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Research report

# Medication treatment perceptions, concerns and expectations among depressed individuals with Type I Bipolar Disorder<sup>☆</sup>

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## Abstract

**Background:** Subjective experience of illness affects outcomes among populations with bipolar disorder (BD). This cross-sectional study combined qualitative and quantitative approaches to evaluate perceived treatment effects, concerns and expectations among 90 individuals with BD.

**Methods:** Adults with Type I BD, mean age 36.6 years, 51% women, completed a semi-structured interview that was audio taped, transcribed, coded and analyzed along emergent themes. Quantitative scales measured depressive symptoms (Hamilton Depression Scale/HAM-D), psychopathology (Clinical Global Impression/CGI), and insight and treatment attitudes (Insight and Treatment Attitudes Questionnaire/ITAQ).

**Results:** Individuals had moderate depression and psychopathology with good insight into need for treatment. Drug treatment was perceived as beneficial, by “stabilizing” or “balancing” mood (42%,  $N=38$ ), decreasing anxiety/depressive symptoms (19%,  $N=17$ ) and improving sleep (10%,  $N=9$ ). While 39%, ( $N=35$ ) of individuals denied medication concerns, nearly 29%, ( $N=26$ ) feared possible long-term effects, particularly diabetes or liver/kidney damage. Media stories and advertisements contributed to medication fears. Hopes and expectations for treatment ranged from those that were symptom or functional status-based, such as desiring mood stabilization and elimination of specific symptoms (23%,  $N=21$ ), to more global hopes such as “being normal” (20%,  $N=18$ ) or “cured” (18%,  $N=16$ ).

**Limitations:** Limitations include relatively small sample, lack of a comparator, inclusion of only depressed individuals and those willing to discuss their illness experience.

**Conclusions:** While individuals with BD appreciate the effects of medications, concerns regarding adverse effects and discrepancy between actual and hoped-for outcomes can be substantial. Subjective experience with medications using qualitative and quantitative methods should be explored in order to optimize treatment collaboration and outcomes.

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**Keywords:** Bipolar disorder; Subjective experience; Mood stabilizer; Qualitative analysis; Patient-centered treatment

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## 1. Introduction

While recent years have seen a proliferation of effective treatments for Bipolar Disorder (BD), residual symptoms and illness relapse remain all too common (American Psychiatric Association, 2002). It is perhaps not surprising that many patients become frustrated with treatment, and treatment non-adherence is known to occur in approximately 40% of individuals with BD (Lingam and Scott, 2002). A number of theoretical models have been developed to explain an individual's response to illness (Becker and Maimon, 1975; Leventhal et al., 1984; Horne, 2003), with most generally putting heavy emphasis on how the individuals cognitively and emotionally interpret illness, and the costs and benefits of treatment. Research in the area of chronic illnesses, including BD, have demonstrated that how individuals perceive illness and treatment is important in shaping illness behavior (Scott and Pope, 2002).

Mixed-methodologies utilizing qualitative, narrative techniques combined with traditional quantitative methods more typically seen in experimental medicine, in which data on human beings is condensed to averages or numerical statistics, have gained increasing acceptance among social scientists (Sherman and Strang, 2004). A limited but growing literature suggests that patient-focused, qualitative methods can add valuable insights on patient beliefs about BD treatment (Clatworthy et al., 2007).

The current study was a cross-sectional, exploratory, pooled, quantitative and qualitative analysis to evaluate attitudes and perceptions of medication treatment among 90 individuals with BD. Specific topics evaluated were perceived effects of medications, fears or concerns regarding possible medication effects, and perceived best-case hopes/expectations of what medications might do for individuals with BD.

## 2. Methods

This analysis pooled data from three research studies by this group of investigators (Study 1/K-23 National Institute of Mental Health (NIMH) MH065599 PI Sajatovic, Study 2/Ohio Department of Mental Health (ODMH), 06.1223 PI Sajatovic, Study 3/Fairview Lutheran Hospital Foundation PI Muzina) all using the same semi-structured qualitative instrument, the Subjective Experience of Medication Interview (SEMI, Jenkins et al., 2005), in a population of patients with Type I BD and similar inclusion/exclusion criteria. Study 1 comprised 40 outpatients with Type I rapid cycling BD, index depressive episode, receiving care in an Academic Medical Center Mood Disorders Clinic ( $N=20$ ) and a Community Mental

