

# How Lengthy and Tortuous is the Pathway to Psychiatric Care among Patients Visiting a Tertiary Care Hospital in South India? A Cross-sectional Study

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## ABSTRACT

**Background:** Mental illnesses (MI) are commonly linked with a higher burden of disease. A large number of patients with mental illnesses do not present to the mental health services directly rather they adopt a pathway that is usually prolonged and tortuous. By the time they reach the mental health services the illness becomes chronic and the resources are exhausted. It is all the more relevant in countries like India where traditional healing practices are easily accessible in contrary to mental health services.

**Aims and objectives:** The aims and objectives of this study were to measure the number of encounters patients with psychiatric illnesses had before meeting a mental health professional and the duration of untreated illness (DUI).

**Materials and methods:** In this cross-sectional questionnaire-based study, we interviewed 150 patients and their caregivers visiting the outpatient services of a tertiary care teaching hospital in South India.

**Results:** The median time taken for any help, from traditional healers, general hospitals, or a mental health practitioner was 12 months (IQR 2–47.25). The median DUI was 18 months (IQR 2.75–60), and the median total duration of illness was 24 months (IQR 4–87). The mean number of encounters was 2.7 (SD ± 1.77). As the first point of contact, 12% had met a traditional healer and 40% had met a psychiatrist. Friends and relatives in 80% of the patients initiated help-seeking. In multivariate analysis, age, male gender, and lower educational status were significant predictors for a longer duration of illness.

**Conclusion:** Patients in India continue to take a long and tortuous pathway to psychiatric care that goes through many encounters.

**Keywords:** Duration of untreated illness, India, Pathway, Traditional healers.

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## INTRODUCTION

Mental illnesses (MI) are commonly linked with a higher burden of disease. In countries like India only a limited proportion of patients with psychiatric disorders attend mental healthcare facilities and only when the condition becomes severe.<sup>1</sup> Many patients are treated inadequately, which delays their presentation to hospitals, and they become chronically ill, which depletes their resources.<sup>2</sup> Duration of untreated illnesses (DUI) not only poses a major challenge in the prognosis of mental disorders but also is associated with high levels of disability.<sup>3,4</sup> Hence, the earlier they reach an appropriate system of care better is the outcome.

This is of special interest in India because of the shortage of access to trained mental health professionals and unique cultural diversity. Pathways to care for mental illnesses are more complicated and prolonged than other illnesses. Analyzing the pathway of care helps us to understand the health service utilization, recognizing reasons for the delay in reaching appropriate carers, and strategically plan solutions.<sup>2</sup>

NMHS<sup>5</sup> revealed that a huge treatment gap exists in India, with a range of 28–83% for other mental disorders and 86% for alcohol use disorders. The availability of psychiatrists (per 1 lakh population) in the 12 states studied by NMHS varied from 0.05 in Madhya Pradesh to 1.2 in Kerala. The limited availability of trained mental health professionals is a major challenge. Also, there is a huge disparity in the distribution of mental health practitioners (MHPs), as most of them live in urban areas.

Mental health problems, from the onset of illness to course and outcome, at every phase are influenced by cultural beliefs. In

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India, blind beliefs and faith in the supernatural etiology of mental illness are highly prevalent among the majority of the population, especially in rural and tribal areas.<sup>6</sup> Traditional healing has a long and significant history in India.<sup>7</sup>

Many studies have been conducted in different parts of the world to analyze the pathways to care.<sup>2,8–10</sup> Also many years ago, World Health Organization (WHO) has conducted a multicentric study including India, to understand various pathways.<sup>11</sup> A recent study conducted in North India included only 50 in-patients which cannot be generalized as, in-patients may represent severely ill population.<sup>12</sup> It is important to have regional research in this aspect,

as it differs depending upon various factors such as culture and religion and only minimal work has been done in South India. It is not only important to research these geographical regions but also in different periods, as customs and cultural beliefs change over time which can impact the pathway.

**AIMS AND OBJECTIVES**

To assess the following:

- **The number of encounters (NOE)** patients had and the cost involved, before visiting an MHP. (Encounter was defined as the first ever help-seeking effort taken for a specific mental health condition).
- **Duration of untreated illness (DUI):** The duration between onset of symptoms and presentation to any mental health professional (MHP).
- To study the association between sociodemographic factors, clinical variables, and the pathway.

