder	Number	Per cent	Mean MRD	Mean MNPT
Schizophrenia	186	74.7	38.0	22.6
BAD	18	7.2	30.4	27.1
Psychosis	20	8.0	33.0	36.5
ADS	7	2.8	22.6	21.3
MR	4	1.6	87.0	21.3
Epilepsy	6	2.4	10.0	4.0
BMD	4	1.6	6.8	0.0
Others	4	1.6	7.5	12.0
BAD= Bipolar Affective Disorder ; MR= Mental Retardation ; BMD= Bipolar Mood Disorder; ADS: Alcohol Dependency Syndrome				

The second possibility looks more plausible as PHCs or even district hospitals do not have adequate stock of medicines most of the time. In this study it is found that respondents from very far off districts (even 400 to 500 kilometres away) visit YMH only for the sake of free medicines (for their patients with major mental illnesses). What is

plausible is either patients with CMD do not get detected at PHC level and patients do not take medicines (or take them for other ailments), or families do not recognise mental illness as an illness and do not take medical treatment for persons with CMD as patients do not become troublesome, aggressive or violent. Hence, patients with CMD are likely to be unnoticed and remain untreated at least in this section (lower income class) of the population. It means that the demand gap for persons with mental illness is total.

### **Distribution of patients by region**

Out of total sample households, 55 per cent are from Pune district of which 34.1 per cent are from Pune city alone and the remaining 20 per cent from the rest of Pune district. Coverage of YMH extends to 12 districts including several districts in Marathwada . Out of 126 patients who came from districts other than Pune, around fifty per cent came from neighbouring districts like Sangli, Satara, Nashik, Solapur and Ahmednagar. The remaining fifty per cent came from districts of Marathwada (map showing region-wise distribution of patients is attached at the end of this chapter- Figure 5.2). Respondents from Marathwada travel 300 to 500 kms in order to reach YMH, taking 10 to 15 hours in a one way journey. Because of the long distance and time required, inconvenience and expenses, some of the caregivers may not be able to reach YMH at all or have discontinuations in treatment because they cannot collect their monthly quota of medicines. When one considers transport facilities a decade or two decade back, one can understand the difficulties in reaching or even having knowledge of a mental hospital in Pune.

In Table 5.6 all the districts have been divided into three categories. First is Pune district which is advanced in terms of social indicators and YMH is nearest to sample respondents. The second category consists of districts adjoining Pune district. The third category includes remaining districts which are mostly from Marathwada, which are relatively backward in terms of social indicators and distance to YMH is longest. Since large number of patients is from Pune district, Pune district is further divided in to Pune rural and Pune urban. In Pune district, average MNPT and MRD is higher as compared to other (which is basically due to Pune rural) but in the remaining two categories we find a

clear trend i.e. for socio-economically backward districts of Marathwada, MNPT and MRD is higher as compared to districts adjoining Pune . Districts adjoining Pune have much lower average MNPT and MRD as compared to districts of Marathwada region. Social and economic backwardness and greater geographical distance may be the reasons for it.

<b>Table No 5.6 Number and percentage of respondents and MNPT and MRD by district</b>				
District	Number	Per cent	Mean MNPT	Mean MRD
Pune (Urban)	66	26.5	15.6	29.0
Pune (Rural)	57	22.9	27.1	62.6
Pune	123	49.4	20.9	44.6
Adjoining Pune*	62	24.9	20.7	22.9
All others (Mostly Marathwada)	64	25.7	29.4	31.3
Total	249	100.0	23.0	35.8
Districts adjoining Pune: Ahmednagar ( 28 ); Sholapur (22);Satara (11): Others (2).				
All other districts (mostly from Marathwada); Beed (9); Jalana (7); Latur (6); Parabhani (5); Others (22).				

### **Non-Psychiatric Treatment (NPT)**

Non- Psychiatric Treatment (NPT) includes all treatments other than psychiatric treatment like Ayurvedi, Homeopathic, Yunani or any other medical system, and services of spiritual gurus, faith healers, temples and temple priests, religious rituals, durgahs, etc. NPT was the first choice of intervention for a majority of the households after they noticed changes in behaviour of person with mental illness. In our study, none of the sample households availed services of Ayurvedic, Homeopathic, Yunani or any other medical system.

### **Pathways to psychiatric treatment**

It was found that patients do not come to YMH or any psychiatric facility as a first portal. They follow various pathways before they reach there. The researcher has studied ‘pathways to psychiatric care’ which provides relevant information regarding individuals’ help seeking and illness behaviour, and promotes organised and efficient action. ‘Pathways

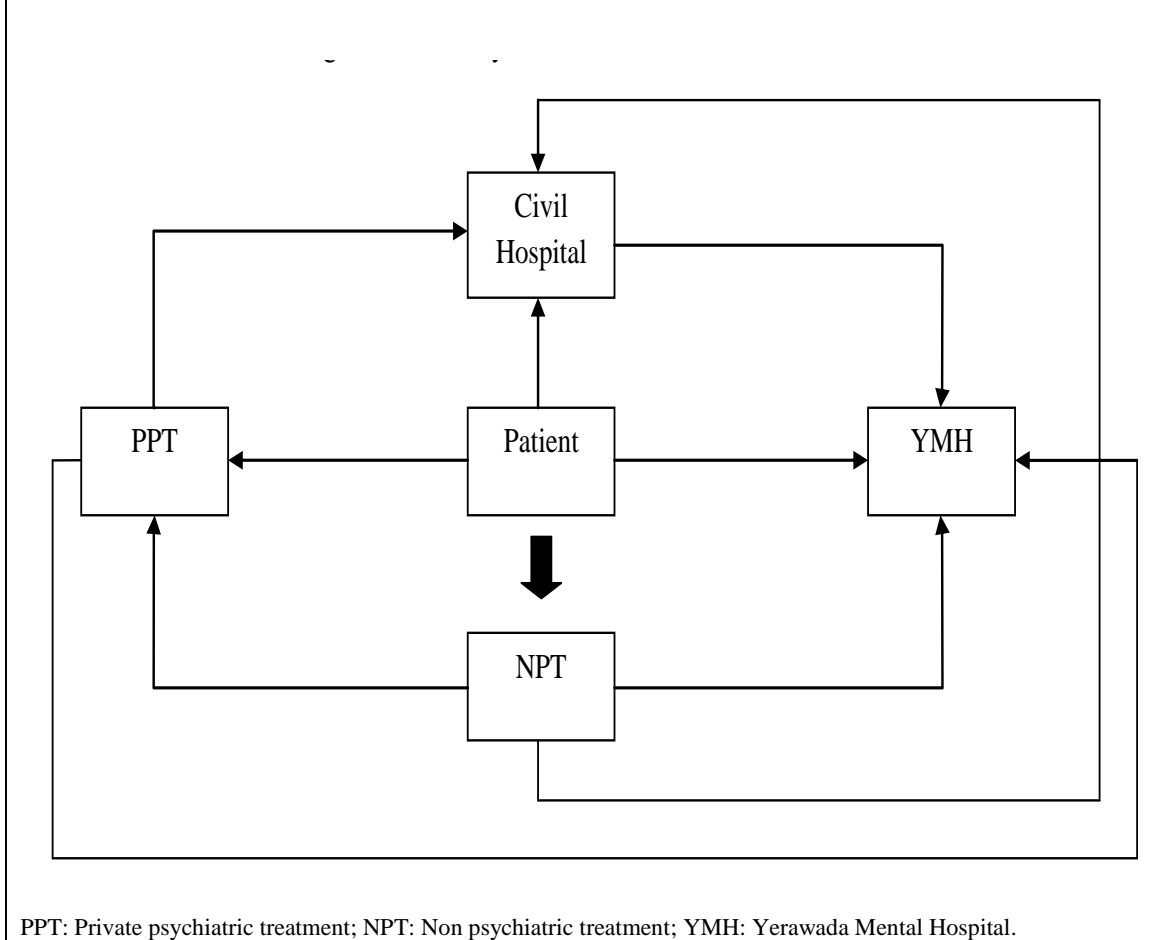
to care' is the sequence of contacts with individuals and organisations, initiated by distressed persons and those of others associated with them, to seek appropriate help (Rogers and Cortes, 1993).

Jain, Gautam, Jain et al.( 2012) records three patterns in pathways to psychiatric care. In the first one, primary care physicians play an important role. Patients generally contact them who refer them further to specialists, i.e., psychiatrists, if necessary. This pattern is found in Western European countries and Australia. In the second pattern, individual patients are allowed direct access to mental health specialists. This is found in Turkey, Poland and Japan. In the third pattern, which is found in less developed countries like India, Indonesia, Pakistan and Nigeria, patients mostly contact faith healers. This is marked by long treatment delays (Jain, Gautam, Jain et al., 2012).

Sixty-eight per cent of the respondents who availed NPT visited religious places, temples, faith healers, spiritual gurus and others as the first point of contact. Predominance of faith healer or religious places as a first point of contact is also recorded by (Lahariya, Singhal, Gupta et.al., 2010; Jain, Gautam, Jain et al., (2012). Treatment from a psychiatrist is generally taken as the last resort. The popularity of other treatments may be because of their easy accessibility, holistic approach, beliefs about mental illnesses in the society, cultural congeniality and cost effectiveness (Torrey, 1986). Thara, Padmavati & Srinivasan (2004) argue that easier accessibility of such healers and their close relationship with the clients often determine effectiveness of their interventions, especially in case of minor mental morbidity.

Figure 5.2 below provides the pathways to care that have been observed in this study. Even though, the first point of contact may be a private psychiatrist or civil hospital physician or even YMH for some patients, for most of the patients the first point of contact is NPT provider, which is shown with a thick arrow in the diagram.

**Figure 5.2 Pathways to mental health care**



In many developing countries mental disorders are commonly considered as non-medical diseases that are caused by invisible, abstract element and supernatural forces. Thus, they are thought to be the domain not of doctors but of traditional healers (Razali, Khan, & Hasan 1996). Moreover, traditional healers while dealing with psychiatric patients often hide their inability to understand and treat these disorders and attribute them to supernatural causes further perpetuating beliefs and superstitions of the patients (Bhana, 1986). Patients go from one healer to another and it is only after not getting any help from them that they turn to psychiatric treatment (Lahariya, Singhal, Gupta et.al., 2010).

Farooq & Minhas (2001) argue that for enormous rural population (up to 70 per cent in developing countries) modern psychiatry does not exist and treatment from a psychiatrist is generally taken as a last resort (Lahariya, Singhal, Gupta et.al., 2010). Many



studies report that traditional healers are important players in contemporary mental health scenario in India and their role cannot be ignored (Bhana, 1986; Ganju, 2000; Jain, et al., 2012; Lahariya, Gautum & Jain, 2010; ). Religious and faith healers are said to be the main gatekeepers towards psychiatric care.

Researchers have found that the nature of treatment of these NPT providers is largely with ‘ashes’, ‘mullets’ or ‘holy water’ (Lahariya, Singhal, Gupta et.al., 2010; Trivedi & Sethi, 1979). Treatment at religious places ranges from a series of rituals such as bathing in the temple tank and circumambulating the temple to prayers at specified times. Traditional healers often employ amalgam of traditional (e.g., dietary and herbal) and biomedical interventions. Physical restraint by chaining patients to a pole or tree is not uncommon. (Thara, Padmavati & Srinivasan, 2004).

### **Period-wise variations in period of NPT**

Average period for availing NPT was 24 months. There is a substantial variation among sample households of period for which they have taken NPT (Table 5.7). Out of the total patients, patients with no NPT were 32.90 per cent, with NPT of one to six months 30.10 per cent, with NPT of 7-12 months 10.00 per cent, with 13-60 months 14.50 per cent and with 61 months and above 12.40 per cent. As one moves from no NPT to higher period of NPT group, the percentage of respondents availing it shows a declining trend. This indicates that as a matter of habit or social pressure or suggestions from others, people turn to NPT but abandon it if they do not get desired results.

<b>Table 5.7 Number, percentage and mean NPT of patients by NPT group</b>			
No of months NPT was taken	Number	Per cent	Mean
No NPT	82	32.9	0.0
1 to 6 months	75	30.1	2.7
7 to 12 months	25	10.0	11.6
13 to 60 months	36	14.5	38.0
60+ months	31	12.4	125.1
<b>Total</b>	<b>249</b>	<b>100.0</b>	<b>23.0</b>

## Cost of treatment

Information about the cost of NPT and Psychiatric treatment (PT) was also collected. Respondents have availed NPT in a number of stages and it was spread over a long period of time. Hence, it was thought that summation of such expenditure is not meaningful. This study asked the respondents to compare expenses made on NPT, PT and services at YMH. Respondents have expressed two views. First one is that the cost of NPT is not insignificant as usually understood and second the cost of treatment of PT at private clinic or hospital is the highest while the cost of treatment at YMH was the lowest. However, respondents had to spend even though treatment at YMH is free as they have to incur transport cost, spend time and suffer loss of income.

## Reasons for RD

Respondents were asked the reasons for the delay. They selected one or more of them. Table 5.8 presents them. This study finds that lack of information is the most important reason and almost applicable to the entire sample households. However, other reasons like shocking incidence, problem in the development phase or physical problem are also important explanations for RD.

<b>Table 5.8 Number and percentage of respondents with reasons for RD</b>		
Reasons for recognition delay	Number	Per cent
Lack of information	204	97.1
Thought that this a physical /some other problem	32	15.2
Thought that this is a problem in the development phase of the patient	24	11.4
Thought that this is due to addiction	32	15.2
Shocking incidence	31	14.8
Any other	96	45.7
Total respondents with RD	210	100.0
Since respondents were allowed to select more than one choice, summation of percentages may exceed 100 per cent.		

While making choices about reasons for delay, respondents from YMH provided some qualitative information about it. This information is classified into five groups and provided in Box 5.1.

In order to understand the complex issues related to reasons for RD, this study also conducted some Key Informants Interviews (KII) of ‘Veteran Caregiver<sup>2</sup> and staff members at YMH. Separate interview guides were prepared for interview of veteran caregiver and interview of YMH staff (Appendix VIII and IX). Key informants, being veteran and hence experienced, were expected to provide a general scenario. Following quotes provide information as given by the veteran caregivers and YMH staff.

**Box 5.1 Reasons of recognition delay**

**Patient’s Nature:**

- Change in behaviour was age related.
- Behaviour of the patient was an attention seeking strategy.
- Ignored due to vices/bad habits.
- Ignoring the patient as he was a habitual babblers and drug abuser.
- Change in behaviour is due to old age.

**Faith on blind beliefs:**

- Its God’s doing.
- Black magic.
- The person is possessed by spirits.
- Spirits of dead relatives have been angered.
- The behaviour is a curse of the gods.
- Slept in the forest and possessed by evil spirits.
- ‘If he was treated earlier, it would have been better. Nobody in the village realized this. Life in the cities is different. We wasted time with gods and godmen. Wasted money. This had happened for the first time in the family. Didn’t even know that such an illness existed.’ – Mother.

**Event or incidence in life:**

- Parents thought that events or incidence in life may change behaviour and so patients behave like this.
- The patient’s behaviour is due to a failed love affair.
- The behaviour is due to failure in profession.

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<sup>2</sup> A veteran caregiver is a caregiver who is not only informed by MI of his/her family member but due to his/her experience, education and overall alertness have enough knowledge to talk about the conditions of PMI in general, pathways that PMI take before taking psychiatric treatment and delay in the process and reasons for it.

- Fighting with the husband and going to the maternal home.
- Change in behaviour is due to too much education and being away from home.
- Was recently married and so due to a change in the house, people and environment.
- Divorce was responsible for the change in behaviour.
- Result of losing money in business.
- Result of abandonment of the wife.
- The behaviour is due to the passing away of the mother.

**Mild symptoms:** If the symptoms are mild, then high chances to ignore mental illness.

- Mildness of symptoms does not warrant treatment.
- Not realizing the necessity of treatment as the patient is able to perform the daily chores properly.
- The symptoms do not seem like those of mental illness.

**Physical illness:**

- Polio has caused the behaviour change.
- Typhoid has caused this behaviour.
- The symptoms were not realized as the patient was deaf and dumb.
- Result of an accident.
- ‘Didn’t realize that this was a mental illness. Thought it was a physical illness.’

## **KI Interview**

### ***Delay in recognition***

As we saw earlier, in the case of mental illness, there is significant RD. Because of the peculiarity of symptoms and their varying intensity, often they are interpreted as quirks of personality. *“Very often parents argue that their patient is lazy, he/she does not want to do anything and makes complain on every small issue. This delays the treatment. Symptoms which parents generally share are –very slow in his work and not taking bath regularly”* (Veteran caregiver, 54 years, male). In mental illness symptoms are woven around aspects of personality. They are seen as a part of patient’s nature. Symptoms get camouflaged as something else. The family takes time to recognize them. Only when these ‘quirks’ or oddities become troublesome to the family economically and socially or becomes physically threatening to the members of the family or society, the family decided to go in for treatment.

Delays occur even after the symptoms are recognized. *“Then patient is taken to the family doctor. But they may not detect or even doubt presence of mental illness.... Sometimes due to someone’s suggestion parents take help of non-allopathic or even non-medical treatment. ‘These treatments are not harmful. Let us at least give a try. If patients benefit from these treatments, then it is well and good’. This is the general thinking of the parents. However, this delays the treatment. Very often parents are given advice to approach a counsellor who examines the patient and gives good advice regarding what patient should do and should not do. The patient also feels nice. However, these are not the solutions to the mental illness (psychosis) of the patient. In all, this entire process takes time and the patient is deprived of treatment for some time.”*

Staff members of YMH and caregivers disclosed that the general practitioners are often not able to recognise the symptoms of mental illness. One caregiver (male, 55 years) narrated, *When we took the patient to a general practitioner (GP) he told us that the symptoms are due to tension and such things happen sometimes’*. Another caregiver (male, 65 years) remarked, *‘There is a delay of two or three years due to inadequate knowledge of GPs. They are not only able to diagnose but are also not able to suspect symptoms of mental illness which consequently aggravates’*. This observation has to be considered in the light of the fact that GPs are considered to be gatekeepers in the Indian mental health system. They fail to recognise the symptoms and hence cannot treat nor refer patients to a specialist in mental health care. This highlights that not only is there a need of awareness among general population but also among GPs and all those who are working for primary health care. Often it is argued that basic mental health care of detection and treatment should be provided at the primary health centre and GPs should be trained in it. However, considering the enormous task of providing training, at least basic information/awareness among GPs should be cultivated so that they can refer at least suspected cases to a mental health specialist. One staff member (male, 36 years) categorically mentioned that YMH is expected to implement DMHP and its officials have been given training to that effect. However, this important work of capacity building of medical officers and nurses at PHC is not undertaken due to several lapses.

Many times RD is perpetuated by confusing symptoms with something else. When people notice symptoms they look for known explanations of odd behaviour. One caregiver (male, 53 years) accepted, “*We could not recognise his odd behaviour as illness as we thought that it is due to the problem of addiction to alcohol. We even consulted a de-addiction centre which too could not suspect the possibility of mental illness. We consulted a doctor only when he started becoming violent. My father was uneducated and I was too young to understand and take action. We lost precious years in the process.*” This account indicates that not only lay persons lack basic information, but even a de-addiction centre which is likely to face such co morbidity, could not suspect mental illness. This suggests the necessity of health workers at such centres to be more careful while diagnosing and treating suspected cases.

### *Role of Family*

Since family members are the main caregivers in the Indian context, family plays a crucial role in the decisions regarding availing NPT, availing PT, discontinuation, medicines, etc. Family provides economic and emotional support to the patient. The amount of time, energy, emotions and finances invested in the treatment of a patient are high. Even in the case of nuclear families, the role of the extended family matters. Mrs Kulkarni (female, 45 years, name changed) who lives with her husband (patient) and two children begins her narrative singularly using ‘*I*’, telling how and when she noticed his symptoms. However, as she proceeded she used ‘*we*’ including their siblings. On noticing changes in her husband’s behaviour she consulted their siblings. Thereafter, all decisions regarding seeking professional advice, giving treatment, etc., were taken collectively by them. This shows that even in the case of nuclear households the extended family plays an important role in decision making.

In case of Mrs. Kulkarni, her sister-in-law resisted the idea of professional advice insisting that matters will improve with time. Because of this for a long time professional help was not taken. Similar delays happened due to stigma, fear of spoiling marriage prospects of the patient or of other family members, etc. This shows that although the family mainly plays a supportive role, it can also be one of the reasons for RD and TD. As

veteran caregiver (male, 65 years) notes, *“Every family has its own way of dealing with the problem. Very often one of the family members suspects the possibility of mental illness but he does not share it with other family members for some time. Even when he/she shares it with others, they may take it lightly or brush it aside all together and suggest some other treatment. Briefly, due to ignorance original doubt gets a twist.”*

### *Nuisance Hypothesis*

One notices that the family is forced to act upon the situation when the patient becomes violent, physically threatening or economically burdensome for it. Caregivers provided following reasons as important incidences for seeking treatment: started tearing his clothes, started talking in abusive and threatening language to family members and neighbour, stealing utensils from neighbours, etc. Such incidences make people take steps and show the patient to a mental health specialist. However, such developments of symptoms may not happen in case of all patients, unless mental illness is acute. This is the main reason of delay for patients especially those in rural, uneducated and low income families.

In some cases even physical illnesses might be ignored and mental illness be given preference for treatment. Among those interviewed, there were two families where treatment for mental illness was being given while other illness/handicaps were not treated as they did not jeopardise day to day functioning of families. In one case, septic in the ear and in another case prevalence of BP were not treated for multiple reasons like lack of visible problem, disruption of work except on some occasions, availability of anyone to accompany the patient, and inability to understand the serious consequences of disease. However, mental illness was treated when the patients were violent and troublesome to others if they were without treatment. One of the caregivers in this example was an agricultural labourer, and father and his son were the only earning members in the family. In another case, the daughter who worked in an office in Pune for six days a week received only a paltry amount and she and her mother were the only earning members in the family. Both these families earned modest income and lived in difficult financial circumstances. They could afford to pay attention to an illness only if it disrupted their daily work and

income earning activity severely. Hence, the hypothesis that illness which is a nuisance to daily work and earning receives attention and treatment. One KI said, 'It is beneficial if there are strong/aggressive symptoms, since it ensures speedy treatment for the patient'. Paradoxically, being a nuisance can set the patient on the path to recovery!

Two more things are observed in this context. A family is tolerant and ready to accommodate the patient as long as he/she does not disturb income earning activity by becoming violent. This means that in rural areas where habitats are dispersed and thinly populated, people are more tolerant than urban areas which are densely populated. The family is ready to tolerate a patient even though he/she does not contribute economically. Being unproductive is not an important issue for some of the caregivers, especially from rural areas where the line between being economically productive and unproductive is blurred due to disguised unemployment.

#### *Family equilibrium*

It was found that families in India are willing to take care and provide treatment even if a patient is unwilling to do so. However, it was observed that after initial attempts to do so, family may give up if they find that he is not aggressive. He may economically become inactive, but it is accepted as long as he is not dangerous. Expectations from him are lowered. Thus, a new 'family equilibrium' is reached with redefined expectations, accepted behaviour, roles and responsibilities of members which may delay treatment for the first time or restart the treatment after discontinuation.

#### *NPT*

As seen earlier, the first channel of treatment chosen is NPT. Only when NPT fails or does not give expected results do the patients approach psychiatric treatment. NPT is approached by people because of a number of factors: easy availability, the bond that NPT practitioners share with their clients, including the time and emotional support that they provide, suggestions by family members, etc. As opposed to medical practitioners who do



not give enough time to their patients or spend time listening to their doubts and grievances, NPT practitioners provide support and assurance.

Most of the KIs agreed that religious treatment or treatment from faith healers is a common practice among those who visit YMH. One YMH staff (male, 49 years) disclosed that such practices are generally not followed in the case of physical illnesses. This indicates that people have different ideas for physical illness and mental illness. However, he also admitted that people approach such healers when a woman does not have a child. Perhaps approaching a healer may be a standard practice when the medical treatment does not work.

Generally, use of NPT is looked down upon in the modern medical system. Some of the YMH staff interviewed attributed the use of NPT to ignorance and illiteracy of the families and patients. Even the caregivers themselves recognize the lowly and non-scientific status given to NPT and perhaps even accept it. This is evident from their reluctance to talk about the NPT that their patients took before coming to YMH or are taking simultaneously with psychiatric treatment.

### *Gender*

With respect to women several reasons lead to neglect and delay. In the case of unmarried girls, due to stigma illness is usually kept hidden and untreated. Where treatment is given, it is discontinued after marriage in order to maintain secrecy. Because of this, a patient experiences relapse. One staff member of YMH stated that in 95 per cent of such cases girls end up with a divorce. A veteran caregiver (male, 65 years) opined, *“In our society career is given importance for boys and education for that is given. But for girls marriage is important.. Such expectations are likely to become a barrier in their development. Very often things start changing when children are in the school. When they say that they have stress; actually it is beginning of illness. However, teachers are neither are aware of it nor have the capacity to cope with it.”*

However, interviews with caregivers revealed that families do not necessarily discriminate against men and women. Father of one female patient said, “We put our daughter in YMH only when it became unbearable. We will take her back when the situation improves.” Thus ‘nuisance hypothesis’ is applicable for both men and women.

#### *Importance of demand for services*

Caregivers and staff members of YMH see the changes that take place over time. One YMH staff member (male, 49 years) and one veteran caregiver (male, 65 Years) said, “*However, changes are seen in the younger generation. Individuals in the new generation approach for treatment much earlier due to increased awareness. While the earlier generation due to lesser awareness delayed approaching for treatment. It is not that several barriers to treatment) take place deliberately now. They keep on happening. Matters will not change by simply increasing services for mental illness as you can take a horse to water but ultimately it is the horse which decides to drink it or not.*”

#### *Physical disorder*

It was told by most of the caregivers as well as staff members at YMH that in the case of physical disorders patients do not resist treatment. In diabetes or blood pressure, patients and family members can quickly have a grasp of the problem, its cause and solution.

Caregivers report continuity in taking medicines for physical illness but irregularity in mental illness. Reasons for this may be various: presence of stigma in mental illness, lesser side effects of medicines, assured success of medicines, etc., among others.

