"If Only We Had Known"

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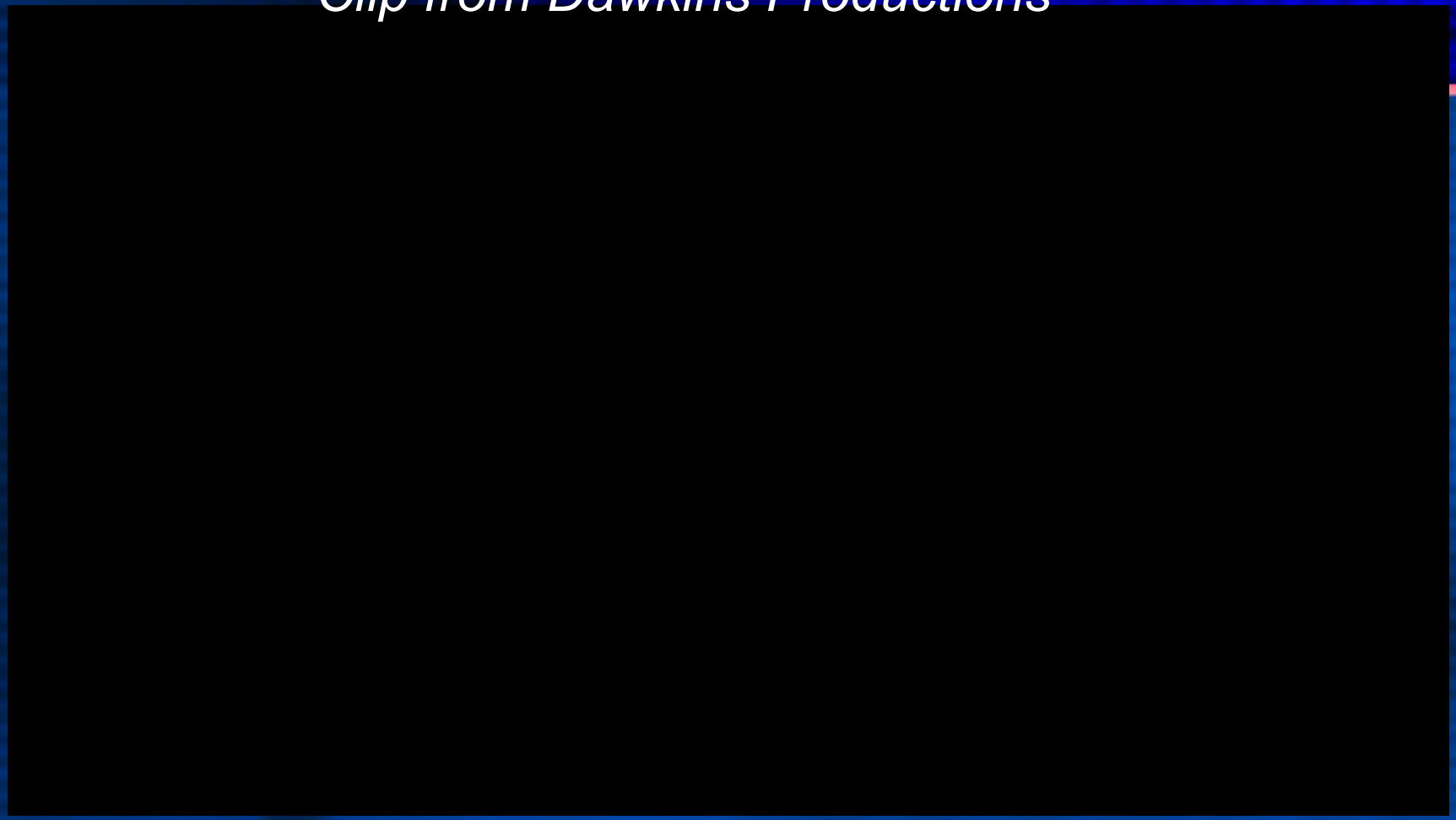
National Education Alliance for Borderline Personality Disorder
www.borderlinepersonalitydisorder.com

Thank you to the National Institute of Mental Health
Thank you to all the researchers for their data and support

Thank you to all the NEA.BPD speakers for providing the data presented at this workshop.

Clip from Dawkins Productions



Hope for Hope!

OUTLINE for TODAY

I. Background:
   - What makes the disorder so challenging?
   - History and the Coming of age: The Present

II. Prevalence and nature of the disorder:
   - Self-injury and suicidality
   - Co-morbidities
   - Medication

III. To Tell or Not to Tell:
   - Disclosing the diagnosis

IV. Etiology:
   - Biosocial theory
   - Brain and Emotions

V. Course and outcome:

VI. Treatments

VII. Families:
   - Impact
   - Help! For Families: Family Connections

Let's First Be Open and Honest

- How many people work with BPD patients?
- How many like working with them?
- How many people refer BPD patients out?

Why?

Perhaps this explains a lot:

Most Stressful for Mental Health Professional

1. Suicide attempts
2. Threats of suicide
3. Patient anger

Hellman, 1988

Borderline Personality: The Disorder Doctors Fear the Most

Ken Duckworth, MD NAMI

"If you hated the patient-- the patient was pissing you off, you would bandy this term about:

'Oh, you're just borderline…'
It was a diagnosis of wastebasket hostility."

Time Magazine, 2009

Myth or Fact?

1. BPD patients try to defeat therapists
2. Patients with BPD do not improve
3. An un-likeable person must have BPD
4. BPD is a death sentence

Myth or Fact?

5. Don’t say the BPD diagnosis
6. Co-morbid disorders can be treated effectively without treating BPD
7. The diagnosis cannot be made before 18 years old

Fact

1. BPD is environmentally induced
2. Patients do not choose to have BPD
3. Recovery is possible and likely
4. After 2 years.. more than 50% patients recover
5. After 10 years.. more than 80% recover
6. 88% remain in recovery

Fact

7. 40% of BPD patients previously diagnosed with bipolar disorder (25% of BPD patients have both).
8. BPD is under-diagnosed, misunderstood and over-stigmatized.
9. The diagnosis of BPD is often withheld from patients and families.
10. BPD is a “good prognosis diagnosis.”

Important to Note:

Borderline Personality is a Disorder of Relationships

Seven of the nine criteria impact relationships

DSM –IV Criteria

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 (e.g., spending, sex, substance abuse, reckless driving, binge eating).

DSM –IV Criteria

5. Recurrent suicidal behavior, gestures, or threats, of self-mutilating behavior.
6. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).
7. Chronic feelings of emptiness.
8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).
9. Transient, stress-related paranoid ideation or severe dissociative symptoms.

Or, BPD Criteria Reorganized

- Interpersonal Dysregulation
  - Abandonment fears
  - Unstable relationships (ideal/devalued)
  - Emptiness
- Affective/Emotion Dysregulation
  - Affective instability (no elations)
  - Inappropriate, intense anger
- Behavioral Dysregulation
  - Recurrent suicidality, threats, self-harm
  - Impulsivity (sex, driving, bingeing)
- Self Dysregulation
  - Unstable/distorted self-image
  - Depersonalization / paranoid ideation under stress

History of borderline personality disorder

BPD as a Variant of?