**MATERIALS AND METHODS**

This hospital-based, cross-sectional study was conducted to collect retrospective information from patients and their caretakers on their care-seeking pathways that lead them to the department of psychiatry, Pondicherry Institute of Medical Sciences of a tertiary care teaching hospital in South India. After obtaining Institutional ethical clearance (PIMS/IEC/20-19) and written informed consent, 150 adult patients accompanied by primary caregivers attending the out-patient department of psychiatry for the first time in the 2 months were selected through purposive sampling. As this was a period-based study, sample size was calculated based on the hospital census. The details were collected from both the patient and caregivers. Caregivers who had cognitive deficits, intellectual disability, hearing deficits, and psychiatric disorders (evaluated clinically), except for nicotine dependence, were excluded. Those who fulfill the inclusion criteria were interviewed using a semi-structured questionnaire and the WHO encounter form.<sup>13</sup> The details of their diagnosis were collected directly from the hospital information system and coded according to the International classification of diseases–Edition 10 (ICD-10). The study adopted the WHO’s collaborative “Pathway Study” encounter form, which was designed for use in a series of studies to understand care-seeking and treatment pathways of patients with mental disorders before they seek formal mental health care. This form was translated to Tamil and back-translated to English by language experts, after getting permission from WHO.

**Tools Used**

- A semi-structured questionnaire to collect the sociodemographic data.
- Pathway to care encounter form by WHO.

**Statistics**

Data were analyzed using the statistical package for social sciences, (IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.). Continuous variables were studied using the median (as the data was highly skewed). Mean values have been mentioned only for descriptive purposes of few data. The Chi-square test was used to determine the association between independent categorical variables and the outcome variables. Mann–Whitney *U* test and Kruskal–Wallis were used for continuous data. Multivariate analysis was performed to assess the predictors

of DUI and NOE. Two linear regression models were created. The first model predicted the DUI with the sociodemographic variables as explanatory variables. The second model predicted the number of encounters as the main outcome using the same sociodemographic variables. Statistical significance was evaluated at a *p*-value of 0.05 using two-sided tests.

**RESULTS**

The mean age of the participants was 36.1 (±14.9). Table 1 illustrates the sociodemographic profile of the participants. The striking feature was the unemployment rate (59.3%) among the patients.

Table 2 depicts the psychiatric diagnostic profiles of the participants.

Even though we had participants diagnosed with the whole spectrum of psychiatric disorders, the majority was suffering from substance use, psychosis, and mood disorders.

**Details of the Pathway**

The median time taken for any help, from traditional healers, general hospitals or MHP was 12 months (IQR 2–47.25). The median

**Table 1:** Sociodemographic detail of the patients

S. no.	Sociodemographic factors of the patients	Frequency	Percentage
1	<b>Gender</b>		
	Male	90	60
	Female	60	40
2	<b>Socioeconomic status</b>		
	Lower	63	42
	Lower middle	82	54.7
	Upper middle	5	3.3
3	<b>Area of residence</b>		
	Rural	35	23.3
	Semi-urban	111	74
	Urban	4	2.7
4	<b>Education</b>		
	Illiterate	16	10.7
	Primary	5	3.3
	Middle school	29	19.3
	High school	33	22
	HSC	25	16.7
	Graduate	36	24
	Postgraduate	6	4
5	<b>Occupation</b>		
	Unemployed	89	59.3
	Unskilled worker	10	6.7
	Semi-skilled worker	26	17.3
	Skilled worker	8	5.3
	Clerical worker	6	4
	Semi profession	1	0.7
	Profession	10	6.7
6	<b>Religion</b>		
	Hindu	130	86.7
	Christian	8	5.3
	Muslim	12	8

