Perceptions and Impact of Bipolar Disorder: How Far Have We Really Come? Results of the National Depressive and Manic-Depressive Association 2000 Survey of Individuals With Bipolar Disorder

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Objective: To assess the experience of selected individuals living with bipolar disorder and compare this experience with that of a similar group of individuals sampled in 1992.

Method: In June 2000, 4192 self-administered questionnaires were sent to National Depressive and Manic-Depressive Association chapters for distribution to support group participants diagnosed with bipolar disorder. By July 31, 2000, the first 600 completed surveys were analyzed.

Results: Over one third of respondents sought professional help within 1 year of the onset of symptoms. Unfortunately, 69% were misdiagnosed, with the most frequent misdiagnosis being unipolar depression. Those who were misdiagnosed consulted a mean of 4 physicians prior to receiving the correct diagnosis. Over one third waited 10 years or more before receiving an accurate diagnosis. Despite having underreported manic symptoms, more than half believe their physicians' lack of understanding of bipolar disorder prevented a correct diagnosis from being made earlier. In 2000, the respondents reported a greater negative impact of bipolar disorder on families, social relationships, and employment than did the respondents in 1992. Overall, respondents were satisfied with their current treatment, which often included medication, talk therapy, and support groups. Respondents who were highly satisfied with their treatment provider had a more positive outlook on their illness and their ability to cope with it.

Conclusion: Individuals with bipolar disorder reported that the illness manifests itself early in life but that accurate diagnosis lags by many years. The illness exacts great hardships on the individual and the family and has a profoundly negative effect on careers. These findings are very similar to those reported nearly a decade ago.

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National Depressive and Manic-Depressive Association (DMDA) is a nationwide patient-directed organization representing people living with mood disorders and their families. Over a decade ago, National DMDA distributed a 154-item survey to its members through 85 individual chapter presidents.[1] The survey addressed course of illness, quality of life, and treatment for patients with bipolar disorder. A return rate of 27% of the 3312 surveys that were distributed occurred, and the first 500 received were analyzed. Although the survey itself was methodologically flawed, the findings provided a description of the experience of living with bipolar disorder and a "snapshot" of the care received at that time.

The 1992 National DMDA constituent survey reported that long delays between the onset of symptoms, the seeking of treatment, and the receipt of an accurate diagnosis were common.[1] The survey also found that when the disorder was identified earlier, fewer personal, social, and work-related problems were experienced, further emphasizing the need for and benefits of early diagnosis. Respondents reported many instances of misdiagnosis, the most frequent being major depression.

The survey was repeated in 2000 in order to learn how much has changed in the experience of being a patient with bipolar disorder during the intervening time period.

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METHOD

Survey Instrument

A survey on bipolar disorder (see Appendix 1) that was very similar to the one circulated by National DMDA in 1992 was developed by Wirthlin Worldwide, a strategic opinion research and consulting firm, in cooperation with National DMDA. The survey consisted of 36 questions covering 3 major topics including the onset of the illness and its subsequent course, its impact on quality of life and psychosocial functioning, and clinical treatment of the illness.

The survey instrument was self-administered (paper and pencil) and was distributed to National DMDA constituents through National DMDA support group meetings. The first item on the questionnaire was, "Have you ever been diagnosed with bipolar disorder/manic depression by a physician (medical doctor)?" Respondents answering "no" were instructed not to complete the survey. Bipolar diagnoses of the respondents were self-reported and were not independently verified.

Sample

In June 2000, 4192 questionnaires were sent to National DMDA chapters for distribution to support group participants diagnosed with bipolar disorder. By July 31, 2000, the first 600 returns were data processed for analysis.

Analysis

The data were analyzed using standard cross tabulation. T tests were used to evaluate differences between subgroups and between 1992 and 2000 respondents at the 95% confidence level.

RESULTS

Unless otherwise specified, results reported are from the 2000 survey. The actual response rate cannot be determined because it is not known how many of the 4192 questionnaires sent to DMDA chapters were actually distributed to people. Further, no count was kept of the questionnaires returned after the original 600 were received.

Sixty-six percent of the respondents to the 2000 survey were female. Most were between 31 and 60 years of age. Regarding marital status, 25% were single, 34% were separated or divorced, 38% were married, and 3% were widowed. Thirty percent had an annual income less than $15,000, 58% were unemployed, and 84% had at least some college. These demographics were very similar to those of the 1992 survey (Table 1).

The results are organized into 5 key areas of experience for patients with bipolar disorder: onset and course of illness, burden of illness, path to treatment, attitude toward/understanding about illness, and treatment received.

Table 1. Demographic Characteristics of the Sample

1992		2000	
Variable	(N = 500) %	Variable	(N = 600) %
Female	64	Female	66
Age, y		Age, y	
< 25	4	< 31	9
25–34	19	31–40	19
35–44	32	41–50	31
45–54	32	51–60	28
55+	14	61+	14
Marital status		Marital status	
Single, never married	24	Single, never married	25
Separated/divorced	27	Separated/divorced	34
Married	46	Married	38
Widowed	2	Widowed	3
Employment status		Employment status	
Full-time	33	Full-time	25
Part-time	17	Part-time	16
Net employed	50	Net employed	41
Unemployed	37	Unemployed	41
Retired	9	Retired	17
Net not employed	46	Net not employed	58
Student	3	Student	1
Household income (mean $31,475)		Household income (mean $37,450)	
Under $15,000	34	Under $15,001	30
$15,000–$49,999	46	$15,001–$50,000	44
$50,000–$74,999	13	$50,001–$75,000	14
$75,000 or more	7	$75,001 or more	12

Onset and Course of Illness

Age at onset. In the 2000 survey, 33% of respondents were under age 15 years when the symptoms of bipolar disorder first appeared, 27% were between 15 and 19 years, and 39% were 20 years or older. These ages were very similar to those reported in the 1992 survey (31%, 28%, and 40%, respectively).