- Schizophrenia (1970's)
- Depression (1980's)
- PTSD (1990's)
- Bipolar disorder (2000's)

BPD's Pejorative Attributions

- "frequent flyers"
- "help-rejecting complainers"
- intractable, treatment resistant
- irresponsible, fickle, egocentric
- "emotional hypochondriacs" (attention-seeking)

Marsha Linehan, Ph.D.

BPD Patients

"Borderline individuals are the psychological equivalent of third-degree burn patients. They simply have, so to speak, no emotional skin. Even the slightest touch or movement can create immense suffering."

Marsha Linehan, Ph. D.
Time Magazine, 2009

“Assuming the worst is destructive”

Marsha Linehan, Ph.D.
Developer of DBT

The Present

"Borderline Personality Disorder is to psychiatry what psychiatry is to medicine"

NIMH Research Funds

Disorder	Amount (millions)	% Population
Schizophrenia	300	0.4%
Bipolar Disorder	100	1.6%
BPD	6	~5.9%

May is BPD Awareness Month

"It is essential to increase awareness of borderline personality disorder among people suffering from this disorder, their families, mental health professionals, and the general public by promoting education, research, funding, early detection, and effective treatments."

House Resolution 1005, April 1, 2008

Prevalence and Nature of the Disorder

What We Need to Know

Prevalence

- General population 5.9%*
- Mental health outpatient 11%
- Mental health inpatient 19%
- Primary care 6%

* Grant B, *J Clin Psychiatry*, 2008

A High Risk Population

- 10% of persons with BPD die by suicide
- With all suicides, 9-33% are by BPD individuals
- Up to 75% of individuals with BPD have cut, burned, hit, or otherwise injured themselves

Suicidality

- 8 – 10% Lifetime Suicide Rate
- Mean age of suicide 30 (Stone) and 37.3 (Paris, Zweig-Frank)
- 60 – 70 % Non-Suicidal Self-Injury
- Limitations in predicting suicide in all diagnostic categories including BPD
- Most patients with BPD do not kill themselves early in the course of the illness

Suicidality and Self-harm

- 65-70% of persons with BPD make at least 1 suicide attempt
- 10% of patients with BPD complete suicide

-Black 2004; Oldham 2006

- Self-injury (cutting, burning, bruising, head-banging, biting) is seen in 75% of patients

-Gunderson 2008

Self Injury

- Self injury in BPD is not suicidal but a means to relieve psychic pain
- Many patients report that they do not feel physical pain at the moment when they cut themselves
- Instead, cutting engenders feelings of relief or well-being
- Often serves as a form of self medication

Functions of Self Injury in BPD

- Feel concrete pain (59%)
- Inflict self-punishment (49%)
- Reduce anxiety/despair (39%)
- Feel in control (22%)
- Express anger (22%)
- Feel something when numb (20%)
- Seek help from others (17%)
- Keep bad memories away (15%)

-Shearer 1994

Impairments in Functioning

- High internal levels of anxiety and distress
- High family stress
- Difficulty keeping jobs
- Overemotional and impulsive
- Self-injurious behavior
- Stormy interpersonal relationships*

Interpersonal Difficulties

- Gunderson (2010) argued for a greater focus on interpersonal dysfunction in understanding borderline personality disorder (DSM-V debate)
- The interpersonal dysfunction of BPD "offers the best discriminators for the diagnosis"
- Mood shifts and self-destructive behaviors in BPD often occur in response to interpersonal triggers
- Verses in bipolar disorder, mood shifts occur from stress and sleep-related triggers

Taking a History

- Are symptoms triggered by interpersonal stress (i.e., breakups)?
- Is the depression “treatment resistant”?
- Does the patient self harm? (And what is the function of the self harm?)
- Are relationships unstable?

What Makes It Even More Challenging

Comorbidity

84.5% of BPD patients met criteria for Axis I disorder, mean = 3.2

Most common =

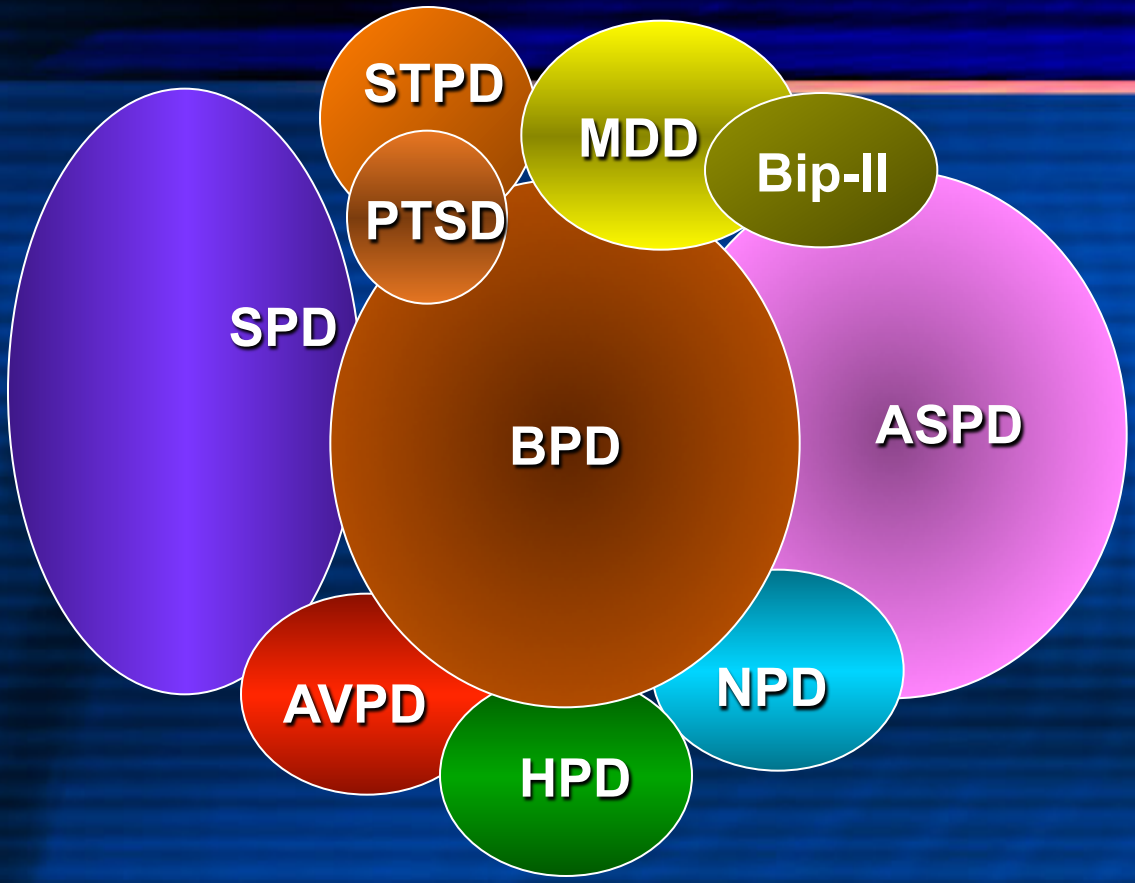
- Mood disorders
- Anxiety disorders
- Substance use disorders

- Lenzenweger et al., *Biol Psychiatry*, 2007

Co-morbidity/Co-occurring Disorders

- Depression
- Substance use
- Eating disorders
- Panic disorder
- PTSD
- Social phobia
- GAD
- Dissociation
- Violence & aggression
- Bipolar disorder
- Attention deficit disorder
- Conduct disorder
- Oppositional/defiant disorder
- Other Cluster B disorders
- Other Personality Disorders

Borders on Disorders



Borderline personality disorder rarely stands alone

How Does Co-Morbidity Impact Recovery

Persistence of MDD in BPD

- Controlling for all Axis I and II disorders, age of onset, number of prior episodes, family history, treatment, and duration of illness, BPD remained the most robust predictor of MDD persistence (OR 2.51 95% CI 1.67-3.77).

