Early Sea Changes in Borderline Personality Disorder

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Introduction

In the 1980s, three major factors converged that resulted in very significant increases in public awareness, destigmatization, and funding for treatment resources and research in the fields of schizophrenia, depression, and bipolar disorder. The first factor was the reports of neuroimaging studies that showed differences in the brains of people with these disorders compared with those of control subjects. These studies provided clear and readily visible evidence that the disorders were associated with anatomical and functional abnormalities of the brain, and that they should be viewed no differently than medical disorders affecting other organs. The second factor was the emergence of a new generation of antipsychotic agents, antidepressants, mood stabilizers, psychosocial interventions, and specific treatment programs that significantly improved the efficacy and safety of treatment for patients with these disorders. The final factor was the emergence of new lay advocacy organizations, such as the National Alliance for the Mentally Ill and the National Depressive and Manic Depressive Association, joining ranks with academic leaders to exert badly needed, powerful political influence. In addition, these two organizations, along with the older National Mental Health Association, collaborated to start The National Alliance for Research on Schizophrenia and Depression. Since 1987, this donor-funded organization has awarded more than \$180 million in grants to established and new meritorious researchers involved in brain research focused on psychiatric disorders.

Over the past 10 years, these same forces have begun to exert their collective influence in the area of borderline personality disorder (BPD). BPD has a prevalence estimated at 1% to 2% of the general population, with a female to male ratio of 3:1 [1,2]. If the larger general prevalence number and the gender ratio [3] are correct, this

would calculate out to one of every 33 women, and one of every 100 men. In addition to the high prevalence rate, the disorder causes devastating effects on the lives of those afflicted and their families. It has a mortality rate of 9%, and high comorbidity rates with substance abuse, depression, panic and anxiety disorders, posttraumatic stress disorder, attention-deficit/hyperactivity disorder, and eating disorders. Nonetheless, BPD has long been considered the backwater of psychiatric disorders. For example, the disorder was not included in Diagnostic and Statistical Manual of Mental Disorders, Second Edition (DSM-II), for decades it was termed a diagnostic "wastebasket," and it was commonly thought to be relatively unresponsive to most, if not all, forms of treatment. Unfortunately, these beliefs are still held by many mental health professionals who are unaware of the recent significant advances in the field. Now, BPD is rapidly gaining more attention by the public and by mental health clinicians and academicians, and is also receiving public and private research funding. What are the specific factors that have contributed to these advances?

First, in 1975, in a widely acclaimed article, Gunderson and Singer [4] set forth operational diagnostic criteria for BPD. Gunderson followed up this work with the development of a structured diagnostic assessment instrument for BPD. Subsequent research using this instrument strongly suggested that the disorder has diagnostic validity and integrity. This body of research led to the inclusion of BPD in DSM-III published in 1980.

Another major advance in the field has been the demonstration by multiple neuroimaging studies of specific structural and functional abnormalities in subjects with BPD compared with control subjects [5]. Critically, these abnormalities have been shown to occur in those brain regions known to be associated with the expression and control of three of the four main behavioral dimensions of BPD: emotional dysregulation, aggressive impulsivity, and cognitive-perceptual impairment [1]. Additional data directly support a role of serotonergic dysfunction in the disorder [6], and indirect data suggest that dopamine dysfunction also may be involved [7]. Other data support the contention that genetic factors enhance the risk of developing BPD [6,8]. Collectively, these and other studies of subjects with BPD

strongly suggest that the disorder has a biological and psychosocial basis [9].

Nonetheless, it is doubtful that we would have experienced a surge of interest in BPD if it were not for the clear demonstration of the effectiveness of specific psychopharmacologic and psychosocial treatments for the disorder [1]. The most frequently reported controlled pharmacologic studies have involved low doses of traditional neuroleptics and atypical antipsychotics. These studies have been uniformly successful in showing efficacy, safety, and tolerability of these agents in the disorder. Other classes of drugs also have been studied in borderline subjects and were shown to have efficacy compared with placebo control conditions. These include selective serotonin reuptake inhibitors, mood stabilizers, and the nutraceutical agent omega-3 fatty acid. These drugs typically have two main effects in patients with BPD: they significantly reduce the primary symptoms of the disorder, and they seem to enable patients to retain and successfully apply the information and techniques they learn in various forms of psychotherapy.

