

# DBSA Survey Center

## Depression Experiences and Treatments Survey

Summary Report: May, 2017

### BACKGROUND

DBSA's Depression Experiences and Treatments Survey was developed to identify experiences and challenges faced by individuals with depression, including what people are looking for in terms of treatment, their perception of various treatment modalities, and use of non-medical self-help and wellness tools.

February 2016 – April 2016, DBSA collected responses to the Depression Experiences and Treatments Survey. Eight hundred and ninety-six (896) individuals participated. The survey was administered using the Survey Monkey online survey program. Individuals were invited to volunteer to complete the survey through DBSA's online monthly newsletter, chapter network and social media pages. The survey link was also shared with several other mental health organizations to be distributed to their members.

### SURVEY RESULTS

In the following section, we provide a summary of the findings. There were a total of 896 respondents that responded to the initial question within the survey regarding their diagnosis. Since the focus of the survey is on depression and bipolar disorder, starting at Question 2 we present the response summaries for individuals with depression and individuals with bipolar disorder with depression.

<b>DEPRESSION GROUP = 447 PEOPLE</b>	<b>BIPOLAR GROUP = 449 PEOPLE</b>
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### DIAGNOSIS

Respondents were evenly split between a diagnosis of only depression and a diagnosis of depression and bipolar disorder.

Diagnosis	Response Percent
Depression	49.9%
Bipolar disorder	50.1%
<b>Total sample = 896</b>	

## SYMPTOMS

Both groups reported experiencing most of the listed symptoms of depression.

SYMPTOMS EXPERIENCED	DEPRESSION GROUP N=447	BIPOLAR GROUP N=449
Answer Options	Response Percent	Response Percent
Irritability, anger, worry, agitation, anxiety	92.2%	93.8%
Loss of energy, persistent lethargy	88.4%	89.1%
Inability to take pleasure in former interests, social withdrawal	85.5%	88.2%
Feelings of guilt, worthlessness	85.2%	87.3%
Prolonged sadness or unexplained crying spells	85.0%	86.0%
Inability to concentrate, indecisiveness	80.1%	87.1%
Significant changes in appetite and/or sleep patterns	79.2%	82.4%
Pessimism, indifference	70.9%	74.8%
Unexplained aches and pains	52.3%	53.5%
Other	15.0%	18.3%

When asked about what symptoms ultimately led them to reach out for professional help, the two groups were similar in their responses, with one exception. A larger portion of the bipolar group reported that symptoms of irritability, anger, worry, agitation, and anxiety were symptoms that led them to seek professional services or treatment.

SYMPTOMS PROMPTING PROFESSIONAL HELP	DEPRESSION GROUP N=427	BIPOLAR GROUP N=438
Answer Options	Response Percent	Response Percent
Prolonged sadness or unexplained crying spells	64.6%	66.4%
Irritability, anger, worry, agitation, anxiety	57.4%	66.0%
Feelings of guilt, worthlessness	48.2%	50.2%
Inability to take pleasure in former interests, social withdrawal	44.0%	47.3%
Loss of energy, persistent lethargy	39.1%	42.9%
Inability to concentrate, indecisiveness	37.2%	39.5%

<b>SYMPTOMS PROMPTING PROFESSIONAL HELP (CONTINUED)</b>	<b>DEPRESSION GROUP N=427</b>	<b>BIPOLAR GROUP N=438</b>
Significant changes in appetite and/or sleep patterns	27.9%	33.3%
Pessimism, indifference	24.4%	23.7%
Unexplained aches and pains	18.5%	16.4%
Other	11.5%	14.8%

## TREATMENT

The majority of people in the depression group had tried five or fewer medications to address their depression, while the majority of the bipolar group tended to have taken three or more medications to control their depression. Over a third of the bipolar group reported trying 10 or more medications to treat their symptoms of depression.

<b>NUMBER OF MEDICATIONS</b>	<b>DEPRESSION GROUP N=410</b>	<b>BIPOLAR GROUP N=417</b>
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Percent</b>
3-5 medications	30.0%	26.1%
6-9 medications	19.3%	30.9%
1 medication	18.8%	2.6%
2 medications	16.1%	6.2%
10 or more medications	15.9%	34.1%

When asked about what wellness strategies they participate in regularly, we found the two groups responded similarly, with a few exceptions. Individuals in the bipolar group tended to use spirituality, peer support services and ensuring adequate sleep at night, more often than people in the depression group.

