Living with Bipolar Disorder: How Far Have We Really Come?

National Depressive and Manic-Depressive Association

Constituency Survey

National Depressive and Manic-Depressive Association
730 North Franklin Street, Suite 501
Chicago, Illinois 60610-7204 USA
www.ndmda.org
(800) 826-3632
(312) 642-0049

National DMDA Constituency Survey

The National Depressive and Manic-Depressive Association (National DMDA) sponsored a survey of people living with bipolar disorder, also known as manic-depressive illness, in 2000. The goals of the study were to better understand the experiences of those seeking and receiving treatment, including the personal impact of the disease, and determine what progress, if any, has been made since a similiar survey conducted in 1992. Bipolar disorder is a chronic disease affecting 2.5 million adult Americans. It is most often characterized by abnormal mood swings consisting of cycles of mania and depression.

The mission of the National DMDA is to educate patients, families, professionals, and the public concerning the nature of depressive and manic-depressive illnesses as treatable medical diseases; to foster self-help for patients and families; to eliminate discrimination and stigma; to improve access to care; and to advocate for research toward the elimination of these illnesses.

Consumers Seeking Help Earlier

Major advances in our understanding of the neuroscience behind mental illnesses have translated into only incremental gains at the front lines of care – particularly for bipolar disorder, which affects 2.5 million adult Americans. According to the National DMDA survey of people with bipolar illness, conducted in 1992 and repeated again this year, those affected are seeking help earlier in the development of the disease. Thirty-six percent now seek help within one year of the onset of symptoms, compared to only 30% in 1992, and fewer are letting their symptoms persist for more than a decade before seeking help. However, nearly one-third still wait at least 10 years before seeking help.

TABLE 1

Lapsed Time from Onset of Symptoms to Seeking Help

	1992	2000
(Base)	(500) %	(600) %
Less than 1 year	30	36↑
1 year, but less than 3 years	12	9
3 years, but less than 5 years	8	6
5 years, but less than 10 years	14	13
10 years or more	36	31

Question: How much time elapsed from when you first exhibited signs of your illness to when you first sought professional guidance and/or treatment?

↑*Significantly higher than 1992 at the 95% confidence level.*

Misdiagnosis Occurs Commonly and Repeatedly

Misdiagnosis is not only common, it occurs repeatedly. Those who were misdiagnosed received, on average, 3.5 misdiagnoses and consulted four physicians before receiving an accurate diagnosis. Depression is, by far, the most common misdiagnosis. Women were more likely than men to be misdiagnosed and much more likely to be misdiagnosed with depression. Men, on the other hand, were twice as likely to receive a diagnosis of schizophrenia.

TABLE 2
Incidence of Misdiagnosis

	1992	2000
(Base)	(500) %	(600) %
Misdiagnosed (yes)	73	69
Not misdiagnosed (no)	26	28

Question: Were you ever misdiagnosed?

No significant differences at the 95% confidence level.

TABLE 3
Incidence, Frequency and Nature of Misdiagnoses

	Total	Men	Women
(Base: Total)	(600) %	(203) %	(391) %
Were misdiagnosed (incidence)	69	62	72↑
(Base: Those misdiagnosed)	(411)	(126)	(283)
	#	#	#
# of times misdiagnosed	3.5	3.4	3.4
# of physicians consulted before receiving accurate diagnosis	4.0	3.8	4.0
Nature of misdiagnosis	%	%	%
Depression	60	43	68↑
Anxiety Disorder	26	26	26
Schizophrenia	18	28	14↓
Borderline personality or antisocial personality disorder	17	17	17

Questions: Were you ever misdiagnosed? How many times? What were the incorrect diagnoses? How many physicians did you consult before receiving a proper diagnosis?

↑↓*Significantly higher/lower than men at the 95% confidence level.*

Misdiagnoses Taking Less Time to Resolve

While the incidence of receiving a misdiagnosis has not shown substantial improvement, those who are misdiagnosed are finding somewhat shorter lag times from seeking help to receiving an accurate diagnosis, with one in five misdiagnosed consumers being correctly diagnosed in less than a year, compared to only 14% in 1992.

These marginal gains, while welcome, belie just how serious the issue of misdiagnosis is. The incidence of misdiagnosis remains high, with roughly seven in ten consumers being misdiagnosed at least once. More than one third (35%) of those misdiagnosed seek help for more than ten years before being accurately diagnosed. This is in addition to the already lengthy time between experiencing symptoms and first seeking help.