- "57% of cases would not have persisted in the follow-up period in the absence of BPD"

Skodol, et al., AJP, 2011

Persistence of MDD in BPD

- National Epidemiologic Survey on Alcoholism and Related Conditions: 40,000 interviews
- 2422 with MDD, 1996 re-interviewed at 3 years
- 15% persisted; 7.3% with recurrence after remission

- *Skodol, et al., AJP, 2011*

BPD and Alcohol/Substance Abuse

- 50% of BPD patients have either alcohol or substance use disorders.
- The prevalence decreases markedly over time.
- Family history studies show strong aggregation with impulse spectrum disorders (notably alcohol/drug abuse.

BPD and Alcohol/Substance Abuse

- Active abuse can cause false positive for BPD.
- Co-occurring substance use disorders slow time-to-remission of BPD more than any other Axis I disorder.
- Sobriety of 3-6 months should be prerequisite for BPD treatment.

Psychopharmacology

A Dilemma

"We can prescribe antipsychotics, but patients with BPD do not have true psychosis.

We can prescribe antidepressants, but patients with BPD do not have classic depression.

We can prescribe mood stabilizers, but the affective instability of BPD is not the same as the symptoms of bipolar disorder."

-Paris 2008 (p. 113)

Goals of Psychopharm

Pharmacotherapy often has an important ***adjunctive*** role, especially for diminution of symptoms such as

- affective instability,
- impulsivity, and
- psychotic-like symptoms

An Engine that fuels…

Mood Symptoms

Anxiety

Substance Abuse

Eating Disorder

Impulsivity

Consider BPD the primary diagnosis

To Tell or Not to Tell

Disclosing the BPD Diagnosis

Why is the diagnosis of BPD is often withheld from patients and families

Disclosing the BPD Diagnosis

Professional Stigma

- BPD symptoms can be frightening and frustrating for clinicians
- Clinicians can misuse the BPD diagnosis as a pejorative term for individuals provoking anger or dismay
- And, other diagnoses with symptoms of suicidality or anger are not considered stigmatizing in the same way

Disclosing the BPD Diagnosis

Transference/Countertransference

- Avoiding disclosure because of closeness and sympathy or hatred and fear
- Is it giving patients “the benefit of the doubt ?”
- Fear of rageful or self-destructive reactions: Consistent with research?

Disclosing the BPD Diagnosis

Reasons to Disclose

Not Disclosing the Diagnosis

Self-Discovery of the Diagnosis

- Learning diagnosis from chart or insurance form
- Learning diagnosis from internet
- Learning diagnosis from referral to treatments for BPD (e.g., DBT, MBT, STEPPS)
- “Why didn’t you tell me?”

Disclosing the BPD Diagnosis

Patient Respect

- Standard of care in medicine now
- Including patient in decision-making
- Respecting patients' values
- Encouraging self-determination

Why Making the Diagnosis is Important

- Without the diagnosis, BPD patients will get misguided treatment
- Accounts for co-occurrence of affective, impulsive, and cognitive symptoms
- The characteristic course can help predict outcome
- Predicting response to medication
- Modifying psychotherapy

Paris, 2008

Etiology

Basic Epidemiology

- Prevalence
  - Roughly 20% of clinical samples
  - 1.2 - 5.9% of the general population
- Gender
  - Approximately 75% female in clinical samples
  - More equal M:F ratio in community samples

How Does the Disorder Develop

Bio-Social Theory

- Genetic factors
- Environmental factors

Three Biological Characteristics Common in BPD

1. High Emotional Sensitivity
   - Quick reactions
   - Highly sensitive to emotional stimuli
   - Notice emotional things that others don't
   - Big emotional events hurt more
   - Takes fewer stimuli to feel emotions than other people

Like an open hand wound, it feels the heat intensity more than the rest of the hand

Three Biological Characteristics Common in BPD

2. High Emotional Reactivity
   - Extreme, more intense reactions
   - Thinking and problem-solving impaired due to high arousal which dysregulates cognitive processing
   - Higher magnitude of response to emotional stimuli than what others experience

Three Biological Characteristics Common in BPD

3. Slow Return to Baseline
   - Long-lasting reactions
   - Longer time to recuperate
   - Contributes to high sensitivity to next emotional stimulus, leaving the BPD person more vulnerable to the next emotional event
   - Like trying to walk on a broken leg before it heals … it's more apt to break again

Genetics of BPD

- Heritability estimates of BPD ranges: 50-60%
- Consistent with studies on the heritability of personality traits broadly
- Prevailing view is that it is the traits or trait clusters, rather than the disorder itself, that is heritable
- Impulsivity and mood lability specifically

Heritability

Schizophrenia	85%
Bipolar	80%
ADHD	75%
BPD	**68%**
MDD	45%
Panic Disorder	40%
PTSD	30%

Lyons & Plomin/Smoller

Possible Environmental Factors

- Poor fit between child and his/her environment(s) – experiencing one as invalidating (*family, home, neighborhood, school, peers, childcare, etc*.)

- Sexual abuse reported among 40% to 71% of BPD patients, usually by a non-caregiver

  (*In non-BPD population, generally said that 25% of young women are sexually abused before age 18*)

- Loss or abandonment as a child (perceived or actual) *Divorce, death, neglect, major illness, extensive family separations and relocations, etc.)*

Brains and Emotions

Neuroimaging data of adult BPD patients suggest that emotional dysregulation may be related to specific dysfunctions in brain planning areas and in the amygdala

-Herpertz et al., *Biol Psych* 50: 292-298, 2001
-Donegan et al., *Biol Psych* 54: 1284-1293,2003
-Schmahl et al., *Biol Psych* 54: 142-151, 2003

Donegan et al., 2003, *Biological Psychiatry*

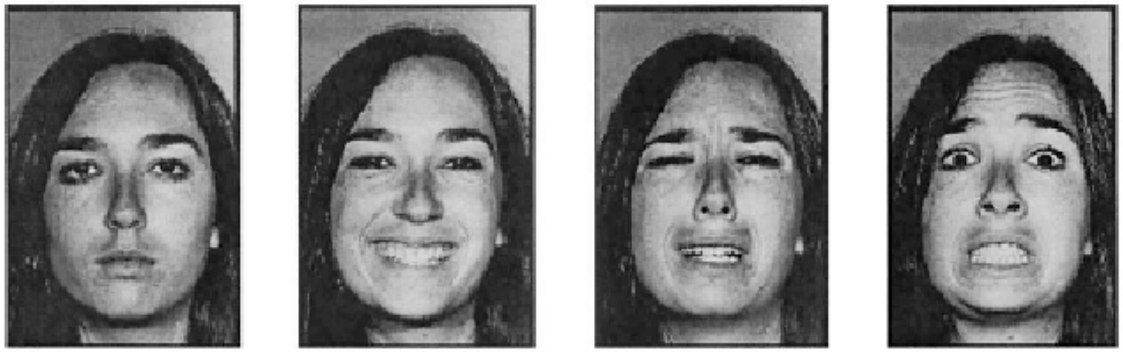


Figure 1. Examples of neutral, happy, sad, and fearful facial expressions from the Ekman and Friesen (1979) series.

