



ORIGINAL ARTICLE

Validation of a brief scale for the assessment of distress associated to bipolar disorder



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KEYWORDS

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Abstract

Background and objectives: Perceived distress and discomfort has received less attention in the literature than other factors that influence the course of bipolar disorder (BD). Given its proven relationship with psychopathology, it is of great importance. However, it is necessary to design an instrument to assess it since there is no scale that measures this feature.

Methods: Descriptive cross-sectional design in which 72 BD euthymic patients were assessed. A scale to measure perceived distress in BD (perceived consequences, impact on interpersonal relationships and disorder self-management), scored from 1 to 10 and developed for this study, was applied. In addition, the Young Mania Rating Scale (YMRS) and the Hamilton Depression Scale (HAM-D) were also applied.

Results: Reliability and validity analyses, as well as descriptive and inferential analysis were done. The developed measure showed adequate reliability and validity properties. Descriptive analyses show that the issues that generate more distress in patients were the burden associated to the disease, the perception of a lack of responsiveness from close people, the negative impact of their illness on those relationships, the alteration of mental functions, and the difficulties of managing daily stress.

Conclusions: The present study offers evidence of the psychometric adequacy and usefulness of the developed scale to assess the distress experienced by patients with BD. It is necessary for mental health professionals to pay attention to the patient's perception of illness.

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Abbreviations: BD, bipolar disorder; DISBIP, Distress Scale for Bipolar Disorder; HAM-DH, amilton Depression Scale; YMRS, Young Mania Rating Scale.

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Introduction

Bipolar disorder (BD) is a chronic and recurrent mood disorder characterized by affective episodes (mania, hypomania, and depression), alternating with periods of euthymia. These mood swings, as well as the possible persistence of subthreshold symptoms and neurocognitive alterations, make this a complex chronic condition that implies significant personal and social costs^{1–3} and a clear impact on quality of life.⁴

It is very well-known that recovery is associated with clinical factors, such as number of previous hospitalizations, severity of symptoms and comorbidity.⁵ Some studies have focused on the impact of gender and diagnosis. For example, it is possible to find differences associated with the subtype of BD (I or II) and predominant polarity (depressive or manic). Type II BD and/or predominantly depressive polarity patients are associated to lower quality of life.⁶ In addition, subthreshold symptoms are associated with poorer outcomes in terms of functioning and quality of life.⁶ Regarding gender, some studies⁷ found lower quality of life in women.

Many other studies have focused on identifying psychosocial factors associated with poorer outcome. Factors are related to lack of awareness of illness,⁸ perceived stigma,^{1,9,10} perceived lack of disease control or coping skills^{11,12} and associated interpersonal and social consequences.¹³ In line with this, some studies¹⁴ highlight the interpersonal problems associated with the disease and the perceived associated difficulties at different levels (personal, social, and work) as highly relevant for patients. For example, variables such as having a close relationship could become better predictors of work adjustment than clinical factors, such as the number of previous hospitalizations.¹⁵ Thus, when only considering clinical factors, functioning and quality of life in patients with BD are not always as expected.

Since difficulties coping with the illness have been found to be associated with depression and perceived distress in these patients,¹⁶ a key aspect to take into account is the existence of negative thoughts towards the illness. Although perceived distress has received less attention, it is of great importance given its proven association to anxiety and depression.¹⁷

The concept of distress is a poorly-defined and, at the same time, widely used construct, including in diagnostic classifications such as DSM and ICD.¹⁸ In general, distress may be caused by physical, psychological, emotional, or social problems as consequences of illness.¹⁹ It is a variable that is often under-recognized and under-attended.²⁰ Emotional distress usually refers to high levels of negative affect²¹ (e.g. high worthlessness, high sadness). In this regard, some authors distinguish between distress, which is defined as a non-specific, biological or emotional response to a demand or stressor that is harmful to the individual, and psychological distress, which is defined as a unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary, or permanent, to the person.²² In this paper we are assuming a general distress approach, meaning that we are considering not only emotional discomfort, but also, psychological and social unease associated to BD.