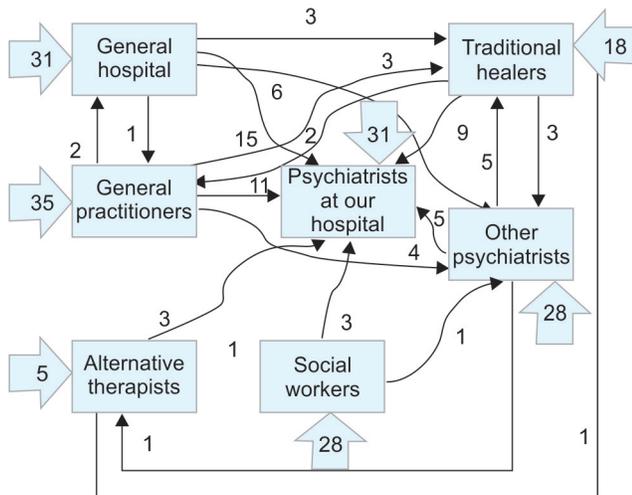


**Table 2:** Psychiatric diagnostic profiles of the participants

S. no.	Diagnosis	No. of patients	Percentage
1	Substance use disorders	35/150	23
2	Schizophrenia and related psychosis	35/150	23
3	Mood disorders	29/150	19
4	Anxiety disorders/obsessive compulsive disorder	22/150	14.7
5	Personality disorders	5/150	3
6	Conduct disorder	6/150	4
7	Organic brain syndromes	6/150	4
8	Intellectual disability	3/150	2
9	Dissociative/somatoform disorders	5/150	3
10	Adjustment disorder	11/150	7
11	Deliberate self-harm	11/150	7
12	Nil psychiatry	7/150	4.7
13	Postpartum illness	2/150	1

**Table 3:** Duration of untreated illness (DUI) and number of encounters (NOE) in different diagnostic categories

S. no.	Diagnosis	DUI (months)	NOE (mean ± SD)
1	Organic brain syndromes	33	1.8 (±0.75)
2	Substance use disorder	90	2.3 (±1.12)
3	Schizophrenia and related psychosis	12	3.2 (±1.7)
4	Mood disorders	9	3.6 (±2.8)
5	Anxiety disorders/obsessive compulsive disorder	36	2.5 (±1.2)
6	Adjustment disorder	2	1.8 (±0.75)
7	Dissociative/somatoform disorders	15	2 (±1.15)
8	Intellectual disability	120	2.3 (±1.15)



**Fig. 1:** Pathway to psychiatric care taken by the participants

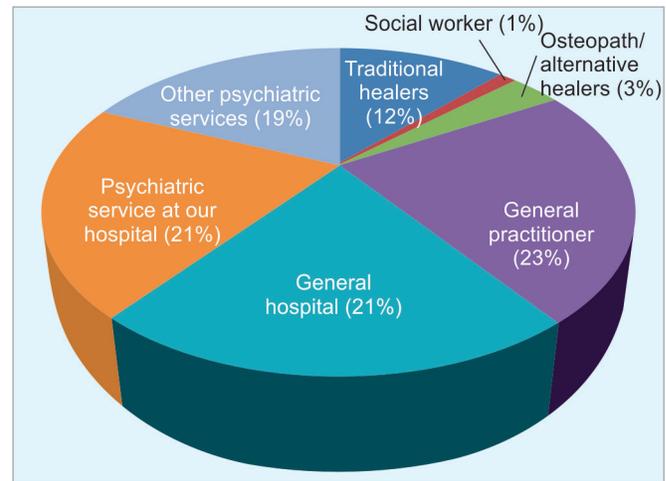
DUI was 18 months (IQR 2.75–60). The median total duration of illness was 24 months (IQR 4–87). Mean number of encounters was 2.7 (SD ± 1.77). Figure 1 shows the pathway to psychiatric care taken by the participants.

**Expenditure**

It was possible to collect details of the expenditure only from 88 patients. Many have forgotten, and some were reluctant to disclose. The range of expenditure was ₹100–6,00,000. The median amount was ₹2,000 (IQR 700–7,000).

Table 3 represents the DUI and NOE participants had before meeting an MHP, among different diagnostic categories. Intellectual disability followed by substance use disorder had a long DUI. Except for adjustment disorder, all other patients had more than 6 months of DUI.

Figure 2 depicts the nature of our participants' first encounter. Among these patients, 84% had medical practitioners including general practitioner (GP) or a psychiatrist as their first contact.



**Fig. 2:** Nature of the first encounter

Figure 3 illustrates the diagnosis of patients who had met the traditional healer as their first contact. Predominantly, patients with major mental illness have met the traditional healers.