WELLNESS STRATEGIES	DEPRESSION GROUP N=399	BIPOLAR GROUP N=409
Answer Options	Response Percent	Response Percent
Listening to music	55.9%	63.1%
Playing with a pet or children	54.6%	56.7%
Spending time with friends or family	45.1%	47.9%
Getting enough quality sleep	43.9%	57.5%
Artistic/creative outlets	38.1%	40.1%
Eating a balanced and varied diet	36.1%	39.6%
Exercise (other than leisure walking)	35.8%	35.0%
Breathing exercises	34.3%	32.0%
Leisure walking	31.1%	35.5%
Meditation	29.3%	29.8%
Spirituality	28.1%	40.6%
Journaling	27.1%	38.1%
Volunteering	24.1%	25.2%
Participating in peer support	19.3%	31.5%
Other	12.8%	15.2%

A larger portion of the bipolar group reported trying group therapy, peer support services, and ECT as components of their treatment plans. On most other measures, the depression and bipolar groups were similar.

<b>NON-MEDICINE TREATMENTS</b>	<b>DEPRESSION GROUP N=378</b>	<b>BIPOLAR GROUP N=392</b>
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Percent</b>
Psychotherapy/Talk therapy	95.0%	93.9%
Professional-led group therapy	31.7%	40.3%
Peer-led support groups	23.5%	40.1%
Other	8.7%	14.5%
Electroconvulsive Therapy (ECT)	7.9%	14.0%
Wellness retreats	6.1%	6.9%
Transcranial Magnetic Stimulation (TMS)	1.6%	3.3%
Vagus Nerve Stimulation (VNS)	1.3%	1.5%

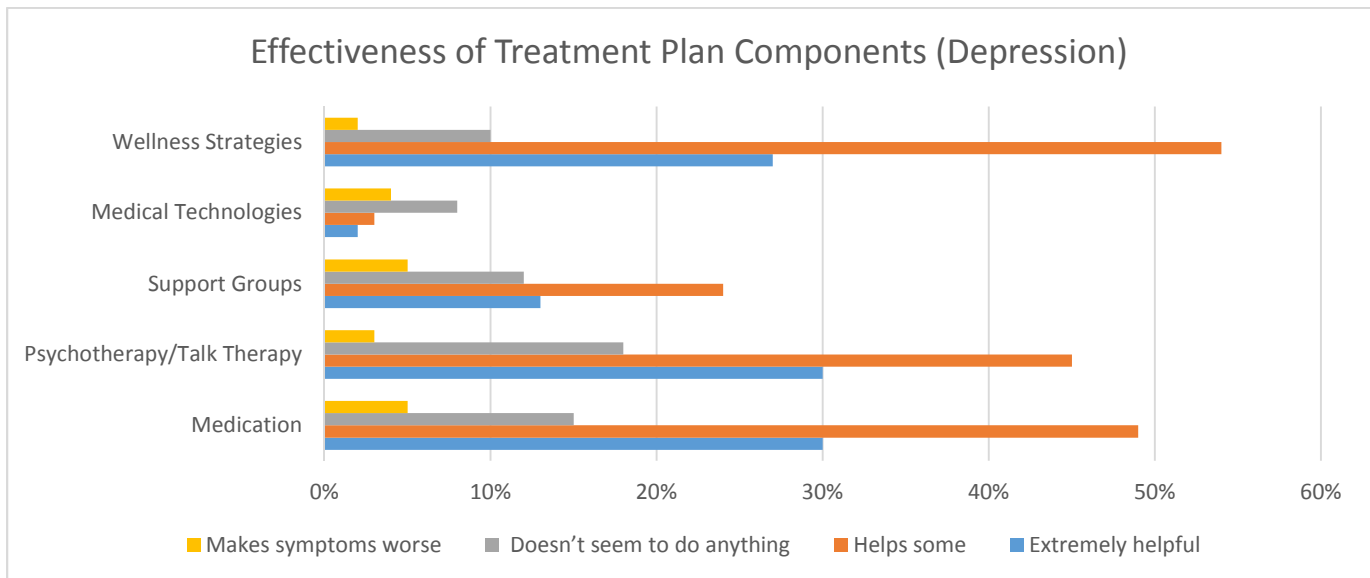
DBSA then asked whether individuals felt that they had found an effective treatment plan. In both groups nearly or more than three quarters (71% depression and 76% bipolar) respectively of the respondents felt that they have a plan that is working, or at least partly working, for them.

