

# A Consumer Perspective of Diagnosis and Treatment of Chronic Major Depression

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© The National Depressive and Manic-Depressive Association (National DMDA) is a nonprofit, mission-driven, consumer advocacy organization that was founded to educate patients, their families, and the public about the nature and management of depressive and manic depressive illness. Although treatments for mood disorders have been available for decades, individuals with chronic major depression are often misdiagnosed or inappropriately treated. Serious gaps in the translation of research findings into clinical management exist and are attributable to patient, provider, and health care system factors. This article discusses the barriers to diagnosis and the ways to improve recognition and treatment of chronic major depression from the consumer perspective.

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The National Depressive and Manic-Depressive Association (National DMDA), founded in 1986 and headquartered in Chicago, Ill., is a nonprofit, mission-driven, consumer advocacy organization that was founded to educate patients, their families, and the public about the nature and management of depressive and manic depressive illness. Additional goals of the organization include fostering self-help for patients and their families, improving access to health care, eliminating discrimination and stigma, and promoting research toward better treatment and elimination of depressive illness (Table 1). National DMDA membership includes individuals who have experienced depression or manic depression, their families and friends, health care professionals, and concerned citizens from all walks of life.

National DMDA has 3 unique strengths. First, the organization is patient directed. The bylaws require that at least 51% of the board of directors have a mood disorder, a requirement that provides the governing body with a unique perspective. Second, the organization has an active (not just honorary) scientific advisory board composed of 65 distinguished researchers and medical experts who participate in all National DMDA programs and advocacy work. Third, the organization focuses solely on issues concerning mood disorders, which eliminates broad categories of

psychiatric illness and the problems thereof. The public relies on National DMDA to provide accurate and unbiased medical information about mood disorders, and the outreach of the national organization is substantial. During a typical month, the organization receives approximately 750,000 hits to the National DMDA Web site and nearly 5000 telephone calls to the toll-free information line. Additionally, more than 60,000 people attended National DMDA support group meetings in 1999.

One explicit recommendation of the Surgeon General's recent report on mental health<sup>1</sup> is, "If you think you have a mental health problem, or think you have symptoms of a mental disorder, seek help." Yet the message is not being heeded. Annually, approximately 7% of Americans experience mood disorders that include major depressive disorder (unipolar major depression), manic depression (bipolar disorder), dysthymia, and cyclothymia.<sup>1</sup> According to the World Health Organization, mood disorder also ranks among the top 10 causes of worldwide disability.<sup>2</sup> Unipolar major depression ranks first in the United States, and manic depression ranks in the top 10. Although effective treatment is available, only 1 of 10 persons with a diagnosis of major depression has received adequate doses of antidepressant therapy for an adequate period of time.<sup>3</sup> Moreover, the total annual cost of major depression in the United States (1990 figures) was estimated at \$44 billion.<sup>4</sup> Despite the prevalence of mood disorders in the general population, chronically depressed persons frequently go unrecognized and untreated.

## BARRIERS TO DIAGNOSIS AND TREATMENT OF DEPRESSION

People who have chronic major depression often suffer the worst possible disability; they are frequently unable to

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**Table 1. Goals of the National Depressive and Manic-Depressive Association**


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Educate patients, their families, and the public
Foster self-help skills in patients and their families
Improve access to health care
Eliminate discrimination and stigma
Promote research toward better treatment and elimination of depressive and manic depressive illness

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work, and many take their own lives. Depression also robs individuals of the ability to become everything they can become. Living a life of “gray” moments, thinking that the symptoms are due to a faulty personality, or having difficult personal or job-related relationships throughout a lifetime—indeed, living a life devoid of joy—is totally unnecessary when safe and effective treatments are available. In this era of great scientific advancement, why are chronically depressed individuals so often misdiagnosed or inappropriately treated? When National DMDA held a consensus conference to discuss the undertreatment of depression,<sup>5</sup> the panel found that there were serious gaps in the translation of research findings into clinical management, and they attributed the gaps to patient, provider, and health care system factors (Table 2).