Presented Facial Expressions to BPD and Healthy Control group while undergoing fMRI scan.

Region of Interest: Amygdala, associated with automatic processing of potentially threatening stimuli

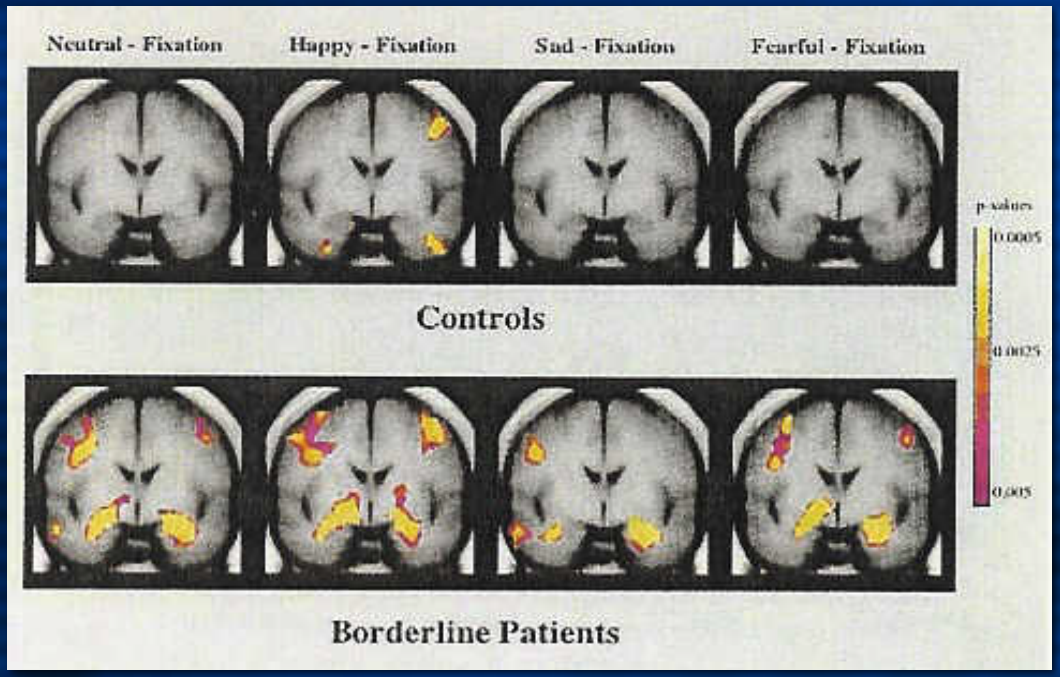
Response to Facial Expressions

- BPD patients show significantly greater left amygdala activation to facial expressions compared with normal controls

- BPD patients attribute negative qualities to neutral faces

- Donegan et al 2003

Amygdala Hyperreactivity (Ekman Faces)



Activation map showing regions in the amygdala slice in which activation exceeded the criterion threshold level of *P*<0.005 for the NC and BPD groups for each of the 4 facial expressions.

NC = normal control.

- Donegan et al. *Biol Psych* 2003;54:1284

Course and Outcome

Age of Onset *Gunderson, 2008*

AGE GROUP	PERCENTAGE
Adolescence (ages 13 -17)	15
Early Adulthood (ages 18 – 25)	50
Young Adulthood (ages 26 – 30)	25
Adulthood (ages 31 – 48)	10

Adolescence

- The idea that we have to wait until 18 to diagnose a personality disorder little clinical sense and flies in the face of current evidence.
- In our clinical experience most adult patients with BPD recognize that their symptoms started in adolescence (or earlier).
- Personality evolves in children. Parents often recognize that their children can have very different personalities from each other.

Adolescence

- In adolescent inpatients, BPD accounts for 49% of the variance.
- Precise risk/window in childhood/adolescence unknown.
- Retrospective studies: adult BPD associated with childhood externalizing disorders (conduct disorder, oppositional defiant disorder, ADHD).

Adolescence

- Adolescent BPD in girls and young adolescent women look a lot like adult BPD.
- Symptoms tend to be based on skill deficits rather than intentional “acting out.
- There is no compelling evidence for the use of medications for adolescent BPD.

Adolescence

- Psychiatry diagnosing most other DSM conditions in younger people.
- No other medical or psychiatric condition waits until age 18 to get targeted treatment.

Efforts to increase public awareness of BPD crucial.

McLean Study of Adult Development (MSAD)

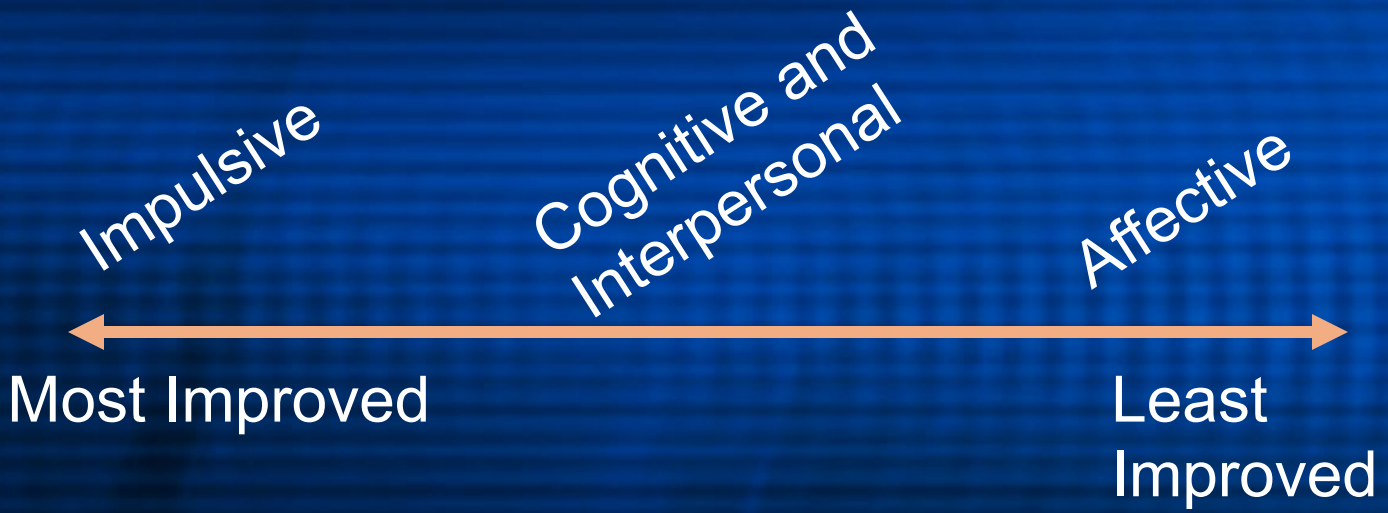
- 362 pts with personality disorders
- All initially inpatient, 1992-1995
- Met both Diagnostic Interview for Borderline-Revised (DIB-R) and DSM III criteria
- Five 2-year follow-up waves completed with >90% retention

