

Medication adherence among persons with bipolar affective disorder: a qualitative study.

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Abstract

BACKGROUND: Disorders of mood sometimes called affective disorders make up an important category of psychiatric illness consisting of depressive disorder, bipolar disorder and, other disorders. The impact of bipolar affective disorder (BPAD) on everyday life can be devastating. Pharmacological interventions remain the primary tool in its management, psychosocial interventions target issues, such as medication adherence, awareness and understanding of the disorder, early identification of prodromal symptoms, and coping skills. The present study aimed to explore the needs of the persons with Bipolar Affective Disorder in maintaining medication adherence.

METHODS: The study used a qualitative approach with exploratory research design. The study was carried out in the inpatient department of Lokopriya Gopinath Bordoloi Regional Institute of Mental Health (LGBRIMH) in Tezpur, Assam. In depth focusses interviews were conducted in order to explore the needs of the persons with BPAD. Data was collected from six persons with BPAD and their family member.

RESULTS: The salient findings of the study are that the persons with BPAD are many and various. The needs can be due to patient related factors, medicine related factors, and family related factors.

CONCLUSIONS: The narratives of the persons with BPAD and their family members focuses predominantly on knowledge regarding illness, insight, stigma associated with illness, interpersonal issues between persons with BPAD and their family.

Key words: Bipolar Affective Disorder, Medication Non-Adherence, Patients.

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I. Introduction

Mood can be defined as a pervasive and sustained emotion or feeling that influences a person's behavior and colors his or her perception of being in the world. Disorders of mood sometimes called affective disorders make up an important category of psychiatric illness consisting of depressive disorder, bipolar disorder and, other disorders.^[1] Bipolar Affective disorder (BPAD) is often quite debilitating because patients usually have highly recurrent courses of illness, patients who have had one manic episode nearly always have another episode even if they were maintained on medications.^[2]

BPAD is often associated with severe social and occupational deficits that persist after the acute phase and during maintenance on pharmacotherapy, since bipolar disorder is a chronic illness with recurrences and relapses, denial, anger, ambivalence, and anxiety may develop as the patient and family adjust to the diagnosis.^[3] Although many individuals with bipolar disorder return to a fully functional level between episodes, approximately 30% show severe impairment in work role function.^[4]

The impact of mental disorders on communities is large and manifold. One specific variety of burdens is the health burden. National mental health survey of 2015–2016 suggests that at least 13.7% of India's general population has various mental disorders and 10.6 percent of them require immediate interventions.^[5] A third of the global burden of disease for mental, neurological, and substance use disorders occurs in India and China.^[6] Haynes et al have stated "increasing the effectiveness of interventions may have a far greater impact on the population than any improvement in specific medical treatments." Approximately 50% of persons with chronic illness do not take their medications as prescribed.^[7]

Failure to adherence is a serious problem which not only affects the patient but also the health care system. Medication non adherence in patients leads to substantial worsening of disease, death, and increased health care costs.

II. Materials and methods

The present study aims to explore the needs of the persons with Bipolar Affective Disorder in maintaining medication adherence. As very less literature was available from this region of the country the study adopted a qualitative approach with an exploratory design towards developing an intervention program to improve the medication adherence.

The universe of the study consisted of all the persons diagnosed with BPAD as per ICD 10, admitted and taking treatment in LGBRIMH. It is the only tertiary mental health care setting providing mental health services to the population covering the entire North-East and nearby region. The institute is run under Department of Health and Family Welfare, Govt. of India. The study was conducted in the in-patient department of the hospital.

Persons with BPAD (diagnosed according to ICD 10 criteria under F31) were the target population for the study. Literature suggested that purposive sampling will help to obtain maximum variation in the samples and also results in documenting heterogeneous and multiple perspectives on persons with BPAD and their primary caregivers, therefore purposive sampling was opted for this need assessment. The total number of study sample was six persons with BPAD and their family members. Participants were selected for inclusion with the goal of capturing diversity of experience, needs, particularly regarding the unique contexts and circumstances of medication adherence.