#### *Barriers to treatment*

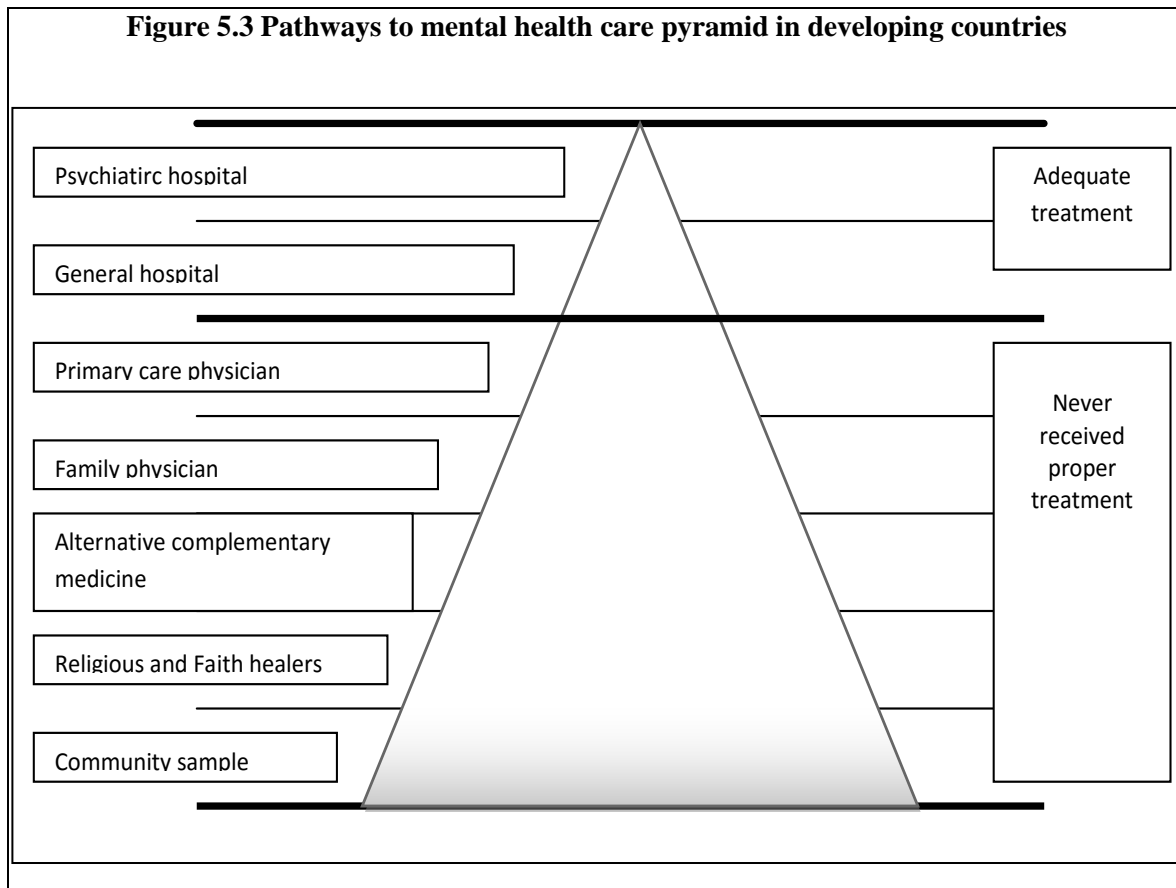
In some cases we found that people could recognise that symptoms are of mental illness. However, several barriers (like those given below) prevented them to start

treatment early. Some reasons for delay in treatment emerged from the interviews of caregivers (Box 5.2).

**Box 5.2 Barriers to take treatment**

- Family was not unanimous about the necessity of treatment.
- Fear that the entire village would react adversely if the patient was admitted in a mental hospital.
- Feeling that the patient would not receive proper treatment in the mental hospital.
- Mildness of symptoms did not warrant treatment.
- Patient's fear of getting admitted to a mental hospital.
- Family did not realize the necessity of treatment as the patient was able to perform his daily chores properly.
- Belief that everything would improve before long.
- Lack of money for treatment.
- There was no companion to go to the mental hospital.
- Postponement of treatment due to a daughter's marriage.
- Strong faith in NPT.
- Family members had no time to go to the hospital.

The information provided by the key informants above shows that family members, school teachers and family physicians are the gatekeepers for timely delivery of mental health treatment. However, they fail to recognise the symptoms of mental illness, which leads to a delay in its recognition and then treatment. The peculiar nature of mental illness like lack of pain or insight, stigma, undue importance to progress in career, importance given to marriage for girls, undermining mental illness like some other illness are the barriers for early recognition and treatment.



Source: Math & Srinivasraju, 2010.

The information provides knowledge about various filters through which patients make journey before reaching psychiatric treatment. Math & Srinivasraju (2010) provide a diagram showing various filters/barriers through which patients/caregivers have to pass. At the bottom of the pyramid, i.e., in community sample, various factors or filters which are internal to a patient/caregiver like level of knowledge, education, belief system and other social, demographic and economic factors, etc., are present.

### **Symptoms that caused decision to avail NPT**

Respondents were asked questions regarding symptoms that caused the decision to take NPT. They selected one or more choices as their answer. Table 5.9 gives number and per cent of respondents who selected specific choices.

<b>Table 5.9 Number and percentage of patients by symptom that caused NPT</b>		
Reason for availing NPT	Number	Per cent
Odd behaviour	163	97.6
Discontinuation of education or job	102	61.0
Troublesome at home and others	125	74.8
Violent behaviour	135	80.8
Physical problem	8	4.7
Any other	17	10.2

Since respondents were allowed to select more than one choice, the percentage may exceed 100 per cent.

Out of sample respondents who availed NPT, 97.6 per cent availed it for odd behaviour, 74.8 per cent for being troublesome at home and 80.8 per cent for violent behaviour of the patient. Discontinuation of education and job as well as physical problem was the reason for 61.0 per cent and 4.7 per cent respondents respectively. This clearly indicates that any visible change in a patient in terms of odd behaviour or becoming nuisance/troublesome at home and to others as also becoming violent behaviour were the main reasons for taking a person for NPT. Unless symptoms become visible and intolerable, people do not approach even for NPT. Tolerance to awkward behaviour, cultural factors and violence are acceptable social factors.

<b>Box 5.3 Reasons for taking NPT</b>
<ul style="list-style-type: none"> <li>• Worshipping God would bring about a solution.</li> <li>• There was some external pressure at play.</li> <li>• Black magic.</li> <li>• Mental manipulation.</li> <li>• Belief that the person is possessed by spirits.</li> <li>• Belief that the spirits of dead relatives have been angered.</li> <li>• Belief that visiting a religious place would have a healing effect.</li> <li>• Already given above</li> <li>• Worshipped gods to solve the problem.</li> <li>• Belief that the behaviour is a curse of the gods.</li> <li>• Slept in the forest and must have been possessed by evil spirits.</li> <li>• Patient visits the church regularly and has belief in divine intervention.</li> <li>• Supposed flaws in the horoscope.</li> <li>• The patient wants to visit a ‘mantrik.’</li> </ul>

While making choices about reasons for taking NPT, the respondents also provided qualitative information about it which is classified in Box 5.3. They also gave reasons for not taking NPT which are presented in Box 5.4.

**Box 5.4 Reasons for not taking NPT**

- No faith in treatment being followers of Buddhism.
- Influenced by the books of Narendra Dabholkar.
- Lack of faith in God.
- Belief that they have been devout followers of God who will take care of them.
- Awareness of a mental problem prevented the necessity of NPT.
- Lack of faith in such things as the entire family is educated.

It is found that respondents did not take NPT by chance elements or due to non-availability of PT in the vicinity. They had strong and specific reasons for not taking NPT. Some of them were staunch followers of Babasaheb Ambedkar and converted to Buddhism and renounced the beliefs of Hindu religion. They had taken an oath not to follow Hinduism as per the twenty-two principles (Appendix VI) given by Babasaheb Ambedkar. Others had specific reasons for not taking NPT.

**Symptoms that induced decision to take psychiatric treatment**

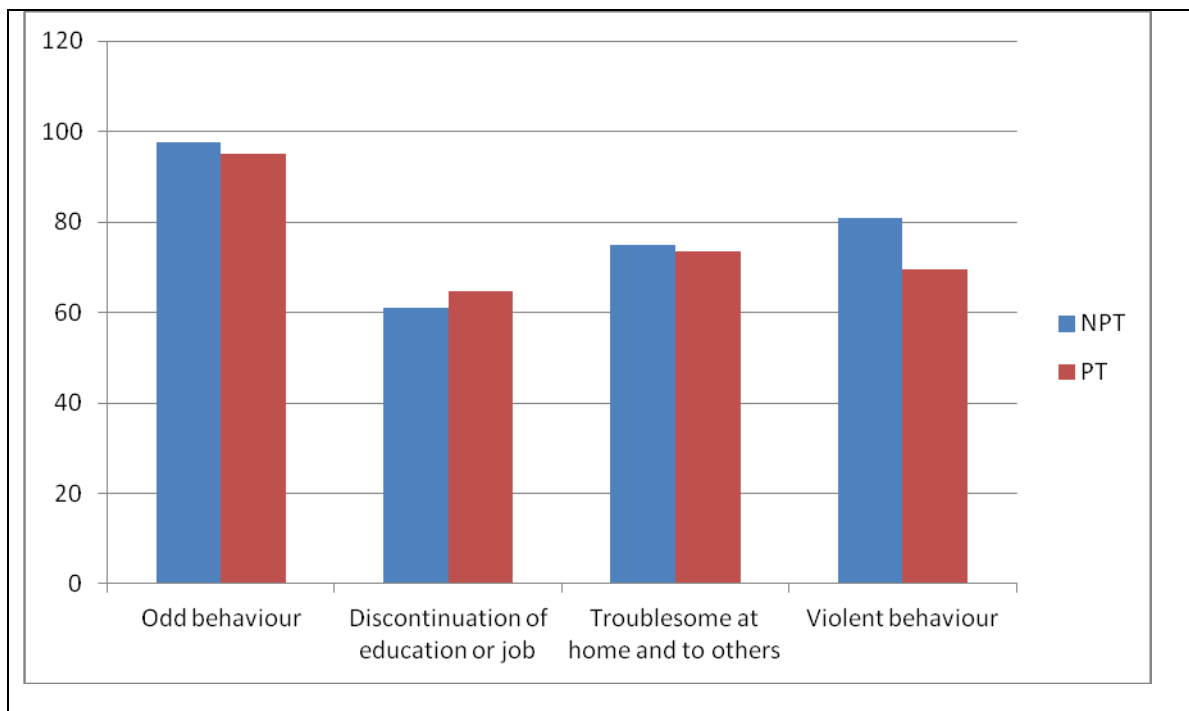
<b>Table 5.10 Number and percentage of respondents by symptoms that induced the decision to take PT</b>		
Symptoms	Number	Per cent
Odd behaviour	237	95.1
Discontinuation of education or job	161	64.7
Troublesome at home and to others	183	73.5
Violent behaviour	173	69.5
Other treatments did not work	57	22.9
“Let us try this one”	40	16.1
Aggravation of the symptoms	100	40.2
Any other	8	3.2
Since respondents were allowed to select more than one choice, the sum total of percentages may exceed 100.		

Respondents were asked regarding symptoms that induced the decision to take psychiatric treatment (PT). They chose one or more symptoms as their answer. Table 5.10 gives the number and percentage of respondents who have specific choices.

Out of sample respondents who availed PT, 95.1 per cent availed it for odd behaviour, 73.5 per cent for being troublesome at home and 69.5 per cent for violent behaviour of the patient. Discontinuation of education and job were the reasons for 64.7 per cent respondents. ‘Other treatments did not work’ and ‘Let us try this one’ were answers for 22.9 per cent and 16.1 per cent respondents respectively. Thus, a patient becoming violent was single most important reason for taking PT treatment. However, odd behaviour or nuisance/troublesome at home and to others were also important explanations for it.

When four important symptoms that caused NPT or PT were compared, it was found that there is marginal difference between percentage of symptoms that either caused NPT or PT. This is shown in Figure 5.4.

**Figure 5.4 Percentage of respondents by symptom that induced decision to take PT**



Figures 5.6, 5.7 and 5.8 below depict the journey of a patient from the beginning of symptoms till the treatment, either medication or hospitalisation starts. The figure 5.6 shows how economic, social, familial, cultural, knowledge and other factors interact to determine the path and delay of a patient towards PT. Figure 5.7 is similar to one given in Figure 5.6 but presented in a different way. Realising or recognising that patterns of abnormality are a symptom of mental illness is a necessary step for initiating PT. Stages towards it are shown in this diagram.

Some of the YMH staff members were interviewed for understanding the response of caregivers/patients to the other treatment modalities like use of services of rehabilitation or day-care centre, counselling, ECT and hospitalisation. This information (Box 5.5) also points out that patients/caregivers delay not only in the treatment of medicines but they also make delay in other treatments for mental illness. Most of the reasons for treatment delay for medicines are also present in delay for other treatments. However, the strength of these reasons vary.

**Box 5.5 Reasons for not availing other types of treatments for mental health**

Reasons for not utilising services of rehabilitation centre.

1. Patients do not join rehabilitation centre due to a long distance.
2. Many do not have resources even for consultation fees and for purchasing medicines. They can't afford services of a rehabilitation centre.
3. Some caregivers do not accept the presence of any illness. This is especially true in single child families.
4. Many caregivers think that their ward should be able to do most of the household chores once he/she joins such centre, e.g., after two or three months there should be sufficient recovery of the patient and he/she should be able to do some of the household chores.
5. Some caregivers doubt the usefulness of RC for their patient.
6. Some caregivers think that their patients are much better than other patients in the centre. They fear that the symptoms of their patients will aggravate by joining and being in company with other patients.
7. Patient is not ready to come to the rehabilitation centre.
8. Social stigma and self stigma prevents people to take services of such centres.
9. Some caregivers argue that the benefits from rehabilitation centres are very slow or



- he/she does all the domestic responsibilities properly and does not need such a centre.
10. There is nobody in the house who will drop and pick up a patient from rehab centre.
  11. Some people, even though live in Pune, are not aware that there exists such a facility in here.
  12. Like surgical conditions, there is no urgency or “Do or die” type situation for taking services of rehabilitation centres.

*Reasons for not utilizing counselling services.*

1. Due to social stigma and self stigma.
2. It is a long term process.
3. Patient is not ready to go for counselling sessions.
4. It is not useful like medicine.
5. Patient is not cured only by counselling.
6. Poor family acceptance of usefulness of counselling sessions.
7. Low awareness of counselling.
8. Difficulty in finding a proper counsellor.
9. Benefits are not easily seen.

*Reasons for not availing services of Electro Convulsive Shock (ECT)*

1. It damages the brain and harms a person’s day to day life.
2. There is a permanent memory loss.
3. It is of no use.
4. The treatment is very expensive.
5. It is a dangerous and painful treatment.
6. No need of ECT

*Reasons for not availing services of hospitalisation*

1. The treatment is expensive
2. Caregivers do not feel like keeping him/her away from home.
3. Nobody gives any guarantee that he/she will recover. (In physical disorders doctors assure that, e.g., there are 50/60 % chances of recovery.)
4. Patient is not willing for t hospitalisation.
5. If the patient is admitted forcibly, caregivers are afraid about his response once he is discharged from the hospital.
6. Caregivers are not aware about the urgency of hospitalization.

*Reasons for not availing services of long stay home*

1. This option is very expensive (by way of either monthly charges or fixed deposit).
2. Difficulty in finding long stay homes.
3. There are few long stay homes.
4. Caregivers don't want to send patients away from home.

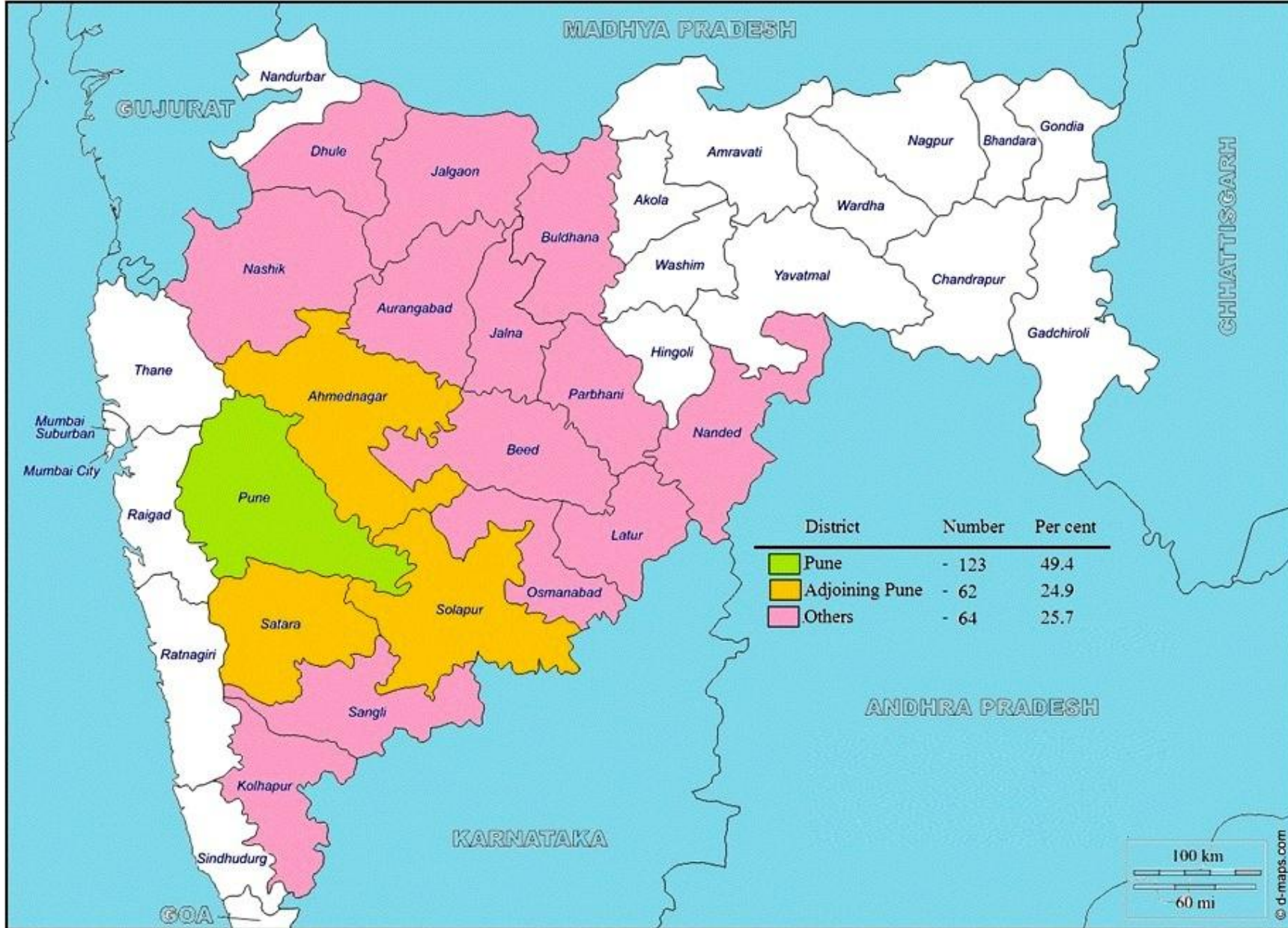
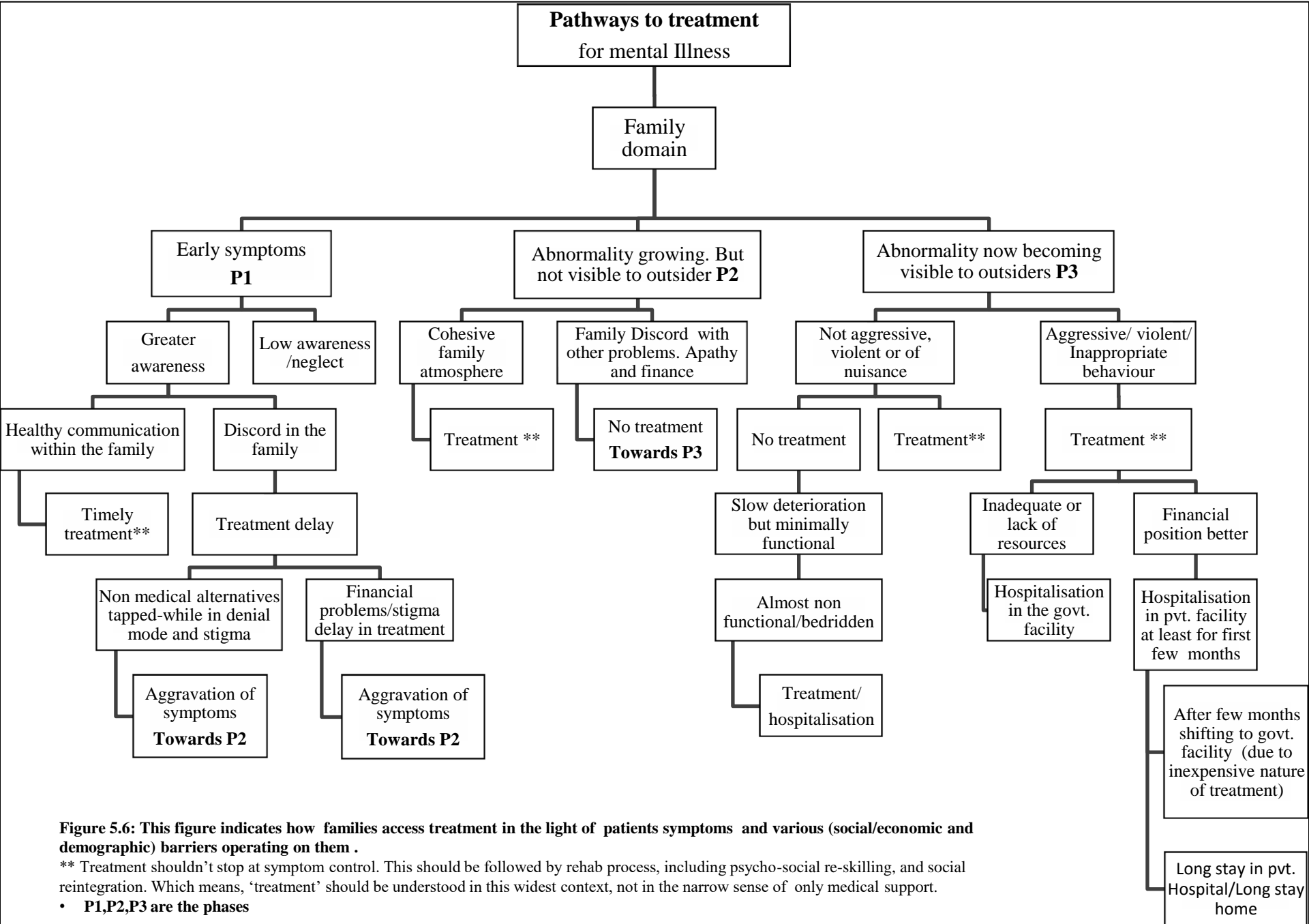
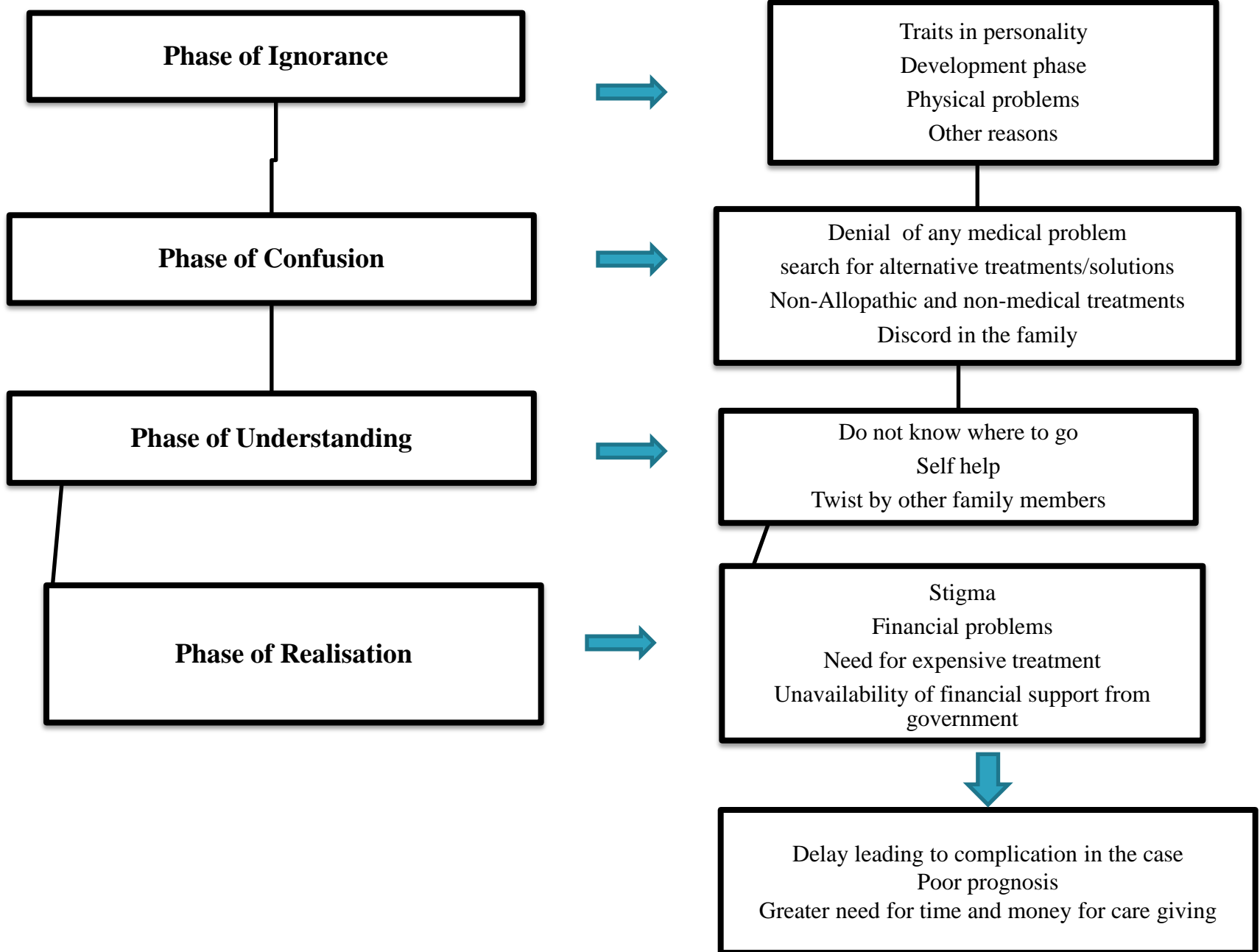
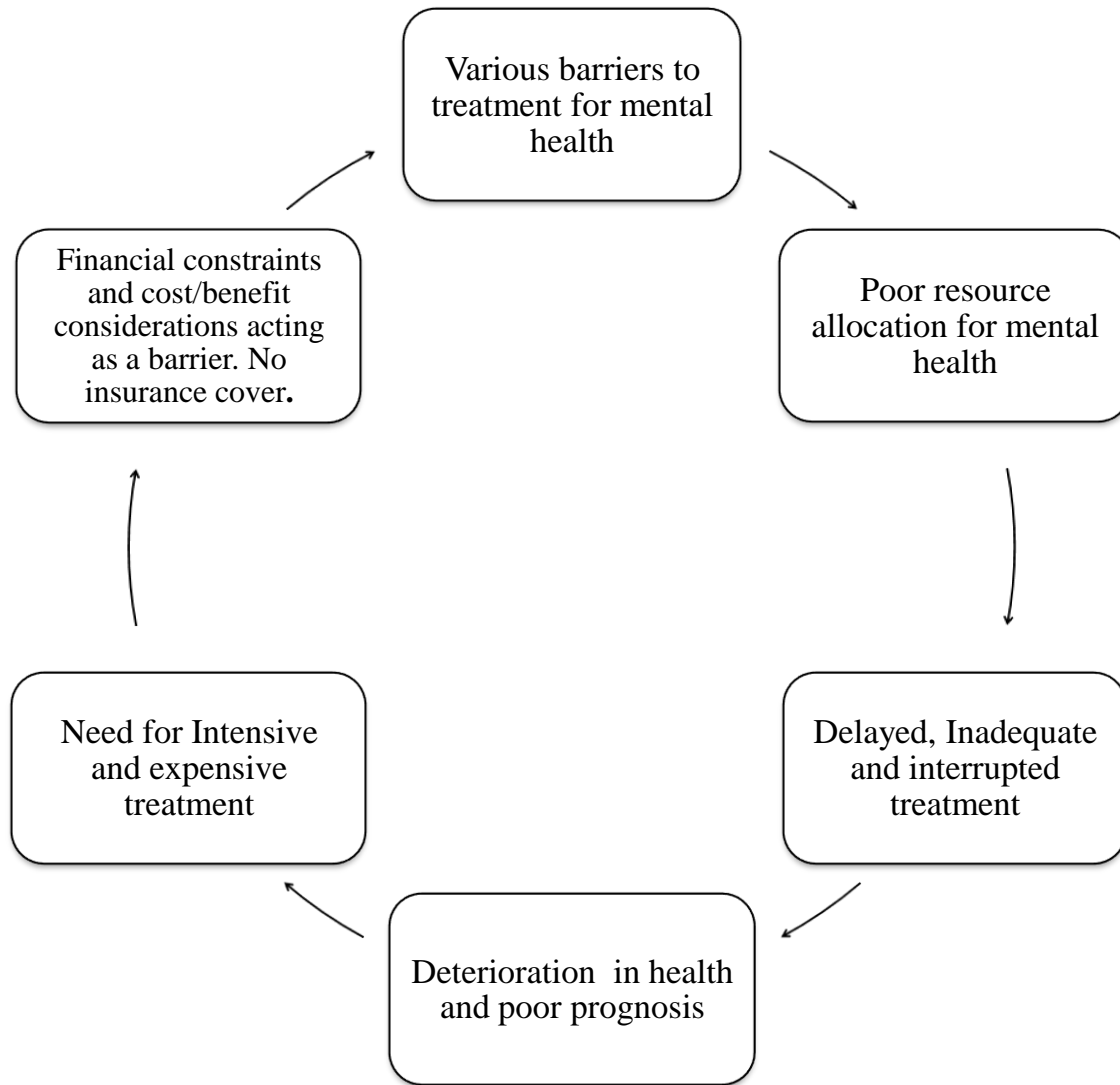


Figure 5.2: Map showing region wise distribution of patients





**Figure 5.7: Phases in the patients journey towards treatment**



**Figure 5.8: Vicious Cycle for mental health**

This figure indicates that initial delay in treatment leads to further delay or no treatment at the higher level of need.

