

Bipolar Disorders Expert Column Series

Reducing the Burden of Bipolar Disorder for Patient and Caregiver

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Introduction

According to the DSM-IV, bipolar disorder is a severe, recurrent, life-long illness that affects up to about 7% of Americans. Lifetime prevalence rates for bipolar I and II disorder range from .9% to 2.1%; for cyclothymia, a milder form of bipolar disorder, prevalence ranges from 3% to 5%.^[1] More recent prevalence estimates are even higher.^[2]

The World Health Organization reports that bipolar disorder was the sixth leading cause of years lived with disability, worldwide, in 1990 and remains among the top 10 causes today.^[3]

Burden in the Patient

Despite the advent of new medications to treat bipolar disorder, bipolar patients continue to experience disability, functional decline, diminished quality of life, mortality from comorbid medical conditions or suicide, and increased service utilization. An economic study found that the lifetime costs of bipolar disorder ranged from \$24 billion to \$40 billion, and include lost wages, caregiver costs, hospitalization costs, and lost productivity due to suicide. If a patient is diagnosed in his 20s and left untreated, he would lose an estimated 12 years of good health, 14 years of work activity, and a life expectancy shortened by 9 years.^[4]

The cyclical nature of the disorder poses unique challenges and barriers to bipolar patients. People often find that their changes in mood significantly impair their ability to function in social situations and, most importantly, to hold down a job. Patients often need to take days off from work either due to worsening clinical symptoms or hospitalization. When at work, problems may result from mood episodes such as poor concentration or low motivation during depression or, conversely, inappropriate behavior during mania. As a consequence, bipolar patients suffer deterioration in their level of employment.^[4]

One 4-year cohort study of 173 people treated for a first episode of mania or mixed affective disorder found that 93% of people no longer met criteria for mania at 2 years and that their median recovery time was 4.6 weeks. Only 36% of these patients, however, had regained premorbid function. Forty percent of patients had a recurrent manic (20%) or depressive (20%) episode within 2 years of recovering from the first episode.^[5]

Occupational disability is extremely costly to bipolar patients. In 1990, bipolar patients accounted for 289 million days of absenteeism.^[6] A study assessing disability associated with psychiatric hospitalization found that 6 months after a manic episode, only 43% of people with bipolar disorder were employed. They also noted that although 80% of the patients were symptomatically recovered, only 21% were functioning at an expected level.^[7]

There are also pathognomic problems directly resulting from mood episodes of bipolar disorder. For example, in mania, a person's behavior is often reckless and self-damaging. During mania,

patients may spend excessive amounts of money that could lead to significant financial distress, or may have excessive urges to drive fast, potentially resulting in personal injury or criminal activity.^[1]

During the depressive phase of the illness, patients may try to self-medicate themselves with alcohol or other substances, leading to problems with abuse or dependence. Over 60% of bipolar I and almost 50% of bipolar II patients have a history of substance abuse, although not necessarily because of mental illness.^[8,9]

Bipolar illness carries both high morbidity and mortality. Suicide is a real threat in bipolar patients. Between 25% and 50% of those with bipolar disorder will attempt suicide at some point, with between 15% and 19% eventually succeeding.^[10]

In addition to these risks, treatments for bipolar disorder may have iatrogenic effects. For example, lithium causes weight gain in many patients, with up to 25% becoming clinically obese.^[11] Antipsychotics, particularly olanzapine, clozapine, chlorpromazine, and thioridazine, frequently result in serious weight gain. Besides leading to difficulties in adherence to medication regimens, weight gain can be a risk factor for medical problems, such as high serum low-density lipoprotein and triglyceride levels, diabetes, and cardiovascular problems. Further, antipsychotics can create problems with cholesterol, triglyceride levels, and diabetes independent of weight gain.^[12]

Nonpharmacologic treatments also have risks. For example, electroconvulsive therapy may lead to anterograde or retrograde amnesia.^[13,14]

Finally, the stigma associated with having a mental illness can exacerbate recovery. Patients who reported concerns about stigma during an acute phase of bipolar disorder had poorer social adjustment with people outside their family 7 months later.^[15]

The Family Burden

Bipolar disorder can have a severe impact on the patient's family and caregivers. During episodes, partners can have significant problems in their relationships with patients, and these difficulties affect caregivers' own employment, legal matters, finances, and social relationships, including parenting.^[16]

In one study, 93% of caregivers reported moderate or great distress in at least 1 burden domain. Some of the distress, over and above distress due to the patient's clinical state and history, was accounted for by family beliefs, particularly illness awareness; perception of the patient; and perception of family control.^[17]

Sharing a household with a person with bipolar disorder also affects the physical health of family members. When other predictors of health were controlled for, people living with a person with bipolar disorder, regardless of the severity of the condition, reported poorer physical health, more limited activity, and greater health service utilization compared with those who did not.^[18]