Self-structured socio demographic data sheet was developed for the purpose of assessing the sample characteristics. Clinical variables were also included in the socio demographic sheet. An expert validated semi structured interview guide was prepared for taking the interview of samples. Researcher used in-depth interview method for data collection, interviews were audio taped, transcribed in English. The researcher verified the transcribed interviews by listening to the audiotape while reviewing the transcript word by word. During this process all personal identifiers were removed and a code number was assigned to protect confidentiality. The resultant 'clean' transcripts were used in analysis. Primary analytic technique was constant comparison, a process through which each piece of data is compared and contrasted with other data to build a conceptual understanding of the categories within the phenomenon of interest. As in-depth interviews continue to elucidate and underline key themes, axial coding was used to connect categories and identify the relationship between the codes. Confidentiality was assured during the interview with the participants.

The semi structured interview guide focused on various areas such as assessing the participants understanding about bipolar affective disorder through personal experiences, the attributive factors that precipitated the illness, impact on their daily functioning, interpersonal relationship, stigma, support system, medication adverse effects and how they coped, knowledge regarding medication, financial issues, substance use.

III. Results

The socio-demographic and clinical characteristics of the sample were documented through a socio demographic and clinical data sheet. During the in-depth interviews, the verbatim of the respondents were audio tape-recorded and translated from Assamese to English language by two experts. The experts were bilingual and well versed in both languages in speaking as well as writing.

Table I - The socio-demographic characteristics of the participants **N=6**

Variable		frequency
Age	18-30	1
	31-40	4
	41-50	1
Gender	Male	3
	Female	3
Religion	Hindu	5
	Islam	1
Education	Upto Class VIII	2
	Metric	2
	Higher Secondary	1
	Graduate	1
Occupation	Unemployed	1
	Agriculture	1
	Elementary	1
	Govt. Employee	1

Marital Status	Housewife	2
	Married	2
	Unmarried	3
	Separated	1
Family Income	<6000	1
	6001 – 10000	4
	>10000	1
Domicile	Rural	3
	Semi Urban	2
	Urban	1
Type of Family	Nuclear	5
	Joint	1
Socio Economic Status	Lower Middle	2
	Upper Lower	3
	Lower	1

Table II - Clinical Characteristics of the participants

N=6

Variable		frequency
Age of onset in years	<18 years	1
	18-25 years	4
	25-30 years	1
Duration of treatment in years	<5 years	1
	5-10 years	1
	>10 years	4
Number of admissions	2	1
	2-4	4
	5	1
Total number of episodes	2	1
	2-4	4
	<6	1
Substance	Yes	5
	No	1
Follow Up	Regular	0
	Irregular	6
Medication Status	Irregular	2
	Stopped	4
Family History of mental illness	Yes	2
	No	4

Table III - Family Members socio demographic characteristics

Family Member code	Patient code	Relationship with the patient	Gender	Age	Marital status	Education	Occupation
FM1	P1	Husband	Male	40	Married	Higher Secondary	Agriculture
FM2	P2	Wife	Female	38	Married	Metric	Elementary
FM3	P3	Mother	Female	65	Widow	Upto Class VIII	Unemployed
FM4	P4	Brother	Male	35	Married	High Secondary	Agriculture

FM5	P5	Father	Male	58	Married	Graduate	Clerk
FM6	P6	Mother	Female	60	Married	Metric	Housewife

Table IV - Themes with sub themes and categories

Theme	Sub Theme	Categories
Patient Related Factors	Lack of Insight	Denial of Illness Blaming others Blaming external factors
	Knowledge regarding illness.	Black Magic Use of Substance
	Medication Adherence	Dosage Discontinuation
	Psychosocial Dysfunction	Lethargy Relationship Dysfunction
	Behavioral Problems	Wandering Anger Substance Abuse Sleep Disturbance Overspending
Medicine Related Factors	Long treatment duration and side effect of drugs	Drowsy Weakness Tremor Feeling of intoxication Unexplained Problem Weight Gain Sexual Dysfunction
Family Related Factors	Knowledge regarding illness	Misconception Treatment Discontinuation Faith Healers
	Inadequate family support	Neglect Burden
	Perceived Stigma of illness	Discrimination Labelling
	Psychosocial Dysfunction	Burden Burn Out
	Socioeconomic dysfunction	Travel expense Lack of Income

Theme 1: Patient Related Factors

1.a: Lack of Insight:

Most of the patients were not aware of or simply did not understand their mental disorders. They refused to admit that they were having mentally illness. They denied having any mental illness or they blamed others or blamed external factors for their illness.

