Care satisfaction, hope, and life functioning among adults with bipolar disorder: data from the first 1000 participants in the Systematic Treatment Enhancement Program

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Abstract

Objective: The Systematic Treatment Enhancement Program for Bipolar Disorder (STEP-BD) is designed to evaluate the longitudinal outcome of patients with bipolar disorder. The STEP-BD disease-management model is built on evidence-based practices and a collaborative care approach designed to maximize specific and nonspecific treatment mechanisms. This prospective study examined the longitudinal relationships between patients’ satisfaction with care, levels of hope, and life functioning in the first 1000 patients to enter STEP-BD.

Methods: The study used scores from the Care Satisfaction Questionnaire, Beck Hopelessness Scale, Range of Impaired Functioning Tool, Young Mania Rating Scale, and Montgomery-Asberg Depression Rating Scale at 5 time points during a 1-year interval. Analyses tested mediational pathways between care satisfaction, hope, and life functioning, depression, and mania using mixed-effects (random and fixed) regression models.

Results: Increases in care satisfaction were associated with decreased hopelessness (P < .01) but not related to symptoms of depression or mania. Similarly, decreased hopelessness was associated with better life functioning (P < .01) but not related to symptoms of depression or mania. Depression was independently associated with poorer life functioning (P < .0001).

Conclusions: This study provided support for the hypothesized mediational pathway between care satisfaction, hopelessness, and life functioning. Findings suggest that providing care that maximizes patient hope may be important. By so doing, patients might overcome the learned helplessness/hopelessness that often accompanies a cyclical illness and build a realistic illness-management strategy.

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1. Introduction

Bipolar disorder affects approximately 2.3 million adults in the United States [1], or about 1.2% of the population more than 18 years old [2,3]. Its typical onset is between the ages of 15 and 19 years [4]. Bipolar disorder is highly recurrent. Over periods of 2 years, relapse rates are close to 60%, and over 5 years, 75% [5,6]. The disorder is also associated with significant psychosocial marital, interpersonal, and occupational impairment [7,8]. Given the degree of individual and interpersonal distress that manic and depressive symptoms can cause, it is not surprising that it is a major contributor to the worldwide disease burden of mental illnesses. Manic and depressive symptoms are second only to cardiovascular conditions in causing lost years of healthy life worldwide [9]. It is therefore imperative that psychiatric research continues to establish what treatments are most effective for which patients with bipolar disorder at what point in their illness. Historically, medication management was the primary treatment for bipolar disorder. Although medications remain an essential component of treatment for bipolar disorder, the addition of psychosocial treatments may further improve patient outcome [10,11].

Treatment strategies for bipolar disorder are increasingly emphasizing a patient and family orientation as a core component of disease-management programs in an effort to
minimize disease burden and improve outcomes [12]. One such model is collaborative care treatment, which emphasizes training patients in self-management strategies and supporting providers’ to engage in joint patient-provider care planning [13-15]. Patients experiencing affective symptoms often have a pessimistic attitude toward the future, inaccurate self-assessments, and unrealistic or unfeasible expectations. Unable to effectively cope with their illnesses, they may become demoralized [16]. Whereas ineffective treatment alliances exacerbate negative expectations of outcomes, hopelessness, loss of motivation, and demoralization [17-19], a collaborative, psychoeducational, patient-centered treatment relationship is expected to enhance patients’ self-efficacy, hope, and life functioning.

In a review of psychosocial interventions for bipolar disorder, Bauer [20] found that a collaborative practice framework characterizes most effective treatment modalities. There is substantial evidence that the coping and symptom relief strategies of the collaborative model are related to increased medication adherence, decreased relapse and rehospitalization, and reduced symptom severity (for a recent review, see Ref. [21]). A manualized version of collaborative care for bipolar disorder was assessed in a mirror-image design. In that study, collaborative care was associated with higher rates of patient retention (90%), the greater usage of outpatient visits, and a decreased use of emergency services, no change in inpatient days or overall direct treatment costs, and increased patient satisfaction [22].

This study examined the longitudinal relationships between care satisfaction, hope, and life functioning among patients in the Systematic Treatment Enhancement Program for Bipolar Disorder (STEP-BD), a multicenter National Institute of Mental Health–funded project designed to evaluate the longitudinal outcome of patients with bipolar disorder. The STEP-BD model involves providers partnering with patients to provide individualized treatment and enhance their coping skills. STEP-BD providers educate patients and family members about bipolar disorder, facilitate involvement of community supports, instruct patients on how to communicate with providers in an efficient manner, and empower consumers to develop treatment plans with their providers. This collaborative treatment model encourages patients and their providers to combine their efforts in deciding the best treatment options available [23].

