

Chapter V

Treatment delay for mental illness: A micro analysis

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

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

Importance of treatment delay

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

Types of treatment delay

Overall Treatment Delay (OTD) is the delay that people make in initiating the treatment since the beginning of symptoms. However, people may make delay at various stages. In their study regarding delays in untreated psychosis, Brunet, Birchwood & Lester (2007) argue that it¹ is not a unitary variable but is composed of distinct intervals. Their study divides it into three components, 1) delays in help seeking, 2) delays in referral pathways, and 3) delays in mental health services. Thompson, Issakidis, & Hunt (2008) divided total delay into two components, 1) recognition delay and 2) delay between problem recognition and actual treatment. In India the prevalence of stigma is extensive which may deter people to consult a mental health professional even after its recognition. Moreover, it due to several other barriers like myths, misconceptions and financial problem, people may not initiate treatment even if they consult a mental health professional. Hence, it was decided to divide OTD into three types, i. e., Recognition Delay, Consultation Delay and Treatment Delay. Recognition Delay (RD) is the time taken in recognising changes in behaviour as a result of mental illness. Consultation Delay (CD) is the time taken to consult a mental health professional after recognising mental illness and Treatment Delay (TD) is the time taken to initiate treatment after consulting a mental health professional. It was decided to use these three variables as the factors that influence these variables are different. RD has more to do with individual, psychological, social and cultural factors while the other two have more to do with economic and logistic factors

Extent of OTD

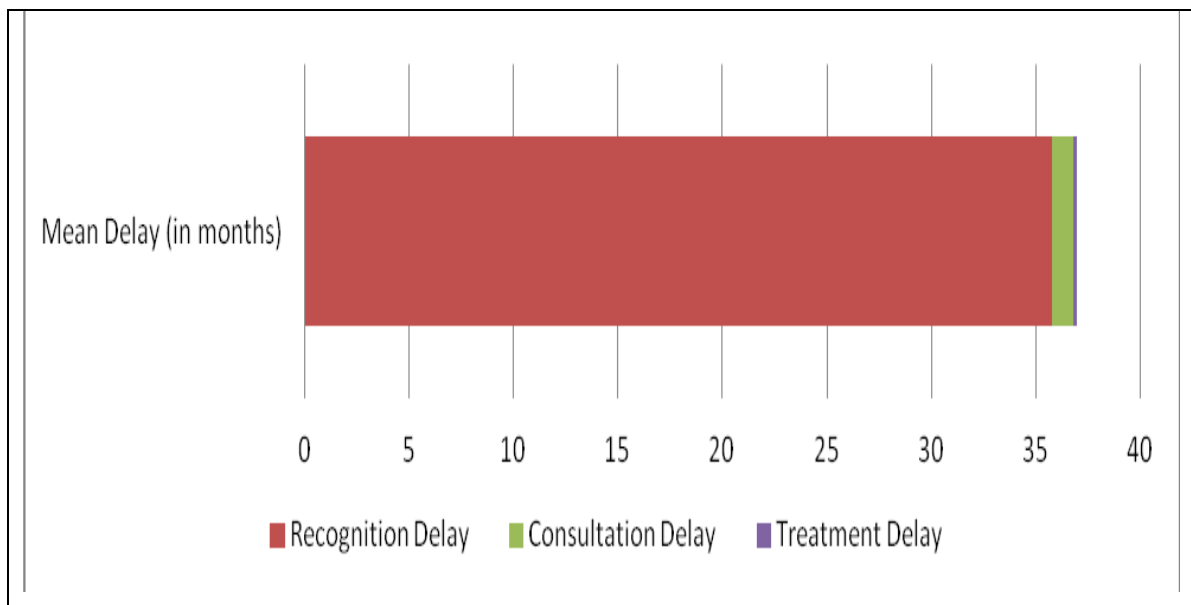
Out of the sample population, OTD was found in 84.3 per cent of the sample respondents (Table 5.1 and Figure 5.1). All of them, i.e., 210 households had RD. While three per cent of the total had either CD or TD or both along with RD. The latter is the most important component with mean of 35.8 months.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

