

Pathways to Care for Patients with Bipolar-I Disorder: An Exploratory Study from a Tertiary Care Centre of North India

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ABSTRACT

Introduction: Understanding the pathways to psychiatric care is important from a public health perspective. Only a few Indian studies have focused on this, particularly for severe mental disorders. The present study was planned to assess it in patients with Bipolar-I disorder (BD-I). **Materials and Methods:** Sixty-four patients with DSM 5 diagnosis of BD-I and their caregivers were included. A semi-structured interview proforma was used to gather information. **Results:** Psychiatrists were the first care provider in 43.8% of the cases, followed by traditional faith healers (32.8%) and general physician/neurologists (17.2%). The median duration of untreated bipolar disorder (DUB) was 21 days (1 day to 152 months). Relatively long DUB (3.5 ± 3.5 years) was found for 17.2% of the sample. The median duration of the first contact with a psychiatrist was 45 days and the interval between the contact with the first care provider and a psychiatrist was 90 days (1 day to 151 months). At the time of first treatment seeking, 64% of patients and caregivers had poor awareness regarding psychiatric treatment. **Conclusions:** Patients with BD-I seek help from psychiatrists, faith healers or other medical practitioners for multiple reasons. There is a need to sensitise the community and various service providers about early identification and optimum management of BD-I.

Key words: Bipolar-I disorder, pathways to care, India

INTRODUCTION


Bipolar I Disorder (BD-I) is an episodic, recurrent and often disabling illness^[1] that negatively influences various spheres of patients' lives. World mental health survey revealed an aggregate prevalence of BD-I to be 0.6% across 11 countries in America, Europe and Asia.^[2] There is an acute shortage of mental health resources to deal with the burden of this illness in

developing countries like India.^[3] A large number of people suffering from psychiatric illness do not seek treatment directly from mental health professionals. Patients and families often approach alternative service providers, including physicians, general practitioners, lay counsellors, local religious leaders, or traditional

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faith healers.^[4] In the developed countries as well, a substantial number of patients with mental illness may consult the general medical sector, comprising general physicians or general practitioners, who in turn refer the patients to psychiatrists.^[5,6]

Mental health specialists are not always the initial source of care for BD-I rather, a combination of healthcare practitioners are approached for treatment.^[7,8] According to a study, BD-I patients mostly sought help from spiritual leaders, general practitioners, psychologists, psychiatrists and traditional healers.^[9] In the USA and Canada, 26% and 62% of these patients respectively do not seek specialized care for their illness^[10-12] while in Mexico, they seek care from general medical services (9.6%), mental health services other than a psychiatrist (12.9%) and psychiatric services (3.6%).^[13] Thus, duration of untreated bipolar disorder (DUB), the interval between the onset of the first mood episode and first treatment with a mood stabiliser, was found to be 3.2-20 years.^[14-18] A longer DUB has been found to have a significant association with relatively poorer clinical outcomes, such as elevated rates of rapid cycling and anxiety disorders, lower levels of current full remission, increased rates of suicidal behaviour, a higher number of mood episodes, increased social difficulties, more employment problems, and higher social costs.^[14-17] Many times, barriers to patients in gaining access to appropriate care would be poor awareness, social stigma, the absence of easily accessible treatment facilities, financial, legal/governmental issues, and cultural construct and beliefs.^[4,7] Therefore, many patients come for treatment later in the course of their illness.

Relatively few studies have been carried out on the help-seeking behaviour of the Indian patients with mental illnesses.^[3,19,20] Those studies have found that a psychiatrist, a general physician or a faith healer are the first ports of call for help.^[3,4,20] Some studies attempted to focus on only a specified group of patients like dhat syndrome,^[21] medically unexplained symptoms,^[22] and alcohol-dependent patients.^[23] However, no prior Indian study primarily focused on BD-I patients.

Thus, understanding the pathways to care for BD-I is warranted in order to gain insight into health-related beliefs and help-seeking patterns in a given cultural context and duration of untreated illness. Additionally, it will help to plan mental health services and policy, to organise training, to promote referrals to psychiatrists from other sources of health and social care, and to increase awareness by identifying the illness.^[24,25] Therefore, this study was formulated to bridge the gap in existing research on pathways of care for the particular diagnosis of BD-I in the Indian context.

MATERIALS AND METHODS

Ethical consideration

Ethical approval was received from the Institutional Ethics Committee. Written informed consent was taken from all subjects prior to participation.