We predicted that the STEP-BD care model would increase care satisfaction that is associated with desirable proximal and distal patient outcomes. It was also predicted that the effects of patients’ satisfaction with their care on functional outcomes would be mediated through the avenue of decreased hopelessness. Because increased functioning is often a more distal outcome, it was expected that decreased hopelessness and increased care satisfaction would predict improved life functioning, but that these relationships would not be as strong as the direct association between care satisfaction and hopelessness. It was further expected that the relationships between care satisfaction, hopelessness, and life functioning would be equivalent to or stronger than the mediational relationships between care satisfaction, symptoms of depression and mania, and life functioning.

2. Methods

The STEP-BD uses broad entry criteria aimed at accrual of a sample that reflects the population of bipolar patients who present for clinical care. The study combines a large prospective naturalistic study and a variety of randomized controlled trials, which share a battery of common assessments [24].

2.1. Sample

STEP-BD patients must be at least 15 years of age and meet Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, criteria for bipolar I, bipolar II, cyclothymia, bipolar NOS, or schizoaffective manic or bipolar subtypes as assessed by the Mini-International Neuropsychiatric Interview [25]. Exclusion criteria are limited to unwillingness or inability to comply with study assessments, or inability to give informed consent. After complete description of the study to the subjects, written informed consent was obtained. STEP-BD was reviewed and approved at both the National Institute of Mental Health and the institutional review boards of all participating sites. The sample for the present study is the first 1000 patients entered into STEP-BD from November of 1999 to May of 2001 (Table 1).

2.2. Procedures

STEP-BD patients were given a workbook and videotape describing the collaborative care model to facilitate a therapeutic alliance, provide psychoeducation, and guide a plan for illness management [26]. Throughout treatment, patients were presented with behavioral and medication management options.

Information on the course and severity of bipolar symptoms, including age of onset, history of suicide attempts, and the longest period of euthymia in the past 2 years was elicited as part of the baseline assessment. All other clinician- and patient-rated instruments were collected longitudinally at study follow-up visits. For this study, data from 5 of the instruments included in the STEP-BD assessment battery were analyzed: the Care Satisfaction Questionnaire (CSQ), Beck Hopelessness Scale (BHS), the Range of Impaired Functioning Tool (LIFE-RIFT), Young Mania Rating Scale (YMRS) and Montgomery-Asberg Depression Rating Scale (MADRS). All instruments but the BHS had data collection time points at baseline, 3, 6, 9, and 12 months. The BHS differed in only being collected at baseline, 6 months, and 12 months.
Patient satisfaction was assessed by the CSQ, a 44-item self-rated scale that is a modified version of the 56-item Consumer Assessment of Behavioral Health Services (CABHS) instrument. The CABHS and CSQ elicit patients’ ratings of their behavioral health care services [27,28]. In a prior study, CABHS internal consistency reliability estimates of scales ranged from 0.55 to 0.87 [29]. Overall ratings are collected on an 11-point scale, with 0 being “worst possible” and 10 being “best possible.” Questions are asked “how often” or “if” something happened using “never/sometimes/usually/always” and “yes/no” response options. Patients are asked to report about some services using “not a problem/small problem/big problem” response options. The amount the patient was helped by treatment is reported using “a great deal/quite a bit/somewhat/not at all” response options. For this study, only the CSQ items relating to the quality of personal interactions between consumers and providers, information given to consumers, continuity and coordination of care, and global evaluation of care were included in data analyses. Items assessing patients’ health insurance plans were excluded.

Table 1

| Mean age | 41.1 ± 12.8 years |
| Age range | 15.7–83.5 years |
| Male (%) | 41.1 |
| Female (%) | 58.9 |
| Race/ethnicity (%) |
| White or Caucasian | 92.6 |
| Black or African American | 3.4 |
| Native American, Eskimo, or Aleut | 0.4 |
| Asian or Pacific Islander | 1.1 |
| No primary race | 0.5 |
| Other | 1.9 |
| Hispanic/Latino | 3.7 |
| Marital status (%) |
| Never married (never lived as married) | 35.2 |
| Married | 36.2 |
| Living as married | 3.6 |
| Separated/no longer living as married | 4.9 |
| Divorced | 18.6 |
| Widowed | 1.6 |
| Employment status (%) |
| Full-time | 34.5 |
| Part-time for pay | 14.6 |
| Homemaker | 5.3 |
| Incarcerated | 0.0 |
| Disabled | 15.3 |
| Leave of absence | 1.5 |
| Unemployed | 22.0 |
| Retired | 5.0 |
| Other | 1.8 |

which supports the instrument’s concurrent validity. Inter-rater reliability was 0.86.

