SPEAKER NOTES

Understanding Borderline Personality Disorder

Summarized by Thomas T. Thomas

Abby Ingber is Executive Director of the National Education Alliance for Borderline Personality Disorder (https://www.borderlinepersonalitydisorder.org). At NAMI East Bay's speaker presentation on June 25, she described this condition and discussed interventions, coping, and strategies.

Ingber was joined by various family members as well as individuals with the diagnosis of BPD:

Saadia experienced symptoms at age 13 but was not diagnosed with BPD until she was 22. Now, with appropriate treatment, she has graduated law school. She contributes to the organization's blog from the Lived Experience Committee, This Borderline Life (https://www.borderlinepersonalitydisorder.org/lived-experience-committee-this-borderline-life/).

Brian is a co-leader in the Family Connections™ course (https://www.borderlinepersonalitydisorder.org/family-connections-programs/). His daughter was diagnosed with mood disorder, bipolar disorder II, and substance abuse disorder before the psychiatrist finally identified her BPD.

Amber is a person with lived experience who was diagnosed at age 36. She also has a daughter with BPD. She said BPD is a true mental health disorder that impacts the way a person thinks and feels about others.

Cesli is also a Family Connections leader. Her son was diagnosed with BPD ten years ago.

Lisa is a leader of the Family Connections course whose daughter was diagnosed with BPD.

The NEABPD was founded by American psychiatrist Marsha Linehan, who developed treating the disorder with Dialectical Behavior Therapy (https://my.clevelandclinic.org/health/treatments/22838-dialectical-behavior-therapy-dbt). The organization provides educational programs on and supports scientific research into BPD. They have testified before Congress and last year worked to remove an exclusion in California law that sends non-violent offenders with BPD to jail rather than to treatment, as with other serious mental illnesses.

The term "borderline personality disorder" is old and misleading, Ingber said, contributing to stigma. It originated with early psychiatrists who decided it was on the borderline between neurosis and psychosis. Actually, a better term would be "chronic emotional dysregulation." The disorder is about a person's ability to manage their emotions and relationships with other people. BPD is treatable, although there is as yet no medication available.

The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5-TR) lists nine symptoms of or criteria for a BPD diagnosis:

1. Frantic efforts to avoid real or imagined abandonment.

2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.
3. Identity disturbance: markedly and persistently unstable self-image or sense of self.
4. Impulsivity in at least two areas that are potentially self-damaging, for example, spending, substance abuse, reckless driving, sex, or binge eating.
5. Recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior.
6. Affective instability due to a marked reactivity of mood, for example, intense episodic dysphoria, anxiety, or irritability, usually lasting a few hours and rarely more than a few days.
7. Chronic feelings of emptiness.
8. Inappropriate, intense anger or difficulty controlling anger, for example, frequent displays of temper, constant anger, or recurrent physical fights.
9. Transient, stress-related paranoid ideation or severe dissociative symptoms.

To receive a diagnosis of BPD, a patient must meet five of the nine criteria. But there is no order to them. A patient meeting the first five or the last five is still diagnosed, and even if two patients present with markedly different symptoms they can have the same diagnosis. There is no test or brain scan for the disorder; it can only be established by meeting and talking with a therapist.

Saadia said she experienced most of the symptoms: impulsivity, self-harm, binge drinking, and high-risk sexual activity. She knew that these were dangerous actions, and she would cry before she went out drinking with friends in the evening.

Cesli said she did not know what her son was feeling. If she and her husband were going out, something would always happen just as they were about to leave the house—which she later understood was his fear of abandonment. He would also jump off the roof and run away from home, indicating impulsivity. Aa an adult, his drinking was out of control, and his relationships with women were volatile. The Family Connections classes taught her and her husband to be empathetic and non-judgmental.

Ingber said people with the disorder have extreme emotions, ones they cannot understand and control. The emotional dysregulation is so pervasive that the person can no longer function in life.