<b>EFFICACY OF TREATMENT PLAN</b>	<b>DEPRESSION GROUP N=410</b>	<b>BIPOLAR GROUP N=417</b>
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Percent</b>
Partial	45.4%	46.5%
No	29.0%	24.0%
Yes	25.6%	29.5%

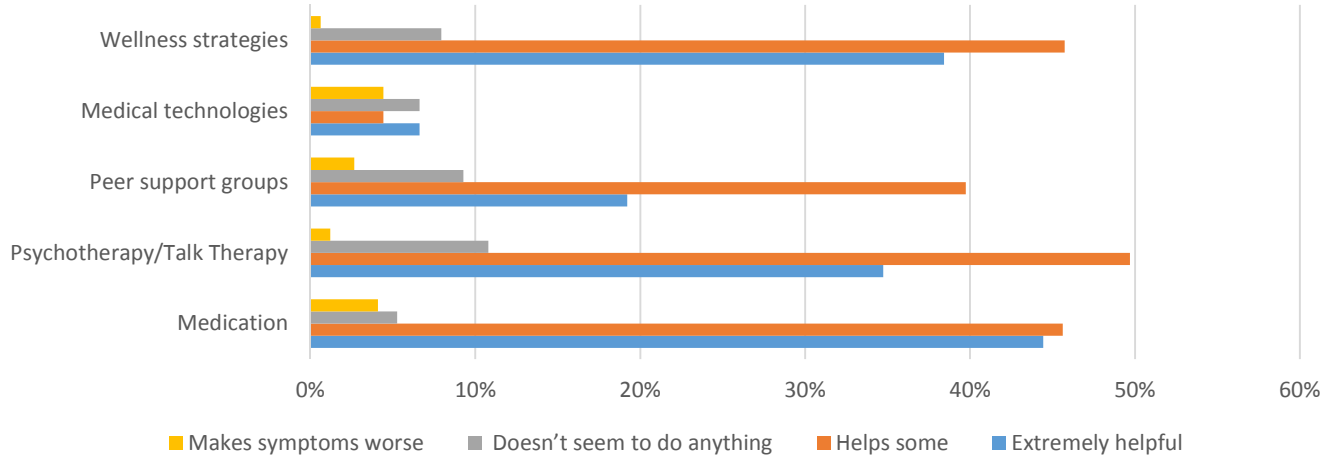
When asked which components made up their treatment plan, a larger portion of the bipolar group reported having all of the listed components in their treatment plan compared to the depression group. The majority of both groups take medication and more than half of each group participates in psychotherapy.

TREATMENT COMPONENTS	DEPRESSION GROUP N=395	BIPOLAR GROUP N=406
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Percent</b>
Medications	75.4%	88.9%
Wellness Strategies (may include things like exercise, spending time with friends, spirituality, etc.)	58.5%	61.8%
Psychotherapy/Talk therapy	53.4%	65.3%
Peer support groups	16.5%	27.6%
Other	12.7%	15.5%
Medical technologies (such as VNS, TMS, or ECT)	2.0%	5.9%

Respondents were then asked to share how helpful they felt the various components of their treatment plan were. The majority of individuals in both groups found medication, psychotherapy/talk therapy and wellness strategies either helpful or extremely helpful. There were fewer individuals with depression who had tried peer support services and this likely affected the percentages for individuals who thought it was helpful or extremely helpful. In contrast, the majority of individuals in the bipolar group found peer support groups to be helpful or extremely helpful. Few people in either group had tried the medical technologies.



## Effectiveness of Treatment Plan Components (Bipolar Disorder)



The next question focused on the reasons that people have changed treatments in the past. For individuals in the bipolar group side effects, impact on physical health, and doctor recommendation to switch had a much larger impact on their decision than the depression group. Cost of treatment also appears to be an important determinant for switching treatments for people in the bipolar group. For those experiencing depression, side effects and the feeling that the treatment was not working sufficiently led the reasons.

REASONS FOR TREATMENT CHANGES	DEPRESSION GROUP N=354	BIPOLAR GROUP N=383
Answer Options	Response Percent	Response Percent
Didn't feel it was working sufficiently	63.6%	69.5%
Side effects	49.4%	71.8%
Doctor recommended a switch	29.1%	47.0%
Cost	21.8%	29.0%
Impact on physical health	20.1%	36.8%
Availability/Access	16.7%	19.8%
Was too hard to incorporate into my daily life	9.9%	9.9%
I have not changed treatments.	9.0%	5.2%
Have to remember to take medication several times a day	8.5%	9.7%
Other	8.5%	10.2%
Way medication is administered (liquid, tablet, injection, etc.)	2.5%	2.6%

When asked how they know that the treatment is working, the highest rated response was, “I don’t feel overly anxious, agitated or irritable.” for both groups. In every answer option listed for this question, a larger portion of individuals in the bipolar group identified it as a sign that their treatment is working.