Family history. Nearly one half of the respondents (45%) said that there were other members of their immediate family who had been diagnosed with bipolar disorder. Among these respondents, an average of 2.1 family members had been diagnosed with bipolar disorder, and 82% reported that a family member had been treated for it.

Manic symptoms prior to diagnosis. Prior to diagnosis, more than 70% of respondents experienced at least 1 of the following symptoms of mania: erratic sleeping, heightened mood or elation, racing thoughts and increased speech production, racing speech or impulsiveness, increased physical and mental activity, or poor judgment. The majority of respondents also experienced excessive irritability or aggressive behavior, reckless behavior, erratic eating, or increased sexual interest or sexual activity.

Respondents did not report all of their manic symptoms to a physician. Only erratic sleeping was reported to a physician by more than half of the respondents. Only about 40% of respondents reported racing thoughts and increased speech production, excessive irritability or

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Figure 1. Most Commonly Experienced Manic Symptoms: % Reported vs. Unreported to Care Provider of the Total Percentage Experiencing Symptom

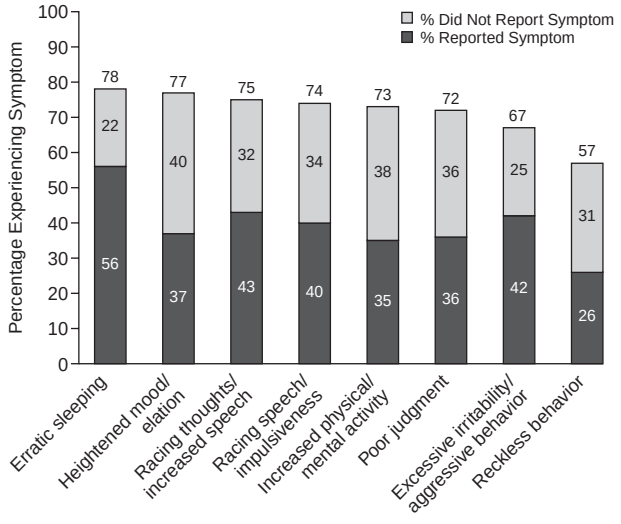
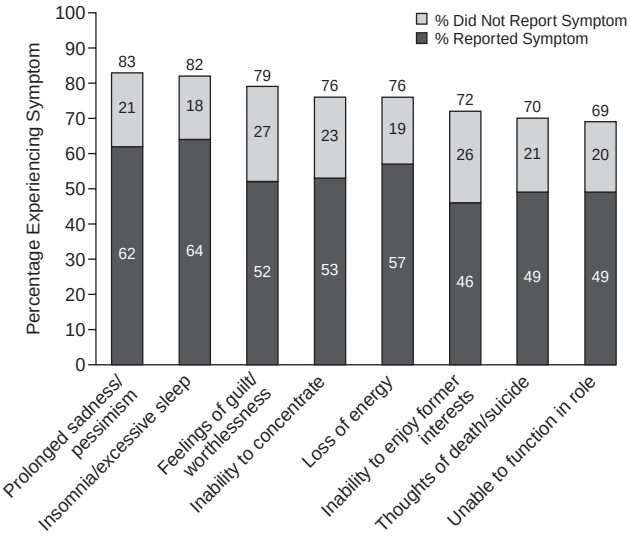


Figure 2. Most Commonly Experienced Depressive Symptoms: % Reported vs. Unreported to Care Provider of the Total Percentage Experiencing Symptom



aggressive behavior, racing speech or impulsiveness, heightened mood or elation, poor judgment, and increased physical and mental activity (Figure 1). Less than a third mentioned erratic eating (29%), reckless behavior (26%), spending excessively (26%), and increased sexual interest or sexual activity (20%).

Depression symptoms prior to diagnosis. Prior to diagnosis, more than three quarters of respondents experienced symptoms of depression such as prolonged sadness or pessimism, insomnia, feelings of guilt or worthlessness, inability to concentrate, and loss of energy. Other symptoms experienced by more than two thirds of respondents included inability to enjoy former interests, thoughts of death or suicide, inability to function in role, and changes in appetite.

As with manic symptoms, but to a lesser extent, symptoms of depression were also underreported to physicians. Five symptoms were reported by more than half of the respondents, including insomnia, prolonged sadness or pessimism, loss of energy, inability to concentrate, and feelings of guilt or worthlessness (Figure 2). Symptoms reported to a doctor by less than half of the respondents included thoughts of death or suicide (49%), inability to function in role (49%), inability to enjoy former interests (46%), changes in appetite (44%), anger or irritability (41%), and changes in body weight (37%).

Burden of Illness

During the time that the illness was untreated or improperly treated, the most frequently experienced psychosocial problems were relationship problems (80%), including interpersonal conflicts with family and friends (68%) and marital difficulties (49%). Job and school related problems (73%), financial difficulties (55%), physical health problems (46%), and alcohol and substance abuse (37%) were next. These percentages were similar to those reported in the 1992 survey.[1]

After receiving treatment, interpersonal conflicts dropped to 53% and marital difficulties dropped to 30%. Job and school related problems dropped to 53%, financial difficulties dropped to 51%, and alcohol and substance abuse dropped to 14%. However, physical and health problems did not improve after the beginning of treatment and were reported by 48% of the respondents. These reductions were substantially smaller than those that occurred in 1992, at which time, treatment conferred a large reduction in problems.

Hospitalization. In 2000, fewer respondents (79%) reported having been hospitalized for bipolar disorder compared with those in 1992 (88%). On average, the 2000 respondents had been hospitalized approximately 5 times (5.1), which is slightly higher than the number reported in 1992 (4.5). The average duration of hospitalizations was just over 5 weeks (5.3), with a median of 2 to 4 weeks.