Given the chronic and recurrent nature of BD, patients may experience a high degree of distress related to the consequences of the disorder and the difficulties associated with its management, and they may feel overwhelmed by not being able to reduce this distress by themselves. The distress could be conceptualized as difficulties to cope with the disorder. Although other issues related with this experience, such as the internal hopelessness and stigma, could also interact with the way patients deal with their conditions, the management of distress has shown to impact on the course of different psychopathological issues.²³ In fact, some studies show that the absence of depressive symptoms does not necessarily reflect psychological well-being, but rather a significant degree of distress,²⁴ so it is expected that people in euthymia experience some degree of distress depending on how they cope with the illness.

Assessment of this construct in BD is highly relevant, given that there may be an important degree of distress even in euthymic patients. There are different assessment instruments to measure distress in both general²⁵ and clinical populations.^{26,27} However, current literature shows little development of specific tools for the assessment of distress associated with mental disorders such as BD. In recent years, some researchers have developed measures such as the Quality of Life Questionnaire on Bipolar Disorder, validated by Michalak and Murray.²⁸ Nevertheless, some of the items include symptoms of the disorder itself (for example, feeling full of energy or having difficulty getting out of bed, among others), which may bias results for estimating distress associated with BD, regardless of clinical symptoms.

Based on the lack of adequate measures to assess distress experienced by BD patients from a comprehensive (i.e. physical, psychological, emotional and social) perspective, the current study reports on the validation process of a measure to assess perceived distress in BD patients in the absence of active clinical symptoms. Reliability and validity analyses, as well as results derived from applying the scale to a sample of BD patients are presented. In addition, four hypotheses are tested: (1) the existence of distress in both interpersonal and cognitive domains is predicted among BD euthymic patients. In addition, (2) higher levels of distress are expected in patients with a diagnosis of type II BD or predominant depressive polarity, as well as (3) significant differences according to gender, with higher distress levels in women. Finally, (4) significant correlations between the developed scale, the YMRS²⁸ and the HAM-D²⁹ are expected.

Methods

Participants

Our sample consisted of 72 bipolar outpatients, aged 24–72 (mean = 48.40 ± 11.48); 59.7% were female. All participants were from the Ramón y Cajal Hospital and the Bipolar Association of Madrid. Sociodemographic and clinical data are shown in Table 1. As can be noted, approximately two thirds of the cases were diagnosed with type I BD and the predominant polarity was depressive. Almost half of the participants required one or two psychiatric admissions. Chi-square analyses show a lack of association between sociodemographic (i.e. age, cohabitation, etc.), and clinical (polarity,

Table 1 Sociodemographic and clinical data.

Variables	Category	N	%
<i>Sociodemographic data</i>			
Sex	Male	29	40.3
	Female	43	59.7
Age	18–29	3	4.2
	30–39	17	23.6
	40–49	19	26.4
	50–59	20	27.89
	≥60	13	18.1
Cohabitation	Alone	20	27.8
	With family of origin	29	40.3
Marital status	With own family	23	31.9
	Single	28	38.9
	Married	21	29.2
	Divorced	21	29.2
Academic level	Widow	1	1.4
	Elementary School or less	7	9.7
	Middle School	29	40.3
Employment status	University	35	48.6
	Employed	27	37.5
	Unemployed	17	23.6
	Retired	28	38.9
<i>Clinical variables</i>			
Diagnosis	BD I	47	65.3
	BD II	25	34.7
Predominant polarity	Manic	25	34.7
Admissions in psychiatry	Depressive	45	62.5
	None	18	25.0
	1–2	26	36.1
	3–5	17	23.6
	6–9	7	9.7
	≥10	4	5.6

diagnosis, psychiatric admissions) and gender, which denote that males and females share similar characteristics.