Participants

It was a cross-sectional study. Sixty-four patients fulfilling DSM-5 criteria for BD-I and their caregivers were recruited consecutively from the outpatient psychiatric department of a tertiary care hospital between July and October 2017. Patients were in the age range of 18-60 years, seeking treatment at the centre, of either gender, and willing to provide a written informed consent. Patients with Bipolar II Disorder (BD-II) and Bipolar III Disorder (BD-III), or having a comorbid psychiatric illness (as per DSM-5 criteria) or neurological disorder and those who refused to provide informed consent were excluded. Due to the abrupt, dramatic onset and unmanageability of manic episodes in BD-I, the routes adopted by BD-I patients and their caregivers and duration of untreated illness (DUI) of these patients are different from patients of BD-II, BD-III and those with other comorbidities. A previous study also highlighted that patients with BD-II had the longest DUI (97.2 months) in comparison with the other groups, including major depressive disorder, BD-I, generalised anxiety disorder, panic disorder and obsessive compulsive disorder.^[14] Thus, the index study recruited only BD-I population for homogeneity and excluded BD-II, BD-III and those with comorbidities.

Assessments

Socio-demographic and clinical data sheet: This data sheet was developed for the present study by the authors to obtain socio-demographic (age, gender, education level, marital status, locality, family type and economic status) and clinical details (age of onset, total duration of illness, family history, untreated duration, episode at presentation, duration of current episode, etc.) of the participants.

Pathways interview proforma: A semi-structured interview proforma was designed specifically for the current study to obtain information about variables related to pathways of care of patients with BD-I and their caregivers (including first care provider, reasons for choosing a specific service, delays on the pathways to psychiatric care, etc.). This proforma was developed after a thorough review of the literature and tools like WHO Pathways Encounter Form. After the development, the proforma was examined for content validity by four subject experts prior to its administration.

Procedure

After informed consent had been obtained, socio-demographic information and clinical details were collected as per the socio-demographic and clinical data sheet. Furthermore, the subjects were examined for their help-seeking pattern from psychiatrist using the specially designed semi-structured proforma. Interviews were conducted by mental health professionals. The duration of the interview session was 30-45 minutes.

Analysis

The data was analysed using Statistical Package for Social Sciences (SPSS), version 21.0 (SPSS, Chicago, IL, USA). Descriptive statistics were applied to examine demographic, clinical and academic variables. These included frequency, percentage, means, standard deviations, median and range. Further, demographic and clinical variables were compared among groups using either one-way analyses of variance (ANOVAs-continuous variables) or Chi-square test with Fisher's exact test (categorical variables). Kruskal-Wallis non-parametric test was used to compare the median values among the groups in the case of a non-normal distribution.

RESULTS

The sample consisted of 64 patients: 46 males and 18 females. The mean (SD) age of the sample was 39.27 (± 13.37) years. Majority of the participants were educated up to graduation or above ($n = 23$), married ($n = 43$), belonged to the Hindu religion ($n = 59$), and had a nuclear family ($n = 36$). Only 12 patients were from lower socio-economic status, and eight were from the rural area, rest of participants were coming from upper or middle socio-economic status ($n = 52$) and urban or suburban locality ($n = 56$). During the time of assessment, participants were either euthymic (65.6%) or in the state of depression (15.6%), mania (12.5%), or hypomania (6.5%). The mean age of onset was 24.67 (SD = 8.6) years, and the median duration of illness was 11 years (range: 2-40 years). Majority of the patients had ≤ 10 years of total duration of illness ($n = 30$), while 22 patients had a total duration of illness between 11 to 20 years, and only 12 patients had more than 20 years total duration of illness. Sixteen patients had a positive family history of psychiatric illness. Currently, all patients were either on mood stabilisers or antipsychotics or a combination of both.

Psychiatrists were the most common care providers chosen as the first contact, which included psychiatrist outside the index institute or direct visit to index institute outpatient service. Approximately 33% of patients had consulted a traditional faith healer in the first instance, whereas 17% went to a general physician

or neurologists and 4.7% consulted an alternative medicine practitioner [Table 1]. Consultation with a psychologist was the first choice of one patient (1.6%). Fifty percent of the patients visited a traditional faith healer at any point of time during the course of their illness, whereas 11% consulted a general physician or neurologist at some time and 11.7% had been to an alternative medicine practitioner. Seventy per cent had sought help from a psychiatrist outside the index institute before coming to our setting.