¹ They used the term as 'duration of untreated psychosis' or DUP

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

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

Figure 5.1 Components of treatment delay



Extent of RD

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

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

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

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

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

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

Period-wise variations in RD

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

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

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

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

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

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

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

Distribution of patients by type of diagnosis

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

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

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

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

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

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

Name of psychiatric disorder	Number	Per cent	Mean MRD	Mean MNPT
Schizophrenia	186	74.7	38.0	22.6
BAD	18	7.2	30.4	27.1
Psychosis	20	8.0	33.0	36.5
ADS	7	2.8	22.6	21.3
MR	4	1.6	87.0	21.3
Epilepsy	6	2.4	10.0	4.0
BMD	4	1.6	6.8	0.0
Others	4	1.6	7.5	12.0

BAD= Bipolar Affective Disorder ; MR= Mental Retardation ; BMD= Bipolar Mood Disorder;
ADS: Alcohol Dependency Syndrome

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

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

Distribution of patients by region

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

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

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

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

Non-Psychiatric Treatment (NPT)

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

Pathways to psychiatric treatment

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

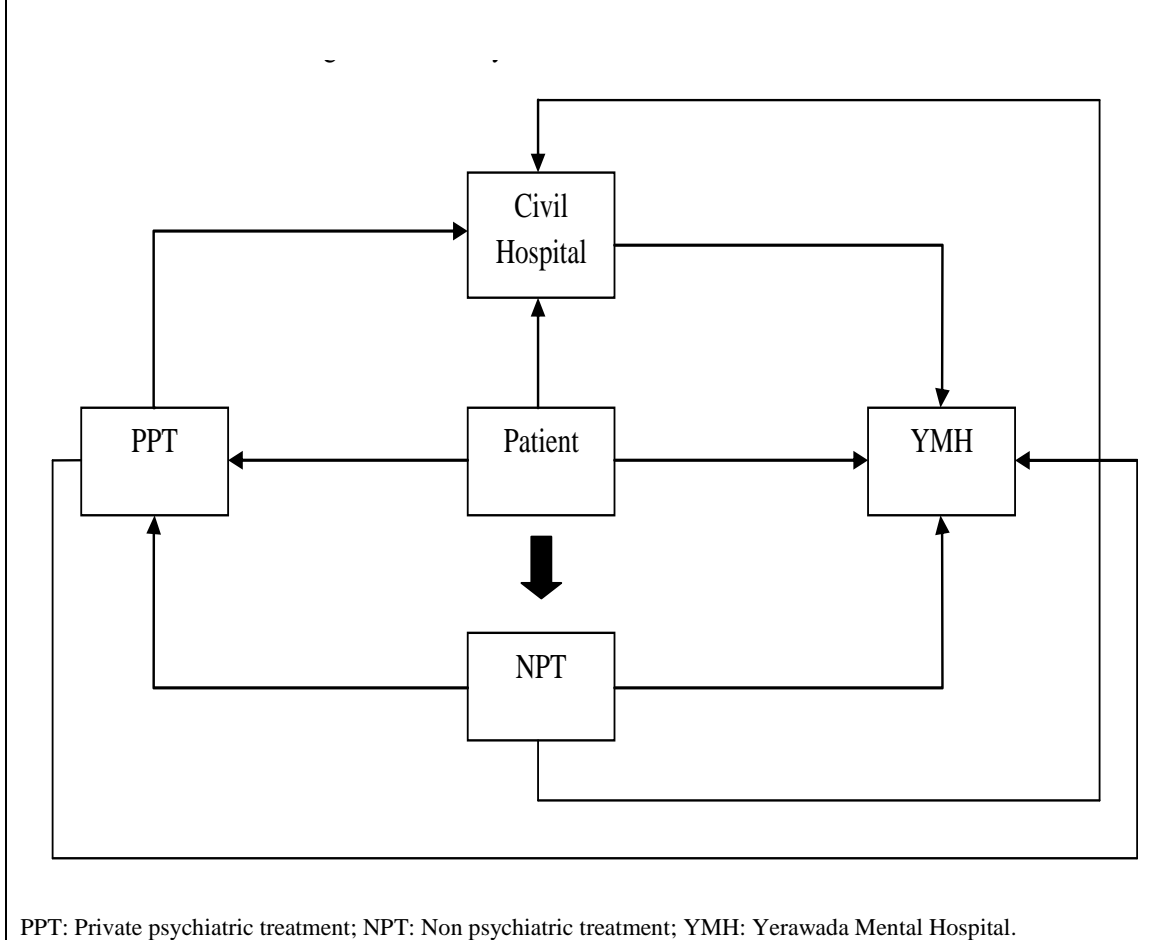
to care' is the sequence of contacts with individuals and organisations, initiated by distressed persons and those of others associated with them, to seek appropriate help (Rogers and Cortes, 1993).