1a.i: Denial of Illness

P5: “I don’t have any illness. I had cough, tonsil, and my throat was paining so my father brought me here”.

P2: “I don’t have any mental illness. I feel bad staying here in this hospital. I know I do not have any mental illness.”

1a. ii: Blaming Others

P6: “I got the mental illness because of my father. He used to beat me so I developed mental illness.”

1a.iii: Blaming External Factors

P4: “My finger had got crushed with a rice grinder. My thumb was bleeding, after seeing the blood I had a headache and then I got the illness.”

1b: Knowledge regarding illness

Most study participants did not know about the illness and they consulted traditional faith healers. They spend a lot of money before reaching to the psychiatric hospital.

1b.i: Black Magic

P4: “I lost a lot of blood when my thumb got crushed by a rice grinder (Dheki) and so I developed mental illness. My mother took me to many faith healers, she took me to a local faith healer, in Nagaon and many others thinking that someone might have done black magic on me. But nothing helped. Finally, they took me to a Medical for treatment.”

1b. ii: Use of Substance

P2: “You do not become mad if you take bhang. If I take that I can do all my work, I get the energy to do work. My brain becomes sharp and alert. I can remember everything. But my family members think, I have become mad after consuming that thing.”

1c: Medication Adherence

It is the most critical area identified while doing the need assessment.

1c.i: Dosage

P3: “At times when I take CPZ 25 I don’t get sleep, so I take one more tablet and then go to sleep. She also verbalized I take the medication only when I feel I am having the problem. If I am feeling low than I take 2 SRT tablet else I take 1 SRT tablet.”

1c. ii: Discontinuation

FMI: “She has been taking medicines regularly, but when she is angry, she does not take her medicines. She does not stay at home”.

P6: “I had not discontinued my medications. I got tired of taking medications. How much of medications should I take? In between I feel better, so I stop taking the medications.”

1d: Psychosocial Dysfunction

Problems in activities of daily living emerged as a critical problem domain in the need assessment. Due to illness either the person with BPAD is doing it excessively or not doing anything. They are not able to maintain the balance.

1d.i: Lethargy

P3: “I cannot do any work. Since Bohaag Bihu I have not cleaned my house. Before I used to keep my house so neat and clean but now, I cannot do anything. Every day I think I will settle my house but I cannot. I can’t imagine how I will settle my house.”

FM6: “Some days he does not get up in the morning, keeps on lying in bed the whole day. Does not take bath, change his clothes. He does not do any work says he is too tired”.

P1: “She takes bath around 3 to 4 times a day. Cooks large amount of food, which we have to eat the next day also, at times we have to throw it because we cannot finish it and it gets spoilt. Some days she keeps on cleaning the house, at night also she will not sleep, but settle the house.”

1d. ii: Relationship dysfunction

FM1: “After the illness my wife and me we fight frequently. She is always irritable and abusive. She is not interested in having sex also.”

FM3: “Earlier my daughter used to go out meet her friends and attend social functions, but now she does not go out, meet her friends, and avoids attending any function, puja, marriages”

1e: Behavioral Problems

Another problem domain emerged in the data analysis was behavioral problems.

1e.i: Wandering

FM1: “My wife she does not stay at home when she gets angry. She goes away and does not come home for one week to ten days. She stays outside in the roadside and in naam ghar. She does not take bath, nor does she eat her food.”

FM2: “He collects garbage and stores at home. He does not allow us to enter his room. He does not listen to us. He does not stay at home and wanders around. Goes to other people’s house and steals things.”

1e. ii: Anger

FM1: “Nowadays he has started picking up fight with villagers and neighbors for silly reasons. All are relation in the village is spoilt because of him.

FM4: “This time when we brought her to the hospital, we had to tie her and bring her. She was very aggressive. Somehow, I could hold her hands. My brother and seven eight villagers we held her and brought her to the hospital. In the vehicle also she was trying to break the glass, so we had to tie her.”

FM5: “When I try to control her from meeting and talking to unknown people she becomes very aggressive and abuses me with bad words. It is very painful to hear such bad words from my own daughter”.