Health Clinic (CMHC) ( $N=20$ ). Study 2 comprised 30 stabilized Type I BD State Hospital inpatients with index depressive episode or mixed/depressive episode, and Study 3 comprised 20 individuals with Type I BD, index depressive episode, age 18–40, receiving care at a private Regional Hospital/clinic. In addition to requiring Type I bipolarity, index depressive episode (except for the 30-patient State Hospital sample which allowed individuals with mixed/depressive symptoms), inclusion criteria included treatment with mood stabilizing medication (lithium, anticonvulsants or maintenance antipsychotics) for at least six months, and illness duration of at least two years. The goal of each of the three studies was to evaluate subjective illness experience, along multiple domains, and across a wide range of individuals with BD using a semi-structured qualitative instrument.

In order to obtain a broad representation of “real world” patients with BD, exclusion criteria were minimal and included only inability to participate in assessments or inability to provide written, informed consent to study participation. Individuals were enrolled following either self-referral in response to posted study advertisement for outpatients or referral from clinic staff in both inpatient and outpatient samples. All studies were approved by the appropriate local Institutional Review Boards (IRB).

Diagnostic status was confirmed using the MINI International Neuropsychiatric Interview (MINI; Sheehan et al., 1998). Depressive symptoms and global psychopathology were evaluated with the 17-item Hamilton Depression Rating Scale (HAM-D-17) (Hamilton, 1960), and the Clinical Global Impression (CGI) (Guy, 1976), respectively. Insight into illness was evaluated with the Insight and Treatment Attitudes Questionnaire (ITAQ) (McEvoy et al., 1981).

Qualitative assessment consisted of the Subjective Experience of Medication Interview (SEMI); a semi-structured ethnographic evaluation of subjective experience of mental illness (Jenkins et al., 2005) modified for use with BD (Sajatovic, in press). Illness experience domains assessed included illness attitudes, attributions and behaviors, social relations, treatment history and medication experience, self-medication, quality of life, stigma, culture/ethnicity, and healthcare logistics. For this analysis there were three primary assessments of interest based upon specific questions in the SEMI: 1.) “What do you think these medications are doing for you?” 2.) “Do you have any worries or concerns about being on the medications?” and, 3.) “What do you most want your medications to do for you?” The SEMI was transcribed from the audiotapes in its entirety and entered into a software program, Atlas.ti (Scientific Software Development, 1997), to code and analyze qualitative data

Table 1  
Demographic and clinical characteristics of 90 individuals with bipolar disorder (BD).

	Academic Mood Disorders Clinic	Community Mental Health Clinic	State Hospital	Regional Hospital	All individuals with BD
	N=20	N=20	N=30	N=20	N=90
Age — mean (SD), range	n=20 41.7 (13.05), 20–62	n=20 36.35 (10.66), 20–53	n=30 36.13 (10.03), 18–55	n=20 32.12 (9.67), 18–53	n=90 36.53 (11.13), 18–62
Gender — n (%)	n=20	n=20	n=30	n=20	n=90
Male	10 (50%)	10 (50%)	17 (56.7%)	9 (45%)	46 (51.1%)
Female	10 (50%)	10 (50%)	13 (43.3%)	11 (55%)	44 (48.9%)
Ethnicity — n (%)	n=20	n=20	n=30	n=20	n=90
African-American	1 (5%)	5 (25%)	7 (23.3%)	1 (5%)	14 (15.6%)
Euro-American	19 (95%)	9 (45%)	19 (63.3%)	19 (95%)	66 (73.3%)
Other	0 (0%)	6 (30%)	4 (13.3%)	0 (0%)	10 (11.1%)
Education in years — mean (SD), range	n=20 15.1 (2.36), 12–18	n=20 13.55 (1.63), 12–17	n=30 11.9 (2.28), 8–18	n=18 13.83 (2.46), 8–18	n=88 13.4 (2.49), 8–18
Age of illness onset — mean (SD), range	n=20 29.35 (11.95), 11–46	n=20 23.55 (9.25), 5–43	n/a <sup>a</sup>	n/a <sup>a</sup>	n=40 26.45 (10.95), 5–46
HAM-D-17 — mean (SD), range	n=20 19.4 (5.22), 10–31	n=20 23.95 (5.44), 13–35	n=30 18.67 (5.24), 10–27	n=20 19.05 (6.85), 2–34	n=90 20.09 (5.96), 2–35
CGI — mean (SD), range	n=20 4.3 (0.80), 3–6	n=19 5.05 (0.78), 4–6	n=30 4.67 (0.71), 3–6	n=20 4.05 (0.76), 3–6	n=89 4.53 (0.83), 3–6
ITAQ — mean (SD), range	n=20 21.05 (2.11), 15–22	n=20 19.4 (2.04), 15–22	n=30 19.23 (4.80), 2–22	n=19 21.37 (1.12), 18–22	n=89 20.13 (3.26), 2–22