Figure 4 shows the diagnosis of patients who had met an MHP as their first contact. Patients with varied diagnoses had met the MHP before seeking help anywhere else.

Figure 5 shows who has initiated the help-seeking for the mental health problem. For 80% of them, the suggestion to seek help for behavioral problems came from friends and relatives.

**Analytical Statistics**

Table 4 depicts the association between the sociodemographic and outcome variables.

Males had a longer DUI than females, which was statistically significant.

**Correlation between the Duration of Untreated Illness and Number of Encounters**

The DUI did not correlate ( $p$ -value = 0.729;  $r$  = 0.028) with the number of encounters.

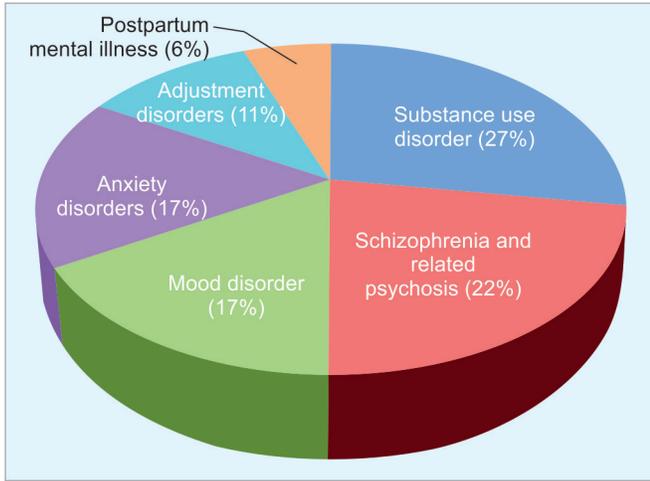


Fig. 3: Diagnosis of patients who had their first encounter with a traditional healer