TABLE 4
Lapsed Time from Seeking Help to Accurate Diagnosis

	1992	2000
(Base: Those who have been misdiagnosed)	(363) %	(411) %
Less than 1 year	14	20↑
1 year, but less than 3 years	17	17
3 years, but less than 5 years	9	11
5 years, but less than 10 years	15	16
10 years or more	41	35

Question: How much time elapsed from the very first time you sought guidance and/or treatment for signs/symptoms of the illness and the time you were correctly diagnosed?

↑*Significantly higher than 1992 at the 95% confidence level.*

Causes of Misdiagnosis

Difficulty in diagnosis is related to the nature of the disease itself. Individuals are more likely to report depressive symptoms than manic ones, contributing to the frequent misdiagnosis of depression. Manic symptoms, while quite common, are more likely to go unreported, suggesting the need for more rigorous questioning by doctors among those reporting symptoms of depression.

Perceived Reasons for Misdiagnosis

Those who were misdiagnosed believe the lack of understanding about bipolar disorder among health/mental health professionals is the primary barrier to more timely diagnoses.

Despite substantial underreporting of symptoms, only 28% of respondents felt that their misdiagnosis was attributable to their own lack of complete reporting of all the symptoms they were experiencing. Those who experienced symptoms for a minimum of ten years before getting an accurate diagnosis were more likely to have unreported symptoms and more likely to see a connection between not reporting all symptoms and their own difficulties getting accurately diagnosed.

TABLE 5
Perceived Reasons for Misdiagnosis

		Lag Time from Onset to Accurate Diagnosis	
	Total	**Medium (<6 yrs)**	**Long (10 yrs+)**
(Base: Those misdiagnosed)	(411) %	(115) %	(250) %
Lack of understanding of bipolar disorder among doctors/professionals consulted	60	48	67↑
Symptoms weren't taken seriously by doctors/professionals consulted	39	29	44↑
Lack of communication between you and your doctor	37	37	38
Did not report all symptoms	28	17	34↑

Question: What do you believe prevented a correct diagnosis from being made earlier?

↑*Significantly higher than those with medium lag times at the 95% confidence level.*

Lag Time from Onset to Appropriate Treatment

The lag time from initial onset of symptoms to an accurate diagnosis is considerable. On average, individuals face ten years coping with symptoms before getting an accurate diagnosis, with only one in four (26%) receiving an accurate diagnosis in less than three years. Among those misdiagnosed, the lapsed time between onset and accurate diagnosis is more than twelve years – nearly six years of experiencing symptoms without seeking help and 6.5 years of seeking help and proceeding from one misdiagnosis to another.

TABLE 6

Lapsed Time From Onset of Symptoms to Correct Diagnosis

	Total	Misdiagnosed	Accurately Diagnosed
(Base)	(600) #	(411) #	(167) #
Average number of years… From onset to seeking help	5.7	5.9	5.5
From seeking help to accurate diagnosis	4.5	6.6↑	0*
Total from onset to accurate diagnosis	10.2	12.5↑	5.5
	%	%	%
Received an accurate diagnosis in… Less than 3 years	26	14↓	51
10 years or more	52	61↑	32

Questions: How much time elapsed from when you first exhibited signs of your illness to when you first sought professional guidance and/or treatment? How much time elapsed from the very first time you sought guidance and/or treatment for signs/symptoms of the illness and the time you were correctly diagnosed?

**Note: Only those who reported being misdiagnosed were asked about lapsed time from seeking help to getting an accurate diagnosis. Those who were never incorrectly diagnosed were assumed to have no lapsed time between when they sought help and when they received an accurate diagnosis. This assumption may underestimate the total lag time from onset to accurate diagnosis.*

↑↓ *Significantly higher/lower than those accurately diagnosed at the 95% confidence level.*

Lag Time to Diagnosis Affects Attitude Toward Illness

Long lag times to diagnosis affect not only the problems people experience, but also their confidence in their own ability to manage the disease, including fears about medication efficacy.