For inclusion in the study, participants had to score ≤ 7 on the YMRS²⁸ and the HAM-D²⁹ scales to ensure that they were euthymic. Patients with co-morbid diagnoses of personality disorder and substance abuse, as well as those with concomitant chronic physical pathologies were excluded from the current study.

Instruments

To assess euthymia, the Spanish version of the Young Mania Rating Scale (YMRS),²⁸ and the Hamilton Depression Scale (HAM-D)²⁹ were used. Likewise, to assess the perceived distress by BD patients, the DISBIP (Distress Scale for Bipolar Disorder) was developed (items, translated from Spanish, are shown in Table 2). This measure consists of 46 Likert type items (1–10), to assess three domains where psychological, emotional, and social distress are present: (1) distress

associated with the perceived cognitive consequences of the disease, (2) distress associated with the management and coping of the disease, and (3) interpersonal distress. The first domain assesses the perceived discomfort associated to changes in emotions, personality and cognitive functions. The aim is to assess distress regarding perceived consequences of the illness from a predominantly cognitive viewpoint. The second domain assesses the extent to which patients feel capable of managing their own disease. That is, the capability to live a normal life, to attain personal goals, and to feel satisfied. Finally, the third domain assesses the impact of the disorder on the patient's social relationships. For all the domains and the total measure, the higher the score, the more distress experienced.

Procedure

First, an item-analysis was carried out by four expert raters who had to rate: (1) the intensity or degree to which each item belongs to a particular category, (2) the degree to which the item is considered adequate to assess BD patients (for both judgments a scale of 1–5 points was used, with 5 being the maximum score); and (3) the valence (positive or negative) of the item. After the ratings, agreement indices were calculated. This allowed us to refine the wording of the items. Then, reliability analysis and confirmatory factor analysis (CFA) were performed.

After receiving the approval of the Ramón y Cajal Hospital Ethics Committee, the initial pool of 46 items was applied to the selected participants, together with a socio-demographic questionnaire and the YMRS²⁸ and HAM-D²⁹ scales. Previous, informed consent was acquired and confidentiality was guaranteed to the participants. Reliability and CFA were performed with a 15-item version of the scale, given the relatively small sample size and the search for an easier-to-administer scale that retains high reliability with evidence of construct validity

Statistical analysis

IBM® SPSS® and Amos v. 23 were utilized for the analyses. Interrater reliability was estimated with the Fleiss Kappa statistic.³⁰ Reliability analyses were performed with Cronbach's alpha statistics. CFA were performed to assess the goodness-of-fit of the proposed three-factor model. Maximum likelihood parameter estimation was utilized as multivariate normality was identified.³¹ Several common fit indexes such as Absolute/predictive fit Chi-Square, the Non-Normed Fit Index (NNFI, also known as Tucker-Lewis index or TLI), the Comparative Fit Index (CFI), and the root mean square error of approximation (RMSEA) were utilized. In general, RMSEA < .06, TLI > .95, CFI > .95 are the suggested cutoff values to support model fit.³² Next, correlational and inferential analyses (Pearson's correlation, Student's *T* test and ANOVA test) were performed to contrast the additional hypotheses.

Results

The analysis of the concordance among raters concerning category resulted in a percent agreement = 89.85% which is

Table 2 DISBIP-S items and factors, with mean and standard deviation scores.