## Chapter VI

### **Inequity and Inefficiency in the recognition delay by households: A micro analysis**

Apart from the extent of treatment delay, inequity and inefficiency are two more attributes of demand for mental health services. Inequity refers to differences in the length of MNPT and MRD within a particular socio-demographic or economic group like sex, caste, religion or income group. Inefficiency examines how households efficiently/inefficiently avail psychiatric services throughout the life course of a patient. This chapter investigates the extent of inequality and inefficiency as shown by sample households. In the beginning inequality is discussed using mean MNPT and MRD across several groups. Strength of inequality is further investigated with other statistical tools like Pearson's correlation, OLS Regression and Logistic Regression. Attributes of Inefficiency are discussed with the help of extent and duration of discontinuations and key informant interviews (KII) of veteran caregivers and selected staff members at YMH.

### **Inequality in delay in treatment and its importance**

RD and TD in mental illness is a common factor across all background characteristics. Inequality in RD is also observed *vis-a-vis* specific background characteristics. This inequality reflects combined effects of various factors that act as barriers or facilitators for early recognition. Understanding inequality in RD is important as it can help policy makers to understand the nature of these barriers and take suitable steps to reduce their effect.

It is said that mental illness is one of the most democratic illnesses. Its prevalence across country, religion, caste, gender and culture does not vary significantly. However, in our study only 32 per cent patients were women. This may be because women are not taken for treatment even at YMH where free consultation and medication is available.

**Table 6.1 Number and percentage of households availing NPT and with RD and mean MNPT and MRD by social-demographic and other variables**

Background characteristics	Number	Per cent availing NPT	Mean MNPT	Per cent having RD	Mean MRD
<b>Current age of patients</b>					
< 25 years	37	70	12.3	65	12.4
26 to 35 years	91	74	22.3	85	34.0
36+ years	121	63	26.9	90	44.2
<b>Sex of patients</b>					
Male	170	73	26.1	88	38.3
Female	79	59	16.4	78	30.2
<b>Marital status of patients</b>					
Unmarried	82	70	22.6	74	32.1
Others	167	67	23.3	89	37.6
<b>Religion</b>					
Hindu	219	69	25.1	87	37.0
Others	30	57	8.0	67	26.6
<b>Caste</b>					
SC	58	59	14.7	74	22.9
Open & others	191	71	25.6	87	39.6
<b>Type of family</b>					
Nuclear	130	63	13.5	82	35.6
Joint	119	73	33.5	86	36.0
<b>Education of patients (years)</b>					
No education	39	51	15.6	82	43.8
1 to 4	18	94	30.3	100	40.7
5 to 10	133	69	23.2	83	36.0
11+	59	68	25.3	85	28.2
<b>Education of caregivers (years)</b>					
No education	32	75	27.5	81	27.2
1 to 4	16	81	22.1	88	41.4
5 to 10	97	68	21.5	86	37.9
11+	104	64	23.2	84	35.5



.....Table contd.

<b>Background Characteristics</b>	Number	Per cent availing NPT	Mean MNPT	Per cent having RD	Mean MRD
<b>Relation with patient</b>					
Father & mother	93	73	21.6	82	24.4
Others	156	65	23.9	86	42.5
<b>Year of first treatment</b>					
Up to 2000	59	70	39.2	67	35.5
2001 and onwards	190	83	18.0	85	35.8
<b>Occupation of patients</b>					
Unemployed	110	72	22.3	81	35.0
Greater public con.	33	61	11.9	82	26.4
Lesser public con.	106	66	27.2	89	39.5
<b>Occupation of caregiver</b>					
Unemployed	3	68	32.0	100	28.0
Greater public con.	105	64	20.0	77	31.7
Lesser public con.	135	71	25.3	89	37.5
<b>Family income (Rs.)</b>					
Up to 5000	53	79	20.2	81	51.7
5001 to 10000	65	69	23.4	86	37.8
10001+	120	63	24.4	85	29.9
<b>Diagnosis of patients</b>					
Schizophrenia	186	68	22.6	87	38.0
Others	63	67	24.4	76	29.0
<b>Age at onset of symptoms</b>					
< 25	149	73	27.7	83	40.3
26 to 35	64	66	19.8	89	28.6
36+	35	51	9.6	80	22.6
<b>District of first treatment</b>					
Pune	123	65	20.9	87	44.6
Adjoining Pune	62	69	20.7	76	22.9
Others	64	72	29.4	88	31.3
<b>Distance</b>					
< 50 km	127	67	21.0	87	29.5
51 to 100 km	45	69	35.6	79	44.8
101+ km	38	79	15.8	90	50.3
<b>Place of residence</b>					
Urban	107	55	16.3	82	30.8
Rural	142	78	28.1	86	39.5
<b>Total</b>	249	68	23.0	84	35.8

When RDs of sample households were classified according to various demographic variables (Table 6.1), it was found that there is a substantial inequality with respect to them. Patients from rural areas and joint family had longer RD. With an increase in education and age of onset of symptoms RD falls. Gender bias is found to be reversed among the respondents and male patients have longer RD. Respondents belonging to Hinduism showed greater delay as compared with Muslims and Buddhists (who showed lowest RD). Respondents from open category (OC) had the highest RD, followed by OBCs and SCs who had the lowest delay.

This study has identified 18 variables which are divided in to five groups, viz., demographic (three), social (seven), economic (three), medical (two) and geographic (three). Each variable was further classified using criterion which is meaningful for further analysis. Bivariate table is constructed giving mean MRD and MNPT cross classified according to social, demographic and other variables.

## **Inequality in TD for mental illness and possible explanations**

### **Demographic variables**

#### *Age of the patient*

The percentage of population that avails NPT and has RD falls as the age of the patient (at the beginning of symptoms) increases. Number of months of taking NPT and of RD fall as the age of the patient increases. A majority of the major mental disorders develop in the adolescent or late adolescent age (Patel, Saxena, De Silva et.al., 2013). Often family members are not aware of the symptoms of mental illness. Moreover, they are taken as a developmental problem or are attributed to grave shocking incidents like failure in the examination, break up of marriage, etc. Hence, this study finds higher delay of treatment at young age and it falls as age advances. This finding is important as early years are the most productive years. Longer delay in recognition of mental illness in this

age group not only negatively affects prognosis, but also contributes significantly to DALYs lost.

### *Gender*

Percentage of male patients who avail NPT and have RD is greater as compared with female patients. Similarly, the mean number of months of taking NPT (MNPT) and mean MRD are more for male patient as against female patients. These results look somewhat contradictory to the general perception that males receive a priority in the Indian society including treatment for health problems. Such a trend may be because of two reasons. First, a majority of the caregivers in India turn to NPT when they notice abnormality in behaviour. Besides, a priority to males is reflected in terms of a higher percentage of males taking NPT as compared with females. Second, when one type of treatment is initiated, it may be difficult for caregivers to switch to another type immediately. People may be approaching a psychiatrist when breaking point is reached, i.e., a patient becomes violent or unmanageable even with NPT. Hence, due to lack of recognition, NPT is the first choice of intervention/treatment and a sense of satisfaction that something is being done may be delaying psychiatric treatment.

### *Marital Status of the patient*

Patients were classified into those who were never married and all others. It is found that there is hardly any difference between these two groups as far as the percentage of persons with NPT or mean period of NPT is considered. However, a marginal difference is observed as far as the percentage of persons with RD and mean period of RD is concerned.

## **Social Variables**

### *Religion*

Hindus are a majority population in this sample having 88 per cent of the respondents, followed by Buddhists with 3.6 per cent. Muslim and Christian respondents are very small. Greater percentage of Hindu population avails NPT and has RD as

compared with Buddhists. The mean period in months of taking NPT and of RD is greater among Hindus as compared with Buddhists. Their population covered in this study is basically SC population which is a staunch follower of Dr. Ambedkar. The Buddhists have taken an oath of renunciation of Hindu practices and rituals. Most of them have not turned to NPT for relief. However, some of them due to influence and advice of people in their locality have availed NPT. In all, the percentage of households that have availed NPT and mean period of NPT is significantly less for Buddhist population. Difference in period of RD between Hindus and Buddhists is not great. It may be due to lack of information about mental illness and its symptoms. This observation underscores the need of dissemination of information for the entire population in the society - whether it avails NPT or not.

### *Caste*

Greater percentage of open category population, followed by OBC category population avail NPT and have RD as compared with SC population. The number of months of taking NPT and of RD is greater for open category followed by OBCs and SCs. People belonging to the open category are highly susceptible to myths, ignorant about mental illness, practise religious rituals and faith healers as compared with OBC and Buddhist population. Hence, the extent of NPT availed and duration of RD is higher in the open category.

### *Types of Family*

A smaller percentage of nuclear families avail NPT or have RD as compared with that of joint families. However, this difference is larger in the case of NPT. Mean MNPT rises as we move from nuclear families to joint families, while MRD shows hardly any change. This indicates a greater use of NPT by joint families. MNPT rises as we move from nuclear to joint family. This is because people belonging to earlier generations, who were a part of a joint family, have greater faith in NPT rather than modern practices. In such families elders usually take decisions and NPT is the first choice of treatment. However, the difference in MRD between joint and nuclear families is small which reveals

that MRD does not change according to the type of family. In other words, factors that affect RD are similar for nuclear and joint families.

#### *Education of patients*

The percentage of patients that avail NPT and have RD falls along with an increase in education. The average period in months of taking NPT and of RD also falls with higher level of education of the patients.

Patients with higher education may be in the families who themselves have better education and hence likely to notice early the abnormal behaviour of the patient. With improved education and employment or a commensurate activity, any abnormal behaviour of the patient may be becoming more visible rather than being camouflaged as in the case of illiterate/less educated patients doing basically menial kinds of work. With better education, patients/family members may be able to utilise information or awareness material on mental health that is available to them. Patients with greater education may be able speak out about their symptoms. Their social milieu is also such that recognition is done early.

#### *Education of caregivers*

The percentage of patients that avail NPT and have RD generally fall along with an improvement in the education of caregivers. Average period in months of taking NPT does not vary significantly with caregivers' education while the months of RD fall consistently with a higher level of their education. This observation is consistent with the relation of MRD and patient's education discussed earlier. Due to higher education, caregivers may have greater awareness about mental illness. This also may be because of greater mobility of caregivers for work, and their better capacity to observe and absorb information that is available in the vicinity.

### *Relation with patients*

The percentage of people that avail NPT falls as we move from relation of caregivers as parents (father and mother) to the category of others, while the percentage of people with RD slightly increases. Average MNPT little increases while MRD significantly increases for a similar change in the category of caregivers. Relation of the patient with caregiver plays an important role. In India a majority of patients live with the family and it is the individuals in the family, parents and others who take the decision regarding treatment. Parents are closest and spend more time with the patient as compared with siblings or other relatives. They are likely to notice symptoms early. This is reflected in lower MRD when parents of patients act as caregivers (24.4 months) while there is higher MRD for others (42.5 months).

### *Year of first psychiatric treatment*

Over time due to the spread of education and information, attitude of people towards NPT and modern psychiatric treatment has undergone radical changes. This study found that patients had mental illness in the range of zero to twenty-five to thirty years. In order to investigate changes in RD or MNPT from this point of view, this study takes year 2000 as a cut off point and compares the use of NPT and MRD before and after this year.

It was found that higher percentage of persons avail NPT and have RD after the year 2000 as compared with the percentage of people before it. However, during this period, the average duration of use of NPT has significantly come down from 39 to 18 months while RD shows only a marginal change. This again indicates that the use of NPT is not a major factor in determining RD.

Reduction in faith on NPT and its lesser use is certainly desirable. But such a change will not automatically lead to a reduction in RD. For early recognition people need to have information about mental illness, mental health services, examples of recovery, etc. Unless these things are put in place, people won't be able to RD early. Perhaps, in the various phases of awareness (as shown in Box 6.1), the respondents in this study may be

still at the second stage of it. It will take time for people to develop scientific attitude about mental illness (and then use mobile or internet facilities to further develop awareness as suggested by Thompson, Issakidis & Hunt, 2008).

**Box 6.1. Phases of awareness**

1. Ignorance, myths and blind beliefs  $\Rightarrow$  2. Lessening of blind beliefs but lack of scientific information  $\Rightarrow$  3. Availability of scientific information  $\Rightarrow$  4. Acceptance of scientific attitude  $\Rightarrow$  5. Choices made are based on scientific attitude  $\Rightarrow$  6. Use of mobile and internet facilities.

In their study Thompson, Issakidis & Hunt (2008) report that younger generations seek help for mental health problems faster than older generations. They argue that this may be because of decreasing negative attitudes towards mental illness in younger generations as well as increasing public awareness of effective treatments in successive generations. They conclude that prolific information about mental health on the internet is likely to reduce RD and TD in the future.

Perhaps lack of information and peculiar characteristics of mental illness may be the major reasons for RD. This is supported by information on reasons for delay as given by individual households in their interview. From the policy perspective this trend is important as it shows that RD may not reduce independently over time. Even though changes occur in several other dimensions of life like increase in the level of education, greater use of media, greater access to health facilities, etc., RD will not decline at its own. Specific and targeted programmes should be organised in order to reach people and reduce the RD (Abramovitz, 2008).

## **Economic Variables**

### *Occupation of patients*

In this study information about occupation of patients and caregivers has been collected and classified into twelve categories. Since almost half of the categories have less than five sample households each, it was decided to regroup the households. Considering the importance of public contact in mental health as a source of information, two categories were made, namely, occupations with greater public contact and those with lesser public contact, apart from unemployed as a separate category. Individuals in private service, government service, pensioners, students and large cultivators were grouped in people with greater public contact, while others except unemployed persons in those with lesser public contact.

It was found that patients with greater public contact have much smaller average MNPT and MRD as compared with persons with lesser public contact. This trend is important as it points out importance of social contact as a source of information for identifying mental illness. Patients who are in government service, private service or students are likely to get information early or due to visibility of symptoms they are likely to get noticed and identified by others in the vicinity.

### *Occupation of caregivers*

Caregivers with greater public contact have smaller average MNPT and MRD as compared with those with lesser public contact. The former are likely to have interaction with others in the service about behavioural changes in their family member and receive information about mental illness. This observation again highlights the importance of information in recognising mental illness. This trend is observed for caregivers as well as patients. The difference is much larger in the case of occupation of the patients than occupation of the caregivers.



### *Family income*

Mean NPT increases by a small percentage but consistently as we move from lower income group to higher income group, while MRD falls sizably and consistently as we move from lower to higher income group, i.e., as income rises RD also rises. This looks contradictory because with an increase in income the family is able to bear the cost of treatment. The possible explanation may be families with higher income can be more stigmatised. This observation underscores the importance of income in RD.

### **Medical variables**

#### *Diagnosis*

The total number of patients was divided for diagnosis of the patients. Difference in the percentage of people availing NPT and having RD is much smaller across the group. However, a significant difference is observed in average MRD of persons with Schizophrenia as compared with others.

In Schizophrenia, the progress of the disease is slow and often patients do not become violent. Moreover, loss of insight to the patients is a characteristic feature. All this leads to a greater delay compared with other diseases. Longest delays were found in cases of mental retardation. Jain, et al. (2012) argues that most patients are brought at a later stage basically for the purpose of certification.

In general, delay is found to be lower for major mental illnesses as compared with CMD(R). In this study numbers of patients with CMD are very few and hence are not compared with other mental disorders in terms of mean MNPT or MRD

### *Age at onset of symptoms*

The percentage of patients availing NPT falls with an increase in age at the onset of symptoms while there is no clear trend in the percentage of patients having RD as age at the onset of symptoms rises. Mean NPT falls, more so in case of MRD, as age at the onset of symptoms rises.

This observation is important as it reveals that if symptoms start at a relatively young age, then MRD is higher and with an increase in age at onset of symptoms MRD falls. In a relatively young age group, i.e., less than 25 years, when young people experience physiological changes, symptoms of mental illness are generally ignored. These symptoms are taken as changes due to physiological changes, or other important developments in an individual's life like education, career or marriage. Recognising symptoms as mental illness is important if they start at an early age. Greater delay imposes a greater burden on individuals, families, society and economy.

### **Geographic variables**

#### *Place of residence*

Smaller percentage of urban households avail NPT and also smaller percentages of it have recognition delay as compared with rural households. Similarly, the average period in months of taking NPT is much smaller for urban households as against rural households. However, months of RD is small by a smaller margin for urban households as compared with rural households.

In urban areas, due to greater spread of education a smaller percentage of people turns to NPT as their first option. Even if, is used, its average period is significantly short, possibly due to wavering faith on it or suggestions from others. However, months of RD continues to be more in urban areas, even though mental health services in urban areas are wide spread and are available close by. Peculiar characteristics of mental illness, its symptoms and lack of information about it, possibly continue to be important factors

behind this. Hence, educating the public or spread of information about mental illness or screening of the probable cases through camps can be a solution.

#### *District of first treatment*

Pune district shows the lowest NPT but highest MRD. This looks surprising. However, a comparison between districts adjoining Pune and other districts shows that mean MNPT and MRD is much lower for districts adjoining Pune as compared with other districts.

#### *Distance of first treatment from residence*

The percentage of respondents that avail NPT and have RD do not show any clear trend with distance of first treatment from residence of the respondents. Months of NPT also do not show any trend. However, MRD shows a rising trend with distance of first treatment from the residence of the respondents.

This is important. In India psychiatric treatment is usually provided by psychiatrists who are available generally at district places or at mental hospitals – both private or public. Greater distance delays treatment. This may be because on the one hand people may be finding difficulty in taking patients for psychiatric treatment and, on the other, greater distance of the venue of psychiatric treatment may lead to a lesser dissemination of information and awareness about mental illness in the surrounding population.

This result is important from the policy point of view. In India psychiatric treatment is not available at the PHCs which exist in large numbers and are distributed across rural and semi-rural areas. If basic psychiatric services are available at such centres, it will reduce TD to a substantial extent. People contact PHCs for all their physical problems. So, having such services at PHCs will have an additional advantage.

## **Results from correlation analysis**

Table 6.2 gives correlation matrix. Eighteen independent variables are considered along with mean MNPT and MRD.

### *Correlation between MNPT and MRD*

In the Indian society the use of NPT is said to be the principal cause of delay of modern psychiatric treatment (Jilani & Trivedi, 2010; Gater, Almeida, & Barrientos, 1991; Lahariya, Singhal, Gupta, & Mishra, 2010; Kurihara, Kato, Reverger, & Tirta, 2006). However, in this study very low association between MNPT and MRD is found which means that variables other than NPT are important determinants of MRD. This has an important policy implication. It is usually argued that widespread use of NPT delays modern psychiatric treatment and hence efforts should be made to demystify use of NPT. However, such a strategy is not adequate. This study finds that population groups, which have very low MNPT like SC population or urban population, are not significantly different in terms of MRD. Hence, any policy to reduce MRD should focus on ways which will improve understanding of mental illness and treatment, and lead to an early utilisation of these services.

### *Demographic variables*

A patient's age has a significant positive association with MRD but weak association with MNPT. His sex and marital status have a positive but weak association with MRD and MNPT.

### *Social variables*

Among social variables, caste and MRD have a significant positive association which means that as we move from SCs to people belonging to other castes MRD rises. This is consistent with our earlier observation that SC population has a shorter mean delay as compared with others. However, caste is weakly associated with MNPT.

Religion has a weak association with MRD. However, it is negatively associated with MNPT which indicates that as we move from Hindus to others, MNPT declines. This observation is consistent with our earlier observation regarding greater mean recognition delay for Hindus as compared with others.

Types of family and MRD have weak association which indicates that whether a family is nuclear or joint, the period of RD does not change much. But its association with MNPT is significant. These observations are consistent with the relationship between type of family and mean MNPT and MRD discussed earlier.

Relation of a caregiver with a patient and MRD has a significant positive association. If parents are alive and are the principal caregivers, then the chances of early recognition and treatment are higher.

#### *Economic variables*

Occupation of a patient and a caregiver has a weak negative association with MRD and MNPT. Family income has a negative association with MRD but a weak negative association with MNPT.

#### *Medical variables*

Diagnosis has a negative association with MRD while it has a weak positive association with MNPT. Age at onset of symptoms is an important determinant of MRD. Its association with MRD is negative but significant. It has also a negative association with MNPT.

#### *Geographic variables*

District and MRD have a negative association which means that the movement from Pune district to adjoining districts and then to far away districts (mostly from

Marathwada) leads to a reduction in MRD. On the other hand, association with MNPT is positive but weak. Distance from residence has a positive association with MRD, while it has a weak positive association with MNPT. The place of residence has a positive association with MRD and MNPT.

### **Results from Ordinary Least Square regression**

In order to investigate relationship of MNPT and MRD with independent variables, we have used Ordinary Least Square (OLS) regression parameters. The eighteen variables that are considered in this study were divided into five groups consisting demographic, social, economic, medical and geographic variables. Five models were developed starting with demographic variables and then adding variables from the next group each time. OLS regression was run taking MRD as a dependent variable and demographic, social, economic, medical and geographical variables as independent variables in five different models. Five models helped to understand the impact of any particular group of variables on MRD (Table 6.3).

As more variables are added, the value of adjusted  $R^2$  increases which is understandable. However, among all the models, change in Adjusted  $R^2$  is highest when social variables are added to the regression. Economic and medical variables increase adjusted  $R^2$  marginally, indicating limited influence of these variables on RD. However, family income as a variable gives a parameter which is statistically significant. In all, 23 per cent of the total variations in MRD are explained by these 18 variables.

In the final model, i.e., fifth model or 'all variables inclusive' model, seven variables show parameters which are statistically significant. They are age at onset of symptoms, marital status (demographic variables), caste, education of the patients, relation with the patient and year of starting first treatment (social variables) and district of residence and distance from the place of treatment (geographic variables). Out of eight variables that show are statistically significant, four are social variables. This indicates significance of this group in deciding the extent of TD.

**Table 6.3 Ordinary Least Square Regression analysis of MRD by social, demographic and other variables as independent variables.**

Independent variable	Demographic	Social	Economic	Medical	Geographic
Age at onset of symptoms	-.275*** (3.921)	-.510*** (6.596)	-.504*** (6.285)	-.511*** (6.334)	-.519*** (6.187)
Sex of patient	.056 (.892)	.043 (.700)	.035 (.544)	.038 (.584)	.042 (.588)
Marital status of patient	.183*** (2.610)	.187*** (2.687)	.261*** (3.541)	.255*** (3.430)	.215*** (2.801)
Religion		-.022 (.343)	.011 (.164)	.002 (.034)	-.057 (.806)
Caste		.126** (2.027)	.141** (2.192)	.131** (2.006)	.138** (2.022)
Type of family		-.053 (.875)	-.020 (.322)	-.018 (.292)	.012 (.188)
Education of patient		-.178*** (-2.742)	-.106 (-1.564)	-.120* (-1.726)	-.158** (-2.187)
Education of caregiver		(-.006 (-.086)	.034 (.466)	.032 (.436)	.029 (.366)
Relation with patient		.272*** (3.767)	.289*** (3.824)	.287*** (3.795)	.219*** (2.785)
Year of first treatment		.268*** (4.075)	.268*** (3.932)	.269*** (3.948)	.339*** (4.667)
Occupation of patient			-.003 (-.054)	-.002 (-.038)	-.002 (-.028)
Occupation of caregiver			-.035 (-.530)	-.028 (-.428)	-.046 (-.651)
Family income			-.143** (-2.128)	-.140** (-2.071)	-.076 (-1.048)
Diagnosis				-.056 (-.876)	-.080 (-1.194)
District of first treatment					-.231*** (-3.375)
Distance					.001 .130* (1.938)
Place of residence					.076 (1.108)
Adjusted R2	.055	.171	.177	.176	.229
N =249					

By taking all these 18 variables together, this study attempted the backward regression analysis which produced results shown in Table 6.4. The results produced eight variables which together explained 24 per cent of variation in MRD.