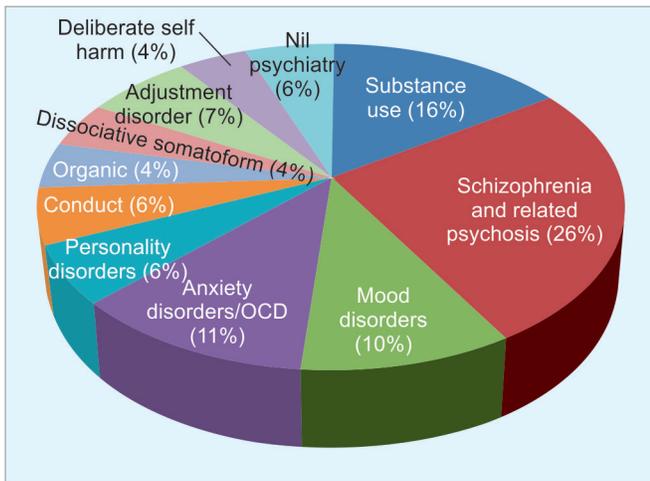


Fig. 4: Diagnosis of patients who had their first encounter with an MHP

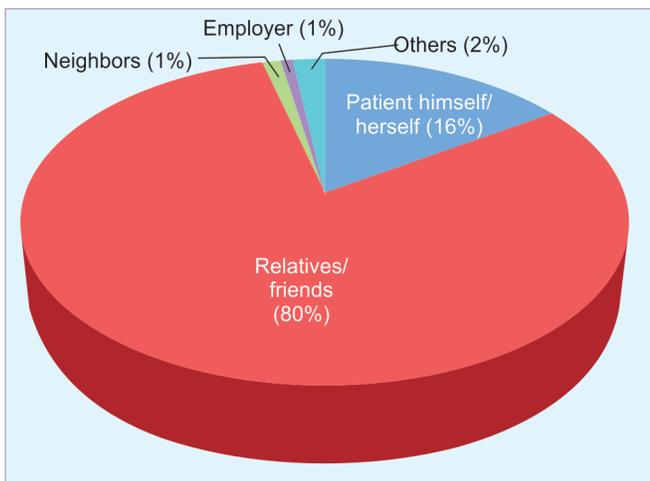


Fig. 5: Help-seeking behavior was initiated

Table 4: Association between sociodemographic and outcome variables

Socio-demographic variable	Descriptive statistics n (%)	DUI (months) (median)	p value	NOE (median)	p value
<b>Gender</b>					
Male	90 (60)	24	0.03*	2	0.664
Female	60 (40)	12		2	
<b>SES</b>					
Lower	63 (42)	18	0.279	3	0.129
Lower middle	82 (54.7)	24		2	
Upper middle	5 (3.3)	5		3	
<b>AOR</b>					
Rural	35 (23.3)	18	0.281	2	0.863
Semi-urban	111 (74)	2		2	
Urban	4 (2.7)	7.5		2.5	
<b>Education</b>					
Illiterate	16 (10.7)	15	0.655	2	0.100
Primary	5 (3.3)	60		3	
Middle school	29 (19.3)	30		3	
High school	33 (22)	12		2	
Higher secondary	25 (16.7)	12		2	
Graduate	36 (24)	18		2	
Postgraduate	6 (4)	26		1.5	
<b>Occupation</b>					
Unemployed	89 (59.3)	12	0.65	2	0.496
Unskilled worker	10 (6.7)	36		2.5	
Semi-skilled worker	26 (17.3)	60		2	
Skilled worker	8 (5.3)	10		2	
Clerical	6 (4)	108		2	
Semi profession	1 (0.7)	1		2	
Profession	10 (6.7)	10		2	
<b>Religion</b>					
Hindu	130 (86.7)	18	0.38	2	0.86
Christian	8 (5.3)	15		2	
Muslim	12 (8)	42		2.5	
<b>Family history of MI</b>					
Present	77 (51.3)	18	0.195	2	0.427
Absent	55 (36.7)	18		2	
Don't know	18 (12)	36		2.5	

\*Significant at <0.05; SES, socioeconomic status; AOR, area of residence; DUI, duration of untreated illness; MI, mental illness; NOE, no. of encounters

With regard to caregiver variables, the education of the caregivers had a significant positive correlation ( $p$  value = 0.014;  $r = 0.718$ ) with the number of encounters.

**Multivariate Analysis**

Linear regression was carried out to identify the predictors of the DUI and NOE. Variables that had a significant association in the simple regression analysis were taken for multiple linear regressions. The results of both the regression models have been combined



**Table 5:** Multivariate analysis of factors predicting DUI and NOE

Predicting variables	DUI					NOE				
	Unstandardized coefficients			95.0% confidence interval for B		Unstandardized coefficients			95.0% confidence interval for B	
	B	t	Sig.	Lower bound	Upper bound	B	t	Sig.	Lower bound	Upper bound
(Constant)	23.107	0.612	0.542	-51.607	97.821	3.573	3.278	0.001	1.417	5.728
Age	0.784	2.118	0.036*	0.052	1.516	0.007	0.701	0.484	-0.014	0.029
Sex	-26.941	-2.305	0.023*	-50.052	-3.830	-0.010	-0.031	0.975	-0.677	0.656
SES	13.679	1.275	0.204	-7.532	34.890	-0.223	-0.722	0.472	-0.835	0.389
Area of residence	2.531	0.212	0.832	-21.064	26.126	-0.122	-0.353	0.724	-0.802	0.559
Education	-8.128	-2.275	0.024*	-15.191	-1.064	0.071	0.684	0.495	-0.133	0.274
Occupation	3.827	1.149	0.252	-2.758	10.411	-0.156	-1.626	0.106	-0.346	0.034
Religion	12.186	1.383	0.169	-5.232	29.604	-0.187	-0.737	0.462	-0.690	0.315
Family history of MI	-0.503	-0.067	0.947	-15.434	14.428	0.386	1.772	0.079	-0.045	0.817
Education (CG)	6.383	1.652	0.101	-1.257	14.023	-0.159	-1.424	0.157	-0.379	0.062
Occupation (CG)	-3.972	-1.353	0.178	-9.777	1.832	-0.079	-0.933	0.353	-0.246	0.088

\*Significant at <0.05; SES, socioeconomic status; CG, caregiver; DUI, duration of untreated illness; MI, mental illness; NOE, no. of encounters

in Table 5. It shows that after adjusting for sociodemographic characteristics, multiple linear regression analysis revealed that DUI was significantly associated with older age ( $B = 0.784; p = 0.036$ ) and lower educational status ( $B = -26.941; p = 0.024$ ) of the participants. Compared to males, females had a shorter DUI.