About 1.6% of people have BPD, about the same percentage as bipolar disorder, and about 3.6% will experience its symptoms over their lifetime. The disorder affects men and women equally, although women are more likely to get treatment, while men are more likely to go to jail. The disorder usually starts in early childhood, increases through the teenage years and young adulthood, and then decreases with age.

BPD research is underfunded. The disorder gets about $6 million per year, compared with $100 million for bipolar disorder and $300 million for schizophrenia. Ingber attributed this lack in part to the fact that there is no medication and so no interest in funding from the pharmaceutical industry.

Psychiatrists and other professional staff tend to avoid a diagnosis of BPD, in part because of the stigma surrounding the disorder, and in part because the symptoms also mirror so many other conditions: anxiety, mood disorder, bipolar, substance abuse, and post-traumatic stress. Research has shown that only 20% of professionals graduating with a degree in psychology or psychiatry have been trained in recognizing and treating BPD.

Saadia said she was not properly diagnosed until she had been hospitalized for self-harm and released. Then she began posting on Reddit, and the platform's algorithms suggested she had BPD. At that point, she began her own program of research, determined her situation, and began getting better. She attributed part of her recovery to Dialectical Behavior Therapy and part to eating well, getting exercise, avoiding substances, and getting rest and enough sleep. "These are small things," she said, "and good for anyone."

Brian and Lisa also reported getting various diagnoses for their loved one, and Amber for herself, before the psychiatrist was forced to consider BPD. Brian noted that most substance abuse recovery programs do not consider an underlying condition of mental illness.

Ingber said that, without proper treatment of BPD, 80% of patients engage in self-harm, 65% to 70% attempt suicide, and 10% of patients die by suicide.

BPD develops because the person has a temperamental vulnerability, usually being more sensitive to emotional experiences in the same way that some people are more sensitive to sounds, and then he or she encounters an environmental trigger, usually in the form of a poor fit to their temperament. Such a trigger can be a teacher with an inappropriate classroom style or a family member with, say, a difficult parenting style. But it is wrong to think that parents are the cause of BPD.

Treatment can take place in a variety of settings: outpatient; partial hospitalization with group meetings and occupational therapy; a residential facility; or a psychiatric hospital—although the latter generally do not have BPD programs. The gold standard of treatment is Dialectical Behavior Therapy, which is effective with 66% of the patient population. It teaches mindfulness and acceptance.

To treat patients through DBT, the therapist must adhere to four principles: there has to be one-on-one therapy; the therapy must include education and skills classes; the therapist must be available 24/7 to address crises; and the therapist must him- or herself be in therapy.

Other effective treatments include mentalization-based therapy, which includes stabilizing the patient's sense of self and sustaining mentalization with an interpersonal focus, and general or good psychiatric management, in which a doctor or other practitioner teaches patients to manage their behavior through understanding their patterns and approaching situations more effectively. Mentalization therapy is currently offered in Los Angeles, Houston, New York, and Boston.

Ingber advised patients to choose a therapist who is skilled and the best fit for him- or herself. And Brian noted that, in dealing with an adult child, the parent has no say in the choosing. Still, family support and emotional involvement in the treatment is crucial.

The Family Connections classes, which are led by family members themselves, teach skills for coping, provide information about DBT treatment, and offer group support. The classes can decrease a family member's stress, grief, and burdens. The classes are in high demand, and there is usually a waiting period to enroll.

Q. There must be something biological happening in the brain, as with other mental illnesses. If so, there should be a medication to treat BPD.

A. We don't yet have enough research to show this. Researchers think the amygdala—which governs human emotions, fear, and motivation—is involved, but whether that's a cause of the disorder, or is affected by the disorder, is unknown.

BPD is about emotions in relationships. If you put a person with bipolar disorder alone on a desert island, they will still have symptoms. But if you put a person with BPD on a desert island, their symptoms will disappear.

Q. How did Saadia achieve such a high level of functioning, as in graduating from law school?

A. She became involved with her disorder and became an expert on it. "No one knows as much about you as you do," she said.