MSAD Outcomes

- Remission common
- Recurrence rare when remission achieved

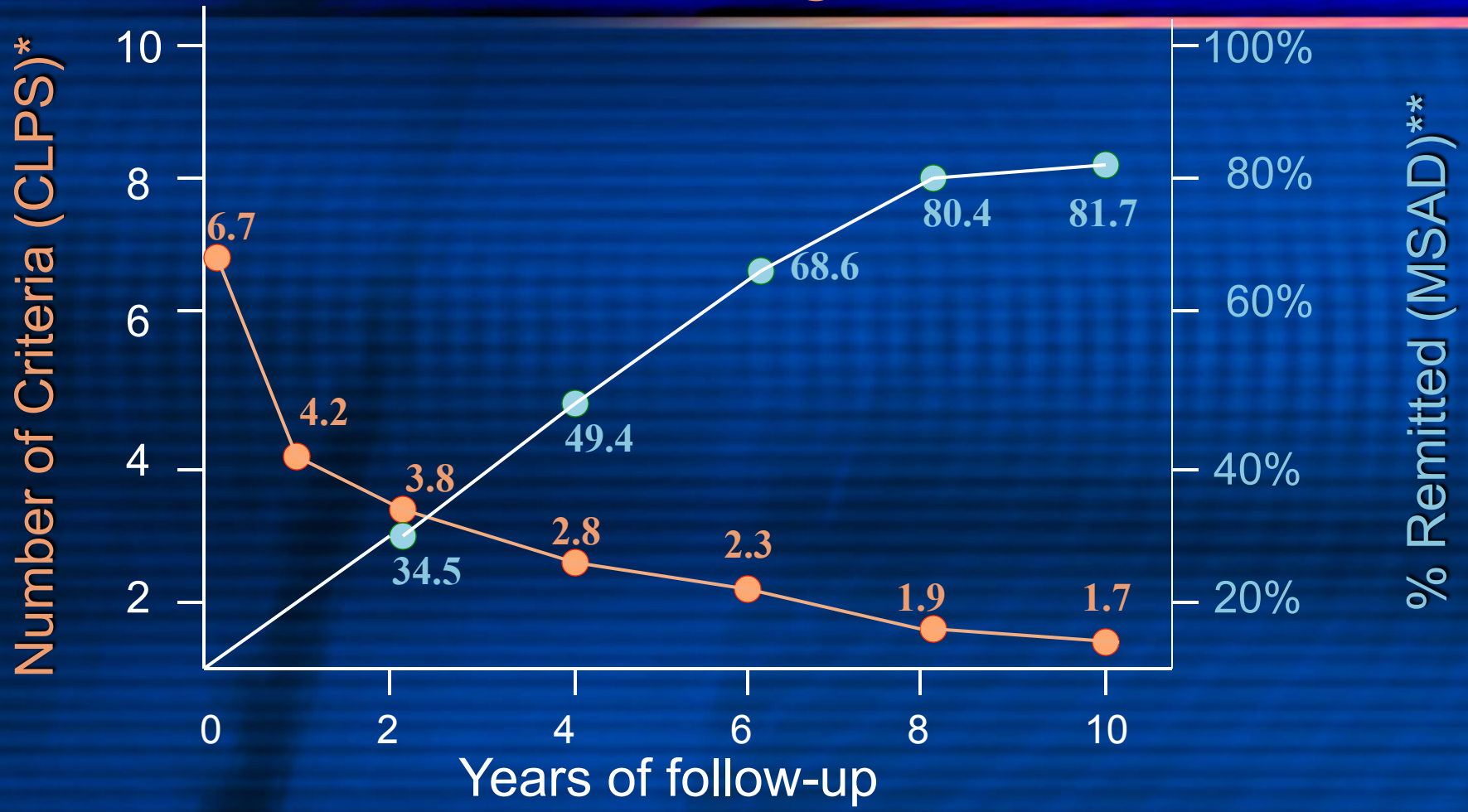
Years Follow-up	Percent Remitted
2	34.5
4	49.4
6	68.6
8	80.4
10	81.7

MSAD Outcomes



- All symptoms declined, but not equally

BPD's Longitudinal Course



*From the Collaborative Longitudinal Study of Personality Disorders (Gunderson, *Archives*)
**From the McLean Study of Adult Development (i.e., Zanarini et al. AJP 2003; 160:274-283)

Treatment

Empirically Validated Treatments

- Dialectical Behavior Therapy (DBT)
  - *Linehan et al., 1993, 2006*
- Mentalization Based Treatment (MBT)
  - *Bateman & Fonagy, 1999, 2001, 2003, 2008*
- Schema Focused Therapy (SFT)
  - *Giesen-Bloo et al., 2006*
- Transference Focused Psychotherapy (TFP)
  - *Clarkin et al., 2007; Levy et al., 2006*
- Systems Training for Emotional Predictability and Problem Solving (STEPPS)
  - Blum et al., 2008
- General Psychiatric Management (GPS)
  - *McMain et al., 2009 (after Gunderson & Links)*

A Spectrum of Approaches

Dialectical Behavior Therapy

- Highest number of research studies
- Effective for treatment of suicidal behaviors and substance abuse
- Most available platform for training
- Prepackaged, easily implemented in a broad number of settings

DBT- The Approach

- Dialectics=> mitigate tendencies towards splitting or black and white thinking
- Validation=> clarifies patient's experience and therapist's understanding, promotes stabilization of sense of self, decreases need for behaviors to respond to emotional states
- Acceptance=> non-reactive acknowledgment of way patient is as an adaptive consequence of biology and environmental factors
- Behavioral principles of shaping, reinforcement

DBT- Skills

- Mindfulness
  - Promotes
    - Participation present to reality
    - Attentive to experiences
    - Regulation of attention
  - Diminishes
    - Reactivity
    - Impulsivity
    - Dissociation
    - Rumination

DBT- Skills

- Distress Tolerance
  - Crisis Survival Strategies
  - Acceptance Strategies
- Emotion Regulation
- Interpersonal Effectiveness Skill
- Cross Integration of Skills
- Expectation of generalization to environments outside treatment

Mentalization Based Treatment

- Longest study shows gains in symptom reduction over 8 years
- Simple, general approach that does not require detailed knowledge of skills but a general understanding of a mentalizing process
- Easy to implement in a treatment setting
- Available brief trainings for any discipline

General Psychiatric Management

- Found to be as effective as DBT (McMain et al., 2009)
- Uses APA Guidelines for treating BPD
- Developed after Gunderson (Gunderson and Links, 2008)
- Employed clinicians who had an interest and experience with treating BPD
- Common features with DBT
  - Supervision/Consultation weekly
  - Helping relationship
  - Here and now focus
  - Validation and empathy
  - Emotion focus

Standards of Care for BPD

Gunderson, 2008

- BPD patients and significant others should receive education about the diagnosis and treatment
- Treatments should be tailored to meet goals for change agreed to by the BPD patient
- BPD patients should have a primary clinician who is experienced with borderline patients or is under skilled supervision
- Impulsive BPD patients should have two or more collaborating components in their treatment until they are stabilized in the community

FAMILIES

Profile of Families

- Burden
- Grief
- Depression
- Anger
- Anxiety
- Shame
- Sadness

Impact of Mental Illness on Families

Catastrophic event for families (McCubbin & Figley, 1983).