HAM-D-17: Seventeen-item Hamilton Depression Scale, CGI: Clinical Global Impression, ITAQ: Insight and Treatment Attitudes Questionnaire.

<sup>a</sup> Data on Age of Illness Onset was not collected from participants in the State Hospital and the Regional Hospital.

systematically. Narrative data from the SEMI was coded into discrete themes and evaluated across participants for each thematic domain.

### 3. Results

#### 3.1. Quantitative findings

Table 1 illustrates demographic and clinical characteristics of the study sample. Mean age of the group was 36.5 years, SD=11.1, range 18–62 years. The sample was nearly evenly split between men and women. Mean age of BD onset was 26.5 years, SD=11.0, range 5–46 years. The majority (N=66, 73%) were Euro-American, while approximately 16% (N=14) were African-Americans. Mean years of education was 13.4 years, SD=12.5, range 8–18 years. Overall, the group was moderately depressed with HAM-D-17 mean scores of 20.1, SD=6.0, range 2–35. Mean ITAQ scores for the entire group of participants was 20.1, SD=3.4, range 2–22, indicating relatively high levels of insight into illness and

treatment. Scores on the quantitative measures generally agreed with qualitative findings in that depressive themes prevailed, and individuals felt that medication treatment for their BD was indicated. Pharmacologic treatments consisted of lithium in 29 (32%) of patients, anticonvulsants in 60 (67%) of patients, antipsychotics in 50 (56%) of patients, and antidepressants in 44 (49%) of patients. Most individuals, 74 (82%), were on some combination of bipolar medications.

#### 3.2. Qualitative findings

##### 3.2.1. Perceived effects of medications

Forty-two percent (N=38) perceived medications as having a “stabilizing” or “balancing” effect (Table 2). The second most common effect (19%, N=17), was a noted decrease in depression/crying or decrease in anxiety. Beyond these two main perceived effects of medications, less commonly reported effects included non-specific benefit/general mood improvement, improved sleep and improved ability to calm down or relax. Approximately 8% of individuals specifically noted no effects.

Table 2  
Perceived effects of medications among 90 individuals with bipolar disorder.

Perceived effect	Academic	CMHC	State	Regional	All	Representative quotes
	Clinic		Hospital	Hospital		
	N=20	N=20	N=30	N=20	N=90	
Stabilization/balancing effect	6 (30%)	10 (50%)	11 (37%)	11 (55%)	38 (42%)	“They get me more level”
Decrease depression/ anxiety/crying	4 (20%)	4 (20%)	5 (17%)	4 (20%)	17 (19%)	“They help me so I’m not so sad, depressed, withdrawn”
Non-specific benefit/ mood improvement	1 (5%)	3 (15%)	4 (13%)	1 (5%)	9 (10%)	“It seemed like my mood was getting better”
Improved sleep	2 (10%)	3 (15%)	4 (13%)	0 (0%)	9 (10%)	“They’re making me more able to get sleep”
Calm down/relax	3 (15%)	2 (10%)	3 (10%)	0 (0%)	8 (9%)	“They keep me calm..to a point”
No effect	3 (15%)	2 (10%)	1 (3%)	1 (5%)	7 (8%)	“I really don’t see a change”
Side effects: sedation, tremor, weight gain	1 (5%)	0 (0%)	3 (10%)	1 (5%)	5 (6%)	“My legs shake”
Reducing hallucinations	0 (0%)	1 (5%)	3 (10%)	1 (5%)	5 (6%)	“Stops all the voices”
Reduces mania	0 (0%)	1 (5%)	1 (3%)	1 (5%)	3 (3%)	“It helps prevent the mania”
Affects brain chemicals	1 (5%)	1 (5%)	0 (0%)	1 (5%)	3 (3%)	“It has something to do with the chemical in my brain—a re-uptake inhibitor”
Decrease suicidal thoughts	1 (5%)	0 (0%)	1 (3%)	0 (0%)	2 (2%)	“They got me out of the suicidal depression”
Decrease irritability	2 (10%)	0 (0%)	0 (0%)	0 (0%)	2 (2%)	“I’m less irritable—I have some patience”
Feel numb/anesthetized	0 (0%)	1 (5%)	0 (0%)	1 (5%)	2 (2%)	“Anesthetizing me”
Improved coping/feel normal	1 (5%)	0 (0%)	1 (3%)	0 (0%)	2 (2%)	“They’re helping me cope better”