1e.iii: Substance Abuse

FM2: “When he stops taking medicines, he consumes ganja.”

1e.iv: Sleep Disturbances

FM6: “Early morning he wakes up and leaves home and goes away, at times he is not sleeping at night and disturbing all of us. I am growing old and I am afraid I will fall sick.”

FM4: “She starts working at night at times. She will wash clothes, utensils and at times sweeps the entire house.”

1e.v: Overspending

FM6: “He suddenly starts buying and wearing new clothes. He buys a lot of unnecessary things like belts, goggles, perfumes and wastes money”

2: Medicine Related Factors

2a: Long treatment duration and side effect of drugs

Almost all family members and person with BPAD complaint about the side effects of medicine, mainly drowsiness, weakness, tremors, feeling of intoxication, excessive sleep, unexplained problems.

2a.i: Drowsy

P6: “I feel drowsy when I take medicine. I cannot get up in the morning. I keep on lying in bed in the morning. I cannot come out of my bed even if I wake up.”

2a.ii: Weakness

P1: “I feel drowsy when I take medicine. I cannot get up in the morning. I keep on lying in bed in the morning. I cannot come out of my bed even if I wake up.”

P2: “I feel weak when I am on medication. It is difficult to do work. I feel my nerves are pulling. When I stop taking the medicines, I feel strong again.”

P3: “when I take medications, I cannot do any work. I feel very weak; I only feel like sleeping, I don’t feel like doing any work. I cannot do any work, so I left taking my medicine. Before I used to wake up at 5.30 in the morning and listen to some prayer songs but now, I cannot get up even at 7 in the morning. I get up and cry now days. I feel like sleeping some more, but what to do if I sleep, I will be late for school so I pull myself out of bed.”

P5: “I feel very weak after taking the medicine. I don’t feel like getting up and walking, I feel like keeping on sitting down. I don’t feel like doing anything after taking the medicines.”

2a.iii: Tremor

FM1: “Her hands were trembling; she could not hold the utensils properly, she also had difficulty cooking food, preparing tea.”

2a.iv: Feeling of Intoxication

P5: “I cannot get up. I always feel intoxicated. At night even when I want to go to the bathroom I cannot get up at once. At day time I cannot do any work. Medicines make me feel intoxicated. I don’t feel like doing any work.”

2a.v: Unexplained Problem

FM2: “I always come and take his medicines; I always keep the medicines in stock for him. But he does not take it, he complaints of having problems after taking medicines. Now if he does not take his medicines, and all the medicines are stored, I also don’t come to get his medicines as I just waste my money coming here.”

2a.vi: Weight gain

P5: “Due to this medicine I have become fat and overweight.”

2a.vii: Sexual Dysfunction

P2: “After taking the medicine I am not able to perform sexually as before. I am afraid I am not able to satisfy my wife s, so she will leave me.”

3 Family Related Factors

3a: Knowledge regarding Illness

Most of the family members did not have proper knowledge about the illness. They had misconception regarding the illness and discontinued treatment, took treatment from faith healers due to lack of proper knowledge.

3a.i: Misconception

P5: “My father asks me not to take the medications when I am having my menstrual cycles.”

3a.ii: Treatment Discontinuation

FM6: “We were taking treatment in Guwahati, from one professor. We took treatment for around six to seven years. He had recovered a lot. The doctor had said to continue the treatment till he does not ask us to stop, but before he could ask us to stop the treatment, we stopped it by ourselves. He had recovered completely so we thought he does not require any more of medications and so we stopped it by ourselves.”

3a.iii: Faith Healers

FM2: “as for the illness I felt may be there was some fault, so we conducted some prayer (Hokaam), went to local faith healer and also went to temples. But when he did not recover, started leaving home and staying outside we brought him here.”

3b Inadequate Family Support

It was found that due to lack of knowledge patients were neglected by their family members,

3b.i: Neglect

P4: “My family members stay away from me. They don’t give me proper food, and they always keep me locked in a room.”

P3: “My brothers and sisters in law, nobody calls me or enquires about me. They never call me and try to find out how I am or how I am feeling. Can’t they call me once and ask me how I am? When I call them, they disconnect the phone and keep the number busy.”