Assessments of functional impairment were made using the LIFE-RIFT, a 9-item clinician-administered scale assessing domains of work, interpersonal relations, recreation, and global satisfaction [31]. Items are rated from 1 (“no impairment”) to 5 (“severe impairment”) based on responses to a semistructured interview. The reliability and validity of LIFE-RIFT has been examined in bipolar I disorder with excellent interrater agreement (r = 0.94) and internal reliability over time, with coefficient α ranging from .78 to .84 [32].

The YMRS and MADRS are clinician-rated instruments to rate symptoms of mania and depression, respectively. In a prior study [33], the 11-item YMRS interrater reliability ranged from 0.66 to 0.95 (P < .001), and concurrent validities with a global rating and 3 other scales were significant at the P < .001 level. Correlations between items ranged from 0.41 to 0.85. YMRS had good predictive validity when scores were correlated with number of days of continued stay in the hospital after completion of the scale (r = .66, P < .001). Previous research has found the 10-item MADRS interrater correlations to be high, ranging from 0.89 to 0.95 [34]. Judged against other scales, the MADRS differentiated well between responders and nonresponders to treatment.

2.3. Data analysis

Analyses were performed in 2 phases. Phase I analyses explored the psychometric properties of the CSQ, BHS, LIFE-RIFT, MADRS, and YMRS. Phase II analyses tested the hypothesized mediational pathway between care satisfaction, hopelessness, symptoms of bipolar disorder, and life functioning over the 12-month study period. It was noted that that some measures had a significant amount of missing data during follow-up (eg, patients did not complete patient-rated forms or there were missing items in these forms). In determining the basic psychometrics of measures, the phase I sample was restricted to study participants who completed all follow-up forms for each measure analyzed. Univariate statistics (analysis of variance and χ²) compared patients who did and did not complete the required scales at follow-up on gender, race, diagnosis, suicidality, education, employment, clinical status, age of onset, age, and CSQ, BHS, MADRS, YMRS, and LIFE-RIFT baseline scores.

Cronbach coefficient α’s were computed for each measure at each point in time. Pearson correlation coefficients determined the relationships between the baseline scores from each of the 5 measures and the corresponding scores at each of the follow-up assessments. Estimated relationships were presented as scatter plots and moving averages, as well as analogous bivariate regression models.

In Phase II of the analyses, mixed-effects (random and fixed) multiple regression models tested the hypothesis that the relationships proposed in the overall mediational model provided a plausible explanation for those relationships that existed in the data. The first model analyzed changes in the
CSQ score (care satisfaction) for 12 months. The second model explored whether CSQ scores were associated with BHS measurements of hopelessness. The third model looked at whether changes in the CSQ scores were associated with life functioning as measured by the LIFE-RIFT. The final model looked at whether changes in the BHS were associated with LIFE-RIFT scores.

3. Results

3.1. Analysis of missing data

There were several variables associated with missing data. Age, history of suicidality, and educational background were significant indicators for missing forms across all measures. Those with no history of suicidality had more missing forms. The findings suggested that individuals with a high school education/equivalent or less had more missing forms than individuals with at least some college education. For all measures but the BHS, those in the "professional" category had fewer missing forms than other categories of employment. Clinical status and age were significant for the BHS, LIFE-RIFT, YMRs, and MADRS, with patients who entered STEP-BD in a recovering or recovered state and older persons more likely to be missing forms. Gender was only significant for the CSQ, with women having more missing forms than men (for all, P < .05). Other relationships of borderline significance were found between the CSQ baseline and YMRs and MADRS, MADRS baseline, and BHS, and BHS baseline and CSQ. All variables with significant associations to missing data were included as covariates in the phase II mediational models.

3.2. Internal consistency

Table 2 presents the internal consistency of each measure at each time point. The internal consistency of all measures was good, with overall α’s ranging from .72 to .83.

3.3. Mediational pathway

Having determined that the basic psychometrics of all of the instruments used were adequate, Phase II analyses examined mixed regression models to determine whether evidence existed for a mediational pathway. As previously stated, care satisfaction was hypothesized to have a direct, inverse effect on reported levels of hopelessness and a more distal effect on life functioning through its direct relationship with levels of hopelessness. Findings provided information on the (1) overall fit of the proposed model to the data, (2) strength of the association between variables in the model, and (3) mediational roles of specific variables included in the model. Table 3 presents findings for regression models with covariates included in the models for adjustment. Again, the covariates were symptoms of depression and mania, gender, age, history of suicidality, educational background, clinical status, and baseline scores for measures.