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error			
(Constant)	-4139.468	869.716		-4.760	.000
Age at onset of symptoms	-2.727	.434	-.516	-6.288	.000
Marital status of patient	26.324	8.306	.233	3.169	.002
Caste	22.108	8.012	.175	2.759	.006
Education of patient	-1.820	.871	-.141	-2.090	.038
Relation	23.513	7.755	.213	3.032	.003
Year of first treatment	2.101	.436	.336	4.820	.000
District	-14.290	4.188	-.219	-3.412	.001
Distance	.088	.042	.135	2.100	.037

**Adjusted R<sup>2</sup> = 0.237**  
**N = 249**

Inefficiency in treatment for mental illness is examined by comparing RD for it and RD for physical illnesses of patients, if any. Out of the total patients, 21.7 per cent had any physical illness and out of that only 4.1 per cent had RD for physical illness. Similar view was shared by KII of YMH staff and veteran caregivers. This indicates that RD is greater for mental illness as compared with physical illnesses. Lack of pain to the patient or visible symptoms were the main reasons for greater delay for treatment of mental illness (Table 6.12).

It is argued that greater treatment delay leads to greater period of hospitalisation. Hospitalisation is expensive i.e. cost of hospitalisation per day per patient is large; whoever provides the service, private sector or government. Inefficiency in utilisation of



treatment for mental illness was examined by finding correlation between period of recognition delay and period of hospitalisation in months. However, we could not get any specific relationship between these two variables.

### **Discontinuation in treatment**

This does not mean minor lapses in taking treatment, either because of forgetting to take medicines or unavailability of them, but significant lapse in taking medication which reduces or eliminates presence of chemicals in the blood stream. This may have a significant effect on the patient in the short and long periods.

Continuing treatment is an important factor for any health issue, especially for mental illness. Many medicines take time to show their full effect. Recognition and initiating treatment for mental illness does not mean that treatment will continue as per professional advice. Due to several reasons, like stigma, lack of cooperation from the patient or distance and un-affordability of medicines, patients may stop taking them. Interruption or discontinuation is a common phenomenon in treatment for many health issues, especially so for mental health issues.

### **Role of discontinuation**

Understanding discontinuation in treatment is important because of several possible effects of it on the patient, family members and society. Discontinuation or break in treatment may lead to eruption of symptoms like aggravation of symptoms, delusions, hallucination, loss of appetite, negative thinking, etc., which may affect his socialisation, cognitive capacities and other faculties. These symptoms may affect his capacity to work consistently and concentration and may lead to disability and loss of work. In other words, discontinuation may affect his productivity and hence increase the number of DALYs lost due to mental illness.

Development of symptoms may also lead to stress in the family, increase time in care giving and lower productivity of the caregivers. Hence, understanding the facets of

discontinuation like its nature, frequency, extent and socio-economic and other determinants is important.

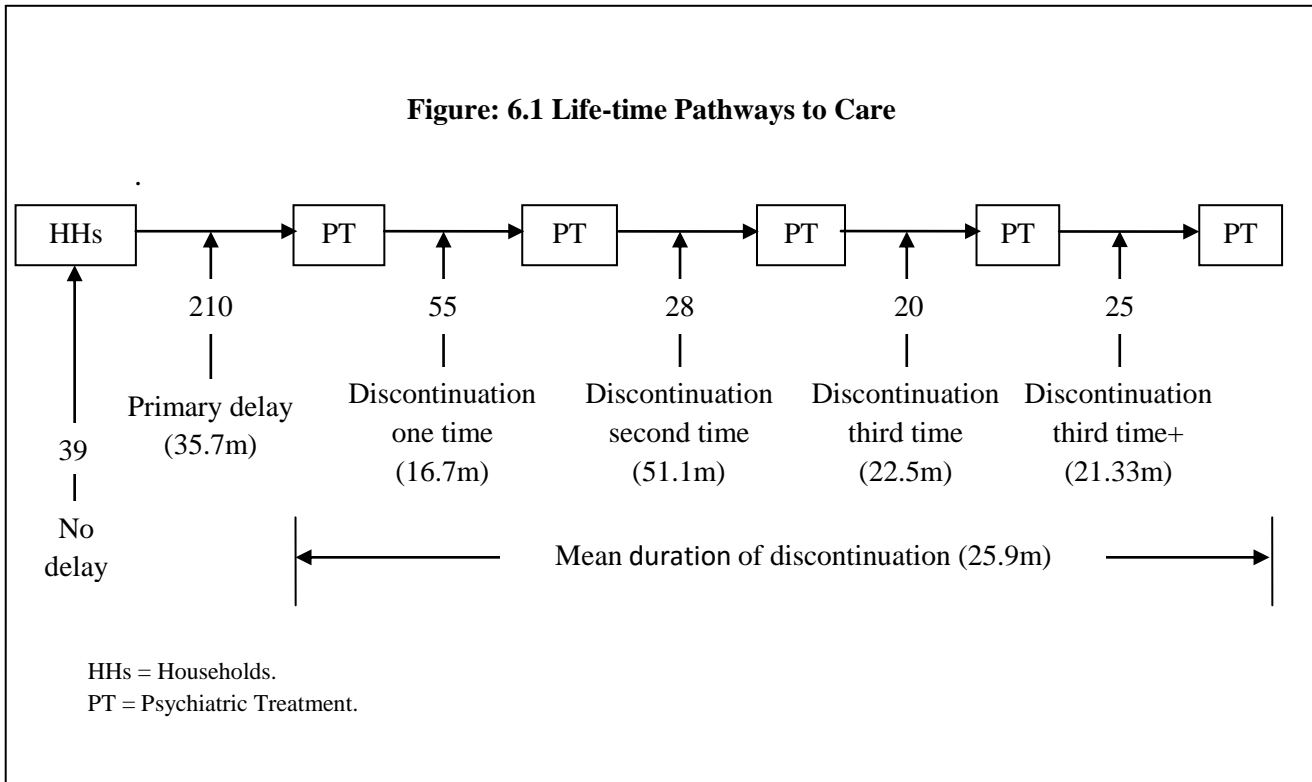
This study finds that discontinuation is a very common phenomenon among patients visiting YMH. Out of 249 patients studied, 128 patients, i.e., more than fifty per cent, had at least one discontinuation. Out of them 55 patients had only one discontinuation, 28 had two discontinuations, 20 had three discontinuations and 25 had more than three discontinuations.

Few studies from developing countries or developed countries on facets of discontinuation like its number, duration, socio-economic, demographic and other determinants are available. This means that they have found treatment delay up to the first contact of psychiatric treatment as the major or only component of delay. However, our study finds that discontinuations are a routine phenomenon for most of the patients in terms of percentage of patients and their average duration. This also means that the commonly understood hypothesis that recognition of mental illness and initiating treatment for it once started will continue or is insignificant if does not happen is not correct.

This study calls the average duration of discontinuation as ‘extended demand gap’ (and RD as primary demand gap). The diagram shows ‘Pathways to care for first contact’ as found in this study (Chapter five, Table 5.1), and which is provided in most of the research. This study goes further and presents the figure for ‘Pathways to care for extended demand gap’ or ‘lifetime pathways to care ’for utilisation of mental health services (Figure 6.1).

It is found that the number of respondents that have one or more discontinuations is 128, which means more than 50 per cent of the households. This number and percentage are not too small to be overlooked. Mean duration of discontinuation was 25 months which too is significant when compared with RD or delay of the first contact with psychiatric treatment of 36 months.

Since the number and duration of discontinuations in treatment for mental illness are significant, it was thought that the concept of pathways to care for the first contact should be modified. Figure 6.1 below is based on the modified concept of 'Life time pathways to care.



### Extent of discontinuations

This study found that discontinuations are more than one for a majority of the sample households who had any discontinuation. Table 6.5 gives the average duration of discontinuation in treatment of patients classified according to the number of discontinuations. Patients with discontinuation of one time, twice, thrice and more have average duration of discontinuations of 16.7, 51.1, 22.5 and 21.4 months respectively. The average duration of discontinuation for all the patients is 25.9 months.

<b>Table 6.5. Number of patients and average duration of discontinuation by number of times of discontinuation</b>		
Number of times of discontinuation	Number of patients with discontinuation	Average duration of discontinuation in months
1	<b>55</b>	16.7
2	28	51.1
3	20	22.5
More than 3	25	21.4
Total	128	25.9

Considering that mean duration of discontinuation is not insignificant for sample households, it was thought that it is not sufficient to study socio-economic determinants of RD alone, but determinants of duration of discontinuations should also be studied in depth. Such an analysis is necessary from theoretical as well as policy perspectives. Knowledge of the determinants of discontinuation will help to develop measures which will reduce its duration and ultimately help to reduce BOD of mental illness.

This study finds that not only is the extent of duration of discontinuation large, but there exists inequality in the mean MDD within socio-economic variables. Eighteen variables were considered in this study which were further classified in five groups- demographic, social, medical, economic and geographical. Table 6.6 provides the number, percentage of sample households and mean duration of discontinuations for them.

It is found that variables like current age, caste, religion, age at onset, occupation, education of the patient, year of first treatment, relation with patient and place of residence show inter-group variations, while sex of the patient shows hardly any change within the group. These results are similar to what we have observed in the analysis of inequality of RD. Family income is the only variable which shows a different trend. MDD rises with rise in income. This may be because of greater stigma among people with a higher income.

**Table 6.6 Number, percentage and mean duration of discontinuations in months (MDD) by background characteristics.**

	Number	Per cent	MDD
<b>Age of patient</b>			
Up to 25 years	16	12.5	7.6
26 to 35 years	48	37.5	18.5
36+ years	64	50.0	35.4
<b>Sex of patient</b>			
Female	37	28.9	26.3
Male	91	71.1	25.3
<b>Marital status of patient</b>			
Unmarried	38	29.7	16.4
Others	90	70.3	29.4
<b>Religion</b>			
Hindu	117	91.4	26.8
Others	11	8.6	12.1
<b>Caste</b>			
SC	23	18.0	10.3
Others	105	82.0	28.9
<b>Type of family</b>			
Nuclear	63	49.2	19.5
Joint	65	50.8	31.4
<b>Education of patient (years)</b>			
Illiterate	14	10.9	12.9
1 to 4	15	11.7	42.3
5 to 10	68	53.1	28.7
11+	31	24.2	16.3
<b>Education of caregiver (years)</b>			
Illiterate	17	13.3	12.6
1 to 4	9	7.0	18.5
5 to 10	54	42.2	26.3
11+	48	37.5	30.7
<b>Relation with patient</b>			
Father & mother	51	39.8	15.1
Others	77	60.2	32.5

Table contd...

	Number	Per cent	MDD
Up to 2000	28	21.9	59.6
2001 and after	100	78.1	16.0
<b>Occupation of patient</b>			
Unemployed	56	43.1	17.8
Lesser public contact	55	43.0	38.3
Greater public contact	17	13.3	10.1
<b>Occupation of caregiver</b>			
Unemployed	3	2.4	10.0
Lesser public contact	73	58.9	28.0
Greater public contact	48	38.7	19.1
Missing	4	0.0	0.0
<b>Family Income (in Rs.)</b>			
Up to 5000	27	21.8	10.3
5001 to 10000	36	29.0	23.9
10001+	61	49.2	34.5
Missing	4	0.0	0.0
<b>Diagnosis</b>			
Schizophrenia	102	79.7	26.4
Others	26	20.3	22.5
<b>Age at onset of symptoms (years)</b>			
Up to 25	77	60.2	30.9
26 to 35	35	27.3	16.2
36+	16	12.5	20.7
<b>District</b>			
Pune	65	50.8	22.1
Adjoining Pune	29	22.7	31.8
Others	34	26.6	26.9
<b>Distance</b>			
0 to 50 km	70	63.1	28.3
51 to 100 km	22	19.8	13.1
100+ km	19	17.1	35.5
Missing	17	0.0	0.0
<b>Place of residence</b>			
Urban	50	39.1	15.3
Rural	78	60.9	32.2
<b>Total</b>	128	--	25.9

The strength of inequality is further examined with the help of three more statistical tools like Pearson's correlation, OLS Regression, taking MDD as a dependent variable and the 12 variables mentioned earlier as independent variables.

Table 6.7 provides correlation coefficient for the duration of discontinuation and social, demographic and other variables. It is found that the current age of patient, year of first treatment and family income have a positive and significant association with MDD.

### **OLS Regression results**

Like OLS regression analysis for RD for the first treatment, 18 variables were converted into five groups and five models were created by adding one group each time. The purpose of creating five models was to understand the effect of each model in explaining MDD. Table 6.8 provides results for the five models and Table 6.9 gives results for OLS regression using backward regression method. It is found that four variables are significant in this analysis. Marital status of the patient, occupation of caregiver, year of first treatment and family income are significant parameters. In all, only 11 per cent of variation in MDD is explained by these 18 variables.

**Table 6.8: Ordinary Least Square Regression analysis of MDD by social, demographic and other variables as independent variables**

Independent variable	Demographic	Social	Economic	Medical	Geographic
Age at onset of symptoms	-.481 (-1.602)	.046 (.139)	.059 (.172)	.035 (.102)	-.119 (-.279)
Sex of patient	.272 (.041)	.825 (.130)	-6.909 (-1.043)	-6.695 (-1.012)	-8.205 (-1.034)
Marital status of patient	15.375** (2.114)	5.838 (.807)	4.503 (.610)	3.302 (.443)	6.584 (.771)
Religion		-1.529 (-.171)	-2.185 (-.244)	-3.378 (-.375)	-2.363 (-.213)
Caste		6.315 (.861)	6.771 (.933)	5.759 (.788)	4.962 (.574)
Type of family		5.978 (1.032)	5.272 (.908)	5.845 (1.004)	5.553 (.825)
Education of patient		.210 (.287)	.268 (.360)	.090 (.118)	.209 (.238)
Education of caregiver		.537 (.838)	.288 (.427)	.251 (.372)	.381 (.487)
Relation with patient		3.945 (.549)	5.330 (.742)	5.019 (.699)	5.769 (.700)
Year of first treatment		-2.054*** (-5.042)	-1.676*** (-4.118)	-1.636*** (-4.011)	-1.869*** (-3.889)
Occupation of patient			1.539 (.358)	1.625 (.378)	2.445 (.460)
Occupation of caregiver			-13.886** (-2.342)	-13.409** (-2.258)	-15.216** (-2.172)
Family income			.000 (1.434)	.000 (1.516)	.000 (1.504)
Diagnosis				-7.828 (-1.141)	-6.026 (-.773)
District of first treatment					-2.264 (-.524)
Distance					-.005 (-.123)
Place of residence					1.825 (.251)
Adjusted R2	.009	.131	.110	.112	.114
N=128					



<b>Table 6.9: Ordinary Least Square Regression- Results from backward regression analysis using MDD as dependent variable and social, demographic and other variables as independent variables</b>					
	Unstandardized Coefficients	Standardized Coefficients		T	Sig.
	B	Std. Error	Beta		
Constant	3989.599	837.373		4.764	.000
Marital status of patient	11.058	6.596	.122	1.677	.096
Year of first treatment	-1.981	.417	-.347	-4.746	.000
Occupation of caregiver	-11.901	5.961	-.147	-1.997	.048
Family income	.000	.000	.149	2.019	.045
<b>Adjusted R<sup>2</sup> =.161</b>					
<b>N=128</b>					

### Reasons of discontinuation

This study collected data about reasons for discontinuations. It was found that lack of cooperation from the patient is the single most important reason for it. Side effects of treatment, no improvement or relief to the patients and expensive treatment are relatively less important reasons (Table 6.10).

<b>Table 6.10 Number and percentage of patients discontinuing treatment by reasons</b>		
Reasons of discontinuation	Number	Per cent
Side effects	18	7.2
Expensive treatment	26	10.4
No improvement	20	8.0
Lack of co-operation from the patient	113	88.3
Others	83	64.8
Since respondents can select more than one choice, the percentages need not add to 100.		

This study also collected data about reasons for restarting the treatment (Table 6.11). It was found that aggressive behaviour and eruption of symptoms are the most important reasons for it. This result is similar to what we have observed regarding reasons for TD in the first contact with mental health service. This results points out that in mental

illness visible symptoms or symptoms that create trouble for others like aggressive behaviour, eruption of symptoms or patient becoming violent are the decisive factors that lead to restarting of the treatment.

<b>Table 6.11 Number and percentage of patients restarting treatment after discontinuation by reasons</b>		
Reason	Number	Per cent
Aggressive behaviour	138	55.4
Co-operation from the patient	4	1.6
Uneasiness of the patient	12	4.8
Eruption of symptoms	88	35.3
Deterioration in the condition of patients	2	0.8
Others	6	2.4
Since respondents can select more than one choice, the percentages need not add to 100.		

These reasons for discontinuation of treatment highlight specific characteristics of mental illness that lead to frequent discontinuations. The study also highlights that violence and aggressiveness resulting from mental illness are the decisive factors for restarting the treatment.

This Chapter investigates inequality in MRD, MNPT and MDD. Understanding inequality is important from both theoretical as well as policy perspectives. This study finds that inequality in these variables is significant with respect to some of the social, demographic and other characteristics. Current age, age at onset of symptoms, caste, religion, type of family, place of residence and year of first treatment influence MRD and MNPT. It is found that mean MNPT varies significantly within groups, but variation in MRD within a group is small. This is also reflected in a weak association between MRD and MNPT. This observation is contrary to the common belief that it is MNPT which is responsible for higher MRD.

The study also finds that discontinuation is a common phenomenon among sample respondents and it calls it as extended demand gap. The study finds that mean duration of

discontinuation is significant which means that along with efforts to reduce RD, specific efforts and strategies should be developed to reduce the duration of discontinuation.

**Table 6.2 Correlation Matrix –MRD, MNPT and social, demographic and other variables.**

	MRD	MNPT	Current Age of Patient	Age at Onset of Symptoms	Sex of Patient	Marital Status of Patient	Religion	Caste	Type of Family	Education of Patient	Education of Caregiver	Relation with Patient	Year of First Treatment	Occupation of Patient	Occupation of Caregiver	Family Income	Diagnosis of Patient	District of First Treatment	Distance	Place of Residence
MRD	1																			
MNPT	.087	1																		
Current Age of Patient	.156*	.032	1																	
Age at Onset of Symptoms	-.196**	-.116	.673**	1																
Sex of Patient	.068	.095	-.166**	-.130*	1															
Marital Status of Patient	.047	.007	.540**	.470**	-.129*	1														
Religion	-.062	-.117	-.127*	-.027	-.066	-.108	1													
Caste	.128*	.097	.078	.007	.073	.018	-.351**	1												
Type of Family	.004	.210**	.039	-.041	.134*	.003	-.107	.090	1											
Education of Patient	-.092	.038	-.391**	-.301**	.201**	-.232**	-.031	.078	-.060	1										
Education of Caregiver	.018	.003	.214**	.167**	-.072	.063	-.104	.120	.159*	.031	1									
Relation with Patient	.158*	.023	.499**	.372**	-.045	.325**	-.097	.066	.124	-.271**	.424**	1								
Year of First Treatment	.061	-.155*	-.427**	.275**	.100	-.106	.105	-.027	-.104	.101	-.069	-.120	1							
Occupation of Patient	-.024	-.035	.024	.079	.045	.169**	-.066	.097	-.060	.132*	.045	.027	.060	1						
Occupation of Caregiver	-.048	-.058	.142*	.128*	-.242**	.051	-.044	.055	-.004	.004	.336**	.229**	-.053	-.017	1					
Family Income	-.116	-.011	.050	.030	.080	-.001	.042	.061	.112	.070	.389**	.223**	-.091	.164*	.168*	1				
Diagnosis of Patient	-.071	.017	-.072	-.076	.039	-.084	-.074	-.138*	.072	-.141*	-.006	-.028	-.036	-.034	.072	.035	1			
District of First Treatment	-.119	.068	-.211**	-.110	.096	-.076	-.043	.083	.050	.081	.086	-.050	.087	.096	-.023	.177**	-.034	1		
Distance	.102	.001	-.074	-.117	.165*	-.046	.058	-.063	-.016	.041	.099	.097	.007	.114	.066	.036	.053	.170*	1	
Place of Residence	.077	.124	.038	-.052	.105	.048	-.227**	.136*	.035	-.077	.040	.034	-.078	-.048	-.136*	-.029	.076	.191**	.111	1

**Table 6.7 Correlation Matrix –MDD and social, demographic and other variables.**

	MPD	Current Age of Patient	Age at Onset of Symptoms	Sex of Patient	Marital Status of Patient	Religion	Caste	Type of Family	Education of Patient	Education of Caregiver	Relation with Patient	Year of First Treatment	Occupation of Patient	Occupation of Caregiver	Family Income	Diagnosis of Patient	District of First Treatment	Distance	Place of Residence	
MPD	1																			
Current Age of Patient	.190**	1																		
Age at Onset of Symptoms	-.047	.673**	1																	
Sex of Patient	.006	-.166**	-.130*	1																
Marital Status of Patient	.105	.540**	.470**	-.129*	1															
Religion	-.098	-.127*	-.027	-.066	-.108	1														
Caste	.130	.078	.007	.073	.018	-.351**	1													
Type of Family	.119	.039	-.041	.134*	.003	-.107	.090	1												
Education of Patient	.001	-.391**	-.301**	.201**	-.232**	-.031	.078	-.060	1											
Education of Caregiver	.124	.214**	.167**	-.072	.063	-.104	.120	.159*	.031	1										
Relation with Patient	.125	.499**	.372**	-.045	.325**	-.097	.066	.124	-.271**	.424**	1									
Year of First Treatment	-.378**	-.427**	.275**	.100	-.106	.105	-.027	-.104	.101	-.069	-.120	1								
Occupation of Patient	.041	.024	.079	.045	.169**	-.066	.097	-.060	.132*	.045	.027	.060	1							
Occupation of Caregiver	-.087	.142*	.128*	-.242**	.051	-.044	.055	-.004	.004	.336**	.229**	-.053	-.017	1						
Family Income	.159*	.050	.030	.080	-.001	.042	.061	.112	.070	.389**	.223**	-.091	.164*	.168*	1					
Diagnosis of Patient	-.058	-.072	-.076	.039	-.084	-.074	-.138*	.072	-.141*	-.006	-.028	-.036	-.034	.072	.035	1				
District of First Treatment	.030	-.211**	-.110	.096	-.076	-.043	.083	.050	.081	.086	-.050	.087	.096	-.023	.177**	-.034	1			
Distance	-.006	-.074	-.117	.165*	-.046	.058	-.063	-.016	.041	.099	.097	.007	.114	.066	.036	.053	.170*	1		
Place of Residence	.136	.038	-.052	.105	.048	-.227**	.136*	.035	-.077	.040	.034	-.078	-.048	-.136*	-.029	.076	.191**	.111	1	

<b>Table 6. Information about number, percentage, period of RD and discontinuations of patient's physical illness</b>	
Without Physical Illness	78.3
With physical illness	21.7
Total	100
<b>Per cent of patients by type of physical Illness</b>	
Type of Illness	Per cent
BP	44.4
Asthma	14.8
Diabetis	22.2
Paralysis	5.6
Others (Skin Disease, Arthritis, .Brain Disease, Slip Disc, Deafness)	13.0
Total	100
<b>Per cent of patients by months of RD for physical illness</b>	
Delay	Per cent
0	95.9
12	2.0
60	2.0
Total	100
<b>Per cent of patients by period of discontinuations</b>	
Discontinuation	Per cent
0	91.3
4	2.2
6	2.2
12	2.2
24	2.2
Total	100
<b>Per cent of patients by reason of giving priority to physical illness</b>	
Reason	Per cent
Visible Illness	100.0
Effective treatment is available	27.9
Absence of stigma	16.3
Acceptance of the illness by the patient	39.5
Pain to the patient	93.0
Cooperation from the patient	37.2
Quick recovery is possible	0.9
Total need not add to 100 as household selected more than one choices	
<b>Perception about expenses for physical illness</b>	
Expenditure	Per cent
Significant	42.6
Moderate	29.8
Insignificant	27.7
Missing Cases	
<b>Amount of expenditure per month on physical illness</b>	
Expenditure (Rs.)	Per cent
0 to 500	65.2
501 to 1000	19.6
1001 to 5000	15.2

## Chapter VII

### Discussion

The Burden of mental illness is huge in India as well as the unmet need of services for it. This need is the result of two factors- ‘supply gap’ (inadequacy of resources) and ‘demand gap’ (failure to demand mental health services by households). In India, the burden of mental illness and rising DALYs lost due to it is a matter of concern. Hence, there is a need to make active efforts to reduce these two gaps. Various measures have been suggested globally as well as in India to address this problem. This study reviews literature on the extent of supply gap and steps to reduce it and at the same time calculates the extent of demand gap, i.e., RD and MNPT on the basis of collection of primary data of 249 patients from YMH. The study also collected data from sample households about reasons for the demand gap. Following recommendations are made which are based on the review of literature on the one hand and the analysis of primary data on the other.

#### **Measures to address Supply Gap in resources for mental health**

##### *1. Greater financial resources through budget*

Increase in the budget for mental health commensurate with BOD of mental health issues is extremely necessary. For reducing the burden of mental illness, treatment (both prevention and cure) facilities should be adequately available. This means that there is a need for greater human resources, more beds and other infrastructure, well-placed legislation, policy and planning - all of which need more resources. It is argued that it is necessary to ensure parity to mental health with physical illnesses in terms of access to treatment and care and persons with mental health problems also need to have full access to universal health coverage (Movement for Global Mental Health, 2015). Hence, it is necessary to increase the budgetary resources substantially. The current share of mental health in the health budget of the Government of India is 1 per cent. It needs to be increased to 5 to 10 per cent in order to make it commensurate with the burden of mental health (WFMH, MGMH, 2013). Increase in state and local level budget on mental health is also required (However, disaggregated data at state or local level is not easily available.). However, it is not feasible to increase it to such a level in a single step. Therefore, a step-

by-step enhancement is necessary. In the meantime, there is a need to utilise the existing resources in an efficient way.

2. *Greater share of other resources through other ministries: social justice and women's empowerment, human resource development, law, rural development, and labour*

Mental health issues have interface with several other health and non-health issues and hence with their respective ministries. In order to address the problems of mental illness effectively, there is a need for dedicated legislation and mechanism to monitor it, social welfare schemes, training and employment opportunities. For all this to happen, there is a need for greater allocation of resources not only from health ministry alone but also from other related ministries like ministry of human resources, social justice and women's empowerment, law, social welfare and rural development and labour.

3. *Effective governance: policy, plan and legislation*

In India where socio economic status of majority of population is low and out of pocket expenditure is the primary source of health financing provision of services in the public domain is necessary. However, having adequate funds for mental health is a necessary but not a sufficient condition. For mental health services to reach the people, well articulated a policy, well designed plans and programmes are necessary. Funding for mental health will have meaning, direction, focus and desired results only when it is accompanied with policy, plan and programmes. It is essential to have comprehensive legislation as well as to implement. Moreover, there is also urgent need for social insurance (Kalyansundaram, 2008); Saxena, Sharan, & Saraceno, 2003a).

4. *Awareness among policy makers: planners/ministries/departments/health officials*

Mental health is a health issue which has been neglected in the past. Policy makers, planners, ministries and concerned departments are not adequately informed about mental health issues. Besides, a stigma is attached to it. Hence, they are not likely to take decisions in the interest of mental health. There is an urgent need to increase awareness among policy-makers, planners, ministries, departments and health officials.