Employment. Bipolar disorder had a more negative impact on employment in 2000 compared with 1992. Fewer respondents were employed in 2000 (40%) than in 1992 (49%). In 2000, most respondents (88%) said that the illness affected their ability to perform job duties, as they did in 1992 (83%). Most found it necessary to change jobs more frequently than their peers (65% in 2000 vs. 58% in 1992). A majority reported being treated differently than other employees (63% in 2000 vs. 52% in 1992). Many were passed up for a promotion (65% in

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Table 2. Impact of Symptoms on Employment When Bipolar Disorder Was Not Being Managed Effectively[a]

Statement	1992 (N = 500) %	2000 (N = 600) %
When the illness was not being managed effectively:		
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.	NA	79

[a]Percentage who agreed strongly or somewhat with statement when given the following instructions: Please rate the impact of your symptoms on your employment by indicating how much you agree or disagree with each of the following statements.
Abbreviation: NA = not included in the 1992 survey. Symbol: ↑ = significantly higher than in 1992 at 95% confidence level.

Table 3. Overall Impact of Bipolar Disorder on Family/ Lifestyle[a]

Statement	1992 (N = 500) %	2000 (N = 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.	NA	95
My illness has had a negative effect on my relationship with my children.	NA	64
Most of my friends/family do not know about my illness.	NA	27

[a]Percentage who agreed strongly or somewhat with statement when given the following instructions: 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. Base: total responding.
Abbreviation: NA = not included in the 1992 survey. Symbols: ↑ = significantly higher than 1992 at 95% confidence level, ↓ = significantly lower than in 1992 at 95% confidence level.

2000 vs. 47% in 1992) (Table 2). Many experienced that mania increased their productivity before having a negative impact on their performance (79%). Many respondents found it necessary to completely change careers or professions (60%).

Overall impact of bipolar disorder on family/lifestyle. Respondents reported that bipolar disorder significantly impacted their family and lifestyle (Table 3). In 2000, fewer respondents (67%) reported having a good relationship with their family compared with 1992 (77%), and fewer reported that their family and friends have a good understanding of bipolar disorder (41% vs. 52%). In addition, more respondents (73% vs. 65%) agreed that their illness has decreased their family's expectations for their success and reported difficulty in maintaining long-term friendships (60% vs. 52%) compared with 1992. Approximately two thirds reported having difficulty maintaining long-term intimate relationships due to their illness (65%) and that their illness has had a negative impact on their relationship with their children (64%).

Path to Treatment

Seeking treatment. Approximately one third of respondents sought help within 1 year of the onset of symptoms in each survey (36% in 2000 and 30% in 1992). However, nearly one third (31%) waited at least 10 years before seeking help, only slightly fewer than those waiting that long in 1992 (36%). Most respondents (63%) said that they finally sought help because their symptoms became unmanageable. Other reasons mentioned for seeking help included intervention of their family, friends, or employer (47%); risk of self-harm (37%); and an emergency situation (33%).

Table 4. Problems of Misdiagnosis in Bipolar Disorder

Question	%[a]
Were you ever misdiagnosed? (N = 600)	
Yes	69
How many times? (N = 411)	
1–3 times	70
4+ times	26
How many physicians did you consult before receiving a proper diagnosis? (N = 411)	
1–4 physicians	68
5+ physicians	26

[a]Percentages do not total 100 due to nonresponse.

After first exhibiting symptoms and signs of the illness, but before being diagnosed as having bipolar disorder, respondents were most likely to see either a psychiatrist (62%) or a physician, family doctor, or obstetrician/ gynecologist (54%) for guidance or treatment. A psychologist (47%) and counselor or social worker (46%) were visited at the next highest levels of frequency, followed by clergy (30%).

Diagnosis and misdiagnosis. In 2000, slightly fewer respondents (69%) reported having been misdiagnosed (Table 4) compared with 1992 (73%). Those who were misdiagnosed received a mean of 3.5 other diagnoses and consulted 4 physicians (compared with 3.3 in 1992)

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Table 5. Lapsed Time From First Treatment Seeking to Correct Diagnosis in Misdiagnosed Patients

Time	1992 (N = 363) %	2000 (N = 411) %
Less than 1 year	14	20↑
Less than 6 months	9	12
6 months–1 year	5	8
At least 1 year, but less than 2 years	10	7
At least 2 years, but less than 3 years	7	10
At least 3 years, but less than 5 years	9	11
At least 5 years, but less than 10 years	15	16
10 years or more	41	35
Don't know/refused to answer	3	1

Symbol: ↑ = significantly higher than in 1992 at 95% confidence level.

before receiving an accurate diagnosis. In 1992, 52% of respondents received an accurate diagnosis from the first or second professional they consulted. However, the remaining 48% consulted 3 or more professionals before receiving an accurate diagnosis.

In 2000, the most common incorrect diagnosis was unipolar depression (60%). Other frequently mentioned misdiagnoses included anxiety disorder (26%), schizophrenia (18%), borderline personality or antisocial personality disorder (17%), alcohol or substance abuse and/or dependence (14%), and schizoaffective disorder (11%).

Women were significantly more likely than men to be misdiagnosed (72% vs. 62%). Women were also more likely than men to be misdiagnosed with depression (68% vs. 43%), while men were twice as likely as women to be misdiagnosed with schizophrenia (28% vs. 14%).

Perceived reasons for misdiagnosis. Respondents who were misdiagnosed believed the lack of understanding about bipolar disorder among the doctors/professionals consulted was the primary barrier to more timely diagnoses (60%). Despite the substantial underreporting of symptoms, only 28% of respondents felt that their misdiagnosis was attributable to their own lack of complete reporting of all their symptoms. Those who experienced symptoms for a minimum of 10 years before getting an accurate diagnosis were more likely to have unreported symptoms and were more likely to see a connection between not reporting all their symptoms and their difficulties in receiving an accurate diagnosis.