#### Patient Factors

One of the barriers to successful diagnosis and treatment of depression (or depressive illness) is that people are unaware that chronic depression is a treatable medical illness, just like diabetes or asthma. Furthermore, many people have no knowledge of the symptoms of depression, or they believe that their symptoms are just an intense response to a stressful situation. Some may also underestimate the severity of their illness and decide to medicate themselves with over-the-counter drugs or preparations from health food stores. Others are unwilling to undergo a full course of supervised medical treatment because of medication side effects, a lack of insurance coverage, or the substantial time lapse between beginning treatment and noticing results.

Primary care patients may have a different understanding and attitude about mental health problems than specialty care patients.<sup>6</sup> Because they may not understand depression as an illness, primary care patients may express symptoms in a way that makes diagnosis difficult, e.g., by emphasizing somatic symptoms, such as fatigue or anorexia. Even when the illness is properly diagnosed, primary care patients may not accept the diagnosis (or treatment) of depression because of the stigma associated with having a mental illness.

#### Provider Factors

Depression is the second most common condition seen in primary care practice; hypertension is first.<sup>7</sup> Yet, primary care physicians may lack the necessary education to

**Table 2. Barriers to Diagnosis and Treatment of Depression**


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Patient factors
Unaware of available treatments
No knowledge of the symptoms
Underestimation of the severity or chronicity
Self-treatment
Unwilling to undergo full treatment course because of
Medication side effects
Lack of insurance
Time lapse between start of treatment and noticeable results
Provider factors
Lack of information about psychiatric disorders
Limited interpersonal skills in managing emotional distress
Fear of alienating patients
Belief that psychiatric disorders are not real illnesses
Time constraints
Poor insurance coverage
Restrictive formularies
Inability to refer to appropriate specialist
Health care system factors
Lack of adequate insurance reimbursement
Poor collaboration among providers
Infrequent monitoring in chronic cases

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make a definitive diagnosis of depression or recommend pharmacotherapy or psychotherapy. Moreover, some physicians may have limited interpersonal skills for managing emotional distress or may hesitate to raise the possibility of depression for fear of alienating the patient. Additionally, because of scheduling demands, some physicians may be unable to take the time required to diagnose and treat a depressive illness. Finally, some primary care physicians in particular may not consider depression to be a real illness. Other barriers to effective diagnosis and treatment of depression from the provider sector include inadequate insurance coverage and the inability to prescribe the best medication available because of formulary restrictions.

Referral from primary care physicians to mental health specialists is often unsatisfactory from both the primary care and specialist points of view.<sup>6</sup> Many patients fail to follow through on referrals, and many specialists fail to give timely feedback to the referring physician. Moreover, managed care organizations limit the number of approved specialists for referral within their own managed care plans, and the primary care physician may not know or feel comfortable with those specialists.

#### Health Care System Factors

Some of the barriers to effective diagnosis and treatment of depression stem from deficiencies in the health care system. Such deficiencies include a lack of adequate insurance reimbursement, poor collaboration among providers, and infrequent monitoring of the patient during the course of illness. Unfortunately, many insurance and managed care companies dissuade patients from using mental health services altogether. Although specific factors vary, in general, many current health care systems view depression as a short-term disorder; they do not recognize the

chronic and recurrent nature of the illness and discourage the frequent monitoring of patients early in the treatment regimen.<sup>8</sup> Moreover, reimbursement may not be provided should the patient require more than one treatment approach or referral to another specialist. As a result, both the depressed patient and the examining physician are placed in difficult situations. Clearly, patient, provider, and health care system factors hinder the effective diagnosis and treatment of depressive disorders.

### **NATIONAL DMDA ONLINE SURVEY**

To determine the level of satisfaction among consumers being treated for depression, an online National DMDA survey was conducted in 1999. Some of the findings were disturbing. Of 1370 persons over the age of 18 years who responded to the survey, 78% were undergoing treatment for depression. Only about 33% of the respondents were "very satisfied" or "somewhat satisfied" with their treatment. A total of 28% indicated dissatisfaction with treatment, and when queried for the reasons, 56% reported that their physician had no understanding of their depression. More than one third of the respondents felt that their physician did not take their illness seriously or had no knowledge of the latest treatment or did not respect or care about them. When the results of the survey were given to psychiatrists and to primary care providers, both groups attributed patient dissatisfaction to the nature of the illness. This may be a valid assumption in some cases; if not, it underscores the importance of having the physician look at treatment from the depressed patient's perspective.