Before the advent of effective pharmacotherapy for BPD, it was commonplace for extended psychotherapy to result in an improved level of understanding by the patient, but an inability to translate that information to a sustained improvement in symptoms and effective changes in behavior. Relapses were frequent and total. This has long been considered one of the hallmarks of the disorder, as reported clearly in a seminal article on BPD by the psychoanalyst Adolph Stern published in 1938 [10]. However, the effectiveness of psychotherapy now experienced in patients with BPD cannot be attributed only to the adjunctive use of appropriate medications. The modifications of traditional forms of psychotherapy to meet the special needs of patients with the disorder, and the development of new forms of therapy have resulted in substantial improvement in treatment outcomes. The most widely recognized new psychotherapeutic approach for patients with BPD, dialectical behavior therapy, was introduced by Linehan [11] in the early 1990s. Multiple, controlled treatment outcome studies of dialectical behavior therapy in subjects with BPD, in the United States and abroad, have consistently shown its effectiveness, especially in the reduction of self injurious and suicidal behaviors, and of the frequency of acute hospitalizations.

The advances in BPD noted above, and the new hope they have provided, have not escaped the attention of borderline personality patients and their family members. Their increased awareness of the disorder and of the effectiveness of comprehensive treatment is primarily the result of three phenomena. The Internet has provided ready access to information about the disorder through several websites. Additionally, many excellent books have been published recently that provide current, detailed information about BPD for the lay public [11–14]. Lastly, two national lay advocacy organizations

focusing on BPD have emerged over the past decade: the Treatment and Research Advancements Association for Personality Disorders (TARA APD), and the National Education Alliance for Borderline Personality Disorder (NEA-BPD). These organizations are dedicated to increasing awareness of BPD, to educating patients and their families about the disorder and how to cope more effectively with it, and to stimulating public and private funding for research on BPD. They have formed alliances with prominent academicians in the field in order to rapidly enhance the quality and breadth of the information that they require, and to optimize their influence and effectiveness. Local chapters have been developed and members of the local chapters of NEA-BPD have been trained to lead family support groups and to distribute help and information to those in need. NEA-BPD and TARA also have sponsored regional educational conferences on BPD for consumers and mental health professionals. By means of their lobbying efforts, these organizations have begun to show their effectiveness in stimulating federal and private interest and funding of BPD research initiatives.

In addition to the factors noted above, other organizations and undertakings have added significantly to the increase in activity in the field. For example, James Breiling at the National Institute of Mental Health has developed a growing list of researchers and clinicians interested in BPD. He regularly distributes information by e-mail (BPD ListServ) in order to "advance the study of BPD and its features by fostering international communication about research grant opportunities, grant awards, research papers, meetings, and job openings; provide a forum for discussion of research issues and the identification and implementation of research priorities; and foster the development of junior investigators." A different task has been undertaken by the Borderline Personality Disorder Resource Center. It has been recently established to help those affected by BPD "find the most current and accurate information on the nature of BPD, and on sources of available treatment."

Two new important private resources for research funding of BPD have begun to have a positive effect on the field. Founded in 1999, the Borderline Personality Disorder Research Foundation (BPDRF) "has mobilized research centers in the United States and Europe to investigate whether BPD is a recognizable distinct entity, and, if so, what the defining characteristics of the disorder are." Initially, it selected and funded four centers to investigate BPD from varying scientific and clinical perspectives. In addition, it has awarded research grants to 22 investigators. Over the past decade, the The National Alliance for Research on Schizophrenia and Depression has expanded its original focus from schizophrenia and affective disorders to other prevalent mental disorders such as anxiety disorders. Recently, it has included BPD in its areas of interest.