### 3.2.2. Expressed fears or concerns regarding medications

Over 1/3 of individuals (39%,  $N=35$ ) reported no concerns with medication (Table 3). A number expressed the notion that they had been taking medications for a long time and had not personally experienced problems with medication, and this largely determined their future concerns or fears. However, 29% of individuals did have specific concerns about medications, predominantly focusing on fear of developing new diseases such as diabetes or organ damage,

such as liver or kidney failure. Individuals volunteered the fact that their fears were often fueled by media reports of adverse effects and law suits regarding medication adverse effects. Some individuals cited examples of legal firms that advertised on the television or radio soliciting calls by individuals who had been treated with atypical antipsychotic medications in particular. Fear of having to take medication long-term or becoming addicted to medication was expressed by only a minority (6%,  $N=5$ ). Concern about costs of medications was expressed by 5% or fewer individuals.

Table 3  
Expressed fears or concerns regarding medication treatment among 90 individuals with bipolar disorder.

Expressed fear/worry	Academic	CMHC	State	Regional	All	Representative quote
	Clinic		Hospital	Hospital		
	N=20	N=20	N=30	N=20	N=90	
No concerns	8 (40%)	5 (25%)	16 (53%)	6 (30%)	35 (39%)	“I’ve been on it for 8 years now—it’s OK”
Concern about possible medical adverse effects/organ damage/new disease production	5 (25%)	8 (40%)	8 (27%)	5 (25%)	26 (29%)	“I just want to make sure it doesn’t do any liver damage or any kind of damage to internal organs”
Not wanting to take medication rest of life/worry of addiction	1 (5%)	1 (5%)	1 (3%)	2 (10%)	5 (6%)	“I’ll get addicted”
Ineffectiveness/loss of effectiveness	0 (0%)	0 (0%)	1 (3%)	3 (15%)	4 (4%)	“It might not work at all”
Costs	1 (5%)	1 (5%)	1 (3%)	0 (0%)	3 (3%)	“I don’t have any health insurance... and I wouldn’t be able to get my prescriptions filled”
Forgetting to take or overdosing	1 (5%)	1 (5%)	0 (0%)	0 (0%)	2 (2%)	“I might forget medications when I go on vacation”
Being forced to take medication/doctor will make prescribing error	0 (0%)	2 (10%)	0 (0%)	0 (0%)	2 (2%)	“My being forced to take it”

### 3.2.3. Hopes/best-case scenario expectations of medications

The most commonly expressed hope/expectation (23%,  $N=21$ ) concerning what medications could or might be able to do for the entire group of individuals with BD was to reduce symptoms and balance mood. Individuals were keenly aware of the effects of mood cycling/“ups and downs” and the destructive outcomes of these mood swings and depressive/manic states. A number of individuals (20%,  $N=18$ ) expressed the desire to be “normal” or “average” as opposed to being a self-identified person with BD. Nearly 20% ( $N=16$ ) expressed the wish to be “cured” of BD while at the same time expressing their disappointment that current medication treatment had not achieved a “cure” for them. Themes of loss and a desire to have these losses somehow restored were expressed by some individuals with BD, including hope for repair of relationships with family members, rebuilding of self-esteem, or restoration of material losses such as a house or car. Some individuals (8%,  $N=7$ ) volunteered humorous answers to this query stating that they would like to have super powers or some other attribute from medication, usually accompanied by another more realistic hope. Finally, the desire to experience a manic state was expressed by only a small minority of individuals with BD (3%).