Lapsed time from first treatment seeking to correct diagnosis. Nearly half of respondents who had been misdiagnosed at least once (48%) reported a lapse of several months up to 5 years between seeking their first treatment and diagnosis. This was roughly comparable to the 1992 results. Twenty percent of those who were initially misdiagnosed received a correct diagnosis within 1 year of seeking treatment in 2000, compared with 14% in 1992. Over a third of those who were initially misdiagnosed in both 1992 and 2000 did not receive a correct diagnosis for 10 or more years after seeking treatment (Table 5).

Attitudes Toward and Understanding of the Illness

A high percentage of respondents (82%) believed that bipolar disorder is primarily a general medical illness. Fourteen percent believed that it is both a general medical illness and a personality flaw or character weakness.

Long lag times to diagnosis were correlated not only with the problems respondents experienced, but also with their attitudes toward their illness. Those who experienced a lag time of less than 6 years were significantly more likely to feel confident in their ability to manage their illness throughout their lives (84%) compared with those who struggled with the illness for more than 10 years before being accurately diagnosed (75%).

Treatment

Types of treatment.

1. Past or presently used treatments. Nearly all the respondents (98%) reported that they have taken medication to treat their bipolar illness. A high percentage also participated in support groups (84%) and one-on-one therapy (psychotherapy, 81%). Nearly half of the respondents (44%) participated in group therapy, while one fifth or fewer received electroconvulsive therapy or alternative treatments.

2. Currently used treatments. There have been substantial changes in treatment over the past decade. Nearly all the respondents (97%) reported presently taking medication, including multiple medications (80%), mood stabilizers (70%), and antidepressants (53%). Two thirds (66%) were active in support groups, and 50% were involved in psychotherapy. In 2000, approximately one third reported taking lithium, 76% took anticonvulsants (including valproate and carbamazepine), and 38% took atypical antipsychotics (including olanzapine). Only 4% took typical antipsychotics. Changes since 1992 included a substantial drop in lithium use (72% in 1992 to 35% in 2000), an increase in valproate use (11% to 33%), and an increase in the use of olanzapine and other atypical antipsychotics (7% to 38%). The percentage of patients who reported taking antidepressants nearly doubled to over half (29% in 1992 to 53% in 2000) (Table 6).

Patient satisfaction. Despite the fact that nearly 9 in 10 respondents (87%) were satisfied with their current treatment, including medication, talk therapy, and support groups, three quarters (76%) reported that it is a struggle to manage their illness, and 64% worry that their medications will stop working.

Eighty-nine percent of respondents taking atypical antipsychotics such as clozapine, olanzapine, and risperidone and 86% taking mood stabilizers such as valproate, carbamazepine, and lithium reported satisfaction with their current treatment.

A majority of respondents (56%) felt that the side effects of their current medication had little or no impact on their daily lives, while 37% considered switching

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Table 6. Types of Treatment Currently Being Used to Treat Bipolar Illness

Treatment	1992 (N = 500) %	2000 (N = 600) %
Lithium	72	35
Valproate	11	33↑
Carbamazepine	16	7
Other anticonvulsants	NA	36
Olanzapine	NA	17
Other atypical antipsychotics	7	21
Typical antipsychotics	NA	4
Antidepressants	29	53↑
High dose thyroid treatment	NA	9
Electroconvulsive therapy	…	1
Support groups	61	66
One-on-one psychotherapy	53	50
Group therapy	8	16↑
Other counseling	14	10
Alternative treatment	NA	8

Abbreviation: NA = not included in the 1992 survey.
Symbols: … = less than 1%, ↑ = significantly higher than 1992 at the 95% confidence level.

Table 7. Attitudes Toward Bipolar Disorder by Satisfaction With Provider[a]

Statement	Very Satisfied With Provider (N = 326) %	Less Than Very Satisfied With Provider (N = 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

[a]Percentage who agreed strongly or somewhat with statement when given the following instructions: Please indicate how much you agree or disagree with each of the following statements.
Symbols: ↑ = significantly higher than those who are less than "very satisfied" with their provider at the 95% confidence level, ↓ = significantly lower than those who are less than "very satisfied" with their provider at the 95% confidence level.

medication due to side effects from their current medication, and 27% often considered discontinuing the medication due to bothersome side effects.

Compared with respondents who were less satisfied with their provider, respondents who were very satisfied with their doctor were substantially more likely to have a more positive outlook about their illness and their ability to cope with it (Table 7).

DISCUSSION

These findings should be viewed with several caveats. The sample is drawn neither from the community, nor from a clinic. It is a modest sample of members of National DMDA who chose to fill out and return the survey and therefore cannot be assumed to be representative of the organization. The respondents are among the more severely afflicted, with nearly 80% reporting hospitalization for bipolar disorder, 44% of whom were hospitalized 5 or more times. The information was entirely self-reported. None of it was corroborated by family members or other informants, and no medical records or research interviews were conducted.

The sociodemographics and clinical course of the sample are striking. The respondents were well educated, with nearly 90% having attended some college. Yet, 57% were unemployed, 60% were unmarried, and over half reported incomes of less than $15,000 per year. This strongly suggests that the illness has deep and lasting adverse psychosocial consequences.