The National DMDA survey also confirmed the difficulty of successfully treating depression. Among 70% of the respondents taking medication prescribed by a psychiatrist, 25% reported no change in their depression, 54% described some improvement, 13% were back to their "previous best," and only 6% felt better than they had ever felt. When asked about medication compliance, 69% of survey respondents reported taking their medication as prescribed. Not surprisingly, side effects were the most common reason for noncompliance and were experienced by 80% of the respondents. Other reasons for noncompliance included a belief that the medication was ineffective, the 3- to 4-week wait for beneficial effects, financial considerations, and inconvenience. National DMDA support groups play an important role in treatment compliance. In another recent survey of more than 2000 active constituents of National DMDA support groups, 45% of the respondents said that they were encouraged by other members to contend with the side effects of medications and continue with their treatment programs. National DMDA will continue to encourage patients to take medications as prescribed, but medications with fewer side effects need to be developed for use in chronically depressed individuals. Patients should not have to choose between the lesser of

two evils—for example, between chronic fatigue and loss of libido—when undergoing treatment for their illness.

One must never underestimate the important role that stigma plays in whether a person will seek treatment for depression. Many people turn a social stigma inward and have a great deal of resistance and shame associated with talking about their illness or seeking treatment. While more than 80% of survey respondents told family members and friends about their depression, only 40% told their employers. Approximately 33% of respondents chose to stay silent about their depression because they were either ashamed of their illness, afraid of losing their jobs, or uncomfortable at the prospect of a negative response from family or friends. There is also a stigma associated with taking antidepressants. Our survey revealed that 23% of those respondents who considered not taking the prescribed medication believed that the drug would change their personality and 18% believed that the drug might be habit-forming.

### **WAYS TO IMPROVE THE RECOGNITION AND TREATMENT OF DEPRESSION**

Chronic major depression is a medical illness, not a character weakness. While National DMDA strives to spread this message, sometimes the symptoms of depression can be a person's worst enemy. Feelings of worthlessness, pessimism, and lack of energy are poor motivators for seeking help. Furthermore, if the symptoms have been present for several years, they become embedded in a person's perception of reality. Depressed persons often do not realize that life can be different or that they can feel better. They must be told repeatedly that chronic depression is not a personality weakness, because the stigma of having such an illness will continue to rear its ugly head. Depressed persons must release their shame about being mentally ill and stop turning the stigma of depression inward. Hopefully, courageous patients—especially young ones—will begin to talk publicly about their own depression and lessen the stigma that is so pervasive. Scientific information also tends to lessen the stigma of an illness, but researchers must share their findings in ways that can be understood by the general public.

National DMDA recently produced a video that proposed ways for mental health professionals to establish effective relationships with patients. The primary purpose of the video was to stimulate mental health professionals to look candidly at their own perceptions, assumptions, and behaviors in their relationships with mentally ill patients. The video was derived from a 2-day roundtable discussion in which practitioners and patients discussed how communication, trust, and respect are the fundamental (yet often overlooked) building blocks of an effective practitioner/patient relationship. They also discussed ways in which hope, family and peer support, and empowerment play sig-

nificant roles in achieving optimal recovery from mental illness. The video, is available free of charge (\$4.95 shipping and handling charge) from National DMDA. Orders are taken at 800-826-3632.

Physicians must query patients about alterations in their thinking, mood, and behavior. To assume that a doctor will make a connection between a vague physical complaint and depression is faulty thinking. I recently had an annual checkup by a new doctor in a large primary care practice at a teaching hospital in Chicago. I was asked to complete a comprehensive questionnaire about my medical history; however, there were *no* questions pertaining to mood, substance abuse, or treatment (past or present) for mental illness. Those questions must be asked—either by direct interview or as items on a questionnaire. Failure to ask those pertinent questions avoids the issue and leaves the depressed person undiagnosed and untreated.

