What's in a name?
Borderline Personality Disorder Label Creates Stigma

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Introduction

What's in a name? In the disability community this question is a hot topic. In fact, the use of negative language has proven time after time to be a major influence on individual and public attitudes towards people with disabilities and as Dahl asserts often constitutes "a major barrier for people with disabilities".[3] However, despite progress being made to use less stigmatizing disability terms, psychiatry has not kept up with these changes. Borderline Personality Disorder, listed in the Axis II section of Diagnostic and Statistical Manual (DSM IV), is an example of one such term and the focus of this paper.[4]

The DSM IV defines BPD as "a pervasive pattern of instability of interpersonal relationships, self-image, and effects, and marked impulsivity beginning by early adulthood…".[4] The mental health disability causes extreme emotional vulnerability, an unstable sense of self, impulsiveness in potentially self-damaging behaviors (e.g., spending, sex, substance abuse, driving, eating, etc.), suicidal or self-mutilating behavior, chronic feelings of emptiness, intense anger or difficulty controlling anger, and periods of feeling removed from reality (dissociation).

This paper will discuss the negative connotations of the term "BPD", examine the origin of the term, the effects it has on treatment and ways the term shapes both individual and public perception of people diagnosed with the disorder. In addition, the paper will explore whether or not the term is an acceptable use of language based on current terminology standards outlined in the government publication "Worthless or Wonderful".[15] Finally, it will propose recommendations for changing the name and identify recent progress towards this goal.

Origin

The origin of the term "BPD" dates back to the early 1900's. At this time people with mental health disabilities were either categorized as neurotic or psychotic. [13] As it became increasingly clear to Dr. Stern (an early psychiatrist) that a growing patient body did not quite fit into these oversimplified diagnostic categories of the day, the term "borderline" was born. According to Dr. Stern's theory, such patient's teetered on the "borderline" between neuroses and psychoses. Although this theory went out of favor shortly after it was proposed, the "borderline" label stuck. [2]

Inaccuracy

Dr. Leland Heller (M.D), an expert in BPD treatment, believes the BPD term is inaccurate and that the 'BPD' label "in and of itself is as if the whole person (and the personality) is flawed…".[7] He strongly objects to this implication because the most recent research on BPD indicates that the cause of the disorder is not a "flawed personality" but rather a biologically based brain disorder. He believes there is a dysfunction of the limbic system of the brain.[7] Heller backs up his objection to the term with recent research on the biological components of BPD. Evidence linking BPD to a limbic system dysfunction is based on current knowledge regarding the function of the limbic circuit and studies examining the biological causes of the disorder. The limbic system, itself, is often thought of as the "emotional centre" of the brain. [1] The amygdala and hippocampus are important components of the limbic system that regulate emotional expression, especially fear, rage and automatic reactions (such as impulsive behaviors) and emotional memory. Although not formally part of the limbic system itself, the pre-frontal cortex (located near the forehead) is another important structure thought to play a key role in emotional regulation. Both areas of the brain have been the subject of a number of studies examining the

neurological origin of BPD. For example, studies examining the connection between BPD and neuroanotomical differences in limbic system found that the volume of the hippocampus and amygdala were respectively, 16 percent and 7.5 percent smaller in the BPD group than those in the control group (people without any form of mental illness). [5] It is hypothesized that these differences may be related to prior abuse experiences, a common issue for people diagnosed with BPD. However, more research is required to prove this theory.

Another study by Paul Soloff, M.D. and his associates found a connection between BPD and low level brain activity in the pre-frontal cortex. Using Positron Emission Tomography (PET) scans, researchers can measure glucose levels to detect brain activity Low glucose levels have been connected to deficiencies in serotonin, a naturally occurring chemical in the brain that helps regulate emotion. In this study, Soloff established two groups. The first group comprised of BPD patients, while the second group, served as the control group made up of participants with no history of mental illness. Subjects from both the BPD group and the control group were either given the serotonin-enhancing drug, Fenfluramine or a placebo. Under both conditions, researchers consistently observed higher level glucose activity in the frontal lobes of control participants than those in the BPD group. [12]

These biological explanations for BPD substantiate Heller's belief that BPD is in fact a biological disorder, and not just a personality flaw.

Dr. Marsha Linehan, Ph.D., another leader in the field of Borderline Personality Disorder, proposes that the condition is a problem with emotional dysregulation.[8] Linehan pioneered the development of Dialectical Behavioral Therapy (DBT), a well-recognized method of cognitive behavioral therapy in the treatment of BPD. Core to the success of this therapy, is

the belief that BPD is a biological disorder characterized by heightened sensitivity to emotion and increased emotional intensity.

Heller has suggested that name “Borderline Personality Disorder” be changed to a more accurate, less emotionally laden term. He has proposed the term “Dyslimbia” [7]. To explain the term he breaks it down into two parts. The first part, “Dys” is the Greek for “disorder” while the second part, “limbia” refers to the limbic system of the brain. Put together the term refers to a biological disorder of the brain’s limbic system. However, more research may be necessary to bring this term into general use. The advocacy organization, TARA – Treatment and Research Advancement Association, would like to see the name changed as well.