Nonetheless, the findings are remarkably consistent with other information in the literature on the experience of having bipolar disorder. For example, The Stanley Foundation Bipolar Network has conducted a survey with a large cohort of bipolar patients.[2] Their sample included 261 outpatients, including bipolar I and II and schizoaffective bipolar outpatients. Mean current age of the sample was 43 years, with the age distribution similar to both Lish et al.[1] and the current National DMDA survey. Employment status and educational characteristics of the Stanley Foundation[2] and currently reported DMDA samples were very similar. In the Stanley Foundation sample,[2] almost 50% of the patients reported working below qualifications. Although 93% of the sample had some education post high school (and 55% were at least college graduates), 39% reported annual household incomes of < $20,000, and 23% reported annual household incomes between $20,000 and $39,999. Forty-three percent of the sample were married, 24% were separated or divorced, and 31% were single. Mean age at the time of first symptoms was 20 years. The mean duration of illness was 20 years. A finding remarkably consistent with the present survey was that the Stanley Foundation patients had to wait, on average, 10 years from first symptoms to first medication. This finding is also consistent with the 1994 report from National DMDA by Lish et al.[1] and a study by Egeland et al.[3]

Similar demographic and clinical characteristics were observed between the present survey and the Stanley Center Bipolar Disorder Registry,[4] which included 2839 patients who identified themselves as having bipolar disorder. The median age in their sample was 40 years, and 65% were women. Mean age at onset of bipolar symptoms was 20 years. Consistent with our sample, over 60% of the respondents had at least some college, 30% completed college, and 11% had postgraduate or professional degrees. Despite the high level of education among the participants, almost 65% were unemployed. Most respon-

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dents were either never married or divorced or separated, with only one third of the participants currently married. Over 50% of the sample received no treatment for their first episode of bipolar disorder.

The relatively low return rate for the 2000 National DMDA survey is of concern. It could certainly reduce the generalizability of the findings if the survey represented the opinions of a few members with the worst experiences and outcomes. We do not know if this is true, but we doubt it because of the similarity in demographics, clinical history, and experience of these respondents to those of other samples of bipolar patients, as noted above.[2–4] In addition, National DMDA staff members were informed anecdotally that many members found that filling out the questionnaire was emotionally painful and stopped.

The issue of failure to diagnose and misdiagnosis of bipolar disorder is a significant clinical and public health problem. Sixty-nine percent reported that they had been misdiagnosed at least once (most frequently with depression, but also with anxiety disorders and schizophrenia). One third said that they had waited a decade or more between seeking help and receiving the correct diagnosis. This study provides no clear explanation for this. Possibilities include health professionals' lack of awareness and patients' lack of insight or discomfort with disclosure (e.g., most respondents did not report key manic symptoms such as racing thoughts, impulsivity, and increased sexual activity to their doctors), as well as widely varied clinical pictures and presenting complaints.

Those who were misdiagnosed were not necessarily passive about their diagnosis. While those respondents were not questioned about their perceptions of initial diagnoses (that is, whether they perceived them to be correct or not), their behavior suggests that they were aware of continuing problems. For example, 26% of those who were misdiagnosed were misdiagnosed on 4 or more occasions and consulted 5 or more physicians. Further, those who were misdiagnosed sought help from a number of different types of providers.

In conclusion, this report provides a snapshot of the problems encountered by patients with bipolar disorder. Bipolar disorder, particularly when untreated, is a heavy burden, not only for those with the illness, but also for their families, friends, and employers.

Drug names: carbamazepine (Tegretol and others), clozapine (Clozaril and others), olanzapine (Zyprexa), risperidone (Risperdal).

Acknowledgment: This survey was conducted by the National Depressive and Manic-Depressive Association (DMDA). National DMDA, now the Depression and Bipolar Support Alliance, is a patient-directed organization. Its mission is to educate consumers, families, professionals, and the public concerning the nature of depressive and manic-depressive illnesses as treatable medical diseases; to foster self-help for consumers and families; to eliminate discrimination and stigma; to improve access to care; and to advocate for research toward the elimination of these illnesses. The survey was conducted with the assistance of Wirthlin Worldwide.

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Appendix 1. 2000 National DMDA Constituency Survey[a]

This survey is for completion by individuals active in DMDA groups who have been diagnosed with bipolar disorder and by National DMDA members with the same diagnosis. This survey includes questions on a variety of topics as they relate to your bipolar illness, also known as manic-depressive disorder. Specific areas addressed include diagnosis and treatment of the illness, the impact of the illness on your relationships, lifestyle, and employment, and finally, financial and insurance considerations of your illness.

Please circle the number that corresponds to your answer for each question. Your responses will be strictly confidential and will only be reported as combined or summary statistics.

Onset/Diagnosis

1. Have you ever been diagnosed with bipolar disorder/manic depression by a physician (medical doctor)?
   1 Yes CONTINUE
   2 No PLEASE DO NOT COMPLETE SURVEY

2. Looking back to the time before you were diagnosed as having bipolar disorder, please indicate, using your best estimate, the age you were when you now believe you first exhibited signs of bipolar disorder.
   1 Under 5
   2 5–9
   3 10–14
   4 15–19
   5 20–24
   6 25–29
   7 30 or older

3. Which of the following symptoms of mania did you experience before being diagnosed? Please circle all that apply.
   1 Heightened mood, elation, increased self-confidence
   2 Excessive irritability, aggressive behavior
   3 Racing speech, impulsiveness
   4 Increased physical and mental activity
   5 Poor judgment
   6 Reckless behavior
   7 Delusions/paranoia
   8 Racing thoughts and increased speech production
   9 Spending excessively and recklessly
   10 Getting into trouble due to verbal arguments or physical altercations with police, family, work, school or college
   11 Erratic sleeping, decreased need for sleep
   12 Erratic eating
   13 Increased sexual interest/activity
   14 Other (fill in): _____

3a. Which symptoms, if any, did you report to a physician? Please circle all that apply.
   1 Heightened mood, elation, increased self-confidence
   2 Excessive irritability, aggressive behavior
   3 Racing speech, impulsiveness
   4 Increased physical and mental activity
   5 Poor judgment
   6 Reckless behavior
   7 Delusions/paranoia
   8 Racing thoughts and increased speech production
   9 Spending excessively and recklessly
   10 Getting into trouble due to verbal arguments or physical altercations with police, family, work, school or college
   11 Erratic sleeping, decreased need for sleep
   12 Erratic eating
   13 Increased sexual interest/activity
   14 Other (fill in): _____
   15 None