TABLE 7

Attitudes Toward Bipolar Disorder by Lag Time to Accurate Diagnosis

% who agree strongly or somewhat with statement

	Medium Lag Time (less than 6 yrs)	Long Lag Time (10 years plus)
(Base)	(220) %	(311) %
I have come to terms with living with bipolar disorder	83	78
It is a struggle to manage my illness	73	77
I feel confident that I will manage my illness well throughout my life	84↑	75
I worry that my medication(s) will stop working	53↓	70
I am angry that I have bipolar disorder	61	60
I feel ashamed/embarrassed because of my illness	52	49

Question: Please indicate how much you agree or disagree with each of the following statements. (Agree strongly, agree somewhat, disagree strongly, disagree somewhat)

↑↓ *Significantly higher/lower than those who had longer lag time to correct diagnosis at the 95% confidence level.*

Burden of Illness Grows with Untreated Time

Bipolar disorder, particularly when untreated, is a heavy burden, not only for those with the illness, but also for their families, friends, and employers. It can touch nearly every aspect of one's life – marriage, friendships, employment, financial standing, and physical health – and often results in such activities as spending sprees, sexual promiscuity and alcohol or drug dependency.

The effects of the disorder are particularly devastating for those who live with it for a decade before being appropriately diagnosed. Compared to those who were diagnosed somewhat earlier (less than six years), these individuals are more likely to experience the entire gamut of personal, social and work-related problems.

TABLE 8

Overall Impact of Bipolar Illness on Family/Lifestyle

% who agree strongly or somewhat with statement

	1992	2000
(Base: Total responding)	(500) %	(600) %
It is important to tell a person you are dating seriously that you have been diagnosed with bipolar illness	91	86↓
My relationship with my family is good	77	67↓
In general my illness has decreased my family's expectations for my success	65	73↑
I have difficulty maintaining long-term intimate relationships (including marriage) due to my illness	62	65
Most of my family members do not believe that my illness has had permanent damaging effects on our relationships	58	63
I have difficulty maintaining long-term friendships due to my illness	52	60↑
My family has always been very involved in my treatment	53	48
Most of my friends/family have a good understanding of what it means to have bipolar disorder	52	41↓
I believe I will have bipolar illness for the rest of my life	*	95
My illness has had a negative effect on my relationship with my children	*	64
Most of my friends/family do not know about my illness	*	27

Question: Please rate the overall impact of your bipolar illness on your family and lifestyle by indicating how much you agree or disagree with each of the following statements.

↑↓ *Significantly higher/lower than 1992 at 95% confidence level.*

**Question not asked in 1992 survey*

Overall, in 2000, bipolar disorder had a more negative impact on social relationships and, when the illness was not managed effectively, on employment, compared to 1992.

Table 9

Impact of Symptoms on Employment: When the Illness Was Not Being Managed Effectively

% who agree strongly or somewhat with statement

	1992	2000
(Base: Those responding)	(500) %	(600) %
The illness affected my abilities to perform job duties	83	88↑
My career aspirations were lower	74	75
I found it necessary to change jobs more frequently than my peers did	58	65↑
I found it necessary to totally change careers/professions	55	60
I was treated differently from other employees	52	63↑
I quit working outside the home	47	58↑
I was passed up for a promotion	47	65↑
I was given decreased responsibility in job duties	40	48↑
My mania increased my productivity before having a negative impact on my performance	-	79

Question: Please rate the impact of your symptoms on your employment, by indicating how much you agree or disagree with each of the following statements when the illness was not being managed effectively.

↑*Significantly greater than 1992 at 95% confidence level.*

Consumers Satisfied with Medication

Nearly nine in ten (87%) consumers polled through National DMDA were satisfied with their current medication, although side effects remain a problem. While satisfaction with medication did not vary significantly by older drugs (carbamazepine, lithium, and valproate) versus newer agents (atypicals such as clozapine, olanzapine, and risperidone), satisfaction with the provider of that treatment did. Consumers prescribed the newer medicines were more likely to report satisfaction with their doctors than those on the older agents.

TABLE 10
Attitudes Toward Care Provider by Medication

	Newer Drug Therapies*	Older Drug Therapies*
(Base)	(213) %	(417) %
% very or somewhat satisfied with person currently providing treatment	90↑	83
% very or somewhat dissatisfied with person currently providing treatment	8↓	16

Question: Overall, how satisfied are you with the treatment you have received from the professional who is currently treating you for bipolar disorder?