Analyzing the proportion of variation in response data explained by the model, care satisfaction increased significantly over the assessment period (F1,164 = 5.00, P < .05). Increases in care satisfaction were associated with decreased hopelessness (F1,79 = 9.22, P < .01), but not related to symptoms of depression (MADRS) or mania (YMRs). Similarly, decreased hopelessness was associated with greater life functioning (F1,109 = 8.80, P < .01), but not related to symptoms of depression or mania. The relationship between care satisfaction and life functioning was weaker.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Cronbach coefficient α</th>
</tr>
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<tbody>
<tr>
<td>基线</td>
<td>3-mo</td>
</tr>
<tr>
<td>CSQ</td>
<td>.82</td>
</tr>
<tr>
<td>BHS</td>
<td>.92</td>
</tr>
<tr>
<td>LIFE-RIFT</td>
<td>.63</td>
</tr>
<tr>
<td>YMRs</td>
<td>.79</td>
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<tr>
<td>MADRS</td>
<td>.89</td>
</tr>
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BHS is only given baseline, 6 months, and 12 months.
than the relationship between care satisfaction and hopelessness ($F_{1,93} = 3.08, P < .10; F_{1,79} = 9.22, P < .01$, respectively). In the unadjusted model, the relationship between care satisfaction and life functioning was significant ($F_{1,102} = 3.96, P < .05$), but was no longer significant when the model was adjusted for covariates. Depression was also strongly associated with poorer life functioning ($F_{1,93} = 262.37, P < .0001$); decreased symptoms of depression accounted for a significant amount of the variation in life functioning scores. Symptoms of mania were not related to life functioning scores (Fig. 1).

4. Discussion

The purpose of the present study was to determine the relationship between care satisfaction, hope, and life functioning in a large sample of bipolar adults treated with pharmacotherapy. Within the STEP-BD sample, the hypothesized mediational pathway between these variables was supported. Participation in STEP-BD was associated with increased care satisfaction over time. Greater care satisfaction was tied to decreased hopelessness and, in turn, higher decreased hopelessness was related to improved life functioning. Thus, as hopelessness decreases, the individual’s ability to participate in work, relationships, and other key activities of daily living increases.

These findings have several implications. Psychiatric treatment of bipolar disorder has traditionally focused on symptom reduction and relapse prevention. Although symptom reduction and relapse prevention remain to be essential goals of evidence-based practices for bipolar disorder, these findings suggest that maximizing patient hope may also be important in enhancing functioning among patients. The present economic climate in which mental health services are provided may be a barrier to taking the time to establish collaborative therapeutic relationships. This study’s findings may be interpreted as support for allocating resources to creating provider-patient partnerships that maximize nonspecific treatment mechanisms such as hope.

The mediational model suggests that levels of hopefulness and symptoms of depression have the strongest direct effects on life functioning. As suggested by past research [35], the depressive component of bipolar illness is strongly linked to quality of life and functioning. This supports a treatment approach for bipolar disorder that is comprehensive and which assists patients to develop coping strategies to reduce the physical, psychological, social, and economic consequences of their illnesses [36]. The STEP-BD model emphasizes symptom reduction through a provider-patient collaborative planning process. This provider-patient partnering model is designed to enhance patients’ active coping mechanisms. The model also assists individuals with bipolar disorder to build the professional, social, and familial supports that are protective factors against depression [37]. It also trains patients to cope with psychosocial stress agents that often exacerbate bipolar illness [38-40]. Patients may become more hopeful when they develop a greater ability to recognize early warning signs of relapse and then make sensible judgments regarding how to manage these symptoms [41].

This study has several limitations. First, it was not a random sample. The data analyses were restricted to patients completing all measures in the standard STEP-BD treatment pathway. Analyses of measure completion determined that persons with bipolar disorder having one or more characteristics including no history of suicidality, a high school education/equivalent or less, employment in “nonprofessional” areas, in a recovering/recovered phase, and of greater age had increased missing data. This study’s findings do not necessarily generalize to other populations of bipolar patients.

Second, the study was naturalistic. A random assignment study of a collaborative care model vs treatment as usual for bipolar disorder might test the causal inferences generated by the current results. Such an investigation would need to further operationalize collaborative care and measure clinicians’ fidelity to the model.

Although previous research on behavioral health care supports the importance of patients’ interaction with providers and staff as a determinant of the overall quality of care provided [42], future studies should investigate what specific components of the collaborative care model for bipolar disorder are most associated with care satisfaction, hope, symptom reduction, and life functioning. There is evidence that hopelessness is a trait attribute for some patients and a state attribute for others [43]. Some patients are consistently high or low on hopelessness regardless of mood state or treatment response. Additional research should explore whether state vs trait hopelessness moderates the impact of care satisfaction on life functioning in bipolar disorder. Future research should also examine whether the increases in life functioning and work productivity associated with collaborative care balance its greater short-term economic costs.

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