> “The name BPD is confusing, imparts no relevant or descriptive information, and reinforces existing stigma. We believe that BPD should be refrained onto a spectrum of its core components-impulsivity and emotional dysregulation.” [11]

They believe that “Emotional Regulation Disorder” or “Emotional Dysregulation Disorder” have the most likely chance of being adopted by the American Psychiatric Association (APA). [11]

Dr. Joel Dvoskin (Ph.D.) seems to agree that something most be done to remove the stigma of the “BPD” diagnosis. He highlights the reality of what the "BPD" label does when applied to an individual. He stresses that "not all mental health diagnoses foster treatment" and goes on to identify BPD as a diagnosis that "hurts people very much".[6] He dislikes the term because it so often results in sub-standard treatment of people diagnosed with the disorder. For example, mental health professionals often label undesired behaviors of BPD clients as "manipulative" and in need of punishment Yet, no matter how many times punishment is administered it has no effect on the so-called "manipulative behavior".

So why persist in "treating" a patient's condition with the reward/punishment model when it clearly does not work? Dvoskin believes when such futile attempts fail, it is easier for the professional to blame the patient for lack of response to treatment or worse, fault the patient for a lack of moral fortitude than admit the professional's own shortcomings. In fairness, one should mention these patients are often regarded as "notoriously difficult to treat". [10] However, Dr. Dvoskin believes that one of the main reasons these clients are considered so difficult to treat is that mental health professionals take out their frustration on the patient, label their patients as purposely causing their own grief and blame their patients for not responding to treatment. He asserts "apparently the greatest sin a patient can commit is the sin of poor response to treatment…".[6]

The last area needing exploration is whether or not the term "Borderline Personality Disorder" meets currently held standards for proper language use in referring to people with mental illness. The report "Worthless or Wonderful" recommends that language which "suggests negative or judgmental connotations" [15] be changed to more objective terminology. As mentioned above, the term "Borderline Personality Disorder" suggests the judgmental connotation that the personality of the individual is flawed. Since personality is commonly viewed as the essence of who we are, the inference of a flawed personality is very insulting. Therefore, according to the latest recommendations on proper language use in referring to a persons with disabilities, the term BPD does not meet current standards.
In light of the out-dated, out of favor theory used to develop the "borderline" label, the negative effect of this label on treatment and patients themselves, and the failing grade given to the BPD term based on recognized disability terminology standards, surely it is the duty of every professional to explore the inaccurarcy of the "BPD" label and its stigmatizing effect on those

diagnosed. Needless to say, the people who are most affected by the stigma of the "BPD" label are those diagnosed with the disorder. Therefore, those diagnosed with "BPD" can also have a major influence on the use of the term by refusing to accept it. As "consumers" of mental health services, such individuals can empower themselves by speaking out about how they are affected by the "BPD" label and how it affects the mental health services they receive. Acting as their own mental health advocates, people diagnosed with BPD can make a difference to change public perception about their disorder and make services more adaptable to their needs.

Now is the chance for people diagnosed with BPD, concerned community members and mental health professionals to speak out. TARA is encouraging people to use a copy of their form letter or write their own letter to the APA to express support for TARA's advocacy efforts (see Appendix). You can also sign an online petition at:

http://www.thepetitionsite.com/1/Advocacy-for-Borderline-Personality-Disorder

Through expressing these concerns, the APA will hear the voice of the people and hopefully, in the next publication of the DSM, do away with the stigmatizing "BPD" label altogether.

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15. Worthless or Wonderful - The Social Stereotyping of Persons With Disabilities. Status of Disabled Persons Secretariat Department of the Secretary of State, Canada, 1988. 30

Appendix

(Please note the address below is no longer valid. A valid address for this advocacy letter is:

David Kupfer J. MD, Chair of DSM-V Task Force
3811Ohara St.
Pittsburg, PA 15213-2593
United States of America

TARA (Treatment And Research Advancement Association) is a non-profit advocacy association for BPD. Their website can be found at www.tara4bpd.org

NOT VALID
Paul Applebaum, MD, President Elect
American Psychiatric Association
100 Berkshire Road
Newtonville, MA 02460-2404

Re: Placement of Borderline Personality Disorder on to Axis I

Dear Dr. Applebaum:

This letter is in support of the APA Assembly resolution of May 2001 to explore moving Borderline Personality Disorder (BPD) to Axis I and changing the name of BPD. Dr. Steve Hyman, former director of NIMH, is in full support of this change. The severity, chronicity and degree of disability of BPD justifies placement of BPD on Axis I.

People with BPD are unfairly penalized when insurance companies deny full coverage to people with BPD because BPD is an Axis II diagnosis. They are also excluded from most parity legislation. The diagnosis of BPD is frequently overlooked or misdiagnosed as major depression, bi-polar disorder and/or PTSD. These disorders are reimbursable by insurance. When clinicians are no longer constrained by the possible loss of benefits to their clients more frequent diagnosis of BPD would result. This will yield more precise epidemiological data on prevalence of BPD and reflect more accurately the actual number of people suffering with the disorder. This type of data would justify new treatment or research programs for BPD. Axis II designation is unfair to patients, families and researchers.

The name BPD is confusing, is not in anyway descriptive of the disorder or the psychic pain that accompanies it, and merely serves to reinforce existing stigma. It allows for the continued trivialization of a very severe and painful disorder. A change in name would be beneficial to patients and families, as it would begin to change the pervasive professional stigma against these patients. It is time to stop referring to BPD as a "**GARBAGE BAG DIAGNOSIS**." (Fuller

Torrey)

We hope you will do all you can to bring about these much needed changes so that people with BPD can have hope, access to appropriate treatment and equal opportunity for recovery as do people suffering with other mental illnesses. Thank you.

Yours truly,

Address

_____

City, Province/State, Postal Code/Zip

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