3b. ii: Burden

P4: “I did not continue my medicines for more than a year as there is no one to get for me my medicines. My in laws say go home and ask your family members to treat you, and my brother says ask your husband to take care of you.”

3c: Perceived Stigma of Illness

Stigma is an integral part of mental illness While assessing the needs of person with BPAD and their care givers stigma became a significant concern for them.

3c.i: Discrimination

P6: “My own uncle discriminates me. When I go to attend some religious function, they ask me to leave. My uncle says my presence will make the ceremony impure. I am mad so I will make the ceremony impure. The villagers tell the children I am mad and ask them to not to come near me.”

P5: “My friends and neighbour thought that I am mental or pagal because taking treatment from LGB. Sister I don't want to come here for treatment.”

3c. ii: Label

P2: “my family members have spoilt my brain. Any time they call me mad. My wife, children, and brothers they call me mad. This word mad has made me sick.”

3d: Psychosocial Dysfunction

Bipolar Affective Disorder affects many aspects of an individual's life and greatly interferes with a person's social functioning.

3d.i: Burden

P4: “My father died, and my mother had lot of other problems as she was a ward member. My brother took admission in college and went to study. I also gave birth to a daughter. My husband went to Kerala to work. My in laws used to trouble me a lot in his absence they used to beat me and threaten to send me out of the house. Later my husband also married again. I came back to my mother's house but my mother also does not stay with me. My brother asks me to go back to my husband's house. I stay alone in a room next to my mother's house. My husband took my daughter also.”

3d. ii: Burn Out

FM1: “taking care of her is not so easy, it's very difficult, sometimes I feel like dying. There is no point continuing family with her. Early morning, she wakes up and leaves home and goes away. When she is fine, she goes for work. She weaves and earns money. But when she gets the illness, she cannot do anything. She does not go for work and wanders around the village”.

3e: Socioeconomic Dysfunction

3e.i: Travel Expense

FM4: “she was on medication for six to seven months and was completely fine. It has been one to one and a half months she is off medications. We got medicine for one month from here (LGBRIMH) and came for the first follow up. After that we went to civil hospital in our place and showed there. To come here every month, it becomes difficult as we need a lot of money to come here. Over here at times we don't get all the medicines also, we need to buy them, so we were buying the medicines over there and not coming for follow up.”

FM6: “To come here for check-up I need money. At least 1000-1200 Rupees is required. So, I thought if I take medication also it's the same and if I don't also it's the same. So, I stopped taking his medications and bringing him for follow up.”

3e. ii: Lack of Income

FM2: “it's very difficult at times, when he takes his medicines, I feel he will be fine now, but again when he stops taking medicines, I face a lot of problem. I have to sell my poultry, and do work to run the expenses of home. I somewhat lose my patience than”.

IV. Discussion

Most of the mental illnesses are chronic illness with multiple relapses and remission. The illness requires the patients to takes their medicine continuously. Non adherence to medication among persons with mental illness is highly prevalent and a big cause for relapse. Identifying risk factors for adherence problems and researching possible ways to address these problems may make a difference to the people with BPAD and their families. Qualitative tools were used to explore the factors affecting the medication adherence, of persons diagnosed with BPAD, the mix of data sources enabled the formulation of themes and identification of various needs.

The interviewed patients were the ones who directly received treatment and they could provide with their real-life experiences on their medication. The care givers who were living with the patients showed the importance and the impact of family's support on patient's medication adherence. The data collected from the interview helped identify the needs of persons with BPAD, these needs were due to three major factors patient related factors, medicine related factors, and family related factors, findings are similar to previous researches.⁸

A variety of pharmacological treatment options are available for persons with BPAD but long-term outcomes are not as expected. In a study conducted by Manhas et.al. in an outpatient department of a govt. psychiatric hospital in Jammu, prevalence of non-adherence to treatment among the bipolar patients was 59.6%.⁹

Lack of insight was identified as an important factor in the need assessment. Poor insight often occurs when persons with mental illness fail to recognize the nature of their illness and the need for treatment,^[10] poor insight is a negative predictor and influences medication adherence.^[11] Lack of insight may decrease the patient's willingness to continue treatment, and the patients may choose not to follow the doctor's advice. Novick et al in their study had found better insight was associated with higher adherence ($p < 0.001$), higher insight was related to a stronger therapeutic alliance.¹²

The other critical area identified was that Person with BPAD and their family member's lack of knowledge regarding the causes, course and prognosis of BPAD. As patients and family members expect a complete cure through medication, they are not prepared for long term care for the person with BPAD. Due to inconsistent knowledge about the illness caregivers tend to misunderstand and misinterpret patients' symptoms. Hence psychiatric nursing intervention should focus on providing correct and consistent knowledge about the illness and the need for preparedness to accept the illness.