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

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

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

Figure 5.2 Pathways to mental health care



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

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

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

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

Period-wise variations in period of NPT

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

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

Cost of treatment

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

Reasons for RD

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

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

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

In order to understand the complex issues related to reasons for RD, this study also conducted some Key Informants Interviews (KII) of ‘Veteran Caregiver² and staff members at YMH. Separate interview guides were prepared for interview of veteran caregiver and interview of YMH staff (Appendix VIII and IX). Key informants, being veteran and hence experienced, were expected to provide a general scenario. Following quotes provide information as given by the veteran caregivers and YMH staff.

Box 5.1 Reasons of recognition delay

Patient’s Nature:

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

Faith on blind beliefs:

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

Event or incidence in life:

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

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

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

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

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

Physical illness:

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

KI Interview

Delay in recognition

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

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

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

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

Role of Family

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

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

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

Nuisance Hypothesis

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

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

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

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

Family equilibrium

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

NPT

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

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

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

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

Gender

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

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

Importance of demand for services

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

Physical disorder

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

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

Barriers to treatment

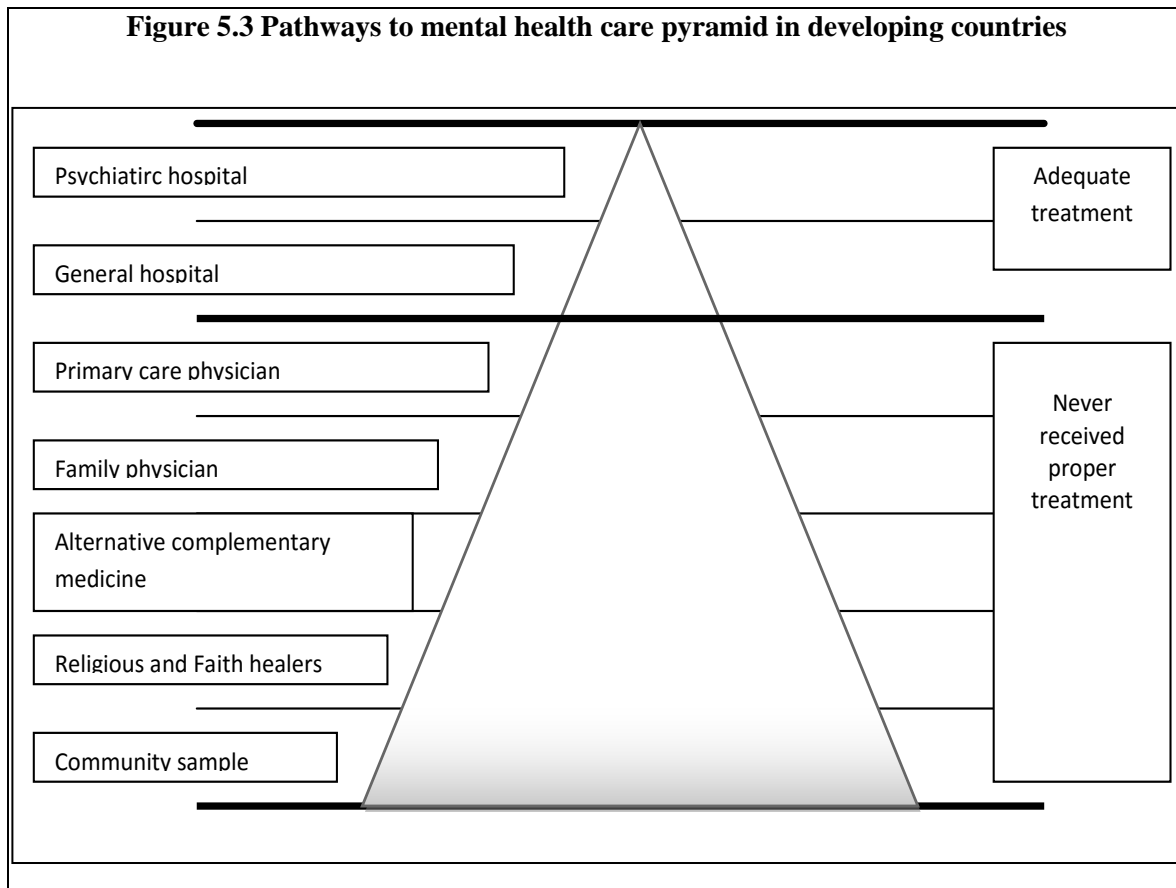
In some cases we found that people could recognise that symptoms are of mental illness. However, several barriers (like those given below) prevented them to start