## DISCUSSION

This was a project initiated by the institute to promote practical knowledge of research among undergraduate medical students. The student participated in every phase of designing the research and collects data under the guidance and supervision of the faculty. The student presented the protocol in the institutional research and ethics committee. The faculty analyzed the results and wrote them up while teaching the student each step of the research.

As with other states of India, Puducherry and Tamil Nadu have unique but have overlapping healthcare practices. The study center caters to the population of the Union Territory (UT) of Puducherry as well as adjacent districts of Tamil Nadu. In a country like India, where people have the freedom to choose their treatment methods in combination with the scarcity of the MHP, the pathway to psychiatric care becomes long and tortuous.<sup>1</sup>

The sociodemographic profile of the participants, in general, reflects the demographic characteristics of the region. Sixty-nine percent of them had more than 8 years of education. This again reflects the literacy rate of the UT of 76%, which is higher than the national average of 59.5%.<sup>14</sup> Among our participants, 59% were unemployed compared to a study from Delhi<sup>15</sup> where only 6% were unemployed. Whether this is secondary to the illness or not was not analyzed in this study. In the 2011 Census of India, patients who self-reported to have mental illness had 78.6% unemployment.<sup>16</sup> Our participants were in the most productive phase of life with a mean age of 36. Unemployment at this phase will lead to a lack of productivity and a poor quality of life. A qualitative study exploring this further would be beneficial. The median total duration of illness was 2 years, that is, longer than what was found by Mishra et al. as 1 year.<sup>15</sup> More than 50% of our

participants had a positive family history of psychiatric illnesses, which did not have any impact on the pathway. We cannot assume that previous exposures to similar or related symptoms in the family may help in earlier help seeking.

In our study, 4.7% of the participants who visited the psychiatric facility had not received any psychiatric diagnosis. In the multicentric study by Gater et al.<sup>11</sup> conducted across 11 centers, it was between 2 and 4%.

The DUI was highest for intellectual disability similar to the study by Jain et al.<sup>1</sup> Intellectual disability was included in the study, as patients with this condition are seen in the general psychiatric facilities in India. Substance use disorders had a median duration of 90 months. This could be due to the common attribution of alcohol use as a habit rather than an illness. These patients visited the health care facilities only when there was a complication related to the substance. Also, males had a longer DUI than females, which was statistically significant. This can be explained by the fact that substance dependence was the most common diagnosis among males. Another study conducted in the same region in 2017 found that most of the patients sought help within a month, and around half of them directly contacted psychiatric facilities.<sup>17</sup> This could be due to the fact that this study included only those with severe mental illnesses.

There were lots of difficulties in calculating the cost spent on help-seeking. In chronic conditions, the caregivers did not exactly remember how much they spent. Even if they remember, the possibility of recall bias cannot be ignored. But it varied from ₹100 to ₹6,00,000. The mean amount was ₹12,823 which is not so different from what was found in Jaipur,<sup>1</sup> i.e., ₹15,475.68. The irony is that all the government hospitals provide psychiatry services for free of cost. Puducherry has two multidisciplinary tertiary care governmental healthcare systems with fully functioning psychiatric departments with in-patient units. In such circumstances, more than accessibility, poor awareness, and sociocultural beliefs could have played a major role.

The mean number of encounters was 2.7, which is comparable to another study in India,<sup>18</sup> but lower than what was found in

Jaipur,<sup>1</sup> i.e., 3.93. This can be attributed to regional differences in cultural beliefs and attitudes, accessibility to MHP that prevail in different states. In our study, 83.4% made the first contact with allopathic practitioners, which shows a healthy development, compared to previous studies. And 39.4% met the psychiatrist at first contact. This is higher when compared to other countries (Table 6). This can be attributed to many factors such as the availability of MHP and accessibility. However, this is still a lower proportion considering the development in other areas such as technology and social connectedness. But there are not many differences in the proportion of patients visiting an MHP or traditional healer compared to the study done in Bengaluru, India, three decades earlier in 1991 (Table 7).

