

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.

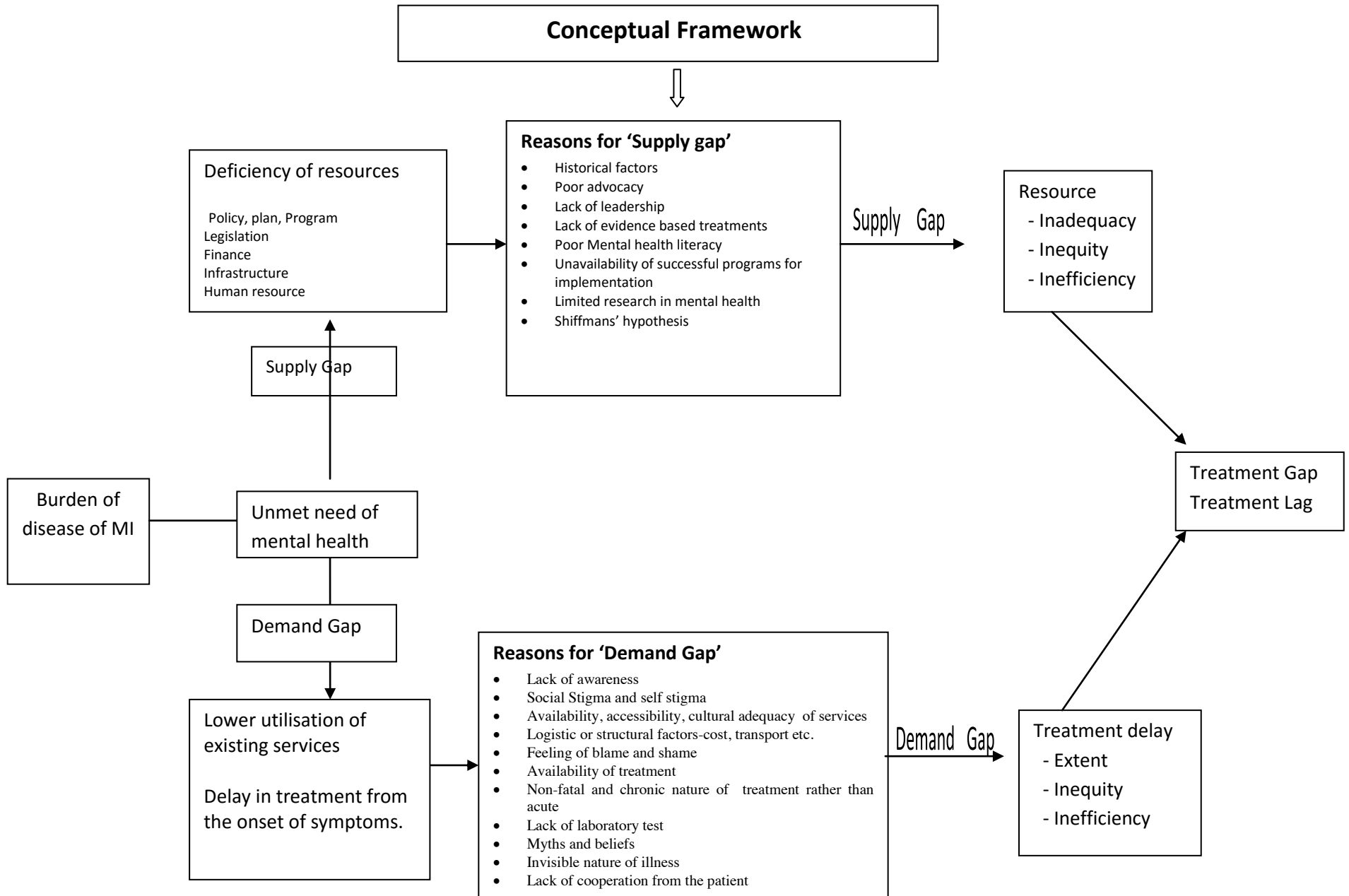
There is supply gap' or inadequate supply of resources and hence supply of services is important. But finally the utilisation of services (and hence the extent of treatment gap and lag) depends upon demand for such services by the individual households. Demand considerations play a dominant role in the 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 professional¹ is a psychiatrist and the treatment that he/she gives is psychiatric treatment which is generally medicines² 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.

¹ Even graduate doctors from other medical systems like AYUSH can recommend medicines.

² 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.