<b>HOW KNOW TREATMENT IS WORKING</b>	<b>DEPRESSION GROUP N=370</b>	<b>BIPOLAR GROUP N=386</b>
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Percent</b>
I don’t feel overly anxious, agitated, or irritable	62.7%	69.7%
My negative self-talk goes down	54.1%	58.5%
I don’t dwell as much on negative experiences	52.4%	58.0%
I get out of bed in the morning/I don’t feel so tired or lethargic	51.4%	56.2%
I am able to maintain concentration for activities, such as reading a book	44.6%	60.1%
I feel hopeful about the future	43.2%	57.8%
I return to activities that I used to enjoy, such as cooking, gardening, or playing a sport	43.0%	51.3%
I can make decisions	38.9%	58.0%
I feel that I offer something to this world	37.6%	44.6%
I go out with friends/family more	34.6%	46.4%
I’m proactive about my life	34.1%	45.6%
I feel happy	31.9%	39.9%
My family/friends comment on positive changes in mood/behavior	28.6%	44.3%
My eating and/or sleep patterns go back to normal	26.8%	46.6%
My physical symptoms disappear (headaches, nausea, etc.)	15.9%	26.7%
Other (please specify)	12.2%	12.2%



## CHANGES IN TREATMENTS

Individuals in both groups indicated that weight gain was the side effect that most commonly led them to discontinue a specific medication. Feeling lethargic/sleepy and anxiety also ranked highly for both groups. For people in the bipolar group this was followed by shaking/trembling and suicidal thoughts. For those in the depression group, blunted emotions and suicidal thoughts were next highest.

SIDE EFFECTS THAT CAUSE DISCONTINUATION OF MEDICINE	DEPRESSION GROUP N=316	BIPOLAR GROUP N=384
Answer Options	Response Percent	Response Percent
Weight gain	43.7%	56.9%
Feeling lethargic/sleepiness	36.7%	49.7%
Blunted emotions	35.4%	31.0%
Anxiety	34.2%	43.7%
Suicidal thoughts	27.8%	38.5%
Sexual dysfunction	27.5%	33.8%
Shaking/trembling	26.6%	43.1%
Dry mouth	26.3%	22.0%
Irritability	24.4%	35.7%
Insomnia	23.7%	33.8%
Gastrointestinal issues	23.7%	26.4%
Headaches/blurred vision	21.8%	29.7%
Loss of balance/dizziness	21.8%	33.5%
Other	17.4%	21.2%
Impact on pregnancy/nursing	4.1%	5.5%

When asked to think about what factors were most impactful on their medical treatment decisions, side effects came in highest for both groups, followed by doctor recommendation. For people with depression, this was followed by the cost of the treatment. For those in the bipolar group, the impact on physical health came in third.

<b>FACTORS IMPACTING TREATMENT DECISIONS</b>	<b>DEPRESSION GROUP N=370</b>	<b>BIPOLAR GROUP N=386</b>
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Percent</b>
Side effects	68.4%	72.3%
Doctor recommendation	48.4%	58.8%
Cost	44.9%	41.2%
Impact on physical health	43.5%	52.8%
How quickly it will begin to work	37.3%	34.2%
How easily it can be integrated into my daily life	30.8%	25.6%
On-going availability	23.0%	24.4%
Frequency of doses	8.6%	11.9%
Family or peer's thoughts about the treatment	7.0%	10.4%
Other (please specify)	6.5%	9.3%
Way medication is administered	5.1%	8.0%
Impact on pregnancy/nursing	3.2%	2.8%

DBSA is frequently told that individuals living with mood disorders are fearful on changing their medical treatments. When asked to share what their three top concerns were, both groups felt that having new side effects was the biggest, followed by not knowing how they would respond to the new treatment and experiencing a return of symptoms.

CONCERNS ABOUT CHANGING MEDICATIONS	DEPRESSION GROUP N=370	BIPOLAR GROUP N=386
Answer Options	Response Percent	Response Percent
New side effects	64.3%	67.4%
Not knowing how I will respond	54.1%	48.4%
Return of symptoms	53.0%	58.5%
The wait for the new treatment to kick in	30.0%	31.9%
Feeling hopeful and then getting disappointed if the treatment doesn't work	26.5%	23.1%
Concern that the current treatment(s) may not work the same for me in the future if I discontinue them now	14.9%	21.0%
I am not concerned about switching treatment	9.2%	10.6%
Other (please specify)	5.1%	6.5%

## SUMMARY AND DISCUSSION

The results of this survey indicate while there are many who are experiencing some effectiveness from their treatment plan, only a quarter of those surveyed felt that their plan was completely effective in treating their mood disorder.

Medication, talk therapy, and wellness strategies were common in treatment plans, but peer support groups and medical technologies had been tried much less frequently. It was also found that individuals who implemented several wellness strategies tended to feel that their treatment plan was more effective. Respondents also shared their concerns about side effects and how they are major factor when deciding on medical options.

DBSA hopes to utilize the information gained through this survey to develop resources to:

- educate individuals on wellness strategy combinations that may be most beneficial
- increase the availability of peer support groups so that may more benefit
- educate individuals on strategies to combat side effects