5. *Suggestions by Shiffman and Smith*



Shiffman and Smith (2007) have studied the allocation of funds by international health networks and allocations between the governments. They ask why some health issues receive less attention and global funding than other health issues that cause a relatively lower burden or mortality on the society. The study concludes that such an anomaly in the matching between the resources and their burden could be explained with the help of 18 factors which are grouped into four broad categories, viz.,

1. Strength of the actors involved in the initiative.
2. Power of the ideas they use to portray the issue.
3. Nature of the political context in which they operate.
4. Characteristics of the issue.

In order to obtain more funding, it is necessary to act and bring about changes in all these factors (Shiffman & Smith, 2007). For generating additional resources, mental health lobby needs to work on all the above categories. Tomlinson and Lund (2012) provide following suggestions using this framework: there is a need for greater mental health community cohesion to ensure unified voice, providing evidence-based and scalable interventions in order to create impact on policy makers, innovative strategies for treatment, stigma reduction and a social and human rights approach. Broadly, for generating greater resources, mental health issues have to be positioned and showcased in a way that policy makers understand their importance, severity and outcome.

#### *6. Advocacy by users and family organisations*

For promoting any health issue, advocacy of stakeholders is important. It consists of various actions aimed at changing the major structural and attitudinal barriers for achieving positive mental health outcomes in population (WHO, 2003). It can be of people who are directly involved with the issue or of outsiders. Among the stakeholders of mental health problems, consumers and family organizations hold the key. In USA, National Alliance for Mentally Ill (NAMI) is one of the biggest organizations of caregivers of persons with mental illness in terms of coverage, membership, number of advocacy initiatives and rapport it has with politicians and policy makers. Through their advocacy efforts, NAMI has helped to maintain the share of mental health at eight per cent of the

national health care budget in USA (HU, 2003), which is one of the highest mental health budget shares in the world.

Besides, non-profit organizations through their efforts of three decades have succeeded in many different ways- 1) Become a powerful voice for having community based rehabilitation services, 2) Successfully pressed for federal legislation for family participation in mental health planning boards, 3) Successfully lobbied for congressional legislation for parity in mental health services, 4) Ensured training of mental health professionals, 5) Provided psycho education-specific information for family members, and 6) lobbied for increased funding for research (Department of Health and Human Resources, 1999).

Sustained efforts of these organizations have led to increased budgetary and other resources, forced government to pass 'Parity laws' for bringing parity in insurance coverage for mental health with other physical disorders, improve quality of services and reduce discrimination (in the allocation of resources both public and private) for mental health problems. At the other level, by educating people, family members and users and by imparting problem management skills, they ensure early detection and treatment on the one side and better care at home on the other.

But all over the world, except in high income countries, family and patient movement is weak or almost absent, especially in low income countries (WHO Atlas, 2011). There is a need for strong and focused users and family organizations to ensure increased resources and improved quality of care. Very few low and low middle income countries have such organizations. However, with an increase in awareness, aspirations and spread of information among users and family members, the necessary changes are not far away (Hu, 2003; Department of Health and Human Resources, 1999; Saxena, Thornicroft, Knapp, 2007).

#### *7. Research in economics of mental health and its dissemination for policy making and treatment*

Unlike physical disorders, limited research has been done in the economics of mental illness (Hu, 2003). This required research needs to be conducted on three fronts:

economic consequences of mental disorders, cost-effectiveness of alternative treatments for them and their financing. This is necessary to convince the government and legislative bodies to allocate additional funding for mental health services. Moreover, research findings have to be disseminated to policy makers and others for further interpretation and action (Hu, 2003).

#### *8. Making mental health a development issue*

A person with a mental illness certainly meets the criterion of vulnerability due to the disability, stigma, prejudice and discrimination he/she has to suffer. Due to this vulnerability, the patient faces stigma, prejudice and discrimination in education and employment. However, unlike other vulnerable groups, persons with mental illness are not a part of a developmental strategy. A WHO report titled ‘Mental Health and Development: Targeting People with Mental Health Conditions as a Vulnerable Group’ strongly advocates the need for inclusion of persons with mental illness in the development strategies and policies. It argues that development stakeholders like governments at national and international levels, international financial institutions and NGOs should consider and target persons with mental illness while giving subsidies, loans, affirmative action and developing access for them in employment and education (WHO, 2010).

### **Measures to address ‘Demand gap’ in utilization of mental health services**

#### *1. Awareness and de-stigmatisation campaigns*

Lack of information and attachment of stigma are the biggest obstacles in accessing treatment for mental health. They not only create delay in seeking treatment but also lead to inadequate and interrupted treatment. There is a need to increase awareness about mental illness, its symptoms, outcome of such symptoms, types of treatment and people to be contacted. Awareness and de-stigmatisation activities can be taken at various levels: an all-community campaign to increase awareness of public in general or activities for target groups like school-based activity or for young people or people in a mental health crisis (Murthy, 2012; Jorm, 2000; Kelly, Jorm & Wright, 2007). Moreover, there is a need for

targeting people not only those developing illness but a range of people in their network (Pavitra KS, 2013).

There is a need that professionals shift to an active mode of empowerment while disseminating information and educating people about mental illness, i.e., they should not only focus on asking people to get rid of their beliefs about mental illness, but should take active interest in disseminating information about it at various levels – individuals, families and community (Murthy, 2012). However, precaution should be taken not to oversell treatment of mental illness. For effectively dealing with the problem of mental illness, participation of a variety of community agents such as teachers, clergy, nurses, hairdressers or any other culturally sanctioned sources of emotional and spiritual support is necessary (Abramovitz, 2008). Dialogue with other systems of care is also essential (Murthy, 2012). Instead of seeing NPT as an opposite or contradictory treatment to psychiatric treatment, some forms of it can be treated as complementary to psychiatric treatment.

## *2. Early detection and intervention services*

Even modest period of untreated mental illness (psychosis) causes distress and disruption to individuals and families. Hence, there is a need to prioritize early detection (Pavitra KS, 2013). Initiatives aimed at reducing untreated illness will not succeed merely by providing more services or swift response, but they also need to target delays in initial help seeking (Pavitra KS, 2013).

This study finds that RD or failure to recognize symptoms as that of mental illness is very large, i.e., about 36 months. This gap is greater for patients in the young age group, i.e., up to 25 years. The 16-25 age group is important in which psycho-social development of a young person takes place and delayed treatment leads to a significant burden on the patient, caregiver and society as a whole in terms of the loss of DALYs. Hence, efforts should be made to detect and initiate treatment as early as possible, especially for people in the young age group. Apart from training of ASHA workers, regular screening camps could be organized for early detection.

### *3. Reducing demand gap due to discontinuation of treatment*

Often primary demand gap, i.e., failure to recognize the symptoms of mental illness and initiate treatment early for the same, is given importance in research and policy initiatives. Secondary demand gap, i.e., failure to continue the treatment is overlooked either due to the assumption of its limited occurrence or its small contribution in the total demand gap. However, this study finds that more than 50 per cent of the total respondents (128 respondents) had at least one discontinuation. The average period of discontinuation was 25 months.

This means that discontinuation is a common feature for a sizable proportion of patients with a significant mean period. Limited research work is available on discontinuation. Hence, there is an urgent need to study its occurrence and duration, and the socio-demographic and other determinants governing it. Second, efforts should be made to disseminate information about mental illness, its treatment and necessity of its continuation, along with the advantages and side effects of treatment. Programmes should be planned and implemented like discharge planning of patients from hospital, their regular follow-ups (on a landline phone, mobile phone or app called What's-up or mobile), creating and circulating material, a highlighting the importance of continuous treatment, counselling and training or awareness-raising among others.

### *4. Integrating mental health services into primary care*

The extent of under-treatment and undetected cases of mental illness are extensive. This is the main reason of a huge burden due to mental illness relatively as well as in absolute terms. For reducing the burden of mental illness, it is necessary to reduce its present state of non-detection and under-treatment. Various studies have shown that treatment for mental health can be provided efficiently at the primary care level, i.e., it can be easily integrated into the general health system (WHO, 2001; WHO, 2008; WHO, 2013; Patel & Thornicroft, 2009). Primary care comprises services of government health centres as well as private general practitioners. It has been found that with training, primary care providers can effectively deliver service of diagnosis, treatment, management, promotion and prevention of mental illness. Such an arrangement has additional advantages. Primary care is also closer to people. Therefore, it is accessible and

affordable. It has fewer stigmas. It is holistic. Moreover, it promotes respect for human rights. From the economic point of view, it is affordable and cost-effective. It requires much less investment and generates good health outcomes (WHO and WONCA, 2008; Patel, 2002; Patel & Thornicroft, 2009; NHRC and NIMHANS, 2008).

The principle of providing mental health care at the primary level is accepted the world over but little has been done in reality. There is an urgent need to introduce this change in India too. But it is not possible in a single step. Therefore, efforts should be made to introduce it in phases.

#### *5. Use of non-government organisations (NGOs) for awareness and prevention of mental ill health*

In India, NGOs play an important role in many walks of life. Their presence is particularly significant in education and health. Although in the last decade or two, some organisations have taken up mental health as their focus of work, very few of them work in the area of mental health which is a sensitive area requiring socio-cultural and psychological knowledge of the population. Due to their inherent advantages, NGOs can play an important role for awareness, promotion and prevention of mental health. The government should encourage them by giving financial and legal concessions (Thara & Patel, 2010; Patel & Thara, 2003) at least on grounds similar to other disability programmes.

#### *6. Training traditional healers*

Traditional healers or non-medical providers like religious healers, faith healers and spiritual healers are the first point of contact for a majority of the patients in India. This situation has hardly changed in the last three decades (Trivedi & Jilani, 2011). Often these providers do not refer their patients for mental health care which leads to long delays and subsequently poor prognosis. These providers should be trained to refer such patients to mental health care providers. ‘Dava and dua’ project at Ahmadabad in which religious healers refer psychiatric cases to mental health care providers has received a remarkable success.

Success of this measure is limited world-wide. However, considering the important role of these traditional healers in India at present and in the future various ways should be considered to involve them in the problem of mental health (Trivedi & Jilani, 2011). They should be trained to detect cases which they cannot handle and refer them to psychiatrists.

#### *7. Effective solutions of other barriers*

Apart from social and cultural factors, other factors like distance, financial expenses, inconvenience with respect to time and place, etc., pose as significant barriers either for the first treatment or for its discontinuation. Hence, efforts should be made to reduce their influence by provision of services in the primary health centres and subsidise travelling to mental health centres.

#### *8. Availability of medicines and psychiatric services at inexpensive rate*

Availability of inexpensive psychiatric services and medicines in the vicinity of the patients is essential for uptake of mental health services (Kohn, Saxena, Levav et. al., 2004). However, such services and experts are not easily available in rural and other inaccessible areas. This deprives people of modern psychiatric services and does not leave any option for them but to contact NPT providers. Besides, it does not allow information about psychiatric practices to spread among them. Many researchers have suggested that basic psychiatric skills – diagnosis, identification, treatment and referral - should be provided to health workers and even to non-health workers. Primary health centres should be supplied with basic psychiatric drugs (Kohn, Saxena, Levav et. al., 2004; WHO and WONCA, 2008).

#### *9. Task sharing and shifting*

Task sharing and shifting are the approaches developed by WHO and World Bank in order to deal with acute shortage of psychiatrists. Treatment for mental health problem does not need much equipment but more of human resources (WHO, 2001). Professional resources for mental health include psychiatrists, psychologists, psychiatric social workers, counsellors, etc., which are in short supply, more so in low and middle income countries. This gap cannot be bridged even in the long term (NHRC and NIMHANS, 2008). The

solution is training of health and even non-health workers to identify and treat such cases at the primary health centres or at the general practitioner's level. These health workers can refer more complicated cases to a psychiatrist whose main role is to train and supervise health workers (WHO, 2003; WHO, 2008; Patel V., 2009; Saxena et. al., 2007; Patel, Maj, & Flisher et. al., 2010).

Task sharing is a situation in which diagnosis, treatment and management of psychiatric cases are addressed by lay health workers and even by non-specialist health workers. In task shifting, expert psychiatrists are expected to get involved in training, supervision, monitoring of health and non-specialist health workers. Besides, they are expected to handle emergency cases, if necessary (Saxena et. al., 2007; Patel V. , 2009).

## **Summary**

Mental illness imposes a huge BOD which is detrimental for the development of society. However, there exists a huge treatment gap and treatment lag in the treatment of mental illness. This is because mental health sector suffers from both the sides, (i) supply gap, i.e., inadequacy in supply of resources for mental health, and (ii) demand gap, i.e., inability to demand and utilise mental health services by households due to several barriers.

In India resources available for the treatment of mental health with the central, state and local governments are grossly inadequate as compared with the incidence of mental ill-health. This inadequacy exists not only in terms of finance but also other respects like skilled manpower, infrastructure, legislation, policy, plans and programmes. The inadequacy has existed historically and now has become chronic. This situation continues even though effective and cost efficient treatments are available which can be implemented through the public distribution system.

In order to reduce this imbalance, there is an urgent need for greater resources to be made available by the governments at central, state and local levels. In order to make resources commensurate with BOD, five to ten per cent of them have to be provided to mental health sector from current one per cent of the budget for mental health in the total health budget of the Central Government (WFMH & MGMH, 2013). Substantial increase



in resources is required in related fields also. However, a steep increase in them may not be possible in one go as it will lead to a reduction of resources for other health issues (NHRC and NIMHANS, 2008,). Hence, a step by step increase in resources is recommended along with changes in other respects -non-fund resources (policy/plans/programmes/awareness/advocacy). It will also be necessary to undertake innovative and human rights oriented steps like establishing community rehabilitation centres, mass awareness campaigns, improving conditions at mental hospitals and selling infrastructure and land to current mental hospitals.

Even though a reduction in supply gap or increase in the supply of resources is a necessary condition, it alone cannot be effective in reducing the BOD due to mental illness. As seen in Chapters V and VI, there exists a huge demand gap or TD, i.e., people do not demand and utilise mental health services due to various reasons. This study finds that this gap exists across all the social, economic and demographic sectors. Use of alternative treatments or non-medical treatment is usually blamed for delay in psychiatric treatment. However, it was found that households with low use of NPT have also a significant demand gap, i.e., TD. It means that other factors are important for demand gap. Lack of awareness about the illness, peculiar nature of illness, social stigma, ignorance and financial difficulties are some of them. Lack of awareness about mental illness is the most important reason for demand gap or TD. A majority of the sample households had discontinuation in treatment and its period is also significant. Discontinuation, usually studied from medical point of view, is sizable and needs to be reduced in order to bring down BOD. Even though free of charge services were available in the vicinity, people did not demand and utilise them which highlights the importance of awareness about mental illness.

### **Need for two way efforts for improving services**

Summing up, efforts are necessary to reduce the gap in supply of resources for mental health. However, considering huge deficit in resources, a steep increase in resources is not possible in the near future. Moreover, changes in the supply side alone are not adequate. There is a need to address the demand gap, i.e., delays in recognising and treating symptoms of mental illness which are significant. These demand side barriers are often historical, chronic and rooted in the culture and peculiarities of mental health issues

and cannot be overcome easily. Creative and well articulated programmes should be designed and implemented which will reach people who have not sought help or whose needs are not recognised (Abramovitz, 2008).

Burden of mental illness is huge and rising. However, unmet need due to supply and demand gap is also huge. Various measures are suggested to reduce supply and demand gap. This study, on the basis of review of literature and primary data, suggests measures to reduce supply and demand gap.

For reducing the supply gap, there is an urgent need to reallocate greater financial, human and infrastructural resources. This will need greater resources from ministry of finance as well as ministries of labour, law, human resource development, etc. For ensuring and sustaining higher resources for mental health at the national and international levels mental health lobby needs to be strong. Primary stakeholders, i.e., families and patients need to form strong lobbies for advocacy. Research on economics of mental health and its dissemination is required to convince the policy makers about the need for it. Additionally, mental health should be regarded as a development issue which will ensure greater resources.

In order to reduce the demand gap, there is a need to spread scientific information about mental illness through awareness and de-stigmatisation campaigns, assertive ways to detect early presence of mental illness, use of NGOs for supplementing mental health services and training of traditional and religious providers. What is urgently required is that mental health services should be integrated with primary health care. For this to happen, existing role of the mental health professionals especially psychiatrists needs to be redefined in terms of task sharing and task shifting.

In all, for reducing unmet need for mental health, not only supply gap should be addressed, but efforts should be addressed to reduce demand gap also.

## **Chapter VIII**

### **Summary and Conclusions**

#### **I. Introduction**

Good health is an important asset for an individual. Traditionally absence of a physical disease was considered a sign of good health. However, considering the importance of other dimensions of health, the World Health Organization (WHO) has defined its concept of health as “a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity” (WHO, 1948). Good health in all its dimensions is essential for an individual not only for its own sake, but also for a happy and peaceful life for developing and maintaining social relationships and for contributing to the productive activity of the society. Good health provides the foundation for stability and growth of individuals, families and society.

Physical and mental disorders impose a burden in various ways. Mental and behavioural disorders are understood as clinically significant conditions characterised by alterations in thinking, mood (emotions), or behaviour associated with personality and/or impaired functioning (WHO, 2013). Instances of mental disorder or illness have negative impact in various ways: (1) An individual has to bear pain, suffering, expenses on treatment and has to bear loss of work; (2) A family has to bear loss of time and income in caring and incur expenses on treatment and face impoverishment due to it; and, (3) The society has to experience loss of working hours and production and their consequent effects. In short, any departure from good health, whether physical or mental, negatively affects all of them.

#### **Burden of mental illness**

In order to understand the severity of a disease and its impact on the society, burden of disease (BOD) measures are used. Mortality and prevalence rates were the conventional measures for measuring the BOD. However, these measures are more suitable for diseases that lead to either full recovery or death (WHO, 2001). Some diseases are chronic in nature and lead to disability, that is, people develop incapacities in several domains of functions.

Global Burden of Disease (GBD) projects used a renewed framework to develop a new matrix DALY (Disability Adjusted Life Years) that includes both the effects of a disease - premature mortality and disability.

Mental illness leads to a much lower premature mortality. Hence, it is ranked at a much lower level in the ranking of diseases where mortality is used as a measure. However, GBD methodology ranks a disease according to its severity. Mental illnesses rank third in the ranking of diseases according to revised measure of DALY (WHO, 2001).

It has been estimated that in the year 2000, 12 per cent of the DALY losses due to all diseases were by mental illness alone. This is expected to increase to 15 per cent by the year 2020 (WHO, 2001). However, recent report of GBD methodology, 2010 has revised it to 7 per cent.

Common Mental Disorders (CMDs) which include anxiety, depression and panic disorders contribute a large share in BOD within mental illnesses. Unfortunately, these health conditions are not taken seriously at the household's level. These findings are important as they help to change the perception towards mental illness at both the micro and macro levels.

Cost of mental illness is another way of measuring its BOD. These costs include both direct and indirect costs. Direct costs cover the cost of medication, fees of treating professionals, counselling and other expenses. Indirect costs include loss of productivity of the person affected due to disorder and his/her family members due to care-giving responsibilities. It has been found that cost of mental illness is huge and rising the world over.

This thesis was undertaken with a view to understanding supply and demand gaps for mental health in terms of its size and determinants. Supply gap and its determinants are widely discussed but demand gap, its components and determinants are discussed to a limited extent. This research was primarily undertaken to fill this gap.

This thesis is divided into eight chapters. Chapter I presents various estimates of burden of mental illness and its trends. Chapter II provides a review of literature of various

concepts of supply and demand gap and determinants of it. Chapter III presents methodology used for collecting data from sample households and nature of questionnaire used. Chapter IV discusses background characteristics of the sample households. In Chapter V findings about the extent of MRD and MNPT are presented. Chapter VI examines inequalities in RD, NPT and PD among sample households according to its various determinants. Inequality is further tested with numerical data, Pearson's coefficient of correlation OLS regression, and adds ratio. In Chapter VII various measures to reduce supply and demand gap are discussed. Finally, Chapter VIII provides a summary of this thesis.

## **II. Review of literature**

### **Huge Treatment gap and Treatment lag**

Even though prevalence, disability and BOD of mental illness are large, use of mental health services is much less. This is so not only in the developing countries, but also in the developed countries. This is indicated by two measures: treatment gap and treatment lag. Treatment gap is the percentage of people who need treatment, but do not receive it. Treatment lag refers to the period for which no treatment is given since the onset of symptoms.

Treatment gap is very large the world over. Even for the developed countries where mental health care system is well organised, treatment gap is 44 to 70 per cent while for the developing countries which have fragile mental health care system it is closer to 90 per cent (WHO, 2003). Research points out that treatment gaps are narrower when the symptoms are severe (Abramovitz, 2008; Andrews, Issakidis & Carter, 2001), more visible and patients are giving trouble rather than those patients whose symptoms are mild or moderate and less visible (Jain, 2012; Lahariya, Gautum & Jain, 2010).

Treatment lag is also significant worldwide and varies from few months to several years. It has been found that treatment lag or delay in initiating treatment is higher for developing countries as compared with developed countries and higher for common mental

disorders as compared with major mental disorders (Jain & Gautam, 2012; Lahariya, Gautam & Jain, 2010; Thompson, Issakidis & Hunt, 2008).

This condition is dismal. It is the result of two gaps: supply gap and demand gap in mental health services. Supply gap is the deficiency in the variety of resources required while providing mental health services. The resources include funding, human resources, hospital beds, other infrastructure, legislation and policy. Demand gap is the time taken to initiate treatment since the onset of symptoms.

### **Supply gap or the deficiency of resources for mental health**

Resources are extremely important to meet the challenges posed by a disease. They include funding, human resources, hospital beds, other infrastructure, legislation, policy, plans, and programmes for mental health. Some of the resources are available in the public as well as private domains, while some others like policy, plans, programmes and legislation are the exclusive responsibilities of the public sector. Mental health services from this sector are inexpensive and are more important for India as a large number of people have a low standard of living. Moreover, ultimately it is the responsibility of public sector to take stewardship in providing an accessible, affordable, and acceptable service to the population.

WHO provides standards for requirement of different resources (Agarwal, Goel & Ichhpujani, 2004; WHO Atlas, 2011). It documents that in most of the developing countries and particularly in India resources for mental health are extremely inadequate in each of its dimensions. The inadequacy varies from one particular type of resource to another and among both developed and developing countries.

### **Supply gap is not justifiable**

Comparing BOD of mental illness and resources allocated clearly indicates that there exists a mismatch between BOD of mental illness and resources for it. Resources are in short supply in all domains (NHRC and NIMHANS, 2008). Often various arguments are made to justify their unavailability: ‘a mental illness does not have effective treatments and even if they are available, they are very expensive,’ ‘treatment for mental health

cannot be implemented through public health system,' etc. However, recent research indicates that such arguments are untenable.

Studies have found that even in low-income countries, older generation anti-psychotic medication along with psychotherapy session, is not only very effective but also cost-effective ((Brundtland,2000; WHO, 2003; Andrews, 2006; Patel, Jenkin & Crick, 2012). Mental health treatment can also be made an integral part of the public health system. Training can be given to mental health staff at primary health centres with simple steps to provide primary mental health care. This huge treatment gap and treatment lag indicates the 'unmet need' of mental illnesses. It is defined as the number and percentage of people and the period for which they are deprived from any mental health service.

### **Reasons of Supply Gap**

In India and other countries, supply gap in mental health has become chronic. Historical, treatment related, programme related and other factors are responsible for such a gap. The discussion on these factors helps us to understand the nature of barriers and solutions to get over them.

Advocacy of stakeholders is important for changing the major structural and attitudinal barriers to achieving positive mental health outcomes in population (WHO, 2003). Among the stake holders of mental health problems, consumers and family organizations are of prime importance. Such organisations are very strong in USA. Through their advocacy efforts, these organizations have helped to ensure higher budgetary and other benefits for mental health. However, the world over (except in high income countries) such advocacy efforts are weak (WHO, 2011) which is one of the major reasons for lower allocation of resources for mental health in these countries.

For ensuring greater allocation of resources having scientific proof of the treatment or treatment being evidence based is very essential. Moreover, there is a need for having successful programmes for implementing the treatment. It is argued unavailability of such treatments with proven evidence and successful programmes limits increased allocation of resources for mental health (Patel, 2000).

Research in mental health from the economic point of view is necessary to justify the need for additional expenditure on it, comparative advantage of such expenditure *vis-a-vis* other health issues and knowledge of most economical treatment modality within such an issue (Tech-wei-HU, 2003). However, very little research has been done on mental health in general and economics of mental health in particular. Moreover, whatever research that is being done, limited effort has been made to disseminate it to policy makers and other stakeholders. Lack of competitiveness of mental health in research *vis-a-vis* other health issues is sighted as another reason for lower allocations. Lack of capacity, i.e., availability of few researchers in mental health, presence of complex issues like identification and consent of research participants, stigma and lack of specific funds reduce the competitiveness of research in mental health (Cyhlarova, 2010).

Shiffman and Smith (2007) highlight the unequal allocation of funds at the global level by international health networks and allocations between the governments. These studies point out that some health issues receive less attention and global funding than others, causing a lower burden or mortality. They identify eighteen factors which are grouped into four broad categories: (i) strength of the actors involved in the initiative, (ii) power of the ideas they use to portray the issue, (iii) the nature of political context in which they operate, and (iv) the characteristic of the issue itself. The failure on these categories has led to lower allocation of funding for mental health even though size of BOD of mental disorders is huge (Tomilson & Lund, 2012).

### **Demand gap**

Demand gap refers to delay in initiating treatment since the onset of symptoms. This is called Overall Treatment Delay (OTD). It can be classified into various components, i.e., recognition delay, consultation delay and treatment delay. Treatment delay varies from few weeks to years. Developed countries with well organised mental health care system also show demand gap. Researchers have found that treatment delay is smaller for major mental illnesses where symptoms are severe, visible and patient is likely to become troublesome to him/herself and others.

In India and many other countries, the demand gap is a regular characteristic of mental health scenario. Various factors related to attitude and belief system of a society,



affordability and convenience of treatment are responsible for it. Discussions on these factors help us to understand the barriers and solutions to get over them.

Mental disorders have been understood according to changing perceptions at different points of time. Many of these perceptions and explanatory models have survived even today. In India many people hold traditional beliefs which are not consistent with modern explanations that are available. Murthy (2012) explains a variety of beliefs, attitudes and practices people hold about nature, causes and treatment of mental disorders. They often delay psychiatric treatment which is based on modern explanation of mental illness. Mental health literacy, i.e. knowledge of a disorder, its nature, symptoms, causes, sources of help, etc., are essential for early identification, intervention, treatment and prevention of a disorder. However in mental disorders large number of people are ignorant about what they can do for prevention, commonly delay or avoid seeking treatment, view recommended treatment with suspicion, and are unsure how to assist others with mental disorders (Jorm, 2000; Kelly, Jorm & Wright, 2007; Jorm, 2011). Ignorance about mental illness, difficulties in understanding or recognising symptoms coupled with ignorance about where to go for help leads to delay in treatment (Pavitra, 2013; Tanskanen, Morant & Hinton, 2011).

