A Consumer Perspective Concerning the Diagnosis and Treatment of Bipolar Disorder

The National Depressive and Manic–Depressive Association (National DMDA) is concerned about the diagnosis and treatment of bipolar disorder. As the nation’s largest patient-directed, illness-specific organization, we represent the millions of people suffering from this disorder. As such, our perspectives may differ at times from those of physicians, researchers, and family members.

The public wants to learn more about bipolar disorder. They are searching for easy to understand, scientifically and medically accurate, unbiased information. Nearly 5000 people call National DMDA’s information line every month. In addition, our website receives a quarter million hits monthly. The primary reasons people contact us are to receive information, to find a doctor with expertise in treating mood disorders, and for referral to a DMDA support group.

While National DMDA and the other consumer advocacy organizations have achieved significant outreach, we have a long way to go. Our efforts continue to be hampered by the stigma these illnesses carry—by the widespread belief of patients and providers that mood disorders are not real illnesses but rather “personality flaws.”

The Undertreatment of Mood Disorders

With bipolar disorder the sixth leading cause of disability in the United States today, with it affecting 2.3 million American adults annually, and with mood disorders costing the U.S. economy more than $44 billion a year, why are less than 50% of the people with bipolar disorder being successfully treated?

Some treatments for mood disorders have existed for decades. In this time of great scientific advancement, why are people with bipolar disorder so often misdiagnosed, receiving inappropriate or inadequate treatment, or not given treatment at all?

The National DMDA Consensus Panel on the Undertreatment of Depression found that these problems are the result of a disconnection between what we know about the treatment of mental illnesses and what occurs in practice. The panel determined the most common barriers to treatment are attributable to patient, provider, and health care system factors (Hirschfeld et al 1997).

Patient factors include a lack of awareness that mood disorders are treatable medical illnesses, no knowledge of the symptoms of depression and bipolar disorder, an underestimation of the severity of the illness, and an unwillingness to undergo a full course of medical treatment because of side effects, lack of insurance coverage, and the significant time lapse between beginning treatment and noticing results. Also, many patients turn society’s stigma inward and have a great deal of resistance to taking psychiatric medication.

Barriers to treatment for the provider include insufficient information about how to diagnose and treat mood disorders due to a lack of access to mental health professionals in the community, an unwillingness or inability due to schedule demands to take the time required to diagnose psychiatric disorders, the inability to prescribe the best medications due to formulary restrictions, and the inability to refer to the appropriate specialist.

Health system factors that block access to treatment include lack of insurance reimbursement, poor collaboration between providers, and infrequent monitoring of progress for chronic cases.

The Underfunding of Research

Why is there an 8-year lapse from the onset of symptoms to treatment for bipolar disorder? Why are suicides by people with bipolar disorder increasing? Why are we asked to make the tough choice between losing touch with reality and possibly developing thyroid, liver, or kidney problems?

Why do serious gaps in bipolar disorder research exist? In particular, why are bipolar disorder in children, adolescents, and the elderly; maintenance therapy of bipolar disorder; and the depressed phase of bipolar disorder hugely understudied?

National DMDA believes the answers to these questions lie largely in the stigma associated with mental illnesses. If legislators do not understand that mental illnesses are “real” and if society believes that people with mental illnesses should have the ability to “pull themselves up by their bootstraps,” how can we hope to increase funding for mental health research?

This stigma carries over to physicians and researchers. How can we expect students to select psychiatry as their specialty when so many professionals also believe these illnesses are not in the same category as “physical” illnesses?
Consumer Satisfaction with Treatment

For those who do receive treatment, National DMDA wanted to determine how satisfied they were with their treatment. We also wanted to know why those who undertake treatment so often end their treatment prematurely. The organization recently conducted an online survey of 1370 people over the age of 18 treated for depression (National DMDA On-Line Survey of Those Who Have Been Treated for Depression 1999). More than three fourths of the respondents were currently receiving treatment for depression and 46% had been told they had bipolar disorder.

The survey findings were troubling. Only one third said they were very or somewhat satisfied with the treatment of their disease. And 28% indicated dissatisfaction with their health care practitioner’s treatment of their depression. When asked “For what reasons were you dissatisfied?,” more than half (56%) did not feel their health practitioner understood. More than one in three did not feel their depression was taken seriously, did not feel their practitioner had the latest knowledge about available treatments, did not feel that their practitioner cared, and/or did not feel respected.

Our survey findings underscored the difficulty in treating depressive disorders. Even with 70% of our respondents having their medication prescribed by a psychiatrist, 25% reported feeling no change in their depression from the time they sought help and only 13% said they feel like they are back to their previous best.

Only 69% reported taking their medication as instructed. The reasons for not complying with their treatment regimen included not believing the medication is working, the usual 3- to 4-week wait for medication to take effect, financial considerations, and inconvenience. Medication side effects were cited as a significant reason for noncompliance, with 80% saying they experienced side effects.