**Newer drug therapies include olanzapine, risperidone, clozapine. Older drug therapies include lithium, valproate, carbamazepine.*

↑↓ *Significantly higher/lower than mood stabilizers at the 95% confidence level*

Satisfaction with Treatment Affects Attitude Toward Illness

Satisfaction with treatment is critical. Beyond, but perhaps related to, the issue of efficacy, consumers who report high levels of satisfaction with their treatment and treatment providers have a much more positive outlook about their illness and their ability to cope with it.

TABLE 11

Attitudes Toward Bipolar Disorder by Satisfaction with Current Treatment

% who agree strongly or somewhat with statement

	Very Satisfied with Treatment	Less than Very Satisfied with Treatment
(Base)	(293) %	(296) %
I have come to terms with living with bipolar disorder	92↑	69
It is a struggle to manage my illness	65↓	87
I feel confident that I will manage my illness well throughout my life	89↑	67
I worry that my medication(s) will stop working	53↓	75
I am angry that I have bipolar disorder	51↓	70
I feel ashamed/embarrassed because of my illness	40↓	60

Question: Please indicate how much you agree or disagree with each of the following statements. (Agree strongly, agree somewhat, disagree strongly, disagree somewhat)

↑↓ *Significantly higher/lower than those who are less than "very satisfied" with their current drug treatment at the 95% confidence level.*

Satisfaction with Treatment Provider Affects Attitude Toward Illness

TABLE 12

Attitudes Toward Bipolar Disorder by Satisfaction with Provider

% who agree strongly or somewhat with statement

	Very Satisfied with Provider	Less than Very Satisfied with Provider
(Base)	(326) %	(247) %
I have come to terms with living with bipolar disorder	88↑	71
It is a struggle to manage my illness	69↓	84
I feel confident that I will manage my illness well throughout my life	85↑	69
I worry that my medication(s) will stop working	60↓	69
I am angry that I have bipolar disorder	54↓	69
I feel ashamed/embarrassed because of my illness	43↓	59

Question: Please indicate how much you agree or disagree with each of the following statements. (Agree strongly, agree somewhat, disagree strongly, disagree somewhat)

↑↓ *Significantly higher/lower than those who are less than "very satisfied" with their provider at the 95% confidence level.*

Conclusion and Implications

There has been little improvement in the diagnosis of bipolar disorder since 1992, despite the increase in public education, the lessening of stigma and the great advances in neuroscience, genetics and behavioral science research. National DMDA is working to improve public awareness of bipolar disorder because more timely diagnosis has a substantial impact on the quality of consumers' lives. To ensure an early, accurate diagnosis, individuals with signs of depression or mania should visit a doctor or mental health professional immediately and fully report all symptoms, even if they have not experienced manic symptoms for months or years. National DMDA advises families, friends and co-workers to urge anyone exhibiting depressive or manic symptoms to seek help.

The general public needs to have a better understanding of mental illness. One way this can be achieved is by doctors talking to patients about these illnesses during routine exams and stressing to patients and family members that they are legitimate illnesses and not due to any personality flaw or character weakness. Reduced stigma and discrimination will go a long way towards improving patients' lives, particularly in social and work environments.

National DMDA recommends that the medical community, particularly primary care doctors, screen for bipolar disorder every time a patient reports symptoms of depression. A diagnosis of depression should never be made without first ruling out the possibility of bipolar disorder. This survey underscores the prevalence of misdiagnosis, especially the incorrect diagnosis of depression. Doctors and other mental health professionals should thoroughly investigate for a history of mania, particularly in light of the fact that patients will underreport manic symptoms.

A self-assessment tool for bipolar disorder can be found on the National DMDA web site – www.ndmda.org. The organization suggests that anyone who believes he or she might have bipolar disorder complete the brief questionnaire and print out the results for his or her physician and/or mental health professional.

For more information about bipolar disorder, call National DMDA at (800) 826-3632 or (312) 642-0049 or visit the web site at www.ndmda.org.

Methodology

The membership of the National DMDA, as well as that of local DMDA chapters, was surveyed via mail in July of 2000. A total of more than 4,000 questionnaires were distributed to constituents. Six hundred (600) individuals diagnosed with bipolar disorder responded. 66 percent of respondents were women; 37 percent of respondents were married; and 37 percent were employed.

Discrepancies between total percentages and/or numbers may exist due to rounding errors, multiple response questions, or questions left unanswered by some respondents.

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