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

Box 5.2 Barriers to take treatment

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

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



Source: Math & Srinivasraju, 2010.

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

Symptoms that caused decision to avail NPT

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

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

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

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

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

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

Box 5.4 Reasons for not taking NPT

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

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

Symptoms that induced decision to take psychiatric treatment

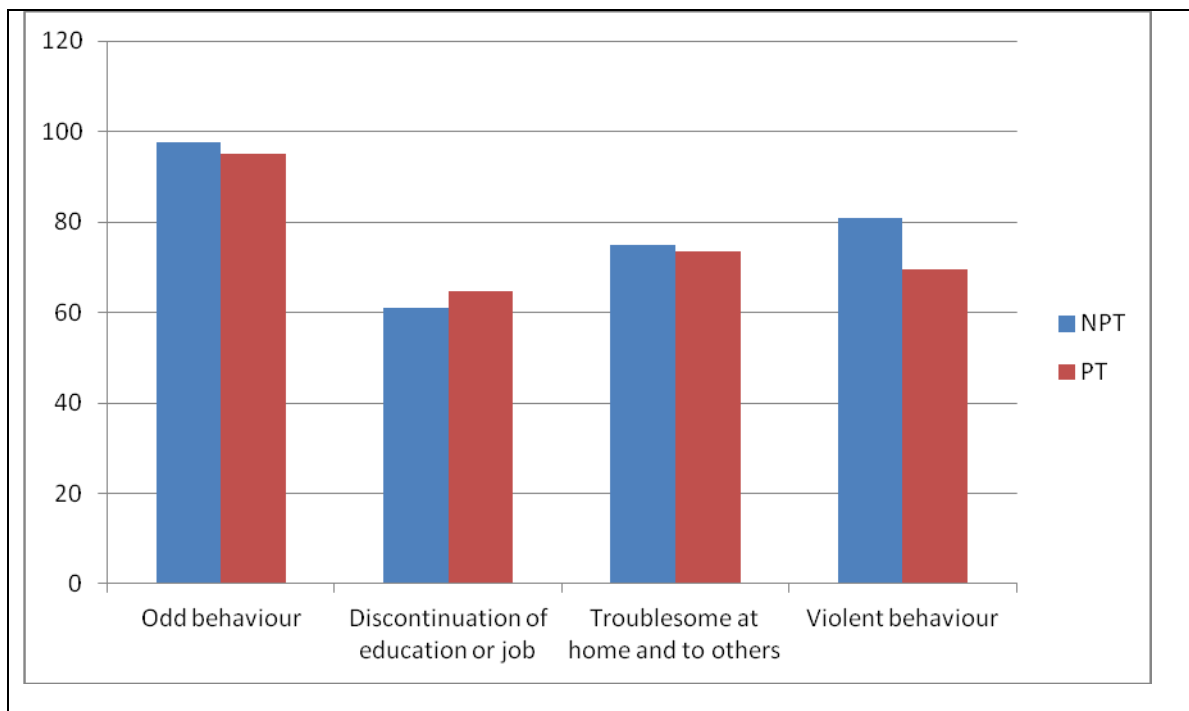
Table 5.10 Number and percentage of respondents by symptoms that induced the decision to take PT		
Symptoms	Number	Per cent
Odd behaviour	237	95.1
Discontinuation of education or job	161	64.7
Troublesome at home and to others	183	73.5
Violent behaviour	173	69.5
Other treatments did not work	57	22.9
“Let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

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

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

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

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



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

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

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

Reasons for not utilising services of rehabilitation centre.