## 4. Discussion

This mixed-methods analysis of medication treatment perceptions, concerns and hopes/expectations for treatment among 90 individuals with BD demonstrates surprisingly consistent responses among groups of individuals from diverse treatment settings. Based upon the results of quantitative psychiatric rating scales, individuals in this sample all had substantial bipolar depressive symptoms and moderately severe global psychopathology in spite of being prescribed medication to treat their BD. Along with extant symptoms, individuals generally had excellent insight into their illness, positive attitudes towards treatment and generally felt that medication treatments were indicated and necessary. Qualitative analysis expanded views on the specific value that individuals with BD attributed to their medications, comfort level with potential side effects and hopes for illness outcome resulting from medication treatments that individuals may or may not have articulated to their clinicians.

Individuals with BD generally perceived benefit from drug treatment, primarily in the form of “stabilizing” or “balancing” mood (42%,  $N=38$ ), decreased anxiety/depressive symptoms (19%,  $N=17$ ) and improved sleep

(10%,  $N=9$ ). Perceived efficacy thus appeared to be predominantly focused on achieving level/euthymic mood and combating depressive symptoms. Anti-manic efficacy was not generally cited as a dominant perceived effect, possibly because this sample was, by study inclusion criteria, experiencing depressive symptoms. While the earliest and largest number of randomized controlled trials (RCTs) of BD treatments have evaluated the anti-manic activity of various pharmacotherapies (Smith et al., 2007), the most salient issue for individuals struggling with bipolar symptoms in the sample reported here appears to be efficacy of treatments for bipolar depression. A recent patient-preference analysis of 469 individuals with BD similarly suggested that patients prioritized reduction of depression severity over mania severity (Johnson et al., 2007). Interventions intended to promote treatment adherence in individuals with BD should emphasize the potential for mood stabilizing drugs to prevent depressive episodes as an issue that is particularly relevant to patients. This may be a critical focus for BD-specific psychotherapies.

Individuals receiving treatment for bipolar disorder acknowledged efficacy on mood symptoms while tempering this with reports of side effects and concerns about future medical comorbidity related to medication treatments. While many (39%,  $N=35$ ) individuals denied specific concerns regarding medication treatments, nearly 29% ( $N=26$ ) expressed fears over possible long-term side effects, particularly diabetes or liver/kidney damage. Individuals cited media stories and advertisements that elicited fears regarding possible risks with atypical antipsychotic medications. Our findings support that of Scott and Pope (2002) who studied individual’s attitudes and concerns regarding bipolar treatments, and found that fear of side effects might actually be a stronger predictor for medication adherence than the actual experienced side effects. Understanding concerns that have been expressed by others, including family, friends or the media as they relate to an individual’s past treatment, current condition, and future worries is thus a critical component of assessing satisfaction or acceptance with medication therapy and optimizing future adherence.

Hopes and expectations for bipolar medication treatment in the sample studied here ranged from a symptom or functional status basis, such as desiring mood stabilization and elimination of specific symptoms (23%,  $N=21$ ), to more global hopes such as “being normal” (20%,  $N=18$ ) or having their illness “cured” (18%,  $N=16$ ). Individuals in this study frequently noted that no one had previously asked them extensively about their own feeling about their illness and treatment and that the types of questions asked in the qualitative assessment

was a novel experience for them. Psychological interventions such as psychoeducation, which has been demonstrated to have utility in improving treatment adherence in populations with BD (Rouget and Aubry, 2007), may assist patients and families in understanding the limitations of medication treatments as well as their strengths, and may be particularly critical in public mental health care settings where discrepancy between what individuals hope to see with medications and what is actually achieved can be substantial.

The findings from this study should be interpreted in the light of a number of limitations including the relatively small sample size (although thematic saturation appeared to have been achieved), lack of a comparison group, and the fact that all of the individuals with BD in these studies were willing to participate in research. As confirmed by the quantitative ITAQ results, most participants in this report were relatively insightful regarding their illness and treatment. This may have led to a bias of overrepresentation by individuals who have positive attitudes towards treatment and medication. Additionally, individuals in this study all had depressive symptoms, and thus the results cannot necessarily be extrapolated to populations who are experiencing either euthymia or predominantly manic symptoms.

## 5. Conclusions

While individuals with BD appreciate the mood-stabilizing and anti-depressant effects of medications, concerns regarding long-term adverse effects and discrepancy between actual effects of medications and hoped for outcomes can be substantial. Subjective experience with medications, and mixed methodologies that combine qualitative and quantitative assessments should be further explored in order to optimize treatment collaboration and outcomes.

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### Conflict of interest

None of the authors have a conflict of interest to report in relation to this study.

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