Comparable to other natural calamities: combat, imprisonment (Marsh, 1992; Spaniol & Zipple, 1994).

November 5-6th Training
Atlanta, Georgia

A mother:
"The doctor said: There is nothing I can do for your daughter."

A father:
"The doctor whispered quietly in my ear: Borderline."

Sitting in a room with family members with 50 borderline personality disorder relatives is witness to ongoing trauma.

Early Research on Mental Illness and Families

Expressed Emotion (EE): families' attitudes (critical comments, emotional overinvolvement and hostility) expressed about patient a predictor of relapse (Brown, Birley & Wing, 1972).

Creation of family psychoeducation programs.

Goal: lower EE levels. Relapse rate reduced by 20%.

Over past three decades family well-being evolved also as a goal (King & Dixon, 1999).

But…nothing for borderline personality disorder.

NAMI Family to Family Education Program

- 12-week course for families and friends.
- Family member well-being the target.
- Course taught by trained family members.
- No charge.
- An evidenced-based program.
- Largest program dissemination: >300,000 graduates.
- Estimate: two BPD families per class.

Joyce Burland, Ph.D.

"There is perhaps no serious mental illness more maligned and misconstrued than borderline personality disorder."

Creator of Family to Family

Why Work with Families

- BPD a relationship disorder
- It is an environmentally-induced disorder
- Working with families is a natural step
- But…(like professionals), families impacted by BPD need special skills
- What do we know about families?

Remember? *Three Most ExtremeStressors for Mental Health Providers*

1. Patient suicide attempts
2. Threats of suicide
3. Patient anger

Hellman et al., 1986

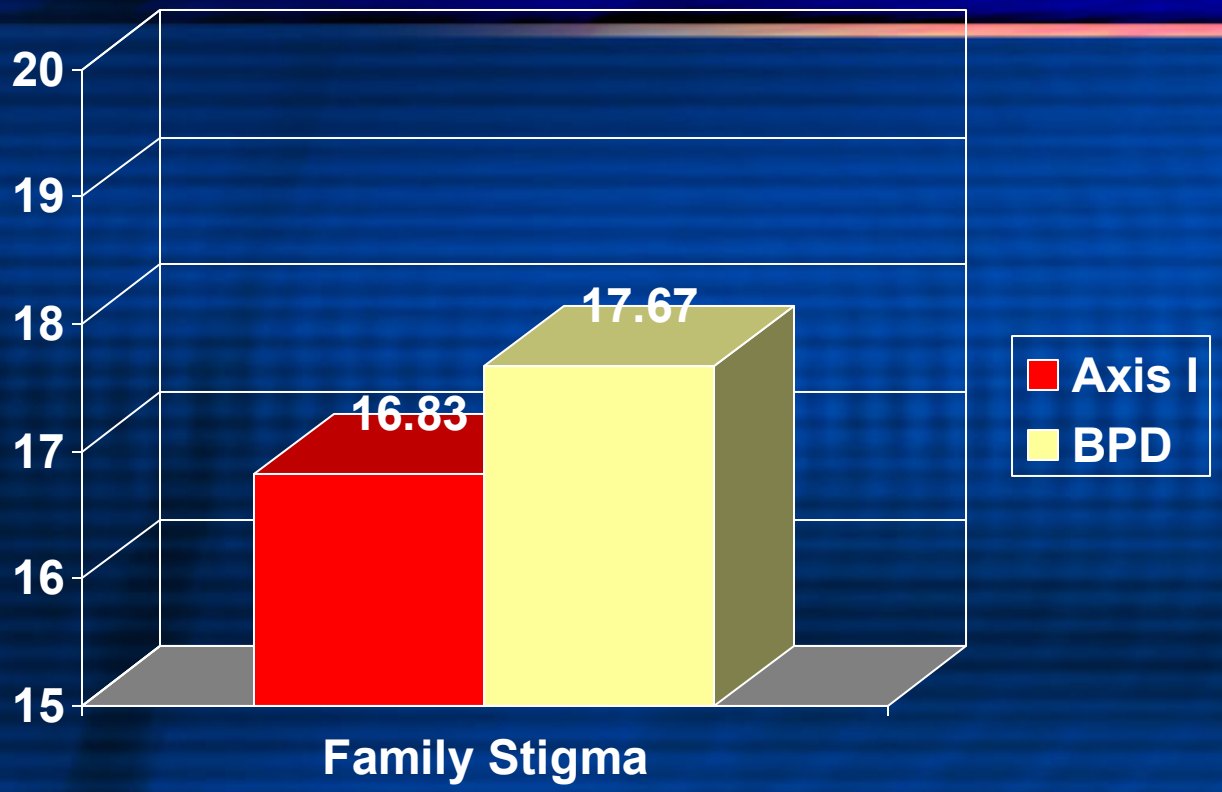
SAME FOR FAMILIES?

Family Perspectives Survey

Perry D. Hoffman, Ph.D.
Ellie Buteau, Ph.D.
Frederick Hellman, M.A.
Emily R. Neiditch, B.A.
Elmer Struening, Ph.D.