Belief about illness as caused by supernatural power, a 'mind illness' or behavioural symptoms, and recommendation from family/friend/routine care provider were the common reasons for choosing a service [Table 2]. Majority of the patients sought help from our centre on the advice of relatives (34.4%), family members (12.5%), or friends (6.3%) or came on their own (15.6%). Twenty patients were referred by general practitioners/specialists (31.3%).

A systematic breakdown of the delays in care is presented in Table 3. The median DUB was 60 days (range: 1 day-152 months) while patients with long DUB in years accounted for 17.2% of the sample (mean \pm SD = 3.5 \pm 3.5; median = 2.5 years). Time to seek help for treatment from the first care provider, time of seeking care from a psychiatrist for the first time, and time for seeking psychiatry care after visiting first care provider varied from 1 day to 152 months. Forty-two families reported that they did not have awareness about psychiatric treatment at the time of the first contact. Furthermore, 11 families expressed intention to continue the faith-healing or traditional healing procedure.

Patients were divided to three groups based on their first contact with care provider, i.e., first contact to psychiatrists/psychologists (Group 1), first contact to non-medical care provider including traditional faith healer (Group 2), and first contact to other medical care provider including general physician, neurologist, and alternative medicine practitioner (Group 3). Groups were compared on demographic and clinical profiles [Table 4]. All three groups were similar on most of the demographic and clinical variables, but differed on

Table 1: Pathways to care (n=64)

Variables	1 st	2 nd	3 rd	4 th
	contact	contact	contact	contact
Traditional faith healer	21 (32.8)	10 (15.6)	7 (10.9)	-
General physician/neurologists	11 (17.2)	6 (9.4)	1 (1.6)	-
Alternative medicine practitioner	3 (4.7)	4 (6.3)	-	-
Psychiatrist	28 (43.8)	35 (54.7)	23 (35.9)	31 (48.4)
Psychologist	1 (1.6)	-	-	-

Values expressed as n (%)

Table 2: Reasons for visiting various treatment facilities at first contact (n=64)

Stated reasons for help seeking	Traditional faith healer (21)	General physician/neurologists (11)	Alternative medicine practitioner (3)	Psychiatrist (28)	Psychologist (1)
Easily accessible	-	-	1 (1.6)	1 (1.6)	-
Family doctor/routine care provider	-	1 (1.6)	-	9 (14.1)	-
Considered a supernatural power	17 (26.6)	-	-	-	-
Considered a physical illness	1 (1.6)	5 (7.8)	1 (1.6)	-	-
A "mind illness"/behavioural symptoms	-	4 (6.3)	-	10 (15.7)	-
Advice of relatives/friends/neighbour/self	3 (4.7)	1 (1.6)	1 (1.6)	8 (12.5)	1 (1.6)

Values expressed as n (%)

Table 3: Delays in the pathways to psychiatric care median (range)

Delay in treatment	Value
Duration of untreated bipolar disorder-DUB (days)	60 (1 day-152 months)
Time to seek initial help from any source (days)	21 (1 day-52 months)
Time to seek help from a psychiatrist (days)	45 (1 day-152months)
Time to seek help from the first care provider to a psychiatrist (days)	90 (7 days-151 months)
Awareness of psychiatric treatment at the time of the first contact	
Yes	22 (34.4)
No	42 (65.6)
Money spent on faith-healing till date (INR)	4000 (100-5,00,000)
Intention to continue the faith-healing simultaneously	
Yes	11 (17.2)
No	53 (82.8)

DUB – Duration of untreated bipolar disorder; INR – Indian Rupees

education level ($P = 0.005$), locality ($P = 0.001$) and awareness of psychiatric treatment at the time of first contact ($P = <0.001$).

DISCUSSION

To the best of our knowledge, this is the first study to specifically assess the pathways to care for a homogeneous sample of Indian patients with BD-I. Such information on routes adopted by patients with BD-I and their caregivers is lacking in the Indian and global context. Here, we present the pathways to care in a sample of patients with BD-I.

The study findings reflect that psychiatrists were the first contact care provider, followed by traditional faith healers and general physician/neurologist. Initially, more than a half of BD-I patients initiated care either with traditional faith healer or general practitioner or alternative medicine practitioners and subsequently consulted psychiatrists. This finding of the psychiatrist as the first contact in a relatively large proportion could also be due to the catchment area of the index institute comprising people mainly from urban areas of states like Delhi, Haryana, Uttar Pradesh, Rajasthan,

Madhya Pradesh and Bihar. These were more educated and aware of psychiatric treatment at the time of the first contact. Secondly, it could be due to the presence of a family history of psychiatric illness in more than one-fourth of patients. Presence of family member or close relatives with known mental illness may lead to sensitisation and early psychiatric consultation and treatment for patients' illness. Alternately, it could also be due to the abrupt, dramatic onset coupled with unmanageability associated with manic episodes, which may facilitate an early medical/psychiatric contact.