In addition, antidepressant medications carry a stigma themselves. Our survey revealed that 23% of those who considered not taking medication did so because they believed the medication would change their personality, and 18% erroneously believed it might be habit forming.

These survey findings are particularly disturbing to National DMDA. A disease as serious as bipolar disorder should have treatments available that do not require choosing between a lessening of symptoms and quality of life.

The Work Ahead

There is much work left for us all. Success will come sooner if clinicians, researchers, and consumers work together. We have a long way to go in our effort to educate people that mood disorders are medical illnesses and not character weaknesses.

This year, National DMDA will increase its public awareness programs. Our public service announcements on radio, television, and in print significantly increase calls for information and visits to our website.

Until more effective treatments are developed, we all have the difficult job of increasing treatment compliance. Depressive and Manic-Depressive Association support groups play an important role. More than 50,000 consumers attended a DMDA group in 1998. We expect that number to have significantly increased in 1999.

National DMDA recently surveyed more than 2000 constituents active in their local DMDA group (National DMDA Support Group Compliance Survey 1998). Sixty-seven percent had a diagnosis of bipolar disorder. Nearly all (95%) described their DMDA group as helping to at least some extent with communicating with their doctor, being motivated to follow instructions, being willing to take medication, making the treatment plan less complex, and/or making follow-up visits to their doctor. The largest number of respondents (45%) said their group helped the most by making them more willing to take medication and cope with the side effects.

Physicians can help by becoming involved in their local DMDA group or by starting groups in communities where none exist. They can also help by referring patients to DMDA groups and by letting their colleagues know we exist. Our support group survey found that only one third of the respondents learned about their DMDA group from a mental health professional and that 57% did not hear about DMDA until more than 1 year after their diagnosis.

Treatments need to be improved so that they work faster, are easier to take, and have fewer side effects. National DMDA will continue to advocate for increased National Institute of Mental Health research funding, encourage our constituents to participate in clinical trials, and post announcements of clinical trials on our website.

We hope our consensus statement on the use of placebo in clinical trials for mood disorders will be published before the end of this year. This article should counteract some of the negative publicity surrounding psychiatric research and should provide a framework for ensuring ethical treatment of patients.

We all need to be able to better identify the symptoms of bipolar disorder so that the average time between onset of symptoms and treatment is considerably shortened.

National DMDA will increase its educational efforts, especially targeting young Americans.

Patients need to stop turning society’s stigma inward and release the shame they feel for having these illnesses. National DMDA hopes its stories of success and of the
courageous people who are willing to talk publicly about their mood disorders will lessen the stigma that is so prevalent. And because science destigmatizes, researchers need to increase the sharing of their findings with the general public, in a language we can understand.

Doctors need to be more empathic toward people with mood disorders and need to approach these people with the same concern they have for those suffering from other chronic illnesses. National DMDA will soon release a video that proposes ways for mental health professionals to establish effective relationships with consumers. Please keep an open mind when we express our frustrations.

Managed care companies need to know we are watching them closely. National DMDA will continue its efforts to hold managed behavioral health companies and organizations accountable for their policies and practices and ensure that appropriate managed care treatment protocols are accessible to network patients and providers.

Educational programs for providers must be improved, with particular emphasis on primary care physicians. National DMDA is helping to develop a self-assessment tool for bipolar disorder. We hope that if patients can get a better understanding of what their symptoms might mean, they might be able to better focus their conversation with their doctor and shorten that 8-year gap between onset of symptoms and treatment.

Psychiatrists need to speak about mood disorders at local meetings of primary care physicians. Also, please use your connections to make introductions so that consumer advocacy groups get invited to speak to these groups.

Educators have to be better informed of the destructive impact mood disorders have on children. You can help by speaking to teachers in your community about the impact of depression and bipolar disorder on kids.

Employers must learn the effect these illnesses, if left untreated, have on the bottom line. Although there is much talk about the huge economic impact on the U.S. economy and the fact that unipolar depression is the number one cause of disability, the business community is not grasping this message. All of us need to talk to local business leaders about the devastating role these illnesses play in the workplace.

Finally, our work ahead must include better communication with legislators so that they understand that, when untreated, mood disorders have a mortality rate of 15–20%.

If National DMDA’s mission had been met years ago, millions of us could have avoided lifetimes of suffering and underachievement. We are dedicated to meeting our mission and want to collaborate with you. From our perspective, it is unfortunate that doctors have more clout and a greater voice than consumers. We know there would be no market for the pharmaceutical companies without us and there would be no careers for researchers and clinicians without us. Yet, we sometimes feel invisible and/or manipulated.

Let us continue discussing our perspectives and find ways to collaborate. When mental health organizations and the top researchers work together, the beneficiaries will be people suffering from mental illnesses.

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References
