

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 lead 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).