Social stigma poses another serious barrier to treatment. Stigma is a mark of disgrace that society holds towards mentally ill persons. Feeling of blame and shame contributes to inhibition of seeking help for mental disorders. (Saxena, Thornicroft & Knapp, 2007) Stigma delays not only treatment but also acts as a barrier in taking right and continuous treatment, finding alternative or complementary treatment. Very often patients or their family members internalise social stigma. This 'self stigma' which is often in the magnified form further delays treatment (Corrigan, 2004 ; Srinivasan, 2015).

Lack of laboratory test to detect and confirm presence of mental disorder and several logistic factors like the cost of treatment, transport, inconvenience of treatment or long waiting for services were also reasons for not utilising or delaying or for not taking the psychiatric treatment or in a timely manner (Ghanizadeh, Arkan, & Mohmmadi, 2008; Gulliver, 2010). In many cultures Common mental disorders (CMDs) like anxiety, depression, etc., and others not considered illness (Jacob, 2001).They attribute such

conditions to life events, fate, supernatural causes and physical diseases (Kleinman, 1980). People do not take psychiatric treatment when symptoms of CMDs are observed.

### **Impact of deficiency in demand**

Jacob (2001) points out the significant impact of deficiency of demand on the commitment of mental health professionals. It leads to absence of urgency to tackle the problems and a consequent lack of translation of plans into action oriented programmes (Agarwal, 1991). Jacob (2001) further argues that this deficiency along with lack of consumer movement have major impact on supply of services (and resources). It leads to lack of political and administrative will of the government.

### **Purpose of current research**

This study was conducted to understand the nature, extent and determinants of supply and demand gap. It addresses issues regarding supply gap with the help of secondary data and issues regarding demand gap using the primary data. A good number of studies has been done to find the extent of supply gap and its determinants. However, very few studies have been conducted in India to find out the extent of demand gap and its determinants. Moreover, all of them focus from the point of view of 'pathways to care' and address the variables related to it. Although these studies address treatment delay, they fail to take cognisance of its components and determinants of it from the point of view of demographic, social, economic, medical and geographic characteristics of the sample households.

Another limitation of earlier studies is that they do not try to find out the extent of NPT or extent of duration of discontinuation in months (MDD) and its determinants. NPT is only seen as an age old practice and it is assumed that it is a major factor for treatment delay. It is hardly tested whether the period of NPT is the cause of treatment delay or some other factors are responsible. This study tries to fill these research gaps by finding out the period of treatment delay, MNPT and MDD and determinants of it. In India, demand gap is significant. However, focus of most of the research and policy is on ways of reducing the supply gap. Hence, this study can be considered as a step towards understanding this relatively neglected area.

### **III. Methodology**

Reducing the supply and demand gaps is an important strategy for reducing the treatment gap and the treatment lag. Chapter I highlights that the allocation of resources by the Central Government is not only inadequate but also inequitable and inefficient. For initiating a timely and adequate treatment, the supply gap should be reduced, i.e., the supply of resources should be adequate or sufficient health services and infrastructure should be made available and well distributed in an area.

It is also necessary to ensure that people demand, initiate or utilise mental health services. Often utilisation of services by the households is taken as granted and it is assumed that the supply or availability of services will automatically lead to the utilisation of services. However, due to various barriers, individual households do not demand or utilise mental health services. Their non-availability is one of the reasons. Demand gap or lack of demand is the other important factor. It is due to ignorance, lack of information, myths, belief systems, social, demographic and geographic factors, stigma and other barriers. These factors are particularly important for mental health sector. However, they are relatively less researched and this study aims to fill this gap.

The study aims to explore the nature, extent, inequality and determinants of demand gap, i.e., inability to demand mental health services at the level of households. Demand gap is measured with Treatment Delay (TD). It equals the time from the onset of symptoms to the initiation of treatment. It is measured in months. This study is basically exploratory. It is undertaken with the following objectives.

#### **Specific objectives of this study**

1. To understand the extent of demand gap or treatment delay, and the number and period of discontinuation for mental illness by the households according to socio-demographic characteristics.
2. To find out the average period for which NPT is used and its relation with the treatment delay.

3. To analyse the inequity in the demand gap or treatment delay, MNPT and in the discontinuation in treatment.
4. To identify the reasons for or barriers to the TD.

### **Conceptual framework**

The burden of a mental illness is huge and so are its ‘treatment gap’ and ‘treatment lag’. Inadequate supply of resources leading to under-provisioning of services for mental health is usually highlighted as the most important factor. This study takes an overview of the supply gap or the inadequate supply of resources for mental health in India and finds that there is acute shortage of it. Apart from the inadequacy of resources, it examines two more facets of supply gap or supply of resources: inequity and inefficiency.

This study is conceptualised around these three facets of Supply gap or inadequate supply of resource and demand gap or delay in demand for utilisation of mental health services (Figure 3.1). Each of inadequacy, inequity and inefficiency has a different connotation at the level of supply of resources (supply gap or macro) and at the level of demand gap (household or micro) level. At macro level, inadequacy in supply gap refers to the deficiency in actual availability of resources as compared with the need according to the standard norms (share of mental health in budget, number of professionals, beds and other facilities per lakh of population). At macro level, inequity refers to the unequal distribution of resources within specific geographical and socio-demographic characteristics of the population. At macro level, inefficiency refers to the misallocation of resources across different treatment modalities or treatment options. Detailed overview of these three facets of resource allocation at macro level is taken in Chapter I.

For actual utilisation of mental health services, people need to demand mental health services. In other words, they need to understand the presence of symptoms of mental illness, acknowledge it, and take action in order to seek mental health services. In other words, early detection or recognition, consultation with a professional and an appropriate action are necessary in order to receive timely treatment. Several barriers may affect the journey of an individual household towards treatment. These demand factors get

reflected in the treatment delay for mental illness. Hence, Treatment Delay (TD) is considered as a measure of demand gap.

As in the case of supply of resources, three attributes of the demand factors or TD are considered in this study: period of TD, inequity, and inefficiency in it. Inadequacy, inequity and inefficiency in it at micro or household level are calculated with the help of primary data.

### **Data sources and methods of analysis**

In order to find out TD, its components and determinants, a semi-structured interview schedule was prepared. It included 78 questions divided into nine sections. This study collected data from 249 caregivers of persons with mental illness who visited the OPD section of Yerwada Mental Hospital (YMH), Pune, during June to August 2014. Questions, regarding the period (in months) of untreated mental illness, recognition delay, number and period of discontinuation and number of months for which NPT was taken, were asked. Information about reasons for delay, reasons for availing NPT, and socio-demographic and other characteristics of respondents were also collected. Ethical guidelines were followed and informed consent was taken. Qualitative data were collected from YMH staff and caregivers from YMH and a guide was prepared for the same. (Questionnaire and guide are provided in Appendix VII, VIII & IX.)

For analysis of data SPSS version 20 was used. Eighteen variables were divided into five groups – demographic, social, economic, medical and geographic were used. Bivariate tables cross classified into these variables and MRD, MNPT and MPD were made. Statistical tools such as correlation coefficients and OLS regression were used for analysing the data.

### **IV. Background characteristics of caregivers and patients**

Out of the total caregivers, 73.1 per cent were male and 26.9 per cent were female, which reflects predominance of male caregivers over female caregivers. Hindu and SC population was slightly over-represented in their respective categories. The mean age and

education of the caregivers were 43.97 and 9.10 years respectively. The most frequently found relation of caregiver with the patient was parent or other family member.

Among 249 patients, 68.3 per cent were males and 31.7 per cent females, which reflects neglect of the female population in taking them even to a mental hospital. Majority of them had experienced the onset of symptoms at early age, i.e., before attaining 25 years. The mean education of the patients was 7.69 years. Most of the patients (as many as 74.44 per cent of the total patients) were diagnosed with schizophrenia.

Majority of the patients were diagnosed with a major mental illness and schizophrenia was the main disorder. Very small percentage of people had any form of a common mental disorder (CMD). This clearly reflects that persons with CMD do not turn to YMH for help. Either the symptoms of CMD are not noticed because of their invisibility or people believe that mental hospitals are basically for severe mental disorders and not for CMD.

As many as 49 per cent of the total patients came from Pune district alone, 25 per cent from adjoining district and 26 per cent from far-off areas like Marathwada and Vidarbha, travelling 300 to 500 kilometres for consulting a psychiatrist and for collecting the monthly quota of free medicines.

## **V. Extent of treatment and recognition delay**

Timely treatment is necessary for mental illness. However, due to several barriers, people with mental illness and their families seek mental health services with time lag. This time lag is called as 'treatment lag' or 'treatment delay' (TD). The period of TD reflects 'demand gap or extent of neglect individuals and families make towards mental illness.

Understanding the extent of TD and its components is important. TD indicates choices made by individuals and families towards a particular health problem. TD is important as it leads to pain and suffering to patient and family members, social-economic costs and poor prognosis of the course of the disease. Hence, greater delay is detrimental from the point of view of individual, family and society. Understanding the extent of TD in

mental illness and its socio-economic and demographic determinants are important from both theoretical as well as policy perspectives.

Overall Treatment Delay (OTD) is the delay that people make in initiating the treatment since the beginning of symptoms. It can be divided into recognition delay, consultation delay and treatment delay. Recognition Delay (RD) is the time taken in recognizing changes in behaviour as mental illness, Consultation Delay (CD) is the time taken to consult a mental health professional from recognizing mental illness and TD is the time taken to initiate treatment since consulting a mental health professional.

In this study out of the total sample of 249, 210 households 84 per cent households have TD. All of them had RD and only three per cent have additionally CD or TD or both. Average overall TD was 37 months and average RD 35.8 months. Since RD is the most dominant component of delay, this study considers it alone for analysis.

Sample households had considerable RD and then presenting persons with mental illness to mental health professionals. The average delay from (revealed) onset of symptoms to recognition of illness is 35.75 months. This is likely to be under-estimate as people who have little knowledge about mental illness are likely to suspect abnormality only till symptoms become very visible or troublesome. This delay is considerably high considering social-economic costs, emotional suffering and poor prognosis of the course of the disease associated with it.

There is a substantial variation of RD among respondents. However, respondents with shorter delay (up to 12 months) and longer delay (from 13 months to 60 months) were numerically dominant (around 70 per cent).

#### *Non- Psychiatric Treatment (NPT)*

Non-Psychiatric Treatment (NPT) includes all treatments other than psychiatric treatment like Ayurvedic, Homeopathic, Yunani or any other medical system and services of spiritual gurus, faith healers, temples and temple priests, religious rituals, durgahs, etc. NPT was the first choice of intervention for a majority of the households (68 per cent), once they notice changes in the behaviour of person with mental illness. In our study none

of the sample households avail services of Ayurvedic, Homeopathic, Yunani or any other medical system.

One hundred and sixty nine respondents (67.9 per cent), who availed NPT, visited religious places, temples, faith healers, spiritual gurus and others as a first point of contact. Predominance of faith healers or religious places as a first point of contact is also recorded by Lahariya (2010) and Jain (2012). Treatment from a psychiatrist is generally taken as the last resort. The reason for popularity of traditional healers may be because of their easy accessibility, holistic approach, belief models of mental illnesses in the society, cultural congeniality and cost effectiveness (Torrey, 1986).

Traditional healers while dealing with psychiatric patients often hide their inability to understand and treat these disorders and attribute them to supernatural causes further enhancing beliefs of the patients in them (Bhana, 1986). One study found that the treatment is largely with 'ashes', 'mullets' or 'holy water'. Patients go from one healer to another and it is only after not getting any relief that they turn to psychiatric treatment ((Lahariya, Singhal, Gupta et.al., 2010).

Average period for availing NPT was 24 months. However, there is a substantial variation, among sample households, of the period for which they have taken NPT. Lack of knowledge about mental illness was the most important reason it. It was also found that patients were taken for NPT or a psychiatrist only when the symptoms became visible. However, symptoms like odd behaviour and violence were in greater percentage while taking patients for psychiatric treatment as compared with NPT.

## **VI. Inequality in RD**

Inequity and inefficiency are two more attributes of demand for mental health services. Inequity refers to differences in length of MNPT and MRD within a particular socio-demographic or economic group like sex, caste, religion or income group. Inequality is examined using mean MNPT and MRD across several socio-economic and demographic groups. Strength of inequality is further investigated with other statistical tools like Pearson's correlation coefficient and Ordinary Least Square regression.



It is said that mental illness is one of the most democratic illnesses. Its prevalence across country, religion, caste, religion and culture does not vary significantly. However, in our study only 32 per cent patients were women. This indicates gender inequality while taking patients for treatment even at YMH, where free consultation and medication are available.

When RDs of sample households were classified within demographic variables, it was found that there is a substantial inequality with respect to RD. Patients from rural areas and joint families had longer RD as compared with patients from urban areas and nuclear families. With increase in education and duration of onset of symptoms, RD falls. Gender bias is found to be reversed among the respondents and male patients have longer RD. Hindu respondents belonging to Hindu religion showed greater delay as compared with Muslims and Buddhist respondents (who showed lowest RD). Respondents from higher castes had highest RD, followed by OBC and SC respondents who had the lowest delay.

Inequality was further examined with the help of Pearson's correlation coefficient, OLS regression and Odds Ratio. Age of patient, caste, relation and age at the onset of symptoms had significant association with MRD, while the type of family and year of first treatment had significant association with MNPT. In OLS regression with MRD as dependent variables, seven variables show parameters which are statistically significant. They are age at onset of symptoms, marital status (demographic variables), caste, education, relation with the patient, year of starting first treatment (social variables) and district of residence (geographic variables). Out of them four are social variables. This indicates significance of this group in influencing RD.

Inefficiency in treatment for mental illness is examined by comparing RD for it and physical illnesses. Out of the total sample households, 21.7 per cent had any physical illness and out of that only 4.1 per cent had RD for physical illness. Similar view was shared by KII of YMH staff and veteran caregivers. This indicates that RD is greater for mental illness as compared with physical illnesses. Lack of pain to the patient or visible symptoms were the main reasons for greater delay for treatment of mental illness.

### *Discontinuation in treatment*

Another finding of this study is that discontinuation in treatment is a regular feature for most of the patients. Over 50 per cent of the patients had at least one delay and the average period of discontinuation is 24 months. This is significant absolutely as well as relatively when compared with mean RD which is 35.75 months.

This study sees the period of discontinuation as treatment gap even after initiating treatment for the first time and calls it as 'extended demand gap'. Research on estimating the period of treatment delay and drawing 'Pathways to care for first contact' has been done for India as well as for western countries. This study extends this approach further and takes life time approach and calculates the period of discontinuation and draws 'life time pathways to care' model.

This study finds that not only the extent of the period of discontinuation is large but there exists inequality in the mean period of discontinuation in months (MD) within socio-economic variables. Eighteen variables were considered which were further classified into five groups: demographic, social, medical, economic and geographical. There exists inequality in MD within the group of caste, religion, current age, place of residence, type of family, relation with the patient, education of caregiver, occupation of caregiver, occupation of patient and age at onset of symptoms.

Inequality was further examined with the help of three more statistical operations, Pearson's correlation coefficient and OLS regression, taking MD as dependent variable and the 18 variables mentioned earlier as independent variables. MD shows significant association with the age of the patient and the year of first treatment when Pearson's correlation coefficient is used. When OLS method is used 11 per cent of the variations are explained by the 18 variables, while the year of first treatment and occupation of the patient give parameters which are significant. Summing up, the year of first treatment and occupation of caregiver are important determinants of the period of discontinuation.

Inefficiency was examined by comparing discontinuation in the case of treatment for mental illness and physical illness. Out of the sample households which had physical illness, only 8.8 per cent experienced discontinuation and none had more than one

discontinuation. This finding was also supported through KII conducted by the staff at YMH and veteran caregivers.

## **VII. Discussion**

Burden of mental illness is heavy in India and so is the unmet need of services for it. The huge unmet need is the result of two factors: supply gap (inadequacy of resources) and demand gap (failure to demand mental health services by the households). Burden of mental illness and rising DALYs lost due to it are a matter of concern for India. Hence, there is a need to make efforts to reduce supply and demand gaps. Various measures to address this gap have been suggested globally as well as for India. In this study, the extent and determinants of demand gap have been estimated. Following are the recommendations based on the review of literature as well as our analysis of primary data.

### **Measures to address supply gap in resources for mental health**

#### *1. Greater financial resources through budget*

Increase in budget for mental health commensurate with BOD of mental health issues is extremely necessary (GOI, 2014). For reducing the burden of mental illness, treatment (both prevention and promotion) facilities should be adequately available. This means that there is a need for greater human resources, more beds and other infrastructure and well-placed legislation, policy and planning - all of which need more resources. Hence, it is necessary to increase the budgetary resources substantially. The current share of mental health in the health budget by the Government of India is 1 per cent. It needs to be increased to 5 to 10 per cent in order to make it commensurate with the burden of mental health (WFMH, MGMH, 2013). Changes in state and local level budgets are also required. However, it is not feasible to increase it to such a level in a single step. Therefore, a step-by-step increase is necessary. In the meantime, there is a need to utilise the existing resources in an efficient way. It is argued that it is necessary to ensure parity to mental health with physical illness in terms of access to treatment and care (Movement for Global Mental Health, 2015). Persons with mental illness also need to have full access to universal health care (Movement for Global Mental Health, 2015).

2. *Greater share of other resources through other ministries: social justice and empowerment, human resource development, law, welfare, rural development, and labour*

Mental health issues have an interface with several other health or non-health issues and hence with their ministries. In order to address the problems of mental illness effectively, there is a need for effective legislation and mechanism to monitor them, social welfare schemes, training and employment opportunities. For all this to happen, there is a need for greater allocation of resources not only by the health ministry but also from other related ministries like those of human resources, social justice and empowerment, law, social welfare, rural development and labour.

3. *Effective governance: policy, plan and legislation*

Having adequate funds for mental health is a necessary but not a sufficient condition. For mental health services to reach the people, well articulated mental health policy, well designed plans and programmes are necessary. Funding for mental health will have meaning, direction, focus and desired results only when it is accompanied with policy, plan and programmes. It is essential to have well established legislation so that it will be enforced.

4. *Awareness among policy makers: planners/ministries/departments/health officials*

Mental health is a health issue which has been neglected in the past. Policy makers, planners, ministries and various departments are not adequately informed about mental health issues, besides it being attached a stigma. Hence, due to inadequate information and stigma, they are not likely to take decisions in the interest of mental health. There is an urgent need to increase awareness among policy-makers, planners, ministries, departments and health officials.

5. *Suggestions by Shiffman and Smith*

Shiffman and Smith (2007) studied the allocation of funds by international health networks and allocations between the governments. They ask why some health issues

receive less attention and global funding than other health issues causing a relatively lower burden or mortality. The study concludes that such an anomaly in the matching between the resources and their burden could be explained with the help of 18 factors which are grouped into four broad categories, viz.,

1. Strength of the actors involved in the initiative.
2. Power of the ideas they use to portray the issue.
3. Nature of the political context in which they operate.
4. Characteristics of the issue.

In order to obtain more funding, it is necessary to act and bring about change in all the factors (Shiffman & Smith, 2007). In order to generate additional resources, mental health lobby needs to work on all the above categories. Tomlinson and Lund (2012) provide following suggestions using this framework: there is a need for greater mental health community cohesion in order to ensure unified voice, providing evidence-based and scalable interventions in order to create impact on policy makers, innovative strategies for treatment and stigma reduction and a social and human rights approach. Broadly, for generating greater resources, mental health issues have to be positioned and showcased in a way that policy makers will understand their importance, severity and outcome if they choose to provide more resources.

#### *6. Advocacy by users and family organisations*

For promoting any health issue, advocacy of stakeholders is important. Advocacy consists of various actions aimed at changing the major structural and attitudinal barriers to achieving positive mental health outcomes in population (WHO, 2003). It can be of people who are directly involved with the issue or of outsiders. Among the stakeholders of mental health problems, consumers and family organizations hold the key. Evidence based treatments and practise and sound research findings are not adequate to persuade government to take action unless they also see a political advantage in it (WFMH and MGMH, 2013). In USA, National Alliance for Mentally Ill (NAMI) is one of the biggest organizations of caregivers of persons with mental illness in terms of coverage, membership, number of advocacy initiatives and rapport it has with politicians and policy makers. Through their advocacy efforts, these organizations have helped to maintain share

of mental health at eight per cent of the national health care budget (Tech-wei-HU, 2003), which is one of the highest mental health budget shares in the world.

These organizations through their efforts of three decades have succeeded in many ways. Their sustained efforts have led to increased budgetary and other resources, forced the government to pass 'Parity laws' for bringing parity in insurance coverage for mental health with physical disorders, improve quality of services and reduce discrimination (in the allocation of public and private resources) for mental health problems. At another level, by educating people, family members and users and by imparting problem management skills, they ensure early detection and treatment and better care at home.

However, the world over, except in high income countries, family and patient movement is weak or almost absent, especially in low income countries (WHO, 2011). There is a need for strong and focused users and family organizations to ensure increased resources and improved quality of care. Very few low and low middle income countries have such organizations. However, with increase in awareness, aspirations and spread of information among users and family members, these changes are not far away (Tech-wei-HU, 2003; Department of Health and Human Resources, 1999; Saxena, Thornicroft, Knapp, 2007).

#### *7. Research in economics of mental health and its dissemination for policy making and treatment*

Unlike physical disorders, limited research has been done in economics of mental health (Tech-wei-HU, 2003). In fact, for many years mental health was starved of funds for research (WFMH & MGMH, 2013) This research needs to be conducted on three fronts: economic consequences of mental disorders, cost-effectiveness of alternative treatments for them and their financing. This is necessary to convince the government and legislative bodies to allocate additional funding for mental health services. Moreover, these research findings have to be disseminated to policy makers and advocates for further interpretation and action (Tech-wei-HU, 2003).

## *8. Making mental health a development issue*

A person with a mental illness certainly meets the criterion of vulnerability due to the disability, stigma, prejudice and discrimination she has to suffer. Due to her vulnerability, she faces stigma, prejudice and discrimination in education and employment (Movement for Global Mental Health, 2015). However, like other vulnerable groups, persons with mental illness are not a part of a developmental strategy. Mental illness should be viewed not only as a medical issue but also as a developmental issue relevant to poverty, productivity and human rights (WFMH & MGMH, 2013). A WHO report titled 'Mental health and development: Targeting people with mental health conditions as a vulnerable group' strongly advocates the need for inclusion of persons with mental illness in the development strategies and policies. It argues that development stakeholders like governments at national and international levels, international financial institutions and NGOs should consider and target persons with mental illness while giving subsidies, loans, affirmative action and developing access for them in employment and education (WHO, 2010; Movement for Global Mental Health, 2015).

### **Measures to address demand gap in utilisation of mental health services**

#### *1. Awareness and de-stigmatisation campaigns*

Lack of information and stigma are the biggest obstacles in accessing treatment for mental health. They not only create delay in seeking treatment but also lead to inadequate and interrupted treatment. There is a need to increase awareness about mental illness, its symptoms, outcome of such symptoms, types of treatment and people to contact. Awareness and de-stigmatisation activities can be taken at various levels: an all-community campaign to increase awareness of public in general or activities for target groups like school-based activity or for young people or people in a mental health crisis (Murthy, 2012; Jorm, 2000; Kelly, Jorm & Wright, 2007; WFMH & MGMH, 2013).

There is a need that professionals shift to an active mode of empowerment while disseminating information and educating people about mental illness. However, precaution should be taken not to oversell treatment of mental illness. For effective solution of the problem of mental illness, participation of a variety of community agents such as teachers,

clergy, etc., is essential (Abramovitz, 2008). Dialogue with other systems of care is also essential (Murthy, 2012).

## *2. Early detection and intervention services*

Early detection and intervention significantly reduces the subsequent lifelong disability (Movement for Global Mental Health, 2015a). This study finds that RD or failure to recognize symptoms as that of MI is large, i.e., about 36 months. This gap is greater for patients in the young age group, i.e., up to 25 years. The 16-25 age group is important in which psycho-social development of young person takes place and delayed treatment leads to a significant burden on patient, caregiver and society in terms of loss of DALY lost. Hence, efforts should be made to detect and initiate treatment for all patients. Apart from training of ASHA workers regular screening camps could be organized for early detection.

## *3. Reducing demand gap due to discontinuation of treatment*

Very often primary demand gap, i.e., failure to recognize the symptoms of MI and initiate treatment early for the same is given importance in research and policy initiatives. Secondary demand gap, i.e., failure to continue the treatment is overlooked either due to the assumption of its limited occurrence or its small contribution in the total demand gap. However, this study finds that more than 50 per cent of the total respondents (128 respondents) had at least one discontinuation. The average period of discontinuation is 25 months.

This means that discontinuation is a common feature for a sizable proportion of patients with a significant mean period of discontinuation. Very limited research is available on discontinuation. Hence, first, there is an urgent need to study its occurrence and length, and the socio-demographic and other determinants governing it. Second, assertive efforts should be made to disseminate information about mental illness, its treatment, and necessity of its continuation, along with the advantages and side effects of treatment. Assertive programmes should be planned and implemented like discharge planning of patients from hospital, their regular follow-ups ( on a landline phone, mobile phone or app called What's-up or mobile), creating and circulating material highlighting



the importance of continuous treatment, counselling and training or awareness-raising among others.

## *2. Integrating mental health services into primary care*

Extent of under-treatment and undetected cases of mental illness is extensive. This is the main reason of a huge burden due to mental illness relatively as well as in absolute terms. For reducing the burden of mental illness, it is necessary to reduce the present state of non-detection and under-treatment of mental illness. Various studies have shown that treatment for mental health can be provided efficiently at the primary care level, i.e., it can be easily integrated into the general health system (WHO, 2001; WHO & WONCA, 2008; WHO, 2013; Patel & Thornicroft, 2009). Primary care comprises services of government health centres as well as private general practitioners. It has been found that with training, primary care providers can deliver service effectively of diagnosis, treatment, management, promotion and prevention of mental illness. Such an arrangement has additional advantages. Primary care is closer to people. Therefore, it is accessible and affordable. It has fewer stigmas. It is holistic. Moreover, it promotes respect for human rights. From the economic point of view, it is affordable and cost-effective. It requires much less investment and it generates good health outcomes (WHO and WONCA, 2008; Patel, 2002; Patel & Thornicroft, 2009; NHRC and NIMHANS, 2008). It is also argued that India's District Mental Health Programme should be expanded in order to ensure low cost psychosocial interventions by appropriately trained and supervised community based workers, availability of acute inpatient beds at district hospitals (Sharma, 2014).

The principle of providing mental health care at the primary level is accepted the world over but little has been done in reality. There is an urgent need to introduce this change in India (GOI, 2002; GOI, 2014). But it is not possible in a single step. Therefore, efforts should be made to introduce it in phases.