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

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

Reasons for not utilizing counselling services.

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

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

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

Reasons for not availing services of hospitalisation

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

Reasons for not availing services of long stay home

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

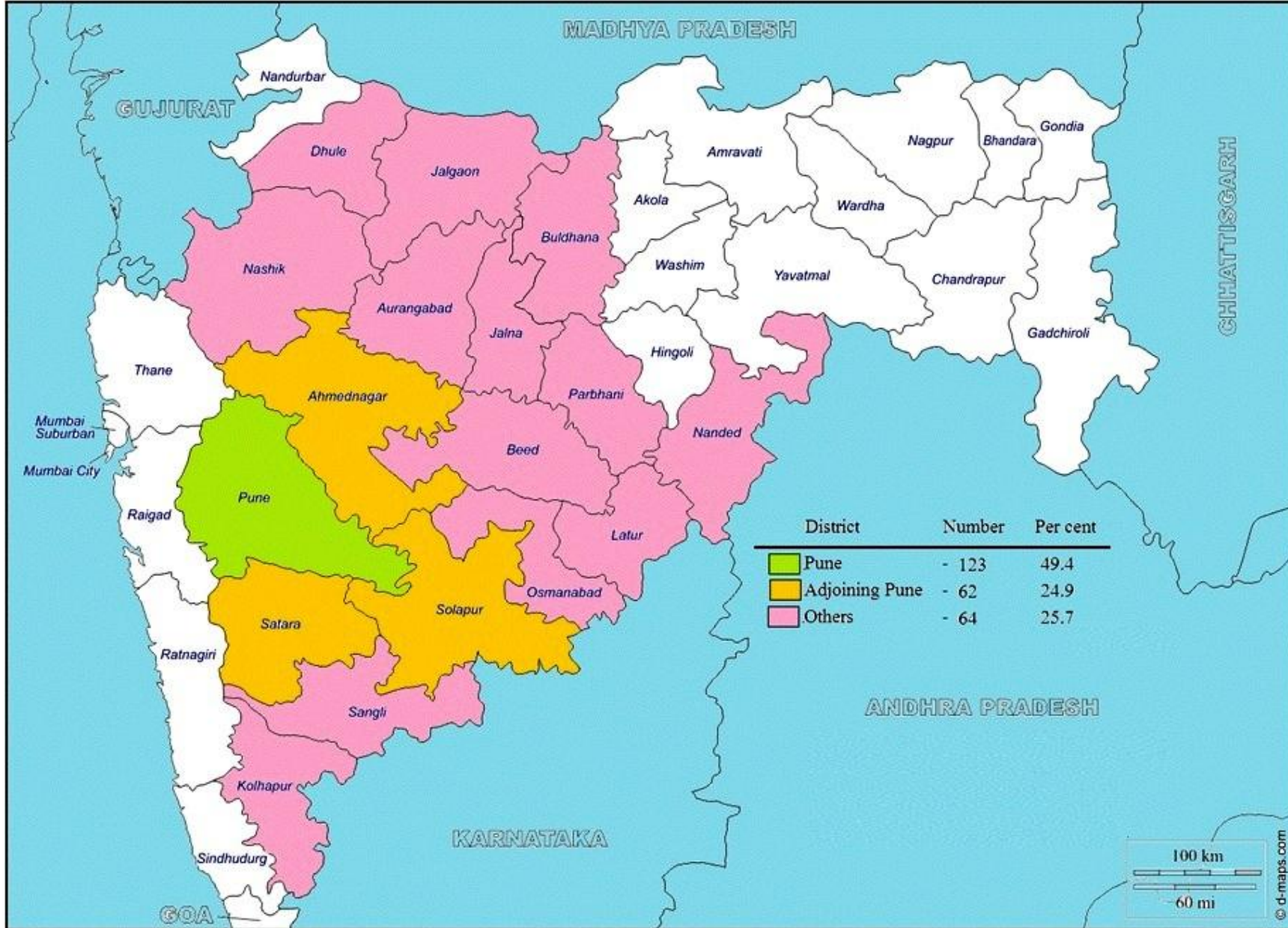
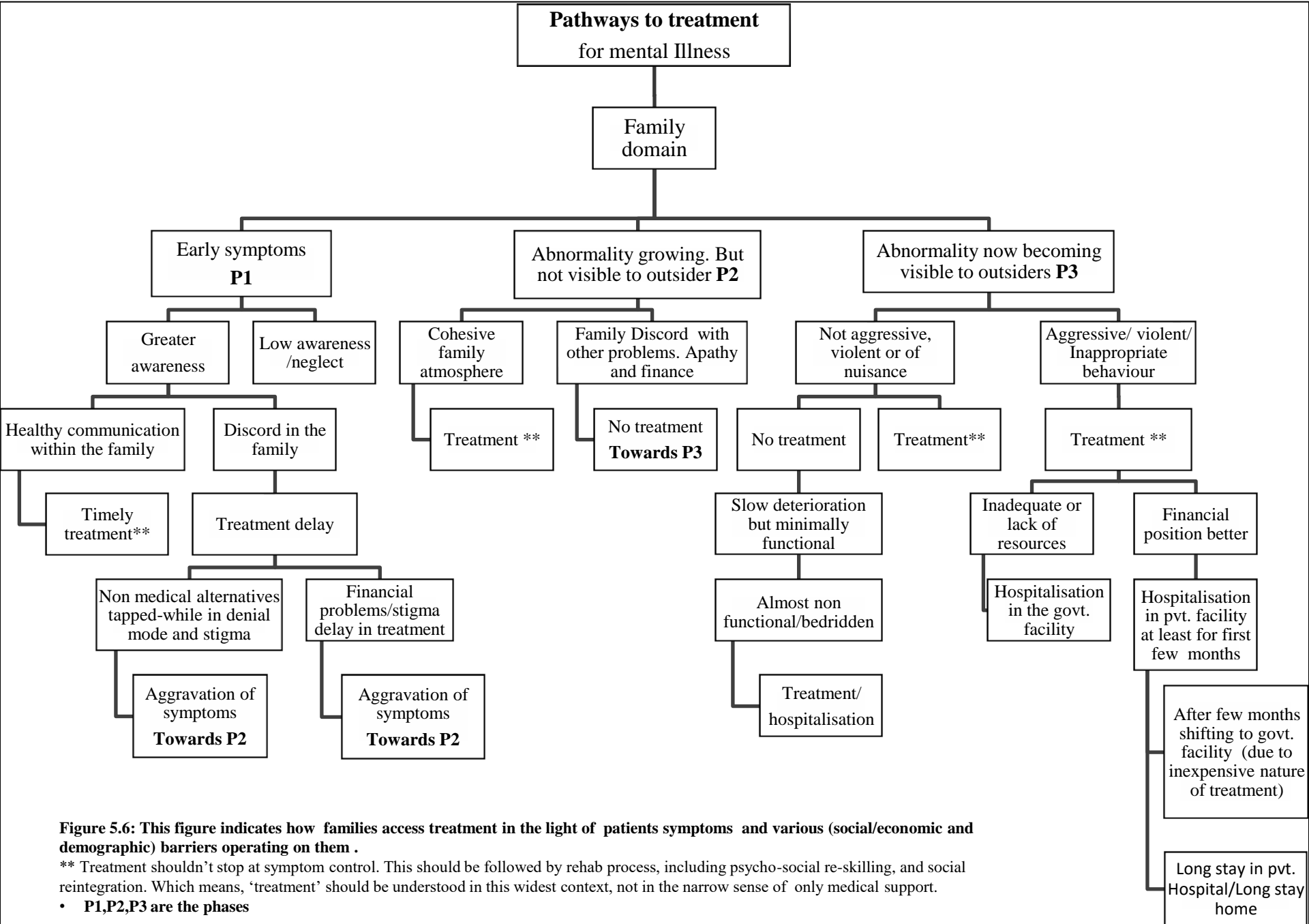