Components of the Stress for Families

*Level of Family Stigma**



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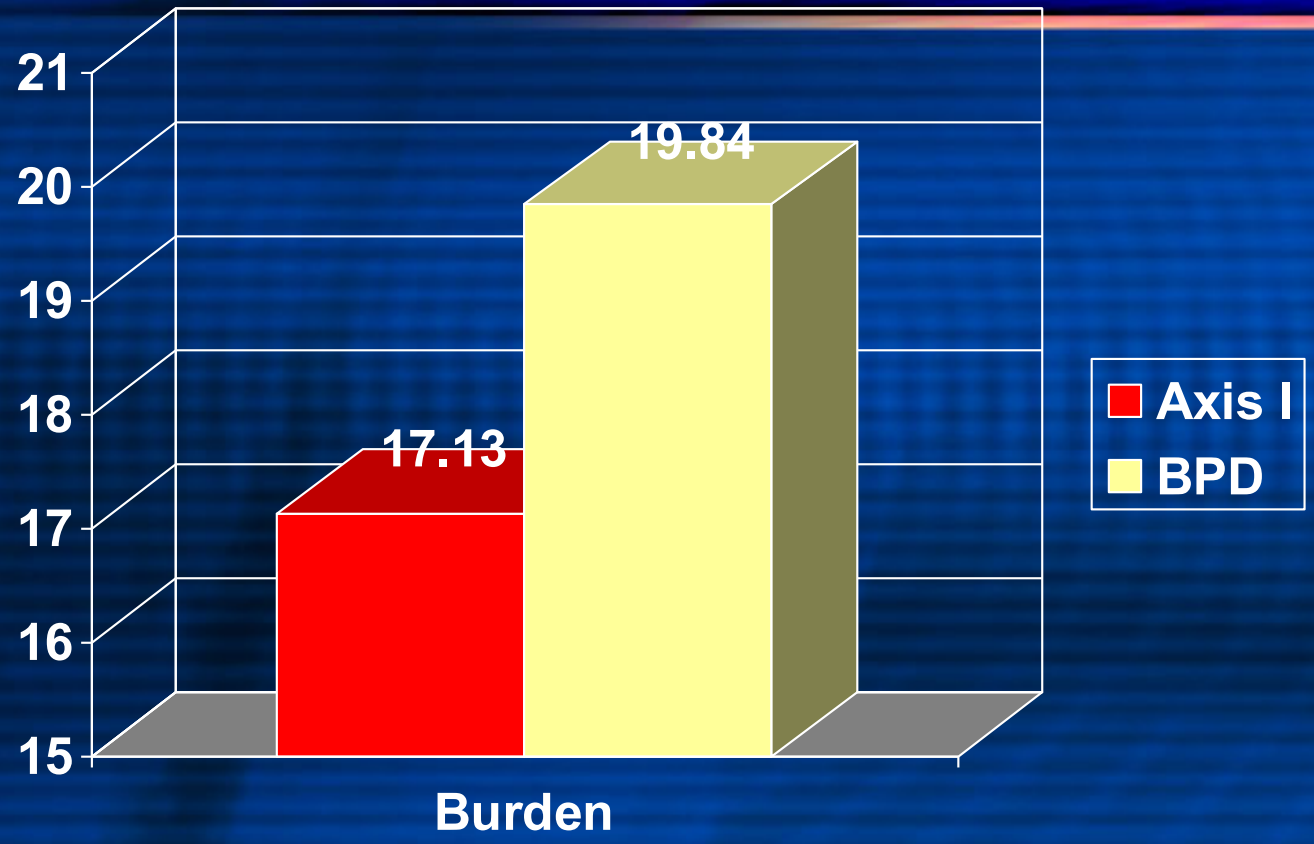
*Level of Burden **



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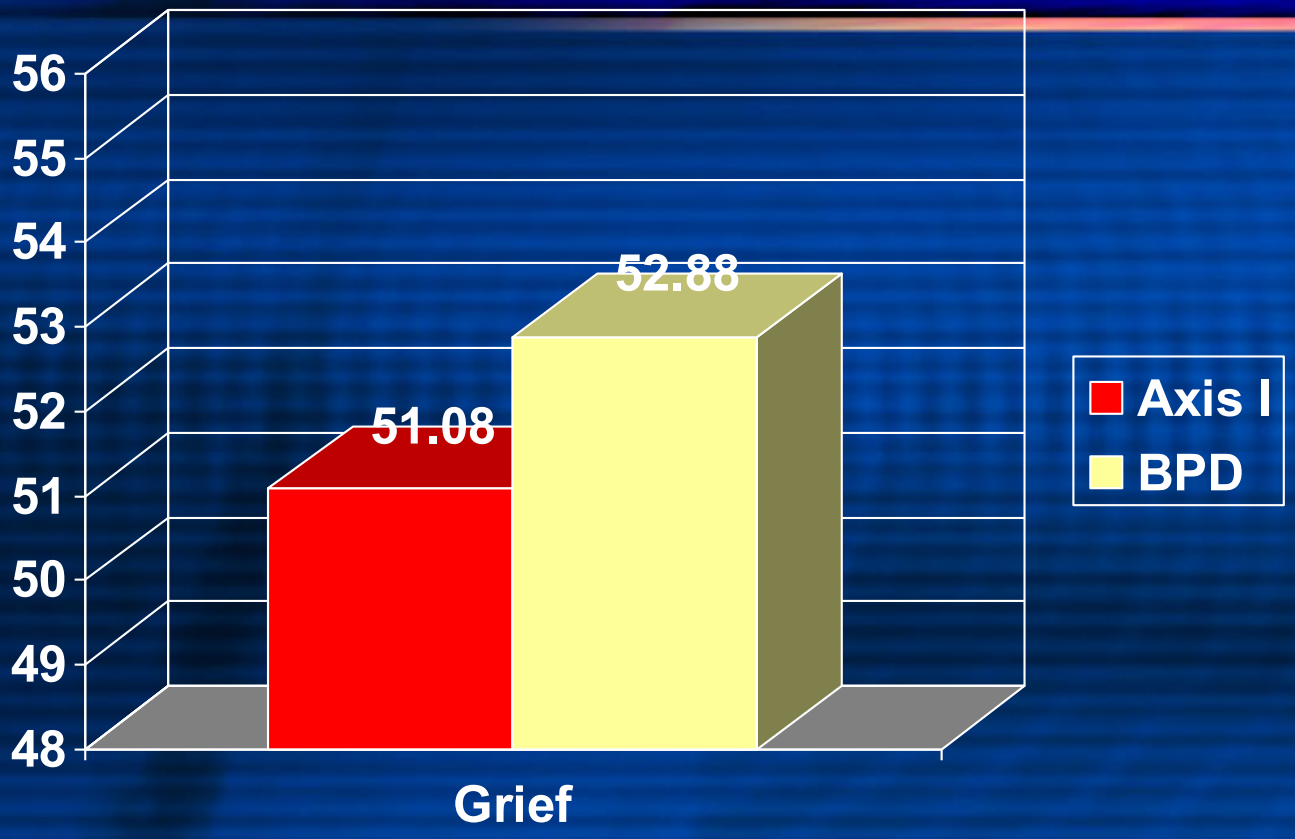
*Level of Grief**