The findings from present study corroborate to some extent with previous studies, showing that the pathways to care in BD-I are composed of a combination of healthcare practices and is through a referral from primary care, mostly allopathic practitioners.^[7,8] They approach spiritual leaders, general practitioners, psychologists, psychiatrists and traditional healers for treatment of their illness.^[9,13] A study had estimated the 12-month prevalence of conventional (i.e., psychiatrists, psychologists, other MDs, nurses, and social workers) and unconventional mental health service (religious advisors and complementary and alternative medicine practitioners) use in major depressive disorder (MDD) or mania. The authors found that majority of the patients with MDD (52.9%) and manic episodes (49.0%) used conventional mental health services, while approximately 21% of patients with MDD or manic episodes used natural health products (e.g., herbs, minerals or homoeopathic products).^[26] Similar to this, an Indian study found faith healers as the first port of contact in more than half of the total psychiatric patients that included a majority of BD-I (45%) or schizophrenia patients (36%),^[20] while other studies have reported psychiatrists as the first contact of help.^[3,4] A multi-centre study on first care providers of general psychiatric patients (mostly neurotic) reported that the samples from Delhi (42%) and Kerala (74%) had approached psychiatrists as the first service provider and samples at Ranchi (43.4%) had shown a higher reliance on faith-healers.^[27]

Table 4: Sociodemographic and clinical variables: group comparisons among group 1, 2 and 3

Variables	Group 1 (1 st contact to psychiatrists/psychologists) (n=29)	Group 2 (1 st contact to nonmedical care provider) (n=21)	Group 3 (1 st contact to other medical care provider) (n=14)	P
Age (years) ^a	40.0±11.0	38.0±13.3	35.8±11.5	0.519 ^c
Gender ^b				
Male	23 (79.3)	14 (66.7)	9 (64.3)	0.487 ^d
Female	6 (20.7)	7 (33.3)	5 (35.7)	
Education ^b				
Up to middle	11 (37.9)	5 (23.8)	1 (7.1)	0.005 ^{***,d}
Higher secondary	4 (13.8)	11 (52.4)	9 (64.3)	
Graduate and above	14 (48.3)	5 (23.8)	4 (28.6)	
Marital status ^b				
Single	9 (31.0)	5 (23.8)	3 (21.4)	0.901 ^d
Married	19 (65.5)	14 (66.7)	10 (71.5)	
Others (separated/widow/divorced)	1 (3.5)	2 (9.5)	1 (7.1)	
Religion ^b				
Hindu	27 (93.1)	19 (90.5)	13 (92.9)	1.000 ^d
Others	2 (6.9)	2 (9.5)	1 (7.1)	
Family type ^b				
Nuclear	14 (48.3)	13 (61.9)	9 (64.3)	0.551 ^d
Joint	15 (51.7)	8 (38.1)	5 (35.7)	
SES ^b				
Upper	2 (6.9)	0	0	0.169 ^d
Lower middle	15 (51.7)	7 (33.3)	6 (42.9)	
Upper middle	10 (34.5)	9 (42.9)	3 (21.4)	
Upper lower	2 (6.9)	5 (23.8)	5 (35.7)	
Locality ^b				
Rural	2 (6.9)	4 (19.0)	2 (14.3)	0.001 ^{***,d}
Suburban	18 (62.1)	4 (19.0)	1 (7.1)	
Urban	9 (31.0)	13 (61.9)	11 (78.6)	
Age of onset ^a	26.1±9.2	22.7±6.9	24.6±9.5	0.391 ^c
Duration of illness (years) ^e	12 (2-40)	11 (3-40)	10.5 (3-20)	0.818 ^f
Family history ^b				
Present	11 (37.9)	4 (19.0)	1 (7.1)	0.082 ^d
Absent	18 (62.1)	17 (81.0)	13 (92.9)	
Awareness of psychiatric treatment at the time of the first contact ^b				
Yes	19 (65.5)	2 (9.5)	1 (7.1)	<0.001 ^{***,d}
No	10 (34.5)	19 (90.5)	13 (92.9)	

^aMean±SD; ^bn (%); ^cF-test; ^dχ²; ^eMedian (minimum–maximum); ^fKruskal–Wallis test; **P=0.01; ***P<0.001. SES – Socioeconomic status; SD – Standard deviation