Figure 5.2: Map showing region wise distribution of patients



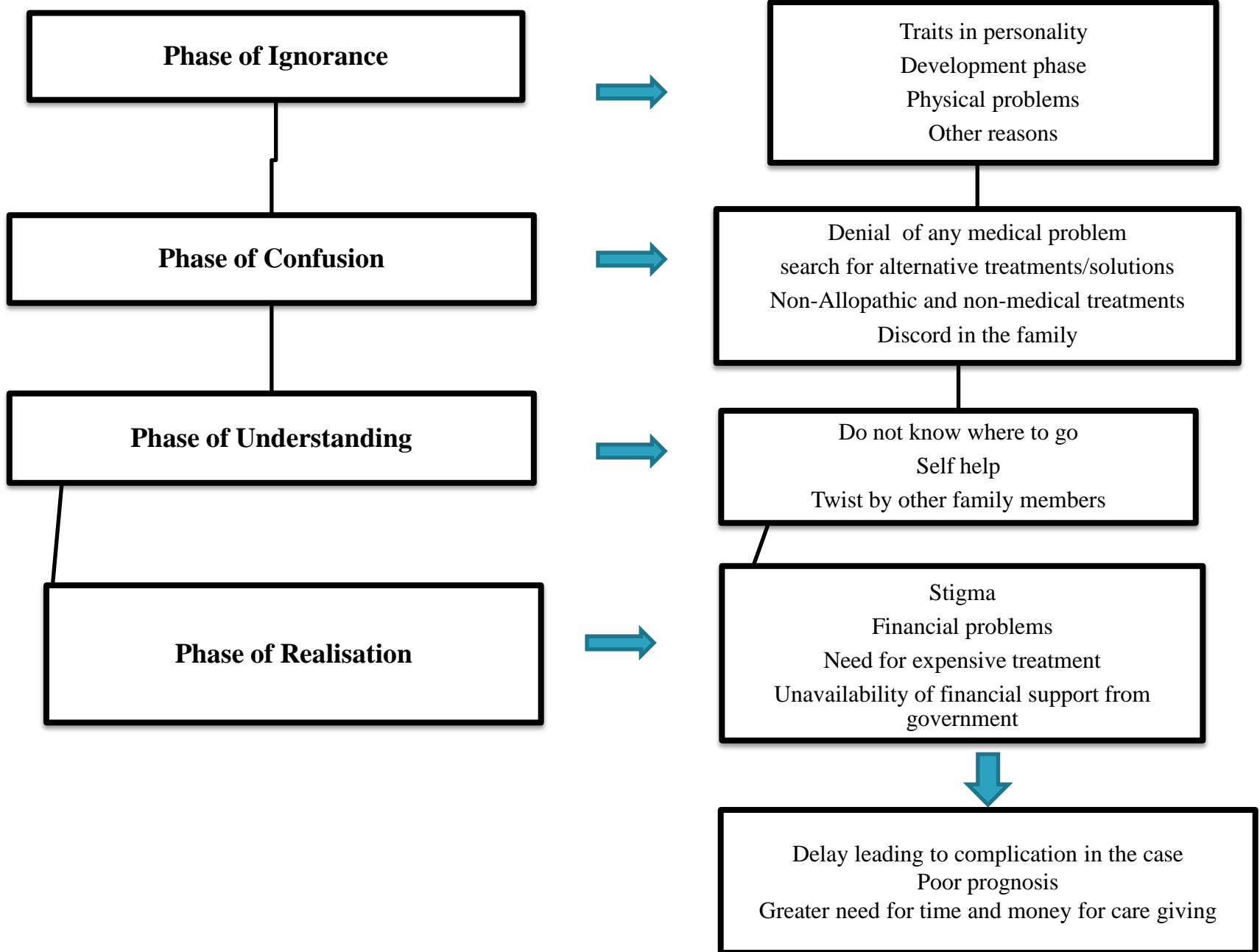


Figure 5.7: Phases in the patients journey towards treatment

