

DBSA Survey Center

Preferences for the Treatment of Bipolar Disorder Survey

Summary Report: May, 2017

BACKGROUND

The Preferences for the Treatment of Bipolar Disorder survey solicited the opinions of people living with bipolar disorder and family members/caregivers on which treatments are most helpful in preventing recurrences or staying well.

Developed by DBSA Scientific Advisory Board Member David Miklowitz, Ph.D., with the support of DBSA, the survey explored preferences related to talk therapy, education, and research with the goal of helping mental health providers determine the most appropriate treatments and helping individuals and their families understand the options available.

Between October 1, 2016 – November 30, 2016, DBSA collected 2,969 responses to the Preferences for the Treatment of Bipolar Disorder survey. The survey was administered using the Survey Monkey online program. Individuals were invited to complete the survey through DBSA's online monthly newsletter, chapter network, and social media pages. The International Bipolar Foundation also provided targeted promotions for the survey. The survey link was also shared with several other mental health organizations to be distributed to their members.

SURVEY RESULTS

DEMOGRAPHICS

In the following section, we provide a summary of the findings. There were a total of 2,395 respondents that identified as having lived experience of bipolar disorder, and 456 respondents that identified as family members and/or caregivers of persons with bipolar disorder.

AGE GROUP

Category	<18	18-20	21-29	30-39	40-49	50-59	60+	Total
Bipolar I	13	20	134	244	198	154	50	813
Bipolar II	7	16	200	338	270	165	68	1,064
Unspecified Bipolar	8	17	129	133	120	79	32	518
Family Member/Caregiver	7	5	50	79	125	119	71	456
None of above	13	4	28	31	26	11	5	118
Totals	48	62	541	825	739	528	226	2,969

USE OF MEDICATION AND/OR THERAPY BY PEOPLE WITH BIPOLAR DISORDER:

YES MEDS, YES THERAPY:	820	(50.4%)
YES MEDS, NO THERAPY:	628	(38.6%)
NO MEDS, YES THERAPY:	4	(.02%)
NO MEDS, NO THERAPY:	28	(1.7%)
TOOK MEDS PAST, NOW ONLY IN THERAPY:	47	(2.9%)
TOOK MEDS PAST, NO THERAPY:	100	(6.1%)

PSYCHOTHERAPY

Clearly, psychotherapy for bipolar disorder is a topic of considerable importance to community members with bipolar disorder (BD) and their family members/caregivers. There were a number of survey highlights relevant to psychotherapy-related preferences:

- The vast majority of persons with bipolar disorder were taking medications (87%) but only 53.6% were receiving psychotherapy. Only 10% of individuals with BD attended support groups.
- Respondents with BD under 30 years of age (n = 652) rated the following as their first or second therapy preference:
 - Individual cognitive behavioral therapy 51.1%
 - Individual interpersonal therapy 41.3%
 - Family therapy 14.9%
 - Group psychoeducation 13.1%
 - Group health habits 11.0%
- When asked “Which type of psychoeducation would you be likely to attend if offered”:
 - 53% of people with BD and 68% of family members/caregivers would attend Family-Focused Treatment (FFT) sessions
 - 83% of caregivers/family members would attend caregiver-only groups
 - 41% of people with BD and 63% of caregivers/family members would attend multiple family groups.

There was a considerable agreement in the responses of individuals with bipolar disorder and caregivers regarding preferences for certain formats of group or family psychoeducation. People with BD and caregivers preferred clinician-run groups (59%-65%) to mutual support groups run by individuals with bipolar disorder or caregivers (10%-39%). Few were concerned about confidentiality (18%-33%), and most (76%) preferred open sharing and problem-solving related to the illness over a lecture/classroom format.

INTERNET-BASED THERAPY

The following represent numbers/percent of patients who agreed or strongly agreed on the following questions about internet-based therapy.

	Number Endorsing:
Prefer Internet-based weekly treatment over in-clinic groups	324 (17%)
Prefer therapy via Skype over therapy in-person	297 (11.4%)
Family would be more likely to attend an online group than an in-person group	311 (9.4%)

OUTCOMES

Of considerable importance for this survey was the ranking of most valued outcomes to examine in research. What outcome variables do participants think are most important to track over time? The numbers below reflect the % of participants rating the following outcome as important or extremely important to them.

Outcome	Patients (all)	Patients (under 30)	Caregivers/family members
Quality of life	88.9%	86.2%	94.5%
Functioning at school/work	84.9%	86.1%	89.8%
Illness Recurrences	82.3%	81.0%	90.2%
Number of days well	80.0%	75.0%	64.7%
Quality of Family Life	76.1%	70.3%	84.3%
Adherence with medications	72.0%	69.4%	78.3%
Quality of Friendships	45.7%	41.3%	60.9%

Quality of individual and family life, functioning, and recurrences were rated as important outcomes across age groups and across patients and caregivers/family members. This is important because many randomized clinical trials only examine changes in symptoms (such as changes from a high to a low score on a depression survey) and do not consider these broader metrics of life satisfaction.

RESEARCH OUTLETS

Respondents were also asked whether they currently use, or would like to use, the following sources for learning of new research findings (2,402 Total Patient Responses and 460 Total Caregiver Responses):

Research Outlets	Currently Use	Would Like to Use
Newsletters		
Patients	813 (34%)	517 (24%)
Caregivers	151 (33%)	81 (18%)
Webinars		
Patients	260 (11%)	731 (30%)
Caregivers	47 (10%)	118 (26%)
Books		
Patients	1007 (42%)	372 (15%)
Caregivers	175 (38%)	57 (12%)
Videos		
Patients	392 (16%)	696 (29%)
Caregivers	67 (15%)	129 (28%)

Most currently rely on newsletters and books as sources of research information about the illness. Many also reported that they were open to, and would be interested in obtaining information from webinars or videos.

SUMMARY AND DISCUSSION

This survey generated a considerable amount of interest. We were pleased that our advocacy organization is able to rapidly engage an age-diverse population regarding their treatment preferences. We are grateful to our respondents for making their opinions known.

We have learned several things:

1. Getting medication only is a more common treatment regimen than is getting therapy only; few people with bipolar disorder (BD) chose therapy by itself. However, the majority received both treatments. Obtaining medications from a physician and therapy from a trained clinician has many merits, although we must make sure that the two clinicians are in regular contact about the patient's progress or side effects (Gitlin and Miklowitz, 2016).
2. The largest proportion of patients preferred individual cognitive-behavioral therapy over group, family, or other therapy modalities. However, the majority said they would attend family intervention sessions with their parents, spouse, or siblings. Patients were less enthusiastic about attending multiple family groups with their caregivers. Caregivers had a clear preference for caregiver-only support/education groups. These results should be considered taking into account that many respondents had not been offered or did not have access to the kinds of treatment they were being asked to rate.
3. As an organization, we are quite aware of how difficult it can be for individuals with BD and families to find therapy that is both supported by research studies and available (and affordable) in one's home community. We expect internet and video chat-based therapy models will become increasingly available to meet this demand. It is not clear yet from research whether one can achieve the same goals in video- or internet-based therapy as one can achieve in person with a trained therapist.
4. People with bipolar disorder and caregivers both emphasize that clinical trial studies should not only track symptom relief or side effects, but should also measure quality of life or personal functioning. Indeed, many people with bipolar disorder define recovery quite differently than do researchers – the ability to function well and meet one's goals despite the ups and downs of bipolar illness.

Reference:

Gitlin, M. J. & Miklowitz, D. J. (2016). "Split treatment": review and recommendations for its optimal use. [Annals of Clinical Psychiatry](#), [28](#)(2),132-7.