Common reasons for choosing the first contact for help were a belief in a supernatural power being responsible for symptoms, viewing illness as a ‘mind illness’/behavioural symptoms, or recommendation by someone or family doctor/routine care provider. Patients and their families considered the mental health problem to be arising due to supernatural causes. Therefore, they sought help from traditional faith healers. Similar observations have been highlighted by previous Indian studies where families believed that supernatural power is responsible for patients’ behaviour.^[3,4,19,25] Wherever the symptoms of mania or depression were considered as a result of a physical or medical illness, they sought help from a general physician or alternative medicine practitioner, while if they found the mood symptoms

as either a ‘mind illness’ or ‘behavioural problem’, they approached a psychiatrist first. The psychiatrist was chosen as the first care provider based on the advice of their family doctor, relatives, neighbour, or friends. Another study too reported similar findings and concluded that, unsurprisingly, the patients or their families would start to discuss illness with friends and relatives when the patient does not improve.^[19]

In our study, 17% of the sample had mean DUB of 3.5 years and that is similar to the rate reported by a multicenter study from China.^[18] However, studies from other countries have reported longer mean DUB figure of 6.7-20 years.^[14-17] The homogeneity of the population and participants with BD-I may partly account for the

inconsistency of the results,^[18] because patients with BD-I are easier to identify.^[14] Median time to reach a psychiatrist after seeing the first care provider in the present study was three months which was lesser than the time reported in studies by Behari *et al.*^[19] and Lahariya *et al.*^[20] Previous literature also reported almost similar time that taken by patients with any psychiatric illness to reach a psychiatrist after seeing a first care provider, i.e., less than a month in Japan,^[28] 0 to 3 months in Eastern Europe,^[29] and six months in Australia.^[6] However, these patients took more time to reach the psychiatrist if they first consulted with traditional healers.^[20] Surprisingly, a few of our patients still had the intention to continue the faith-healing simultaneously with psychiatric treatment. A study also reported a similar proportion of patients in Delhi (16%) who had an intention to continue the faith healing procedure alongside the medical treatment.^[30]

Furthermore, it was observed that majority of patients who had the first contact to non-medical or other medical care provider group were less educated and were unaware of psychiatric treatment at the time of the first contact, as compared to those with the first contact to psychiatrists/psychologists. This may have influenced patient's decision to seek help from different services. A study also reported that a majority of patients who contacted faith-healers first were significantly less educated as compared to patients who sought help from a psychiatrist or other services.^[20] Generally, the majority of patients and their family members were not aware of the existence of a mental illness like BD-I at the time of the first contact, which is probably why they took a long route to reach a psychiatrist. Patients who had a family history and awareness about mental illness within the family were most likely to contact psychiatrists first.

The study findings should be contextualised with its strengths and limitations. The strength of the study lies in its being the first Indian study to specifically assess and report the pathways to care in a homogeneous sample comprising of BD-I patients only. The relatively large number of BD-I patients adds to the study strengths. There are a few important limitations of the current study that need to be mentioned and addressed in future studies. First, though this is the first hospital-based study that included more number of patients with BD-I, there is still a need for a larger sample and study in a community setting so that the findings can be generalised. Second, this study was conducted at a tertiary care centre with high medical expertise and easy affordability that attracts patients from all over the country. Different results may be found in a community centre or a multicentric study. Third, multiple hypothesis testing was carried out without

any correction. Another important limitation would be recall bias that may happen during the collection of information from the caregivers and the patients in such studies. Though we have tried to assess information from multiple sources and corroborate with family, still, due to the long duration of illness, recall bias is inevitable.

CONCLUSIONS

The first care provider plays a significant role in the direction of the path taken by the patient to reach a mental health professional. In BD-I, patients took treatment from a multitude of healthcare providers including psychiatrists, traditional faith healers, general physicians, and alternative medicine practitioners. In recent years, awareness about mental illness has increased and that minimises the stigma associated with mental illnesses and encourages families to seek help directly from the psychiatrists. However, a certain proportion of families still relies on faith healers due to lower education and has poor awareness within the family and community. Thus, traditional healers should be educated for prompt referral to mental healthcare centers, and general physicians should be trained to manage BD-I to some extent. The study opens a gateway towards understanding the pathways to care adopted by BD-I patients and families, prompting adoption of necessary steps for sensitisation in order to prevent prolonged and undue delays in initiation of appropriate treatment of BD-I.

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Conflicts of interest

There are no conflicts of interest.

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