Among the 150 participants, 44% had visited other nonpsychiatric allopathic practitioners. In a country like India with a scarcity and unequal distribution of resources, this can't be avoided. At the same time, it is well established that GPs do not have appropriate training to diagnose or treat psychiatric conditions.<sup>19</sup> Delayed or misdiagnosis by them will lead to a lack of trust in the health system. Also, only six patients were referred by the GP to psychiatrists. Neither the existing medical curriculum nor the continuing medical services (CMEs) for the practitioners seem to do justice for psychiatric training.

Patients had visited different health providers even after meeting a psychiatrist. In this study, six participants have met traditional healers, after meeting the psychiatrists. The nature of the illness' delayed response to treatment or side effects could be the reason for this.

In the majority (80%), help-seeking was initiated by friends or relatives. Only 16% sought help on their own. This can be understood, in the closely knit culture of the Indian context. People

volunteer suggestions, whether asked or not, and most of them don't consider that as an intrusion. Sometimes, they go out of the way to help their friends who are ill. This cannot be fully explained by Indian culture alone as studies done in Europe,<sup>20</sup> Ethiopia,<sup>21</sup> and Singapore<sup>22</sup> also found that most of the time others initiate the treatment rather than the patients.

The education of the caregiver had a positive correlation with the number of encounters. This is a surprising finding if we assume that educated people seek direct psychiatric help earlier. Probably they are more distressed by the symptoms of the patient and take them to various health care providers. However, direct causality cannot be established.

In multivariate analysis, age and education of the patients were significant predictors for longer DUI. It was surprising to know that education doesn't have a positive impact on the pathway to care. A qualitative study conducted by the authors among these participants explained their experiences during their pathway to psychiatric care.<sup>23</sup>

### Strength and Limitations

We have used the WHO's encounter form that has been validated in India. We included all the patients visiting the psychiatric outpatient unit without restricting to any diagnosis. However, the participants were recruited from a tertiary care teaching hospital, and the findings may not be generalizable to community settings. Being a retrospective study, the risk of recall bias cannot be ignored. Allopathic practitioners who might be biased toward their system of treatment conducted this research. We could not calculate the exact expenditure.

The implications of this study would be to reiterate the incorporation of adequate psychiatric training in the undergraduate

**Table 6:** Comparison of our participants' pathway to psychiatric care with other countries

Sl. No.	Country	Year of study	First encounter with an MHP	First encounter with a TH	DUI (months)	NOE
1	Bali <sup>9</sup>	2006	4%	78%	6.5	
2	China <sup>24</sup>	2014	4.2%		30.4	3.6
3	Malawi <sup>8</sup>	2015	11.7%	22.7%		
4	Ghana <sup>10</sup>	2016	52.3%	23.3%		
5	Singapore <sup>22</sup>	2018	21.8 %	1.3%	1.1	
6	The current study, Puducherry	2019	39.4%	12%	18	2.7

DUI, duration of untreated illness; MHP, mental health professional; NOE, no. of encounters, TH, traditional healer

**Table 7:** Comparison of our participants' pathway to psychiatric care with other Indian studies

Sl. No.	Place	Year of study	Cost (₹)	DUI (months)	NOE	Percentage of patients with their first visit to faith healers	Percentage of patients with their first visit to MHP
1	Bengaluru <sup>11</sup>	1991	—	1.5	—	12	39
2	Central India <sup>2</sup>	2010	—	10.54	—	68.5	9.2
3	New Delhi <sup>15</sup>	2011	822.11	6	2.11	8	45
4	Jaipur <sup>1</sup>	2012	15475.68	36.7	3.93	39.5	27.6
5	Delhi <sup>25</sup>	2012	2,00,000	4.5	—	56	28
6	Bilaspur <sup>25</sup>	2012	500.00	3	—	64	12
7	Mysuru <sup>26</sup>	2012	—	6.53	—	26.9	22.1
8	The current study (Puducherry)	2019	2000.00*	18	2.7	12	39.4

DUI, duration of untreated illness; MHP, mental health professional; NOE, no. of encounters

curriculum and CMEs for practitioners. It's a combined responsibility of all the stakeholders to break the myths and enhance the awareness of the public and traditional/and alternative healers so that they can make early referrals.

## CONCLUSION

In Puducherry, a coastal town in South India, nearly 40% of the patients had their first visit to psychiatrists. The DUI was seen more in males than in females. Neither education of the caregiver nor the patient had any impact on the number of encounter (NOE).

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