

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
Current age of patients					
< 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
Sex of patients					
Male	170	73	26.1	88	38.3
Female	79	59	16.4	78	30.2
Marital status of patients					
Unmarried	82	70	22.6	74	32.1
Others	167	67	23.3	89	37.6
Religion					
Hindu	219	69	25.1	87	37.0
Others	30	57	8.0	67	26.6
Caste					
SC	58	59	14.7	74	22.9
Open & others	191	71	25.6	87	39.6
Type of family					
Nuclear	130	63	13.5	82	35.6
Joint	119	73	33.5	86	36.0
Education of patients (years)					
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
Education of caregivers (years)					
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

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Background Characteristics	Number	Per cent availing NPT	Mean MNPT	Per cent having RD	Mean MRD
Relation with patient					
Father & mother	93	73	21.6	82	24.4
Others	156	65	23.9	86	42.5
Year of first treatment					
Up to 2000	59	70	39.2	67	35.5
2001 and onwards	190	83	18.0	85	35.8
Occupation of patients					
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
Occupation of caregiver					
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
Family income (Rs.)					
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
Diagnosis of patients					
Schizophrenia	186	68	22.6	87	38.0
Others	63	67	24.4	76	29.0
Age at onset of symptoms					
< 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
District of first treatment					
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
Distance					
< 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
Place of residence					
Urban	107	55	16.3	82	30.8
Rural	142	78	28.1	86	39.5
Total	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 R² = 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.

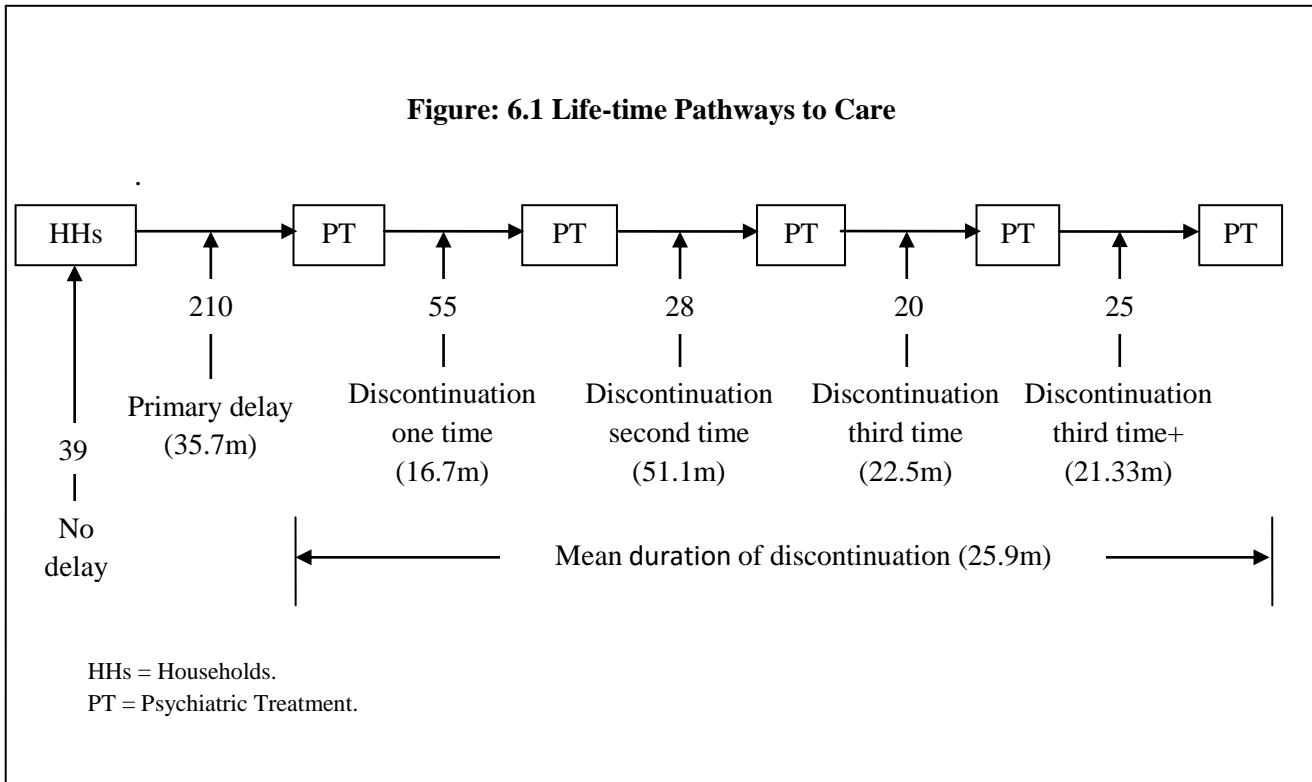
This study finds that discontinuation is a very common phenomenon among patients visiting YMH. Out of 249 patients studied, 128 patients, i.e., more than fifty per cent, had at least one discontinuation. Out of them 55 patients had only one discontinuation, 28 had two discontinuations, 20 had three discontinuations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

Table 6.5. Number of patients and average duration of discontinuation by number of times of discontinuation		
Number of times of discontinuation	Number of patients with discontinuation	Average duration of discontinuation in months
1	55	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
Age of patient			
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
Sex of patient			
Female	37	28.9	26.3
Male	91	71.1	25.3
Marital status of patient			
Unmarried	38	29.7	16.4
Others	90	70.3	29.4
Religion			
Hindu	117	91.4	26.8
Others	11	8.6	12.1
Caste			
SC	23	18.0	10.3
Others	105	82.0	28.9
Type of family			
Nuclear	63	49.2	19.5
Joint	65	50.8	31.4
Education of patient (years)			
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
Education of caregiver (years)			
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
Relation with patient			
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
Occupation of patient			
Unemployed	56	43.1	17.8
Lesser public contact	55	43.0	38.3
Greater public contact	17	13.3	10.1
Occupation of caregiver			
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
Family Income (in Rs.)			
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
Diagnosis			
Schizophrenia	102	79.7	26.4
Others	26	20.3	22.5
Age at onset of symptoms (years)			
Up to 25	77	60.2	30.9
26 to 35	35	27.3	16.2
36+	16	12.5	20.7
District			
Pune	65	50.8	22.1
Adjoining Pune	29	22.7	31.8
Others	34	26.6	26.9
Distance			
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
Place of residence			
Urban	50	39.1	15.3
Rural	78	60.9	32.2
Total	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					

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					
	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
Adjusted R² =.161					
N=128					

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).

Table 6.10 Number and percentage of patients discontinuing treatment by reasons		
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.

Table 6.11 Number and percentage of patients restarting treatment after discontinuation by reasons		
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

Table 6. Information about number, percentage, period of RD and discontinuations of patient's physical illness	
Without Physical Illness	78.3
With physical illness	21.7
Total	100
Per cent of patients by type of physical Illness	
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
Per cent of patients by months of RD for physical illness	
Delay	Per cent
0	95.9
12	2.0
60	2.0
Total	100
Per cent of patients by period of discontinuations	
Discontinuation	Per cent
0	91.3
4	2.2
6	2.2
12	2.2
24	2.2
Total	100
Per cent of patients by reason of giving priority to physical illness	
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	
Perception about expenses for physical illness	
Expenditure	Per cent
Significant	42.6
Moderate	29.8
Insignificant	27.7
Missing Cases	
Amount of expenditure per month on physical illness	
Expenditure (Rs.)	Per cent
0 to 500	65.2
501 to 1000	19.6
1001 to 5000	15.2