Physicians must approach depressed patients with the same empathy and consideration shown to other chronically ill patients. They should listen to the concerns of depressed patients and their families and become active negotiating partners in attempting to achieve the common goal of symptom reduction. Physicians involved in research should remember that many of the subjects recruited into clinical trials are suffering human beings who have been coping with depressive illness for decades. Additionally, physicians must take the time to explain to the patient how the treatment works. Package inserts and other types of pharmaceutical literature are often difficult to understand. Unless patients understand the course of a depressive illness, they may discontinue taking antidepressants when they start to feel better—just like they often discontinue antibiotics when a fever goes down. Potential side effects must also be discussed. Patients should be told that medication side effects can remit over time and that the same medication may not work for everyone.

It is predicted that major depression will become the second most disabling condition—after ischemic heart disease—in the level of disability and cost to society by the year 2020.<sup>9</sup> Increasing the recognition rate and treating depression effectively have the potential to reduce the burden on health care resources and increase work productivity.<sup>7</sup> Like the 7 warning signs of cancer, the public must be made more aware of the symptoms of depression, so that the average time between the beginning of symptoms and the onset of treatment can be shortened. Until a cure for chronic depression is found, medications must be improved so that they are easier to take, have fewer side effects, and provide more rapid beneficial effects. Medical education in the primary care sector must be expanded to include mood disorders, and since the rates of depression and suicide are increasing in young people, the importance of paying attention to this target group cannot be overemphasized. Managed care organizations should take extra precautions to recruit competent mental health specialists

to provide additional training to primary care providers located in areas where specialty care is sparse.<sup>7</sup> National DMDA will do everything possible to hold managed care companies accountable for their policies and practices and to ensure that appropriate treatment protocols are accessible to networking patients and providers. Employers must provide rehabilitation support for depressed employees just as they do for employees with drug, alcohol, and nicotine problems. Moreover, employees must be assured that their confidentiality will not be breached; it is deplorable when workers fail to file medication or psychotherapy charges on insurance claims because of the fear of losing employment or ruining a career.

As an advocacy organization, National DMDA continues to press for increased research funding. Announcements of clinical trials are posted on the National DMDA Web site at [www.ndmda.org](http://www.ndmda.org), and our constituents are encouraged to participate. Although the data are not yet analyzed, National DMDA recently completed a survey of 1000 depressed patients and 500 primary care physicians. The purpose of the survey was to determine if the patient perspective of treatment differed from that of the primary care physician. If there is a gap between patient and provider perspectives, National DMDA will work with both groups to develop ways to close the gap. Additionally, a consensus statement on the use of placebo in clinical trials of mood disorders is being readied for publication. The purpose of the publication is to counteract some of the negative publicity surrounding psychiatric research and to provide a framework for ensuring ethical treatment of subjects enrolled in clinical trials.

## CONCLUSION

Depressed people are often immobilized by fear: fear that families will tire of their neediness, that partners will leave them, and that employers will find a legal way to fire them. Stigma surrounding depressive illness is pervasive, making it an illness of isolation. If the mission of National DMDA had been met years ago, millions of people with depression and manic depression might have avoided a lifetime of suffering and underachievement. The diagnosis and treatment of chronic depressive illness will improve only when patients, their families, medical professionals, and the public all work together to battle the stigma and ignorance surrounding this illness. According to David Satcher, M.D., Ph.D., Surgeon General of the United States, “Promoting mental health for all Americans will require scientific know-how but, even more importantly, a societal resolve that we will make the needed investment. The investment does not call for massive budgets; rather, it calls for the willingness of each of us to educate ourselves and others about mental health and mental illness, and thus to confront the attitudes, fear, and misunderstanding that remain as barriers before us.”<sup>1</sup>

*Disclosure of off-label usage:* The author has determined that, to the best of her knowledge, no investigational information about pharmaceutical agents has been presented in this article that is outside U.S. Food and Drug Administration–approved labeling.

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