	Items (and factor)	Mean	SD
1.	I feel that bipolar disorder allows me to live a normal life. (M)	4.39	2.71
2.	When I think about living with a bipolar disorder, I feel sad, angry and/or scared. (C)	5.13	2.83
3.	Having a bipolar disorder does not stop me from doing those things which are important to me. (M)	4.39	2.89
4.	Having a bipolar disorder allows me to live my life like anyone else. (M)	4.35	3.11
5.	My bipolar disorder conditions my personality. (C)	5.75	3.16
6.	I think my mental functions are impaired due to bipolar disorder. (C)	5.71	3.23
7.	I can't do the daily chores as I would like to do because of my bipolar disorder. (M)	4.63	3.31
8.	Having bipolar disorder does not prevent me from reaching my goals. (M)	4.40	3.11
9.	People who have bipolar disorder must face the heavy burden of the illness. (C)	5.89	3.27
10.	If someone asks me if I think that I live a satisfying life despite having bipolar disorder, I would say yes without a doubt. (M)	4.08	3.04
11.	Having this disease causes me great distress that I find difficult to cope with. (C)	4.50	3.00
12.	Even though I have a bipolar disorder, I feel that I live a satisfying life. (M)	3.80	2.88
13.	People who do not have bipolar disorder do not understand me. (I)	5.43	2.94
14.	I think people close to me are well informed about what bipolar disorder is. (I)	4.92	3.19
15.	My friends treat me like anyone else who doesn't have a disease. (I)	3.82	3.13
F1	Management of the disease	4.32	2.30
F2	Cognitive distress	5.38	2.30
F3	Interpersonal distress	4.72	2.34

Table 3 Unstandardized loadings (standard errors), standardized loadings, and r^2 value for 3-factor confirmatory model.

			Unstandardized (SE)	Standardized	r^2
M1	←	Management	1.000 (–)	.802	.644
M2	←	Management	.810 (.152)	.610	.372
M3	←	Management	1.128 (.153)	.788	.620
M4	←	Management	.951 (.173)	.625	.391
M5	←	Management	.799 (.167)	.559	.312
M6	←	Management	1.073 (.151)	.770	.593
M7	←	Management	1.148 (.139)	.864	.747
C1	←	Cognitive	1.000 (–)	.631	.399
C2	←	Cognitive	1.157 (.259)	.655	.430
C3	←	Cognitive	1.162 (.263)	.645	.415
C4	←	Cognitive	1.151 (.265)	.629	.396
C5	←	Cognitive	1.249 (.255)	.744	.553
I1	←	Interpersonal	1.000 (–)	.532	.283
I2	←	Interpersonal	1.469 (.405)	.721	.519
I3	←	Interpersonal	1.183 (.355)	.590	.348

Note: Dashes (–) indicate the standard error was not estimated. r^2 = Squared Multiple Correlations

very high,³⁰ and four items were revised for the wording and content. The agreement on the intensity and adequacy of the items required that only one item be reviewed. Finally, with respect to valence, it was suggested that one of the items be reviewed.

The 15-item version of the measure (see Table 2) was selected for further analyses. Cronbach's alpha for the scale was .90. The reliability was .88 for Management of the disease ($n=7$ items), .80 for Cognitive distress ($n=5$ items), and .64 for Interpersonal distress ($n=3$ items). These results support the reliability of the measure.

Table 3 shows the parameter estimates (unstandardized and standardized) and r^2 values for the model when using ML estimator. Note that all the items have medium-high r^2 values, as well as high loadings in their respective factors.

The hypothesized model appears to be a good fit to the data: χ^2 (87)=115.876; $p=.021$; $\chi^2/\text{df}=1.332$. The CFI is .93; RMSEA is .068 (90% CI: .028 to .099). The correlation between latent variables Management and Cognitive was .799 (covariance=3.064, SE=.833); the correlation between latent variables Interpersonal and Cognitive was .537 (covariance=1.479, SE=.611); the correlation between latent variables Interpersonal and Management was .770 (covariance=2.576, SE=.828). Altogether, the results offer support to the proposed three-factor model.

Regarding the second hypothesis (see Table 2), the descriptive analyses of the items showed that the issues that generate more distress were cognitive in nature, namely the perceived burden associated with the disease (5.89 ± 3.27), the perceived alteration of personality (5.75 ± 3.16), and

the alteration of mental functions (5.71 ± 3.23). Some Interpersonal issues, such as perception of a lack of understanding from people who do not have this disorder (5.43 ± 2.94), are also noteworthy. Medium-moderate levels of distress associated to the disease are identified among the three factors.