What have been the effects of these and other related efforts? First, I am not aware of any direct assessments of public awareness of, and the level of stigma associated with, BPD. However, indirect indices such as the growing number of local chapters of BPD lay advocacy organizations, the volume of sales of books written for the lay reader about BPD, the frequency of inquiries about the location of clinicians skilled in the field, and the attendance rate of consumers and mental health professionals at national, regional, and local conferences on BPD all suggest substantial movement in the right direction. Also, from fiscal year 2000 to 2004, the National Institute of Mental Health increased its awards from \$5.5 million to \$6.7 million on research for BPD, and from 18 grants to 23 grants. Although this is still less than 1% of total awards by the National Institute of Mental Health, and a modest increase in the number and dollar amount of federally funded research grants on BPD, it is an indication of progress. Though relatively small, the increase in combined federal and private research funding and activity, both here and abroad, has added substantially to our fundamental and clinical knowledge of BPD. Lastly, there seems to be a discernable increase in attention to BPD by the media and the entertainment industry. National and local television networks and newspapers have hosted representatives of lay advocacy organizations and academic experts to discuss varying aspects of the disorder. In addition, films such as Looking for Mr. Goodbar; Girl, Interrupted; and Fatal Attraction have featured a leading character with BPD.

Despite the above advances, significant problems remain to be solved if progress in the field is to continue. Public and professional awareness of the disorder remains low compared with other mental and physical disorders that are less prevalent and devastating in their effects. A cursory examination of medical records on psychiatric inpatient services and in outpatient clinics readily reveals that the most common Axis II diagnosis recorded is "deferred," and that the diagnosis of BPD is rarely made. However, there is consistent evidence that BPD occurs in approximately 20% of all psychiatric inpatients and 10% of outpatients. Therefore, it is not uncommon to see patients in whom the diagnosis has been missed for more than a decade of psychiatric care. There also is a serious shortage of psychiatrists and other mental health care providers who are experienced in the diagnosis and comprehensive treatment of patients with BPD, even in large metropolitan areas. As a result of the efforts to expand public awareness of BPD, we are reaching a point where the demand for skilled care is exceeding the supply. Inadequate insurance coverage for borderline and other personality disorders is also a major problem. For example, there is no Medicare billing code for BPD. This results in the alternatives of submitting codes of cooccurring Axis I disorders, miscoding, or not being paid for services rendered. In addition, relatively few academic

departments of psychiatry have specific clinical, research, and training programs in BPD, thereby limiting the clinical expertise of their trainees in this area, and the supply of junior investigators to meet the need for a new generation of young academicians committed to the field.

As indicated in the title of this commentary, we are in the early phases of expansion of general awareness of, and scientific and clinical knowledge about BPD. The forces that propelled historic advances in schizophrenia and affective disorder have now fallen into place for BPD. Therefore, despite the problems confronting the field, over the next one or two decades, we should anticipate an exponential growth in all areas important to the alleviation of suffering caused by this prevalent, devastating, and too-long neglected mental disorder.

Resources

Borderline Personality Disorder Resource Center 888-694-2273 www.bpdresourcecenter.org

National Education Alliance for Borderline Personality Disorder (NEA-BPD) 914-835-9011 NEABPD@aol.com

www.borderlinepersonalitydisorder.com

Treatment and Research Advancements National Association for Personality Disorder (TARA APD) 212-966-6514 TARAAPD@aol.com

http://www.TARA4BPD.org

BPD ListServ 301-443-3527 jbreilin@mail.nih.gov

Borderline Personality Disorder Research Foundation 212-421-5244

bpdrf.usa@verizon.net

http://www.borderlineresearch.org

National Alliance for Research on Schizophrenia and Depression (NARSAD)

516-829-0091

http://www.narsad.org

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