4. Which of the following symptoms of depression did you experience before being diagnosed? Please circle all that apply.
   1 Prolonged sadness, pessimism
   2 Changes in appetite
   3 Insomnia
   4 Loss of energy
   5 Feelings of guilt, worthlessness
   6 Inability to concentrate
   7 Inability to enjoy former interests
   8 Thoughts of death/suicide
   9 Unexplained aches and pains
   10 Anger/irritability
   11 Insomnia or excessive sleep
   12 Changes in appetite (poor appetite or eating to excess)
   13 Changes in body weight (loss of weight or gain in weight)
   14 Inability to take care of one's needs (grooming, washing, cooking, etc.)
   15 Concerns about health
   16 Unable to function in role (work, student, housewife, etc.)
   17 Other (fill in): _____

4a. Which symptoms, if any, did you report to a physician? Please circle all that apply.
   1 Prolonged sadness, pessimism
   2 Changes in appetite
   3 Insomnia
   4 Loss of energy
   5 Feelings of guilt, worthlessness
   6 Inability to concentrate
   7 Inability to enjoy former interests
   8 Thoughts of death/suicide
   9 Unexplained aches and pains
   10 Anger/irritability
   11 Insomnia or excessive sleep
   12 Changes in appetite (poor appetite or eating to excess)
   13 Changes in body weight (loss of weight or gain in weight)
   14 Inability to take care of one's needs (grooming, washing, cooking, etc.)
   15 Concerns about health
   16 Unable to function in role (work, student, housewife, etc.)
   17 Other (fill in): _____
   18 None

continued

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Appendix 1. 2000 National DMDA Constituency Survey[a] (cont.)

4b. What caused you to seek help? Please circle all that apply.

1 Symptoms became unmanageable
2 Intervention of family/friends/employer
3 Emergency situation
4 Risk of self-harm
5 Risk of harm to others
6 Other (fill in):

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

1 Less than 6 months
2 6 months–1 year
3 At least 1 year, but less than 2 years
4 At least 2 years, but less than 3 years
5 At least 3 years, but less than 5 years
6 At least 5 years, but less than 10 years
7 More than 10 years

6. Please indicate below all of the professionals from whom you sought guidance and/or treatment after you first exhibited symptoms/signs of the illness and before you were diagnosed as having bipolar illness. Please circle all that apply.

1 Clergy
2 Counselor, social worker
3 Psychologist
4 Psychiatrist
5 Physician/family doctor/obstetrician/gynecologist
6 Other (fill in):

7. Were you ever misdiagnosed?

1 Yes CONTINUE
2 No PLEASE SKIP TO Q.10

7a. How many times?

1 1–3
2 4–6
3 7–9
4 10+

7b. What were the incorrect diagnoses? Please circle all that apply.

1 Depression (unipolar)
2 Schizoaffective disorder
3 Schizophrenia
4 Attention deficit disorder
5 Anxiety disorder
6 Conduct disorder
7 Borderline personality or antisocial personality disorder
8 Alcohol or substance abuse and/or dependence
9 Other (fill in)

7c. How many physicians did you consult before receiving a proper diagnosis? Please record number on line below.

_____

7d. Who misdiagnosed you? Please circle all that apply.

1 Psychologist
2 Psychiatrist
3 Physician/family doctor
4 Other (fill in)

8. 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?

1 Less than 6 months
2 6 months–1 year
3 At least 1 year, but less than 2 years
4 At least 2 years, but less than 3 years
5 At least 3 years, but less than 5 years
6 At least 5 years, but less than 10 years
7 10 years or more

9. What do you believe prevented a correct diagnosis from being made earlier? Please circle all that apply.

1 Did not go to mental health professional
2 Did not report all symptoms
3 Symptoms weren't taken seriously by the doctor(s)/ professional(s) consulted
4 Lack of understanding of bipolar disorder among doctor(s)/ professional(s) consulted
5 Lack of communication between you and your doctor
6 Lack of communication among team of doctors
7 Lack of support from family and friends
8 Other (fill in):

10. Do you believe that bipolar disorder is primarily a …

1 Medical illness
2 Personality flaw/character weakness, or
3 Both

11. To the best of your knowledge, have other members of your immediate family (e.g., parents, siblings, grandparents, children who are related to you by blood) been diagnosed with bipolar disorder?

1 Yes CONTINUE
2 No PLEASE SKIP TO Q.12

continued

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Appendix 1. 2000 National DMDA Constituency Survey[a] (cont.)

11a. How many?

1 One
2 Two
3 Three
4 Four
5 Five or more

11b. Have any of them been treated?

1 Yes
2 No

Impact of Bipolar Disorder

12. During the time your illness was untreated or improperly treated, did you experience any of the following social and/or financial events or circumstances as a result of bipolar disorder? Please circle all that apply.

1 Unemployment (involuntary)
2 Fired from job
3 Interruption of education
4 Financial difficulty/bankruptcy
5 Receipt of public assistance
6 Alcohol/substance abuse
7 Excessive gambling
8 Spending sprees
9 Sexual promiscuity
10 Self-injury
11 Injury to others
12 Marital difficulties (if applicable)
13 Relationship difficulties with family and friends
14 Committed a crime (including writing bad checks or shoplifting, regardless of whether or not convicted)
15 Physical health problems

12a. How were these experiences a direct result of your illness? Please describe below.