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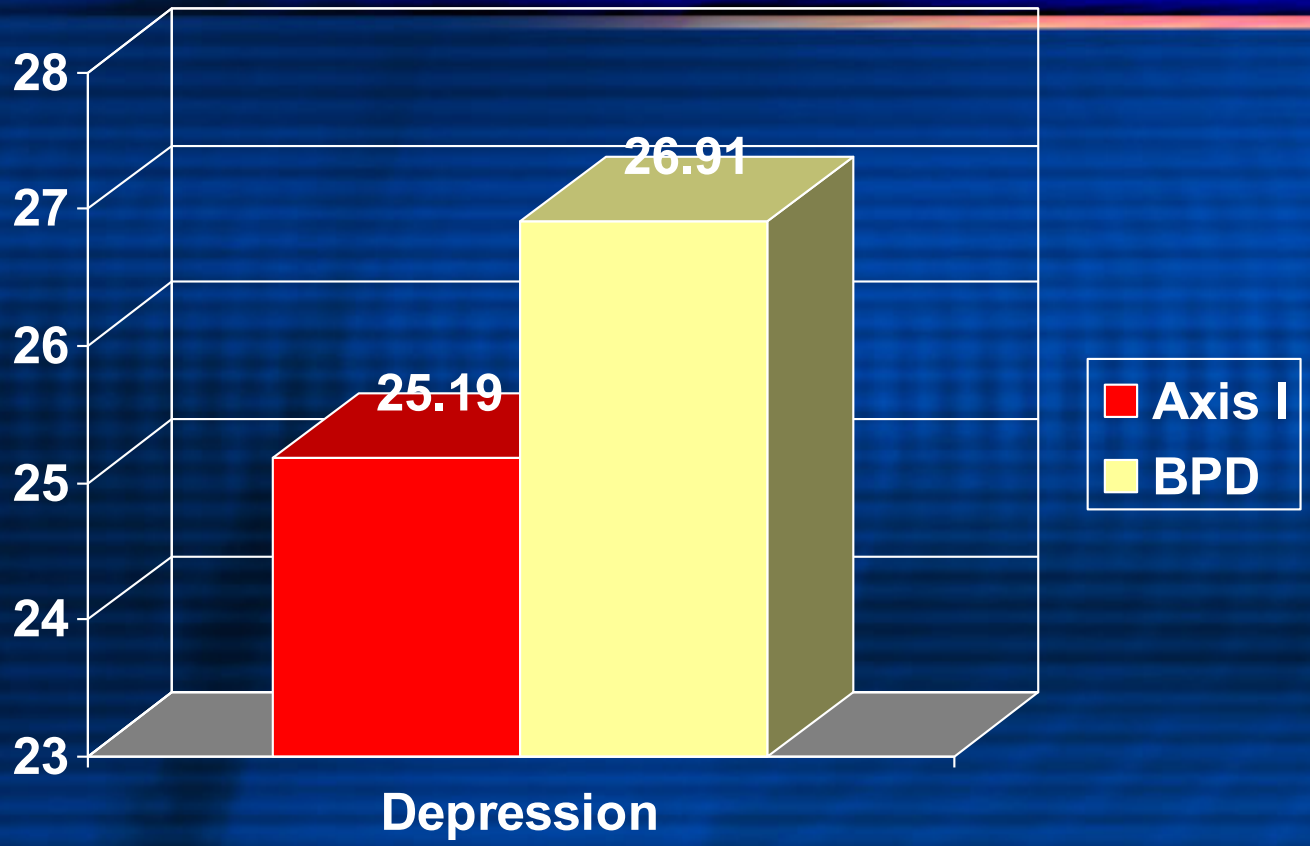
*Level of Depression**



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Family Involvement

Expressed Emotion

Robust psychosocial predictor of relapse.

Schizophrenia, major depression, anorexia nervosa bipolar disorder, alcoholism.

Key components of Expressed Emotion

1. Critical Comments
2. Emotional “over”involvement
3. Hostility

EE and Borderline Personality Disorder: Summary

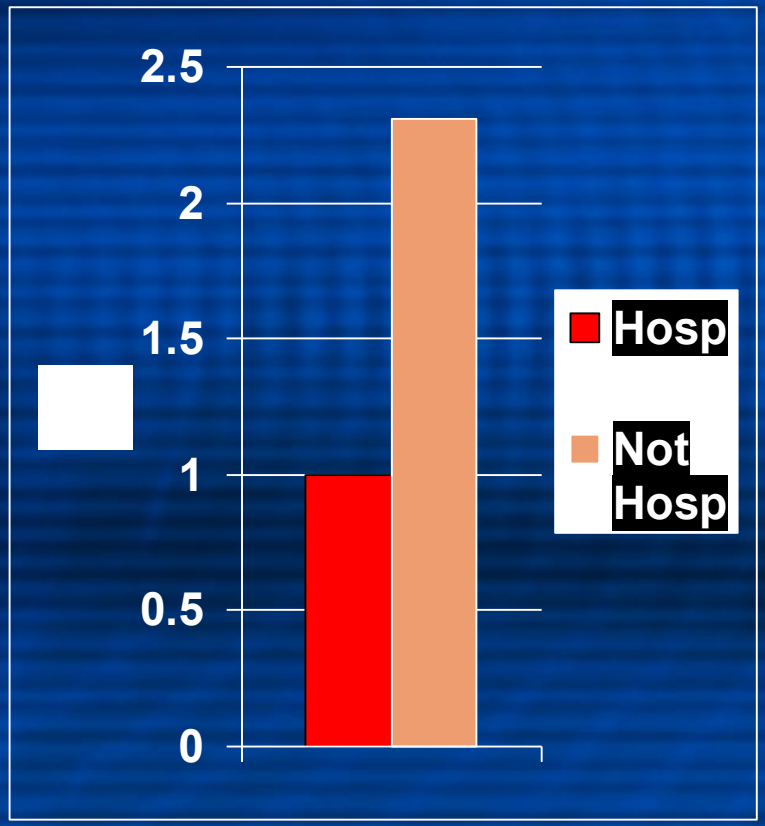
Criticism and hostility *not* predictive of overall outcome.

Overall clinical outcome and rehospitalization are predicted by emotional overinvolvement (EOI).

Higher EOI is associated with *better* outcome.

Expressed Emotion and Clinical Outcome

- EOI predicts clinical outcome (1-5 scale)
  r (35) = - .40, p < .02
- EOI predicts rehospitalization
  r(35) = - .44, p < .02
- Patients do better the *more* emotionally involved their relatives are



Hooley and Hoffman, AJP, 1999

Predictors of 2-Year Outcomes

- Level of BPD severity
- Level of functionality
- History of childhood trauma
- Current family relationships

Gunderson et al., AJP., 2006

The Well-Being of the Family Member

Loss of Judgment

"Here he comes, Earl. … Remember, be gentle but firm … we are absolutely, positively, *not* driving him south this winter."

Family Members Desperate for Knowledge

Family Members' Knowledge about Borderline Personality Disorder: Correspondence with their Levels of Depression, Burden, Distress, and Expressed Emotion

Perry D. Hoffman, Ph.D.
Ellie Buteau, Ph.D.
Alan E. Fruzzetti, Ph.D.
Martha Bruce, Ph.D., MPD

Family Process 2003

Family Member Well Being

- Grief
- Burden
- Depression
- Stigma

Correlates of Relative's Knowledge

- Information-Hostility r=. 40
- Information-Burden r=. 44
- Information-Subjective burden r=. 51
- Information-Depression r=. 52
- Information-Brief Symptom Inv. r=. 65

Burden

- Worry about patient's future: 94%
- Intensity of family friction: 87%
- Impact on own ability to concentration 87%
- Upset household routine: 84%
- Reduced leisure time: 78%
- Fear own behavior makes patient worse: 77%
- Worry how much patient changed: 74%

Overview

- Families with BPD struggle with reactions and responses that are similar to those of professionals working with these patients
- Therapists need special training for work with BPD patients
- Coping skills for families are equally important
- There seems to be a common misunderstanding between the patient and the family member
- Find a balance between patient and family member needs