## *3. Use of non-government organisations (NGOs) for awareness and prevention of mental ill health*

In India, NGOs play an important role in many aspects of life. Their presence is particularly significant in education and health. Although in the last decade or two some

organisations have taken up mental health as their focus of work, very few of them work in the area of mental health which is a sensitive area requiring social-cultural and psychological knowledge of the population. Due to their inherent advantages, NGOs can play an important role for awareness, promotion and prevention of mental health. The government should encourage them by offering various financial and legal concessions (Thara & Patel, 2010; Patel & Thara, 2003).

#### *4. Training traditional healers*

Traditional healers or non-medical providers like religious healers, faith healers and spiritual healers are the first point of contact for a majority of the patients in India. This situation has hardly changed in the last three decades (Trivedi & Jilani, 2011). Often these providers do not refer their patients for mental health care which leads to long delays and subsequently poor prognosis. These providers should be trained to refer such patients to mental health providers. 'Dava and dua' project at Ahmadabad in which religious healers refer psychiatric cases to mental health care providers has received remarkable success.

Success of this measure is limited world-wide. However, considering the important role of these traditional healers in India, at present and in future, various ways should be considered to involve them in the problem of mental health (Trivedi & Jilani, 2011). They are able to detect cases which they cannot handle and refer them to psychiatrists.

#### *4. Effective solutions of other barriers*

Apart from social and cultural factors, other factors like distance, financial expenses, inconvenience with respect to time and place, etc., pose as significant barriers either for first treatment or for discontinuation. Hence, efforts should be made to reduce their influence by provision of services in the primary health centres and subsidise travelling to mental health centres.

#### *6. Availability of medicines and psychiatric services at inexpensive rate*

Availability of inexpensive psychiatric services and medicines in the vicinity of the patients is essential for uptake of mental health services (Kohn, Saxena, Levav et. al.,

2004). However, such services and experts are not easily available in rural and other inaccessible areas. This deprives people of modern psychiatric services and does not leave any option for them but to contact NPT providers. Besides, it does not allow information about psychiatric practices to spread among them. Many writers have suggested that basic psychiatric skills – diagnosis, identification, treatment and referral - should be provided to health workers and even to non-health workers. Primary health centres should be supplied with basic psychiatric drugs (Kohn, Saxena, Levav et. al., 2004; WHO and WONCA, 2008).

### *7. Task sharing and shifting*

Task sharing and shifting are the approaches developed by WHO and World Bank in order to deal with acute shortage of psychiatrists. Treatment for mental health problem does not need much equipment but more of human resources (WHO, 2001). Professional resources for mental health include psychiatrists, psychologists, psychiatric social workers, counsellors, etc., which are in short supply, more so in low and middle income countries. **Moreover, migration of professionals to developed countries adds to this shortage. Increasing post-graduate seats in psychiatry or discouraging migration of professionals can be the policy measures.** However, this gap cannot be bridged even in the long term (NHRC and NIMHANS, 2008). Its solution is training of health and even non-health workers to identify and treat such cases at the primary health centres or at the general practitioner's level. These health workers can refer more complicated cases to a psychiatrist whose main role is to train and supervise health workers (WHO, 2003; WHO, 2008; Patel V., 2009; Saxena et. al., 2007; Patel, Maj, & Flisher et. al., 2010).

Task sharing is a situation in which diagnosis, treatment and management of psychiatric cases are addressed by lay health workers and even by non-specialist health workers. In task shifting, expert psychiatrists are expected to get involved in training, supervision, monitoring of health and non-specialist health workers. Besides, they are expected to handle emergency cases, if necessary (Saxena et. al., 2007; Patel V. , 2009).

## **Contribution of this research**

This study was conducted to understand the nature, extent and determinants of supply and demand gap. It addresses issues regarding supply gap with the help of secondary data and issues regarding demand gap with primary data.

Very few studies have been conducted in India to calculate the extent of demand gap. Moreover, all of them look at the problem from the point of view of ‘pathways to care’ and address the variables related to it. However, this study tries to address the demand gap along with its components and determinants from the viewpoint of demographic, social, economic, medical and geographic characteristics of the sample households. It tries to unfold the role of these variables and understand the determinants of demand gap which are an integral part of the social milieu of Indian society. It emphasizes the role of demand gap in unmet need of mental health care which is relatively less addressed and advocates measures to reduce it.

This study further calculates the number of times and period of discontinuation (PD) which is rarely studied in the literature. Few studies that are available are from developed countries. Mostly medical professionals have done this research and they have studied it from the point of view of compliance or adherence to medications. Hardly any study is available from the point of view of the extent of discontinuation (extended demand gap) and inequality within it and reasons thereof. This study highlights this relatively neglected area and suggests measures to reduce it.

Most of the research on NPT providers is from the point of view of their variety, practices and its association with the Indian society. There is little discussion about the period for which it is used, its determinants and its relation with demand gap. By incorporating NPT, this study highlights finer intricacies among NPT, RD and other variables. It highlights the role of lack of information and stigma as a determinant of demand gap rather than NPT, which is commonly understood as the principal determinant.

By underlining the role of demand gap, this study urges policy makers to pay attention to it, primary and extended, and implements measures to reduce it.

## **Limitations of this study**

The results of the study need to be interpreted with caution as it has the following limitations: (a) Caregivers who visited YMH were not necessarily primary caregivers of the patients and in few cases there is likely to be deviation in the information given by primary caregiver and the interviewee caregiver. In such cases, interviews were conducted only after confirming that the accompanying caregiver knows the history of symptoms and treatments; (b) Information was collected from the caregiver of the mental ill person who visited YMH outpatient department (OPD) during the survey period. Most of the patients were previously hospitalised at YMH for psychotic problems. Hence, this is study of patients visiting OPD of YMH only and the findings cannot be generalised for the whole population; (c) Caregivers from YMH represent people from the lowest socio-economic strata of the society. Hence, the study is of them and not of the entire society; and, (d) Reliability of the information collected depends on the willingness of the participating caregivers. No scale was used to measure reliability of the information given by family members.

## **Conclusion**

Summing up, mental illness imposes a huge BOD which is detrimental for the development of society. However, there exists a huge ‘treatment gap’ and ‘treatment lag’ in the treatment of mental health. This is because mental health sector suffers from both the sides, (i) supply gap, i.e., inadequacy in supply of resources for mental health and (ii) demand gap, i.e., inability to demand and utilise mental health services by households due to several barriers.

In India resources available for the treatment of mental health with the central, state and local governments are grossly inadequate as compared with the incidence of mental ill-health. This inadequacy exists not only in the terms of finance as well as other dimensions like skilled manpower, infrastructure, legislation, policy, plans and programmes. The inadequacy has existed historically and now has become chronic. This situation continues even though effective and cost efficient treatments are available which can be implemented through public distribution system.

In order to reduce this imbalance, there is an urgent need for greater resources by the governments at central, state and local levels. In order to make resources commensurate with BOD, five to ten per cent of them have to be provided to mental health sector from current one per cent of the budget for mental health in the total health budget of the Central Government (WFMH & MGMH, 2013). Substantial increase in resources is required related fields also. However, a steep increase in them may not be possible as it will lead to a reduction of resources for other health issues (NHRC and NIMHANS, 2008,). Hence, a step by step increase in resources is recommended along with changes in other dimensions- non-fund resources (policy/plans/programmes/awareness/advocacy). It will also be necessary to undertake innovative and human rights oriented steps like establishing community rehabilitation centres, mass awareness campaigns, improving conditions at mental hospitals and selling infrastructure and land of current mental hospitals.

Even though a reduction in supply gap or increase in supply of resources is a necessary condition, it alone cannot be effective in reducing the BOD due to mental illness. As seen in Chapters V and VI, there exists a huge demand gap or TD, i.e., people do not demand and utilise mental health services due to various reasons. This study finds that this gap exists across all the social, economic and demographic sectors. Use of alternative treatments or non-medical treatment (NPT) is usually blamed for delay in psychiatric treatment. However, it was found that households with substantial low use of NPT have also significant demand gap, i.e., TD. It means that other factors are important for demand gap. Lack of awareness about the illness, peculiar nature of illness, social stigma, ignorance and financial difficulties are some of them. Lack of awareness about mental illness is the most important reason for demand gap or TD. A majority of the sample households had discontinuation in treatment and period of discontinuation is also significant. Discontinuation, usually studied from medical point of view, is sizable and needs to be reduced in order to reduce BOD. Even though free of charge services were available in the vicinity, people did not demand and utilise them which highlights the importance of awareness about mental illness.

### **Need for two way efforts for improving services**

Summing up, efforts are necessary to reduce the supply gap or gap in supply of resources for mental health. However, considering huge deficit in resources, a steep increase in resources is not possible in the near future. Moreover, changes from the supply side alone are not adequate. There is a need to address the demand gap, i.e., delays in recognising and treating symptoms of mental illness which are significant. These demand side barriers are often historical, chronic and rooted in the culture and peculiarities of mental health issues and cannot be overcome easily. Creative and well articulated programmes should be designed and implemented which will reach people who have not sought help or whose needs are not recognised (Abramovitz, 2008).

## Appendix I

<b>Mental Health Resource Map of India</b>																					
Sl. No.	State (1)	Population (2)	Density/sq km (3)	Estimated case load (4)		Existing facilities Hospital beds (5)		Manpower resources (6)													
				Major mental disorders	Minor mental disorders	Govt. sector	Pvt. sector	Psychiatrists			Clinical psychologists			Psychiatric social workers			Psychiatric nurses			Dist. wise distribution of psychiatric facilities	
								Available	Ideal req.	Deficit	Available	Ideal req.	Deficit	Available	Ideal req.	Deficit	Available	Ideal req.	Deficit		
1.	A & N	356265	43	3562	18810	10	-	1	4	3	-	6	6	-	8	8	-	3	3	1	1
2.	Andhra Pradesh	75727541	275	757275	3766375	1020	210	180	757	577	8	865	857	3	1154	1151	Nil	123	123	NA	NA
3.	Arunachal Pradesh	1091117	13	10911	54555	10	-	1	10	9	-	15	15	-	20	20	-	1	1	1	12
4.	Assam	26638407	340	266384	1331720	500	-	29	266	237	5	450	445	1	564	563	1	50	49	23	17
5.	Bihar	82878796	880	828787	4143935	-	-	28	828	800	13	1214	1201	NA	1656	**	NA	**	**	NA	NA
6.	Chandigarh	900914	7903	9009	45045	57	-	31	9	+22 (surplus)	14	14	-	10	18	8	1	6	5	1	-
7.	Chhattisgarh	20795956	154	207959	1049795	10	3	15	207	192	1	304	303	2	414	412	-	2	2	1	15
8.	Daman & Diu, Dadra & Nagar Haveli	158059, 220451	1411, 449	3785	18925	10	-	1	4	3	-	6	6	1	8	7	4	1	+3	1	3
9.	Delhi	13782976	9294	137829	689145	329	113	155	137	+18 (surplus)	43	207	164	13	274	261	172 **	32	+140 (surplus)	7	7
10.	Goa	1343998	363	13439	77195	210	-	26	14	+12 (surplus)	2	21	19	3	28	25	2	21	19	2	-
11.	Gujarat	50596992	258	505969	2529845	853	326	97	505	408	12	753	741	12	1010	998	-	118	118	20	5
12.	Haryana	21082989	477	210829	1054145	89	98	39	210	171	2	315	313	-	420	420	1	19	18	9	10
13.	Himachal Pradesh	6077248	109	60772	303860	14	3	8	61	53	2	90	88	-	122	122	-	6	6	3	9
14.	Jharkhand	26909428	338	269094	1345470	1173	145	50	270	220	15	405	390	10	540	530	NA	135	**	3	15
15.	J & K	10069917	99	100699	503495	120	-	4	100	96	1	150	149	1	200	199	-	12	12	2	12
16.	Karnataka	52733958	275	527339	2636695	1341	1113	198	527	329	69	762	693	56	1052	996	175	245	70	18	9
17.	Kerala	31838619	819	318386	1591930	1937	1539	238	318	80	42	477	435	40	636	596	14	348	334	13	-
18.	Lakshadweep	60595	1894	605	3025	-	-	-	1	1	-	2	2	-	4	4	-	1	1	-	-
19.	MP	60388118	196	603881	3019405	592	NA	12	603	591	-	905	905	-	1206	1206	1	60	59	6	39
20.	Maharashtra	96752247	314	967522	4837610	6073	652	486	967	481	33	484	451	44	1934	1890	117	672	555	17	18
21.	Manipur	2388634	107	23886	119430	10	-	6	24	18	1	36	35	2	48	46	-	1	1	2	6
22.	Meghalaya	2306069	103	23060	115300	70	-	5	23	18	-	35	35	-	46	46	2	7	5	1	6
23.	Mizoram	891058	93	8910	44550	14	-	4	9	5	1	13	12	1	18	17	2	2	-	2	6
24.	Nagaland	1988636	120	19886	99430	25	-	5	20	15	-	30	30	-	40	40	1	3	2	3	5
25.	Orissa	36706920	236	367069	1835345	118	-	19	367	348	5	550	545	1	734	733	-	11	11	4	26
26.	Pondicherry	973829	2029	9738	48690	44	20	15	10	+5 (surplus)	1	5	14	13	20	7	20	7	-(+13)	4 (surplus)	-



Table Continued...

i	ii	iii	iv	v	vi	vii	viii	ix	x	xi	xii	xiii	xiv	xv	xvi	xvii	xviii	xix	xx	xxi	xxii
27.	Punjab	24289296	482	242892	1114460	580	267	89	242	153	18	363	345	21	484	463	10	85	75	11	6
28.	Rajasthan	56473122	165	564731	2823655	627	110	75	565	490	12	798	786	4	1130	1126	-	74	74	16	16
29.	Sikkim	540493	78	5404	27020	20	12	2	5	3	-	7	7	-	10	10	-	3	3	2	2
30.	Tamil Nadu	62110839	478	621108	3105540	1800	NA	262	621	359	7	910	903	21	1242	1221	-	180	180	30	-
31.	Tripura	3191168	304	31911	159555	16	-	9	31	22	-	45	45	-	62	62	-	2	2	1	3
32.	Uttaranchal	8479562	159	84795	423975	-	-	6	84	78	-	126	126	-	168	168	-	-	-	1	12
33.	Uttar Pradesh	66052859	689	1660528	8302640	1750	275	115	1660	1545	20	2490	2470	35	3320	3285	-	202	202	10	60
34.	West Bengal	80221171	904	802211	4011055	1471	210	83	802	719	28	1204	1176	-	1604	1604	4400*	1604	+4258 (surplus)	20	-
	<b>Grand Total</b>			<b>10270165</b>	<b>51251625</b>	<b>20893</b>	<b>5096</b>	<b>2219</b>	<b>9696</b>	<b>7477</b>	<b>343</b>	<b>13259</b>	<b>12926</b>	<b>290</b>	<b>19064</b>	<b>17118</b>	<b>** (6527)</b>	<b>4036</b>	<b>**</b>	<b>219</b>	<b>311</b>

Notes

\* Figures unreliable: Nurses with some psychiatric training but without a Diploma in Psychiatric Nursing (DPN) appear to have been included.

\*\* Figures unreliable

**Column 2.** The population figures have been taken from the Census of India-2001 as published in **Provisional Population Totals** (Registrar General Census Commissioner, India).

**Column 3.** Population density per square kilometre together with geographical terrain is a useful input in planning deployment of mental health resources.

**Column 4.** Case-load in respect to major mental disorders has been calculated at the rate of 1% of the population and that of minor mental disorders at the rate of 5% of population.

**Column 6.** (a) While the exact requirements of mental health personnel have not been definitively prescribed, the ideal required number of mental health professionals has been calculated as under:

Psychiatrists: 1.0 per 100,000 population                      Clinical Psychologists: 1.5 per 100,000 population  
 Psychiatric Social Workers: 2.0 per 100,000 population      Psychiatric Nurses: 1.0 per 10 psychiatric beds

(b) District-wise data in respect of psychiatric facilities are not available for the states of Andhra Pradesh (total districts—23) and Bihar (total districts—40).

Total number of psychiatrists trained in the country during 2000-2001

Qualification	Male	Female	Total
MD	36	9	45
DPM	15	6	21
<b>Grand Total</b>			<b>66</b>

**Source:** National Survey of Mental Health Resources carried out by the Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India, during May and July 2002 in Goel et al, 2004, pp.15.

## Appendix II

### Reasons for investing in mental health

Promote human rights and inclusion	Reduce the human impact of mental health	Prevent premature death	Reduce the economic costs to society	Reduce poverty and social disadvantage	Put knowledge of cost effective treatments into practice
<p>People with mental health problems are more likely than others to experience social exclusion, violent victimization and human rights abuse.</p> <p>Access to evidence-based treatment and care would have a direct positive impact and would greatly promote human rights and the chances of recovery and inclusion.</p>	<p>There is no health without mental health. Mental health problems lead to extremely distressing symptoms for the affected person and burden for family members. In addition, they are closely associated with physical health problems.</p> <p>There is a high level of co-existence of non-communicable diseases and mental health problems which compromise treatment and prevention efforts.</p>	<p>People with severe mental health problems die up to 20 years earlier than people without mental health problems, even in high-income countries.</p> <p>Excess mortality is due to suicide, unhealthy lifestyles such as high smoking rates, poor physical health, and poorer physical healthcare for people with mental health problems.</p>	<p>In 2010, the global economic costs of mental health problems were estimated at US\$2.5 trillion and are projected to rise sharply to US\$6.0 trillion by 2030.</p> <p>Around two-thirds of these costs are related to lost productivity and income - the consequences of untreated mental health problems.</p>	<p>Poverty, social disadvantage and mental health problems are intimately related to one another.</p> <p>Mental health interventions can help improve the social and economic well-being of people affected by mental health problems.</p>	<p>The treatment of mental health problems is as cost effective as other health treatments such as antiretroviral treatment for HIV/AIDS.</p> <p>The returns on investments in mental health are considerable. Every US\$1 spent on programs such as early intervention for psychosis, suicide prevention and conduct disorder leads to a benefit or cost saving of US\$10.</p>

(Source: Patel and Saxena 2013, p,7-8)

## Appendix III

### Mental Health Problems

Mental health problem	Description	Life course stage
Developmental disorders	A group of conditions characterized by impairments in intellectual, movement, sensory, social, or communication abilities (e.g., autism, intellectual disability and cerebral palsy).	Infancy onwards
Anxiety disorders	A group of conditions featuring excessive worrying, tension and fear, and physical symptoms such as palpitations, headaches and	Childhood onwards
Child behavioural disorders	A group of conditions characterized by impairments of attention and disruptive behaviour (e.g., attention deficit hyperactivity	Childhood onwards
Alcohol use problems	A group of conditions characterized by the consumption of alcoholic drinks to the level of causing harm to the person's health and social/personal relationships.	Adolescence onwards
Depression	A condition characterized by low mood, loss of interest and enjoyment, fatigue and reduced energy, and sleep and appetite disturbances.	Adolescence onwards
Drug use problems	A group of conditions characterized by regular use of substances such as opioids, sedatives or cocaine causing harm to the person's health and social/personal relationships.	Adolescence onwards
Self-harm and suicide	Intentional self-inflicted poisoning or injury which may lead to death.	Adolescence onwards
Schizophrenia	A condition characterized by distortions of thinking and perception (e.g, hallucinations and delusions), behavioural abnormalities and emotional disturbance.	Adolescence onwards
Bipolar disorder	A condition characterized by episodes of elevated or lowered mood and activity levels, often with complete recovery between episodes.	Adults
Dementia	A condition characterized by a progressive deterioration in mental functions, such as memory and orientation, leading to behavioural problems and loss of the ability to care for oneself and, ultimately death.	Late life
<p>This list of mental health problems is based on those prioritized in the World Health Organization mhGAP Intervention Guide for Mental, Neurological and Substance Use Disorders in Non-Specialized Health Settings. 2010, Geneva: Switzerland.</p>		

**Source:** (Patel and Saxena, 2013,p,40)

## Appendix IV

<b>Difference in physical illness and mental illness</b>		
	<b>Physical illness</b>	<b>Mental illness</b>
1	Symptoms are mostly visible. There may be a group of symptoms but each distinct from the other.	Invariably symptoms are of invisible nature. Cluster of symptoms which, many times, being concurrent with others, diagnosis takes time and becomes difficult which, in turn, lengthens treatment.
2	Tests are available for diagnosis and for understanding changes in progression	Objective tests for diagnosis and for course of progression are not available. Thus diagnosis being primarily subjective, it can vary from doctor to doctor. This leads to greater stress & frustration for the shubharthi and the shubhankars.
3	Much information about these illnesses is available not only with the doctors but also is available in the public domain (print, media ).	Very little information is available even with the new doctors and much less in the public domain for the families. Families have to rely on psychiatrists.
4	Working and malfunctioning in the physical illness is well understood by the medical science	Working and malfunctioning of the brain and nervous system are still in exploratory/research stages even for the medical scientists.
5	Effective treatments are available more widespread and with various options to the patients.	Effective treatments are not available for various reasons such as * diagnosis is delayed because of overlooking initial warning signs by families * acute shortage of whole range of MH professionals in towns/cities & non-availability in rural areas * non-accessibility to medicines in rural areas * ignorance about MH issues at the family level.
6	Variety of treatments (medicines/non medicines) having varying side effects, recovery period, duration of effect are available	Treatment options backed with hospitalisation are very limited. E.g. hospitals treating MI with homoeo-pathic/ayurvedic/unani are almost non-existent. So in acute state, treatment to allopathic has to be switched & face consequences.
7	Substantial research has been done with significant breakthrough in anatomy, physiology and pharmacology of the illness	Comparatively limited research in different aspects of mental illness seems to have been done.
8	Effective treatments are available for last several decades	Effective treatments are available, relatively in recent times.
9	Premature mortality is possible in major/complicated illnesses/accidents.	Premature mortality is a possibility in small percentage of suicidal cases.

Table Contd...

10	Due to spread of knowledge and visible nature of illness, self-stigma is not a problem. At times, others may come forward to help e.g.rushing to help a person with crutches to cross the road/offer a seat in a bus.	Due to misunderstanding and myths, society have stigma towards MI, which acts as a barrier towards availing treatment. Also in case of an emergency, hardly anyone will come forward to help for fear of violence by mentally ill.
11	Affected persons of chronic illnesses and disabilities receive sympathy and help	Due to invisible nature and other factors affected persons may be avoided or teased or ridiculed.
12	Services –govt. Or private are being developed for last several decades.	Due to limited knowledge and effective treatments; services-govt. Or private are much below the huge requirement in the society.
13	HH have higher response rate(in availing services) to the needs of PMI	HHs have lower response rate(in availing services) due to several barriers

## Appendix V

<b>Difference in New and Veteran caregivers</b>		
	<b>New caregivers</b>	<b>Veteran caregivers</b>
1	Limited or no knowledge about the illness/symptoms and future course. Hence likely to give incomplete/incorrect information	Significant knowledge. Well informed. Hence likely to give adequate/accurate amount of information.
2	Since, still novice, are likely to experience emotional problems during the interview, affecting quality of feedback	Long experience of illness has made them tough, even being sensitive to the problem. Can share personal information not only without hesitation but will appreciate how their sharing Can help the cause of MI persons/their families.
3	Relatively young in age i.e in forty's or early fifty's.	Senior in age. In their sixty's or seventy's. Because of high costs of treatment male caregivers have to go out to earn while caregiving becomes the responsibility of female relatives. Consequently, if the lady caregivers are less educated/read, they may not realise value of sharing for this survey.
4	Factors like social stigma and one's own stigma are dominant	Due to years of experience, CGs have adjusted to feeling/handling issues of stigma
5	Treatment, medicines are changing.	Treatment, medicines have reached stability for last several years.
6	PMI is still in active age. CGs are hoping to experience full recovery and return to normal life.	PMI is at a advanced age and CGs are aiming for objective of independent living of PMI or lifelong residential care

Codebook					
Variable	Code	Variable	Code	Variable	Code
<b>PT Current Age</b>		<b>PT Occupation Group</b>		<b>MRD Upto 12 Mon.&amp;above</b>	
1 to 25	0	Unemployed	0	Upto 12 Months	0
26 to 35	1	Lesser Public Contact	1	13 Months & above	1
36+	2	Greater Public Contact	2	<b>MNPT Zero &amp; Above</b>	
<b>CG Sex</b>		<b>CG Occupation Group</b>		No NPT	0
Female	0	Unemployed	0	1 & above	1
Male	1	Lesser Public Contact	1	<b>MNPT Upto 3 Mon.&amp;above</b>	
<b>PT Sex</b>		Greater Public Contact	2	Up to 3 Months	0
Female	0	<b>Family Income</b>		4 Months & above	1
Male	1	Up to 5000	0	<b>MNPT Upto 6 Mon.&amp;above</b>	
<b>Marital Status</b>		5001 to 10000	1	Up to 6 Months	0
Unmarried	0	10001+	2	7 Months & above	1
All Others	1	<b>Diagnosis</b>		<b>MNPT Upto 12 Mon.&amp;above</b>	
<b>Religion</b>		Schizophrenia	0	Upto 12 Months	0
Hindu	0	All Others	1	13 Months & above	1
All Others	1	<b>Age Begin. Sym.</b>		<b>District</b>	
<b>Caste</b>		1 to 25	0	Pune	1
SC	0	26 to 35	1	Ahmednagar	2
All Others	1	36+	2	Beed	3
<b>Type of Family</b>		<b>FT District Pune &amp; Else</b>		Aurangabad	4
Nuclear	0	Pune	0	Jalna	5
Joint	1	Else	1	Latur	6
<b>PT Education</b>		<b>FT District</b>		Parbhani	7
No Education	0	Pune	0	Nanded	8
1st to 4 <sup>th</sup>	1	Adjoining Pune	1	Usmanabad	9
5th to 10 <sup>th</sup>	2	All Others	2	Solapur	10
11+	3	<b>Distance</b>		Satara	11
<b>CG Education</b>		0 km to 50 km	0	Sangli	12
No Education	0	51 km to 100 km	1	Nasik	13
1st to 4 <sup>th</sup>	1	101+ km	2	Buldhana	14
5th to 10 <sup>th</sup>	2	<b>Place of Residence</b>		Mumbai	15
11+	3	Urban	0	Others	16
<b>Relation with Patient</b>		Rural	1		
Father & Mother	0	<b>MRD Zero &amp; Above</b>			
All Others	1	No MRD	0		
<b>YFT B&amp;A 2000</b>		1 & above	1		
Before 2000	0	<b>MRD Upto 3 Mon.&amp;above</b>			
After 2000	1	Up to 3 Months	0		
<b>PT Occupation</b>		4 Months & above	1		
Unemployed	0	<b>MRD Upto 6 Mon.&amp;above</b>			
All Others	1	Up to 6 Months	0		
<b>CG Occupation</b>		7 Months & above	1		
Unemployed	0				
All Others	1				

## Appendix VII

Respondent No-
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### Questionnaire for Primary Caregiver of Person with mental illness.