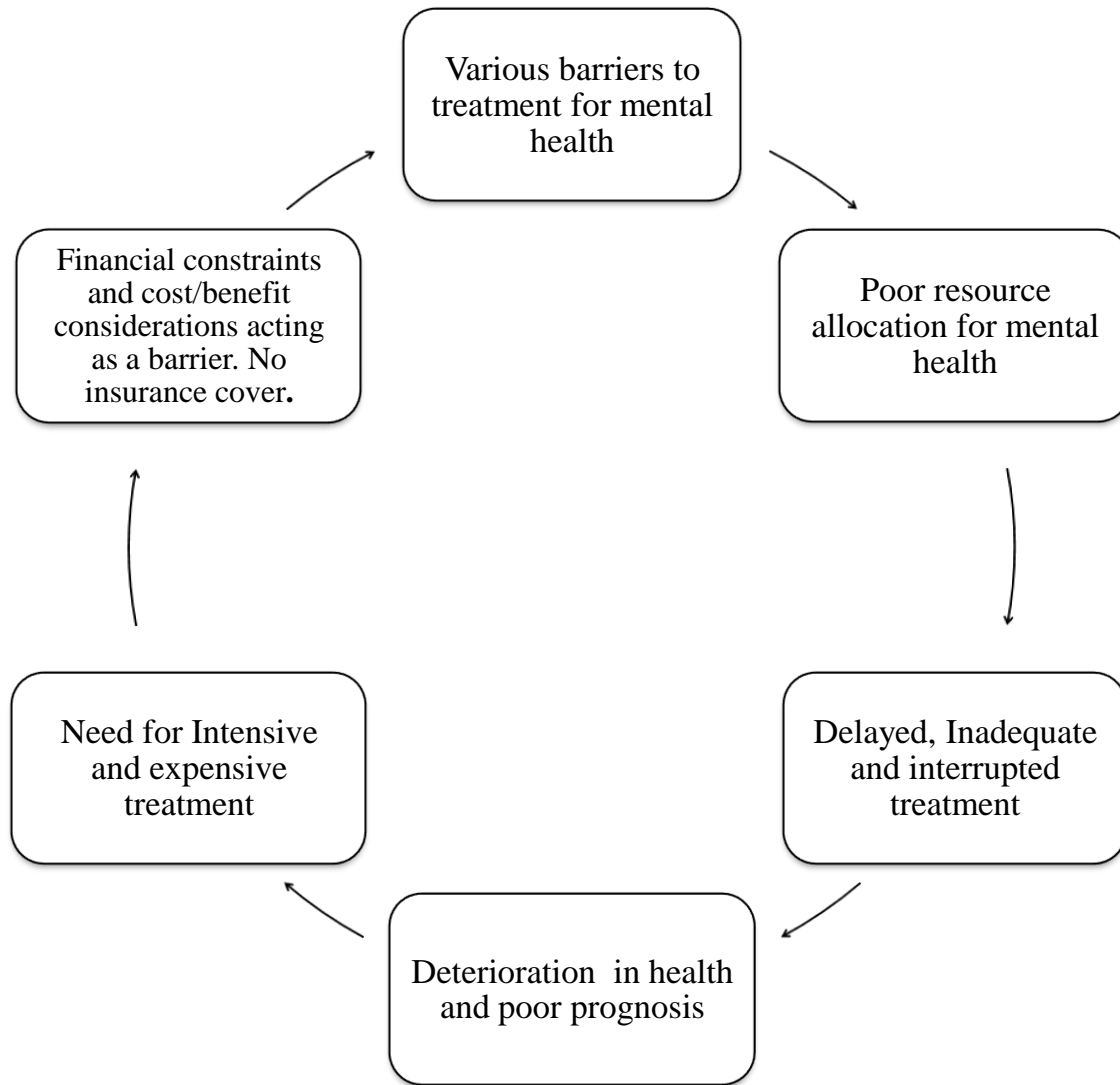


Figure 5.8: Vicious Cycle for mental health

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