_____

_____

_____

13. Since you have received treatment, have you experienced any of the following? Please circle all that apply.

1 Unemployment (involuntary)
2 Fired from job
3 Interruption of education
4 Financial difficulty/bankruptcy
5 Receipt of public assistance
6 Alcohol/substance abuse
7 Excessive gambling
8 Spending sprees
9 Sexual promiscuity
10 Self-injury
11 Injury to others
12 Marital difficulties (if applicable)
13 Relationship difficulties with family and friends
14 Committed a crime (including writing bad checks or shoplifting, regardless of whether or not convicted)
15 Physical health problems

14. 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.

	Agree Strongly	Agree Somewhat	Disagree Somewhat	Disagree Strongly	Not Applicable
In general, my illness has decreased my family's expectations for my success	1	2	3	4	5
My relationship with my family is good	1	2	3	4	5
I have difficulty maintaining long-term friendships due to my illness	1	2	3	4	5
I have difficulty maintaining long-term intimate relationships (including marriage) due to my illness	1	2	3	4	5
It is important to tell a person you are dating seriously that you have been diagnosed with bipolar disorder	1	2	3	4	5
My illness has had a negative effect on my relationship with my children	1	2	3	4	5
Most of my friends/family do NOT believe that my illness has had permanent damaging effects on our relationships	1	2	3	4	5
Most of my friends/family have a good understanding of what it means to have bipolar disorder	1	2	3	4	5

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Appendix 1. 2000 National DMDA Constituency Survey[a] (cont.)

My family has always been very involved in my treatment	1	2	3	4	5
Most of my friends/family do not know about my illness	1	2	3	4	5
I believe I will have bipolar illness for the rest of my life	1	2	3	4	5

15. Please indicate how much you agree or disagree with each of the following statements.

	Agree Strongly	Agree Somewhat	Disagree Somewhat	Disagree Strongly
I feel confident that I will manage my illness well throughout my life	1	2	3	4
I worry that my medication(s) will stop working	1	2	3	4
It is a struggle to manage my illness	1	2	3	4
I have come to terms with living with bipolar disorder	1	2	3	4
I feel ashamed/embarrassed because of my illness	1	2	3	4
I am angry that I have bipolar disorder	1	2	3	4

16. Thinking about the time before you were diagnosed and effectively treated, was there a time period during your employment when you had symptoms/signs of the illness?

1 Yes CONTINUE
2 No PLEASE SKIP TO Q.17
3 Not applicable PLEASE SKIP TO Q.17

16a. In total for what length of time did this affect your work?

1 Less than 1 year
2 1–2 years
3 3–4 years
4 5 or more years

17. 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 …

	Agree Strongly	Agree Somewhat	Disagree Somewhat	Disagree Strongly	Not Applicable
The illness affected my abilities to perform job duties	1	2	3	4	5
My career aspirations were lower	1	2	3	4	5
During this period, I found it necessary to change jobs more frequently than my peers did	1	2	3	4	5
I found it necessary to totally change careers/professions	1	2	3	4	5
I quit working outside the home	1	2	3	4	5
I was passed up for a promotion	1	2	3	4	5
I was treated differently from other employees	1	2	3	4	5
I was given decreased responsibility in job duties	1	2	3	4	5
My mania increased my productivity before having a negative impact on my performance	1	2	3	4	5

18. Are you currently employed?

1 Yes CONTINUE
2 No PLEASE SKIP TO Q.21

18a. Is your employer aware that you have bipolar disorder?

1 Yes PLEASE SKIP TO Q.18C
2 No CONTINUE

18b. Why not?

1 I have not disclosed my illness for fear that my employer will treat me differently.
2 I have not disclosed my illness because I am afraid of losing my job if I do so.
3 I have not disclosed my illness because it is not important for my employer to know.
4 Other (fill in)

PLEASE SKIP TO Q.19

continued

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Appendix 1. 2000 National DMDA Constituency Survey[a] (cont.)

18c. Has your disclosure affected your life on the job?
- 1 Yes, positively
- 2 Yes, negatively
- 3 No, not affected

19. Did you ever ask for an accommodation at work?
- 1 Yes
- 2 No

19a. Have you ever received an accommodation at work?
- 1 Yes
- 2 No

20. Has your personal income been reduced as a result of the illness' impact on your employment?
- 1 Yes
- 2 No

Treatment

21. Who is currently treating you for bipolar disorder? Circle only one.
- 1 Psychiatrist
- 2 Psychologist/social worker
- 3 Nurse
- 4 Primary care physician
- 5 Other (fill in)

21a. Overall, how satisfied are you with the treatment you have received from the professional indicated in Q.21?
- 1 Very satisfied PLEASE SKIP TO Q.22
- 2 Somewhat satisfied PLEASE SKIP TO Q.22
- 3 Somewhat dissatisfied CONTINUE
- 4 Very dissatisfied CONTINUE

21b. If you are somewhat or very dissatisfied, please indicate why. Please circle all that apply. I do not feel he/she:
- 1 Takes my illness seriously
- 2 Has the latest knowledge about available treatments
- 3 Cares
- 4 Understands what I'm going through
- 5 Spends enough time with me
- 6 Respects me
- 7 Other (fill in)

22. What types of treatment have been used to treat your bipolar illness? Please circle all that apply.
- 1 Medication
- 2 One-on-one therapy (psychotherapy)
- 3 Group therapy
- 4 Support groups
- 5 Other counseling
- 6 ECT (shock therapy)
- 7 Alternative treatment(s)
- 8 Other (fill in)