Name of the Interviewer:

Place:

Date:

1		Background Information about the family
1.1	<b>Religion</b>	Hindu -----1 Muslim-----2 Christian-----3 Sikh-----4 Buddhist/Neo Buddhist---5 Jain-----6 Others-----7 -----Specify-----
1.2	<b>Caste</b>	SC-----1 ST-----2 NT-----3 OBC-----4 OPEN-----5 Others—(specify)-----6
1.3	<b>Type of family</b> (At the time of Beginning of Illness-BOI and current)	BOI- Joint ---1,Nuclear --2 Current: Joint ---1,Nuclear ---2
1.4	<b>No of members in the family</b> (At the time of Beginning of Illness-BOI and current)	BOI- Current:

2		Information about primary caregiver and patient							
		Name	Relations With the patient	Age	Sex M/ F	Marital status	Education and qualification	Occupation	Income of the family
2.1	Information about primary care giver								
2.2	Information about the patient								
<p><b>Codes for occupation-</b>1.Cultivator (large farmer) 2.cultivator (small/marginal farmer), 3.Agricultural labourer, 4. Non-agricultural labourer, 5. Government service, 6. Private Service, 7. Business, 8. Self-employed 9. Pensioner, 10. Home maker, 11.Others (specify).</p>									

**Age & Education** in completed number of years.



## पालकांसाठी अनुमती पत्र

प्रिय सहभागी,

आपण आपल्या कुटूंबातील जाणकार अशा व्यक्ती आहात. आम्हाला आमच्या सर्वेक्षणासाठी आपली मुलाखत घ्यावयाची आहे. हे सर्वेक्षण विद्यावचस्पती (Ph.D) या पदवीसाठी आवश्यक असणाऱ्या संशोधनासाठी असून 'गोखले अर्थशास्त्र संस्थे'मध्ये या विद्यार्थ्याची नोंदणी झाली आहे. ही मुलाखत प्रशिक्षित मुलाखतकर्त्याकडून घेतली जाईल. या मुलाखतीसाठी साधारणपणे 45 मिनिटे ते 1 तास लागेल.

तुम्हाला जे प्रश्न विचारले जातील त्याचे स्वरूप खालीलप्रमाणे असेल –

1. तुमच्या कुटूंबातील सदस्यांची सामाजिक आर्थिक इ. माहिती
2. मानसिक आजार (अथवा शारीरिक आजार) यांच्या उपचारांविषयी आपण घेतलेले निर्णय आणि हे निर्णय घेताना त्यावर प्रभाव पाडणारे घटक

आपण जी माहिती द्याल त्याचा उपयोग कुटूंबाचे आरोग्यविषयक अग्रक्रम कसे असतात आणि आरोग्यावर खर्च कसा केला जातो हे समजून घेण्यासाठी होणार आहे. आपण देत असलेली माहिती गोपनीय ठेवली जाईल आणि इतर कोणालाही ती उपलब्ध होणार नाही. आपण देत असलेल्या माहितीचा उपयोग फक्त संशोधनाच्या कामासाठी केला जाईल. आपले नाव, पत्ता आणि इतर व्यक्तिगत माहिती प्रश्नावलीतून काढून टाकली जाईल आणि तुमचे नाव व उत्तर दर्शविण्याकरिता कोड नंबरचा वापर केला जाईल. आपली मुलाखत पूर्ण होण्यासाठी अत्यंत आवश्यक असेल तरच किंवा अधिक माहितीसाठी भविष्यात आपल्याशी संपर्क साधला जाईल.

या सर्वेक्षणातील आपला सहभाग पूर्णपणे ऐच्छिक असेल आणि मुलाखतीस सुरुवात झाल्यानंतर केव्हाही आपण आपला सहभाग काढून घेऊ शकाल. प्रश्नावलीतील कोणत्या प्रश्नांना उत्तर द्यायचे अथवा नाही याचे पूर्ण स्वातंत्र्य आपल्याला असेल. या सर्वेक्षणाविषयी आपणाला कोणतीही शंका असेल तर आपण माझ्याशी संपर्क साधू शकता. (अनिल वर्तक [avartak@yahoo.com](mailto:avartak@yahoo.com), 020-24483650(R) & 9503710859 (M))

3	<b>We are going to ask you questions that are related to several years in (Name)'s past life. You can take time to answer each question. If you remember anything later, do not hesitate to bring it to our notice. Now, we would like to ask you about the psychiatric treatment that (name) is taking currently (past).</b>	
3.1	Is/was (name) taking psychiatric treatment for mental illness?	
3.2	What is the nature of the current (last) treatment?	Medication .....A Counselling.....B Day care centre.....C Hospitalisation.....D ECT.....F Any other (Specify).....

3.3	What is the name of the treating doctor?	
3.4	Will you specify his/her diagnosis?	
3.5	How long is he/she taking this treatment at this center?	
3.6	What is the frequency of your visit to the treatment centre?	
3.7	How much on an average you have to spend per month on this treatment (out of pocket)?	Items of cost
		Consultation charges
		Medication
		Transport
		Total expenses
		Any other (specify)

<b>4 (Name) is taking treatment for psychiatric problems for some time. We will like to know about his/her journey towards psychiatric treatment. First, we will like to know your experience of treatments other than psychiatric treatment. If he/she has not taken any treatment other than psychiatric treatment, then please go to next section.</b>			
<b>4.1</b>		<b>Nature of Intervention (treatment)</b>	<b>Additional information</b>
	Did you give (name) any other treatments?*,**	Tantric/mantric/tradioanl herbal treatment (vaidu)/fortune teller/spiritual persons/any other.....1  Medical treatment from other pathies- ayurvedic/ homelpathy/unani/any other.....2  Alternative treatment –naturopathy/massage /panchkarma/yoga/meditation/any other....3  Any other (Specify).....	
	When was this treatment given for the first	Year .....and month .....	
	How long was this treatment given ?	Year .....and month .....	
	What symptoms caused the decision to take this treatment?	Odd behaviour .....A  Discontinuation of education or job.....B  Troublesome at home and to others.....C  Violent behaviour.....D  Physical problem.....E  Any other (specify).....	
	Was the treatment given for physical problem or mental problem? Give details.		

	What was the problem that		
	Distance from residence?  NPT ----  District  place --		
	How old was (name) then?		
	What was his/her education then?		
	How did (name) occupy himself/herself then?		
	What was his income then?		
	Did anyone suggest to give this treatment?	Suggestion from Family member/community leaders.....A  Patient.....B	
	Why do you think that the decision to follow that suggestion was taken?	We have faith in it .....A  Due to personal experience.....B  Stigma.....C  Non acceptance by the patient.....D  Will be of help.....E  Available in the vicinity.....F	
	How will you compare these expenses of the past to expenses on treatment by other service providers?	<b>Treatment at YMH(VsV NPT)</b> --Very high/high/almost same/lower/much lower  <b>Treatment at Private Trt. Centre (VsV NPT)</b> --Very high/high/almost same/lower/much lower	

*\*If you have given any other treatment even after or along with psychiatric treatment, fill this section.  
 \*\* (if there is more than one treatment or overlapping treatment then pl. give the details of each treatment  
 Separately in the order in which they were taken*

**Recognition delay, (consultation delay) and treatment delay**

5	<b>For treating someone with mental illness, it is necessary for families to recognise early the symptoms of mental illness in the patient. Now, we would like to ask you some questions about how you recognised that these symptoms are related to psychiatric problem.</b>	
5.1	What is the nature of the current (last) treatment?	Medication.....A Counselling.....B Day care centre.....C Hospitalisation.....D ECT.....E Any other
5.2	When was the psychiatric treatment started for the first time?	Year ..... and month ...
	What was the distance from your place of residence?	
5.3	What symptoms caused decision to give this treatment?	Odd behaviour .....A Discontinuation of education or job ...B Troublesome at home and to others ...C Violent behavior .....D Other treatments did not work .....E Let us try this one .....F Aggrevation of the symptoms .....G Any other (specify).....H
5.4	Now, when you look back, do you think that (name) 's symptoms/problem has started even before you started any treatment (Psychiatric treatment or non-psychiatric) for the first time?	Yes .....1 No .....2
5.5	If yes, how much time did it take? If no, then proceed to next question.	Years..... and months.....
5.6	What may be the explanation for time taken to recognise that something is wrong?	Lack of information .....A  Thought that this is a physical problem/ some other problem .....B  Thought that this is a problem in the development phase of the patient .....C  Thought .....due to addiction .....D  Thought ..... due to shocking incident .. E  Any other .....H

5.7	Do you think it took some time for you to consult someone even after recognising that something is wrong with (name)?	Yes.....1 No.....2
5.8	If yes, how much time did it take?  If no, go to next question.	Years..... and months.....
5.9	Do you think there are reasons for not consulting any one immediately?  Give details.	Confusion due to myths-(since when, what was the nature of myth) ..... A  Could not decide ..... B  Did not know where to go .....C  Lack of cooperation from the patient (any specific event) .....E  Thought will-self help .....F  Services were not available in the vicinity .....G  Feeling of stigma- to the patient, to the family members (since when, any specific event/opinion ) .....H  Any other reason. (Specify) .....
5.10	Do you think that it took some time for you to start treatment (or routinely) even after consulting someone?	
5.11	How much time did it take?	Year ..... and month .....
5.12	Do you think there are reasons for not starting treatment immediately? What are those reasons?	Feeling Stigma (to the family members, patient) .....A  Did not know where to go .....B  Services were not available .....C  Thought/found that treatment is expensive .....D  Thought treatment will be of no use.....E  Thought patient will improve over time .....F  Any other .....
5.13	Will you specify your overall experience of delay in receiving treatment?	

**Discontinuation of the treatment –**

6	<b>Discontinuation of treatment is a common phenomenon in mental illness. Several reasons are given by families. Now, we would like to know about your experience of discontinuation of treatment.</b>		
6.1	After starting initial treatment, were their instances of discontinuation of the treatment?		
6.2	Which was the first instance?	Year ....and month....	
6.3	How did (name) occupy him/her self then?		
6.4	Why do you think that treatment was discontinued?	Side effects.....A Expensive treatment.....B No improvement from the treatment.....C Lack of cooperation from the patient.....D Any other .....E	
6.5	When did you start treatment again?	Month..... and year.....	
6.6	Do you think someone suggested you to start treatment?		
6.7	Were there symptoms due to which did you start treatment again?	Aggressive behaviour from the patient.....A Cooperation from the patient...B Uneasiness of the patient .....C Eruption of the symptoms.....B Deterioration in his/her condition Any other .....D	

7	<b>Sometimes patient has to undergo treatment other than pharmacological treatments. Now, we will like to ask you, your experience of such treatments. If (name) has not taken any such treatment then go to next section.</b>
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<b>7.1</b>	Which are the other treatments that were suggested to you earlier by your psychiatrist?(or you came to know about it through other sources) If answer is no, then go to next section.	Day care.....A ECT.....B Hospitalisation.....C long stay home.....D Any other.(specify).....
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<b>7.2</b>	If have not availed it or with significant delay what are the reasons for it?				
Treatment 1	Reasons for not availing or delay in it	Treatment 2	Reasons for not availing or delay	Treatment 3	Reasons for not availing or delay in it
	No available in the vicinity.....A Do not know where it is .....B Expenses were too high .....C Patient was not violent. Hence, thought that it is not necessary .....D Patient was not ready to come .....E Stigma- what others will think .....F Nobody was there to accompany him/her .....G B Thought, it will not be of help .....H Thought he will improve over time ..I Any other		No available in the Vicinity .....A Do not know where it is .....B Expenses were too high .....C Patient was not violent. Hence, thought that it is not necessary.....D Patient was not ready to come .....E Stigma- what others will think.....F Nobody was there to accompany him/her.....G Thought, it will not be of help.....H Thought he will improve over time ..I Any other		No available in the Vicinity .....A Do not know where it is .....B Expenses were too high.....C Patient was not violent. Hence, thought that it is not necessary.....D Patient was not ready to come .....E Stigma- what others will think.....F Nobody was there to accompany him/her.....G Thought, it will not be of help.....H Thought he will improve over time..I Any other

<b>8</b>	<b>Sometime patient or someone in the family may have undergone treatment for chronic physical illness like TB, Ashtama or any other. We will like to ask you questions about it. If your answer is yes, then go to next question. Otherwise go to next section.</b>		
8.1		Information about (name )	Information about other family members
8.2	Who was affected by any chronic illness?	Name .....	Name .....
8.3	What was the illness?		

8.4	Can you tell when did you start treatment for this disease?	Year ..... and month...	Year ..... and month...
8.5	What was the nature of treatment? Give details.	Pharmacological treatment.....A Surgery.....B Any other treatment. (specify).....	Pharmacological treatment.....A Surgery.....B Any other treatment. (specify).....

8.6	How did you come to know about (name)'s illness?		
8.7	What were the symptoms of it? Give details.		
8.8	How old was he/she then?		
8.9	How did he/she occupy himself/herself?		
8.10	What was his/her income then?		
8.11	Is(was)he/she taking continuous treatment since then? If yes, then go to 12.		
8.12	Has the treatment been terminated as per the advice of treating physician? If yes, then go to 12.		
8.13	Was it discontinued for some time?		
8.14	How many times and how long?		
8.15	Is (name) suffering from this illness even now?		
8.16	What is the nature of treatment and how frequently (name) has to take it?		
8.17	How much do you have to spend per month?		
8.18	Do you think that it is significant expenditure for you?	Significant/moderate/insignificant	Significant/moderate/insignificant
8.19	Do you think that there was any delay in recognition of symptoms?		
8.20	How long was the delay?	Years..... And months .....	Years..... And months .....
8.21	If yes, what is the reason?		



8.22	Do you think that there was delay in consultation and treatment of the (name)'s physical illness?		
8.23	How long was the delay?	Years..... And months .....	Years..... And months .....

8.24	If yes, what are the reasons for that?		
8.25	Do you think that, you have given treatment for physical illness much timely as compared to treatment for mental illnesses?		
8.26	If yes, what factors might have contributed such decision?	Visible illness .....A Effective treatment is available .....B Absence of stigma.....C Acceptance of the illness by the patient.....D Pain to the patient .....E Cooperation from the patient.....F Quick recovery is possible .....G Any other.....	Visible illness .....A Effective treatment is available .....B Absence of stigma.....C Acceptance of the illness by the patient.....D Pain to the patient.....E Cooperation from the patient.....F Quick recovery is possible .....G Any other.....

<b>9</b>	<b>You have taken treatment for physical illness and mental illness and you have experienced barriers while taking treatment for each of the illness. Now, we will like to ask you questions about these barriers.</b>	
<b>9.1</b>	Now, we will like to know from you –how will you differentiate between nature and treatment of physical illness as well as that of mental illness.	
<b>9.2</b>	How do you compare barriers -while recognising and availing treatment for mental illness Vis a vis physical illness? Pl. substantiate your argument.	
<b>9.3</b>	What measures will you suggest to do away with these barriers? Pl. suggest measures barrier wise.	

Name:-		Address :-	
Contact No.			

## Appendix VIII

### Interview Guide for Veteran Caregivers<sup>1</sup> at YMH

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How do caregivers (CG) understand or conceptualise mental illness (MI)?

How do CGs come to know about the mental illness of their family member?

What are the symptoms of MI?

What are the symptoms which generally make CG realise that there is some problem?

What is their reaction once they notice symptoms?

What are the symptoms that CG generally find alarming? Do they understand gravity of the symptoms?

How much time is passed in recognising symptoms as mental illness since its onset?

Do they consult someone once they think that symptoms are alarming? Who are these persons?

How much time do they spend once they notice symptoms till consultation or treatment?

What is the advice usually do they get?

How do they work on it? What is their response? What action do they take?

What are the pathways patients usually follow before reaching a psychiatrist?

Do they find relief during Non-psychiatric treatment? Do they continue with such treatment? How long?

How much time do they spend to initiate psychiatric treatment once they notice symptoms?

Do you think that this pattern is same across all socio economic and demographic groups?

Do people with different socio/eco./demographic back ground show change in such pattern?

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<sup>1</sup> A veteran caregiver is a caregiver who is not only informed by MI of his/her family member but due to his/her experience, education and overall alertness have enough knowledge to talk about conditions of PMI in general, pathways that PMI take before taking psychiatric treatment and delay in the process.

## **Appendix IX**

### **Interview Guide for staff at YMH**

How many patients visit OPD of YMH per day and per month?

What is socio-economic and demographic background of such people?

What is social background of these people? Caste/religion/family type

What is the economic back ground of these people? income group/ occupation/type of farmer?

What is demographic background of such people? District/distance

How do they conceptualise mental illness?

What is idea of mental illness of patients and caregivers?

How do people come to know about their mental illness?

What are the symptoms which generally make people realise that here is some problem?

What do they do before such symptoms become visible?

What is their reaction once they notice such symptoms?

Do they understand gravity of the symptoms?

Do they consult some one? Who are these persons?

What is the advice usually do they get?

How do they work on it? What is their response? What action do they take?

What are their pathways?

Do they find relief? Do they continue with such treatment?

How much time do they spend once they notice symptoms till consultation or treatment?

Do you think this pattern is same across all socio economic and demographic groups?

Do people with different socio/eco./demographic back ground show change in such pattern?

## **Appendix X (10.1)**

### **Mental Hospitals in India**

The mental hospitals in India have evolved over time. There is a record of an institution for mentally ill patients in Muhammad Khiljis time in 15<sup>th</sup> century (Krishnamurthy, Venugopal, & Alimchandani, 2000). Prior to this, patients were kept in temple and religious places. Mental hospitals i.e. asylums, as they were called earlier, is a British conception. They were started in England to provide custodial care to patients in 16<sup>th</sup> century. The first asylum in India was started in Calcutta in 1787 called as lunatic asylum. In India, these asylums were started mainly for European soldiers posted in India at that time. European and Indian patients were segregated in separate wards or institutions (Krishnamurthy, Venugopal, & Alimchandani, 2000; Weiss, 1983). The purpose of these hospitals was to separate mentally ill persons from mainstream society. There were hardly any medicines and treatment that was given was basically of opium, hot baths, leeches to suck blood and sometimes music to calm patients down (ibid).

In 1858 Lunacy Act was passed which provided guidelines for establishment of asylums and admission procedure. From 20<sup>th</sup> century onwards, development of mental hospitals started from a humanitarian angle. Hospitals which were under inspector general of Police were now put under charge of civil sergeant (Banerjee, 2001). During two wars, efforts were to made raise the standard of treatment and care. During this period, asylums were renamed as mental hospitals. The importance of occupational therapy and rehabilitation received importance gradually. Bhore Committee which was set up in 1946 surveyed all the hospitals and gave several suggestions for improvement. From 1947 onwards, number of hospitals increase and in 2008 their number was 37 (NHRC and NIMHANS, 2008) Conditions prevailing in mental hospitals deteriorated over time due to inadequate resources, inadequate staff and general neglect towards mental health.

The available beds in all hospitals in India are 26,989 (20,893 in government and 5096 in private hospitals). In India, psychiatric beds per 10,000 population is only 2.5 as compared to 3.9 in Australia, 7.7 in USA and 1.08 in China. In India, majority of these beds

i.e. 80 per cent of them are in mental hospitals rather than being in general psychiatric units, private hospitals or community based hospitals. Considering the need for long term care and hospitalizations of PMD, the availability of total beds in private and government hospital is very low.

Lack of updated infrastructure, overburdened staff and doctors, very few rehabilitation programmes, etc are the major problems faced by mental hospitals in India. Additionally, mental hospitals are stigmatized in society at large. People shudder while passing them; mental hospitals are the butt of jokes. Restricted access, high and barbed walls, lack of visibility for the outsider, secluded location in the city, contributes further to the marginal position of mental hospitals.

The first modern mental institutional care as we see it today was established in India during the colonial times. The first mental hospital was started in Calcutta in 1787. Over the years, several mental hospitals came up, yet there remains a huge gap between the capacity of public mental hospitals and the need. There exists a huge gap between number of beds available in mental hospitals and the actual requirement of inpatients. The ratio of number of psychiatrists to the total population is also disproportionate.

Human right violations are noted to occur in mental hospitals. Erwadi fire incident which happened in 2001 is an example of this. 28 inpatients of the Erwadi mental hospital died in a fire. They were chained and hence they could not escape. Later a lot of abusive practices were discovered. Human Rights Watch has noted human right violations in case of inpatients.

Several conferences, workshops were held in the last two three decades in order to improve the quality of service and human right standards in these hospitals. However, little has changed so far. NHRC 1999 and 2008 have done audit from the point of view of quality of services and human rights for all the mental health hospitals and made several suggestions to improve their functioning.

National human rights commission (1999) in their finding says -

“The findings reveal that there are predominantly two types of mental hospitals, The first type do not deserve to be called ‘hospitals’ or mental health centres. They are ‘dumping grounds’ for families to abandon their mentally ill member, for either economic reasons or a lack of understanding and awareness of mental illness. The living conditions in many of these settings are deplorable and violate an individual’s right to be treated humanely and live a life of dignity. Despite all advances in treatment, the mentally ill in these hospitals are forced to live a life of incarceration. The second kind are those that provide basic living amenities. Their role is predominantly custodial and they provide adequate food and shelter. Medical treatment is used to keep patients manageable and very little effort is made to preserve or enhance their daily living skills. These hospitals are violating the rights of mentally ill persons to appropriate treatment and rehabilitation and a right to community and family life”.

However, conditions at mental hospitals have not changed much in a decade after 1999 (NHRC and NIMHANS, 2008). A recent trend is towards deinstitutionalization of mental hospitals, admission of voluntary patients, creation of general hospital psychiatry units rather than building more mental hospitals and reliance on community based rehabilitation alternatives.

In a developing country like India, with vast majority of poor people, public mental hospitals play a crucial role in facilitating access of people to psychiatric care. Use of mental hospitals can be minimized by community based services and general hospital psychiatric units. However, for severely ill patients there is no alternative to mental hospitals. Hence, efforts are necessary to improve their functioning (Krishnamurthy, Venugopal, & Alimchandani, 2000).

## **Appendix X (10.2)**

### **Yerawada Mental Hospital**

Yerawada mental hospital, Pune, is one of the oldest mental hospitals in India. This hospital which was originally established in Colaba in 1889 was shifted to Yerawada, Pune in 1915. Currently it has a capacity of 2400 beds, 1400 for men and 1000 for women.

YMH has very huge campus. YMH, which was located on the outskirts of Pune and near prison, now, due to growth of the city, is a very much part of the city and surrounded by tall software companies. Hospital buildings and other infrastructure is very old and maintenance of building and campus is very poor. YMH has shortages of staff especially in the category of psychiatrists. The hospital receives patients from several districts – Pune, Ahmednagar, Nashik, Satara, Kolhapur, Beed, Jalna, Nanded, Usmanabad, Latur and even from districts outside Maharashtra.

Mental hospitals, due to their inferior conditions, command fear and stigma by lay people. Patients in general or caregivers do not want to visit or utilise services at mental hospitals unless they do not have any option to do so. The researcher due to his work with an NGO had prior contact with YMH. Some of the awareness programs were conducted in YMH in which the researcher took part. However, the students who assisted the researcher in collection of data were under tension due to lack of information and myths about mental illness and mentally ill persons. However, after their first visit their fear subsided and realised that patients are not harmful or violent as it is understood by lay people. They were comfortable in collecting data from caregivers and patients.



## **Appendix X (10.3)**

### **Debates in Mental Health – Positions and Assumptions of the Researcher**

The topic for this PhD thesis stems from my long term academic and activist interests: economics and mental health. I have been an activist in the field of mental health for two decades now, working closely with users, families, psychiatrists and other professionals. Diversity of experiences and reflecting on them have led me to have my own takes on two important debates in mental health i.e. role of family and psychiatry.

Position on the role of the family:

As notes Srinivasan, there are three categories of mental illness patients/users in India: those in or requiring institutional care, those in family care and those on the road i.e. the homeless and hence not on treatment. Majority of the users are within family care. Community care is almost absent, and is extremely expensive. Across categories, even for patients in institutional care, those availing psychiatric treatment in private or public hospitals and clinics and even those who are availing NPT or no treatment at all, family plays an important role in caring, supporting emotionally as well as financially. Family becomes the safety net for the patient.

Thus India, where social security is absent and disabled being a marginalized community, public expenditure is very low and there are hardly any community care centres. Hence, the responsibility of the giving care as well as support lies on the family. Their concern for patients is almost round the clock. One leading caregiver's organisation in India has made an apt comment "Family is the 24X7 care provider. More than 90 per cent of mentally challenged patients live in their families (Srinivasan, 2015)

Users may take help from professionals but for other forms of care i.e., domestic care, rehabilitation care and emergency care, family is the only source to rely upon. In India, family support is the backbone for the users. Thara, Padmavati, & Srinivasan(2004) says

“...This underscores the importance of cultural, social and family factors in service utilisation. In a country like India it is not easy or appropriate for a health care service to bypass the family to reach the potential patient; the family may have to be persuaded first of the need for treatment. More positively, however, this situation reflects the intrinsic coping style of the community and the family in dealing with disability, which may contribute to the better outcome of treated schizophrenia in India”

Care giving by families is recognized at different levels-individuals, professionals and policy makers. National Mental Health Programme of India seeks to deliver mental health care through community based approaches. This programme is based on premises that the locus of care, for persons with serious mental illness, will continue to be natural kin network. The report further says “In India community care often translates in to care by the family”. However, this is not to say that one can glorify the family. In many instances family is the site of coercion, violence, forced institutionalization or even the cause of neglect and ignorance, taking decisions detrimental to the patients’ interests. This has led many activists in India and elsewhere to argue for an individual based approach, for individual rights in decision making. The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) can be taken as a case in point. Advocacy activists in mental health are arguing individual rights to supersede the rights of the family.

My personal position is that in the Indian context family plays an indispensable role in care of the patient. The State is not equipped and will not be equipped in the near future to fully provide for patients’ needs. Instead of attempting to weaken the role of the family, we must recognize its contributions. Rather than aiming to delink the individual from the family, we must try to strengthen the relation of patient, family vis a vis psychiatric care.

Patients, policies, care are contextual. Context needs to be understood for effective policy design and implementation. The immediate context of the patients is family. They are embedded in the values, practices of familial relations. To be effective in terms of reach and use, policies targeted at users, should be targeted towards the family. Caregivers rights cannot be compromised on.

### **Position on psychiatric treatment:**

In the field of mental health, an important debate is on psychiatric treatment itself. Psychiatric drugs have severe side effects and with little guarantee of results. Anti-psychiatry movement has evolved over the last century being particularly strong in the 1960s and the 70s. Psychiatry is seen as oppressive and a tool to repress and subjugate patients. It is seen to create unequal relationship of power between patients and doctors, between 'normal' people and those requiring psychiatric treatment. This line of thinking continues even today, and there are people who oppose psychiatric treatment on these grounds, and valorise non psychiatric treatment.

However, I hold the view that NPT cannot be a substitute for psychiatric treatment. Some forms of NPT can be complementary to PT, but not a substitute. In spite of the side effects, psychiatric treatment does help the patient and set him/her on the path to recovery. This is the underlying assumption of the thesis: that there is no alternative for psychiatric care.

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