Reducing the Burden

Psychoeducation for caregivers appears to reduce their subjective perception of burden significantly. For example, twelve 90-minute sessions of psychoeducation about bipolar disorder and coping skills can increase caregiver knowledge of the disorder, change their beliefs about the connection between the patient's illness and their objective burden, and reduce distress.^[19]

Family-focused therapy (FFT) also appears to reduce emotional burdens for both caregivers and patients. FFT integrates family therapy with individual sessions of interpersonal and social rhythm therapy to improve the relationship between patients with bipolar disorder and their relatives. Randomized trials found that families who received FFT showed more positive nonverbal interaction during a 1-year posttreatment problem-solving assessment^[20] and had fewer hostile verbal exchanges with patients.^[21] Not surprisingly, patients assigned to FFT showed greater reductions in mood-disordered symptoms and better adherence to medication regimens.^[22]

Because caretaker burden predicts adverse clinical outcomes,^[23] and professionals underestimate this burden,^[24] it would behoove professionals to become more sensitive to the distress of family members and to consider helping them as well as the identified patient.

Since the 1970s, advocacy and self-help groups have reduced the burden of people with mental illness and their families by lobbying for better services or parity in insurance coverage; fighting stigma; educating patients, caregivers, and the public; offering job training; and providing support groups. The 1999 Report of the Surgeon General notes that one of the greatest contributions of consumer organizations has been the proliferation of self-help groups that have improved the lives of thousands of patients.^[25] Perhaps this effect is achieved through the validation received in support groups and the "redemptive power of role models" who restore self-esteem and hope.^[26]

The efficacy of support groups for individuals with psychiatric disabilities has been documented. For example, a 1-year prospective study of people with depression who used an Internet chatroom found that members who had high scores on the Center for Epidemiologic Studies Depression Scale and were socially isolated perceived considerable benefit from the group. At 1-year follow-up, 72.6% of respondents still participated in the online group; 81.0% were still receiving face-to-face depression care. Heavy users (defined as members averaging 2.5 hours per week in the chatrooms) were more likely to resolve their depressions.^[27] Double Trouble in Recovery support groups of people with substance abuse and psychiatric diagnoses also show the efficacy of support groups.^[28]

The Depression and Bipolar Support Alliance (DBSA), formerly known as the National Depressive and Manic Depressive Association, is the largest patient-run, illness-specific organization in the United States. It began in 1986 as a collection of small local support groups scattered throughout the country. Later, with the help of mental health professionals, it expanded into a network of over 1000 support groups with a Chicago office providing a toll-free information and referral line; brochures, books, programs, and videotapes reviewed by its prestigious scientific advisory board; Congressional testimony; media representation; conferences; a Web site; and other services. According to the DBSA, over 85% of support group members reported that attending the support group helped them adhere to their treatments.^[26]

Other organizations that reduce the burden for bipolar patients and their families include the Child and Adolescent Bipolar Foundation, Families for Depression Awareness, and the international Depression and Related Affective Disorders Association.

Besides the illness-specific groups named above, there are 2 major omnibus mental health organizations that reduce the burden on patients and families: the National Alliance for the Mentally Ill (NAMI) and the National Mental Health Association (NMHA).

NAMI was founded in 1979 as a grassroots organization to provide education, support, and advocacy for people with serious mental illness, their families, and friends. It claims more than 1000 local affiliates and 50 state organizations that support increased funding for research; advocate for improved rehabilitative services, housing, job opportunities, and legislation; and combat stigma. Popular programs include the free 12-week Family-to-Family Education Program, where trained family members teach other family members about clinical treatment and practical

coping skills for the particular disorder. The program enables family members to understand the patient's experience, see their own need, set limits, and so on. NAMI also has a 9-week, consumer-taught program for patients interested in recovery.

NMHA is the oldest nonprofit mental health organization in the United States. It has 340 affiliates nationwide that address all aspects of mental health and mental illness but focus on helping Americans with mental disorders through education, advocacy, and research. Services range from annual conferences to lobbying to support groups led by volunteer professionals.

Finally, the US government's Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (SAMHSA) has funded self-help demonstration projects within traditional community mental healthcare agencies as well as agencies managed and staffed by former patients. The latter provide self-help groups, peer counseling, and drop-in services that serve as substitutes or adjuncts to traditional facilities.^[26]

Conclusion

Bipolar disorder is a life-long illness that has far-reaching, often devastating, consequences to both people afflicted with the illness and caregivers. Nevertheless, with increased research on treatment, an improved understanding of how the burdens of patient and caregiver can be reduced through psychosocial support, and advances in the consumer and advocacy movement, this burden may be reduced.

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