Regarding the third hypothesis, predominant polarity was associated to significant differences in Management of the disease and Cognitive distress, in 6 of the 15 items. Patients with depressive polarity experience significantly higher distress in both domains. Regarding the fourth hypothesis, significant differences ($p < .05$) in the item concerning mental functioning (item 5, perceived difficulties), were more severe for men than for women. No additional differences were found by gender.

With regard to the associations between the utilized measures, contrary to our expectations, non-significant correlations were obtained between YMRS²⁹ and the three factors of the developed measure. As expected, correlations with HAM-D³⁰ were positive, medium-high and significant ($p < .01$) with the three domains of the scale: .657 (Management), .500 (Cognitive), and .414 (Interpersonal).

Discussion

This study offers evidence of the psychometric adequacy of the developed scale. First, the interrater agreement supports the scale content and face validity.³³ Additionally, reliability indexes for the three factors and total scale support its internal consistency. The different indexes suggest the three-factor model fit to the data, which also offers support to the construct validity of the measure. The findings reveal the perception of burden associated with the disease itself, as well as with its impact on interpersonal life, is consistent with previous studies.¹⁴

As expected, the differences found by diagnosis and predominant polarity are congruent with previous studies⁶ and reveal that patients with type II BD and/or predominant depressive polarity experience worse quality of life. These results also support the validity of the scale to adequately discriminate between diagnostic subgroups.

With regard to the differences by gender, contrary to our expectations, there was a general lack of significant differences based on this variable. Previous studies have found poorer quality of life in women. Such findings are explained by comorbidities such as physical conditions, particularly if they involve pain.⁷ Therefore, current findings could be explained if we consider that this study excluded patients with concomitant chronic physical pathologies.

On the other hand, and in line with the fourth hypothesis, the analysis of the association between the items and the HAM-D²⁹ showed significant correlations with all the dimensions of the scale, although no significant correlations with the YMRS²⁸ were found. As the sample only included euthymic patients, these findings may show that distress related to BD euthymic patients is more closely associated to depression than to mania. Given the tendency of these patients to suffer from subclinical depressive symptoms at follow-up, and the association of these symptoms with worse functioning and poorer quality of life,^{34,35} the developed scale may be used as a screening tool to better meet each

patients' needs. In addition, as the findings suggest that the difficulties perceived by BD patients may occur at personal and interpersonal levels, interventions aimed at learning how to cope with their illness are essential to promote their wellbeing.^{9,35}

The current study has a number of limitations that should be considered. First, this cross-sectional study was conducted at two institutions and with a relatively small sample. Therefore, caution should be noted when using the findings of this study to make generalized conclusions. Also, more homogeneous subsets in terms of age and diagnosis are also advisable and expected in further studies. The use of already validated measures to compare the current findings and the impact of distress in other dimensions (stigma and beliefs about the disease, for example) is recommended and planned for in future phases of the study. Also, the application of the current measure to a larger sample will allow performing additional reliability and validity analyses as expected in a scale validating process, leading to the definitive version of the scale.

Conclusions

In sum, this study offers evidence of the usefulness of the developed scale to assess the distress experienced by BD patients. The scale has shown adequate content, and construct (convergent and discriminant) validity, as well as reliability. It has also shown that being euthymic does not preclude experiencing distress in personal and interpersonal domains. The need to validate a measure which makes it possible to identify these issues is clear and is potentially useful for both clinical work and research. It would be a useful measure in terms of tertiary prevention, with the aim to promote psychosocial functioning and to prevent further deterioration. In short, it will allow us to improve the care of these patients, making it easier for the clinician to identify issues beyond the symptomatology, which can interfere both in the course of the disease and in their adaptation to the daily life.

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Conflict of interest

The authors have no conflict of interest to declare.

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