Problems in social functioning and activities of daily living emerged as a problem domain in the need assessment. The problems included interpersonal relationship, lethargy. Hence psychiatric nursing intervention should focus on preparing patients and their caregiver for their social functioning and activities of daily living, considering the episodic and chronic course of illness.

Managing behavioral problems was identified as the most difficult care giving challenge. These included wandering behaviors, anger outburst, substance abuse, difficulties in sleep, overspending. Patients with co-occurring substance use disorders have more and prolonged affective episodes and are less compliant with treatment.¹³ Self-medication with alcohol, illicit drugs, or misuse of prescription medication to relieve affective symptoms is common among individuals with mood disorders and rates of self-medication are found to be higher for alcohol than for drugs. Although the persons with BPAD may be using substances with the intention of improving their mood, self-medication is a strategy which is associated with significant mental illness comorbidity.¹⁴

Almost all the person with BPAD had discontinued the medicine, various patient related, treatment related, system related, caregiver related may be associated with non-adherence.¹⁵ According to Sharifi et al non adherence appears to start form the early stages of maintenance therapy which could be explained by "late adherence" phenomenon. Even fully adherent patients with no predicting factor of non-adherent could potentially become moderately adherents or non-adherents during even a short course of maintenance treatment.¹⁶ Psychiatric nursing intervention should focus on treatment adherence and vocational rehabilitation aiming to gain full functional recovery.

Adverse effects such as weight gain, tremors, cognitive impairment, and sedation are very much concerning to the patients and have been found to be more likely to be associated with non-adherence.¹⁰ Drug compliance is significantly associated with factors such as perceived drug related factors influencing noncompliance which included multiple drug regime, side effect, inconvenient timing, quick recovery not noticed, negative attitude towards medicine, feeling fed up of taking medicine ($p < 0.005$), treatment access related factors such as treatment setting, cost of medication, travel cost ($p < 0.005$), quality of interaction with treating team ($p < 0.005$), family support, attitude towards illness and relatives insight towards mental illness ($p < 0.001$).¹⁷

The most consistent risk factors for medication non adherence is co morbid personality, substance abuse disorders, self-report of side effects, single marital status/living alone, limited family or clinician support, limited insight/knowledge about the disorder^[18] these risk factors have also been identified in the present study. 23% to 68% non-adherence was reported by Perlick et al in their study which was a patient centered review of research findings.¹⁸ The researchers had also suggested that their result should help develop interventions targeted at non adherence in bipolar disorder. Berk L in their comprehensive literature review had found a number of factors associated with medication non adherence, some of those factors are amenable to change.¹⁹ Forgetfulness, adverse effects and medication cost as major reasons associated with medication non adherence was observed by Mishra et al also in their study along with this lack of information on disease and medications, lack of disease concern and social support were also seen in few of the cases.²⁰

Inadequate family support led to neglect, poor patient care, family burden. The perceived stigma related to mental illness led to discrimination and labelling of the patients by the relatives and family members. It has been found that people often perceive persons with mental illness as dangerous and disruptive. Stigma manifest most often in form of labelling, rejection, social exclusion and unemployment.²¹

Adherence occurs on a spectrum, at one end of the spectrum is total adherence and at the other end is total non-adherence. Non adherence on the other hand can also refer to patients taking more than the dose prescribed²² which has been seen in the patients during the interview.

V. Conclusions

From the above need assessment findings, the researcher came to a conclusion that the person with BPAD and their family members needs are many. Researchers have suggested multifaceted interventions to create supportive environment for patients and their caregivers. A supportive social and health care system program will help alleviate medication non adherence.²³ It is necessary to establish an integrated approach to boost the therapeutic alliance and thus improve the medication adherence.

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