22a. What type of treatment is <u>currently</u> being used to treat your bipolar illness? Please circle all that apply.
- 1 Lithium
- 2 Valproate (Depakote)
- 3 Carbamazepine (Epitol)
- 4 Other anticonvulsants (gabapentin, lamotrigine, topiramate, tiagabine)
- 5 Olanzapine (Zyprexa)
- 6 Other atypical antipsychotics (Risperdal, Clozaril)
- 7 Typical antipsychotics (Haldol)
- 8 Antidepressant medications (Prozac, Wellbutrin, etc.)
- 9 Alternative treatment (light therapy, herbal treatment)
- 10 High dose thyroid treatment
- 11 Other medications (fill in)
- 12 One-on-one therapy (psychotherapy)
- 13 Group therapy
- 14 Support groups
- 15 Other counseling
- 16 ECT (shock therapy)
- 17 Other treatment (fill in)

23. Please rate the current treatment by indicating how much you agree or disagree with the following statements.

	Agree Strongly	Agree Somewhat	Disagree Somewhat	Disagree Strongly	Not Applicable
I am satisfied with my current treatment	1	2	3	4	5
I often <u>consider</u> discontinuing medication due to bothersome side effects	1	2	3	4	5
I am likely to discontinue medication in the next 6 months to one year because of side effects	1	2	3	4	5
I am likely to discontinue medication in the next 6 months to one year because of the high costs	1	2	3	4	5
I am likely to discontinue medication in the next 6 months to one year because I feel better	1	2	3	4	5

continued

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Appendix 1. 2000 National DMDA Constituency Survey[a] (cont.)

I am likely to discontinue medication in the next 6 months to one year because I do not want to be on medication forever	1	2	3	4	5
I have considered switching to another medication due to side effects from my current medication	1	2	3	4	5
The side effects of my current medication have little or no impact on my daily life	1	2	3	4	5

24. If you are currently taking medication for your bipolar disorder, have you, during the past 12 months … (Please circle all that apply)

1 Taken prescribed dosage every day, or as instructed
2 Missed at least one dosage per week, because you forgot
3 Missed at least one dosage per week, because of unpleasant side effects
4 Missed at least one dosage per week, because it was inconvenient
5 Taken it only when you felt you needed it
6 Missed dosages or stopped taking it because you did not feel it was working
7 Stopped taking it because you could not afford it
8 Stopped taking it because you felt better
9 None of the above
10 Not currently taking medication for bipolar disorder

25. Have you ever been hospitalized for bipolar disorder?

1 Yes CONTINUE
2 No PLEASE SKIP TO Q.26

25a. How many times have you been hospitalized?

1 Once
2 2–4
3 5–7
4 8–10
5 More than 10

25b. What was the average duration of the hospitalization(s)?

1 Less than one week
2 1 week but less than 2 weeks
3 2 weeks but less than 1 month
4 1 month but less than 6 months
5 6 months but less than 1 year
6 One year or more

26. Have you ever been discriminated against for reasons related to your illness?

1 Yes CONTINUE
2 No PLEASE SKIP TO Q.27

26a. Please describe an instance in which you were discriminated against.

_____

_____

_____

27. Do you have insurance or a health plan that covers a portion of the cost of … (Please circle all that apply.)

1 Mental health visits to primary care physician
2 Mental health visits to psychiatrist
3 Mental health visits to counselor-therapists
4 None of these

27a. Does your insurance or health plan cover the cost of your medications for bipolar illness?

1 Yes, completely without a co-payment
2 Yes, with a co-payment
3 No, does not cover any of these costs

27b. What is the amount of the co-payment for these medications?

1 Less than $5
2 $5–9
3 $10–19
4 $20 or more
5 Not sure

27c. Does your health plan have any restrictions or limitations on specific medications that they will cover to treat bipolar disorder?

1 Yes CONTINUE
2 No PLEASE SKIP TO Q.28
3 Not sure PLEASE SKIP TO Q.28

27d. Please specify which restrictions are imposed (if known).

_____

_____

_____

continued

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Appendix 1. 2000 National DMDA Constituency Survey[a] (cont.)

28. Please indicate your provider.
    1 Personal plan
    2 Employer-based plan
    3 Medicaid/Medicare
    4 Military/VA/Champus
    5 Not sure
    6 Other (fill in):

29. Where do you get most of your information about bipolar disorder? Please rank-order the following sources from 1–11; a 1 means it is the greatest source of your information, and an 11 means it is the poorest source of information. You should use every number from 1 through 11.
    _____ Doctors
    _____ Nurses/Other healthcare professionals
    _____ Other patients
    _____ Patient organizations
    _____ Books/Library
    _____ Internet
    _____ TV/Cable
    _____ Radio
    _____ Newspapers/Magazines
    _____ Friends
    _____ Other (fill in)

Profile

30. Please indicate gender.
    1 Female
    2 Male

31. What is your age?
    1 Under 21
    2 21–30
    3 31–40
    4 41–50
    5 51–60
    6 More than 60

32. What is your marital status?
    1 Single (never married)
    2 Married
    3 Separated/divorced
    4 Widowed

33. What is the highest grade completed in school?
    1 Grade school
    2 Some high school
    3 High school graduate
    4 Some college
    5 Technical/vocational graduate
    6 4-year college graduate
    7 Post college

34. What is your employment status?
    1 Employed full time
    2 Employed part-time
    3 Unemployed
    4 Retired
    5 Student

35. What is your total annual personal income?
    1 $5,000 or less
    2 $5,001–10,000
    3 $10,001–15,000
    4 $15,001–25,000
    5 $25,001–35,000
    6 $35,001–50,000
    7 $50,001–75,000
    8 $75,001–100,000
    9 Over $100,000

36. What is your total annual household income?
    1 $5,000 or less
    2 $5,001–10,000
    3 $10,001–15,000
    4 $15,001–25,000
    5 $25,001–35,000
    6 $35,001–50,000
    7 $50,001–75,000
    8 $75,001–100,000
    9 Over $100,000

THANK YOU VERY MUCH FOR YOUR COOPERATION. PLEASE PUT THE SURVEY INSIDE THE POSTAGE PAID ENVELOPE AND MAIL IT TODAY.

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