Family Psychoeducation and Its Historical Context

The mental health field over the past six decades has recognized the impact on the family of having a relative with a mental illness. In fact, since the 1970’s, the mental health profession has undertaken significant efforts to provide programs for families of the mentally ill. This has been due, in part, to deinstitutionalization and the fact that families, once again, play an increasing role in caring for their mentally ill loved ones.

More recently, the family-as-provider concept and the family movement in general have been strengthened by the recognition that family members experience severe distress in coping with a mentally ill relative and, therefore, may benefit in their own right from participation in family programs.

To give a little history: In the 1970’s, the first programs for family members with a relative with schizophrenia were developed and implemented. The modality, or form of family services, known as Family Psychoeducation, was subsequently adopted and adapted to serve other diagnoses as well, including bipolar disorder and major depression. Research showed that such programs have positive treatment outcomes for both the patient and the participating family member(s). For patients, the rate of relapse was shown to be reduced (McFarlane et al). In the early ’80, attention began to include the well-being of the relatives. This effort then showed a reduction in stress and feelings of burden.

There are two key aspects to general family psychoeducation:

1) dissemination of accurate and current information on the particular diagnosis
2) development of a support network
   and
3) teaching and application of coping skills.

Family Connections was created to meet these three objectives;

Family members receive facts and data relating to the specific disorder, including symptomatology (symptoms), etiology (origins of the illness, presumed causes), treatment options, medication issues, and community resources.

The underlying assumptions of the family psychoeducation model are that knowledge about the disorder is helpful to families and that providing information helps both one’s own well-being and ability to help the relative. However, research studies have shown that knowledge alone is not enough. The didactic component of the program requires complementary skill acquisition and skill generalization.

But before we get into learning these skills,

we’ll first begin with some basic education about the disorder.
Important Considerations

▲ The disorder is heterogeneous with over many “looks” or presentations.

▲ Medication effects are usually modest at best, and can have negative effects as well (in particular, negative long term medical consequences). Meds often target anxiety, depression, mood swings, and impulsivity. However, there is no medication that improves relationships, and none specifically for BPD. NO medication has been approved (FDA) to treat BPD per se.

▲ BPD rarely stands alone. Many other disorders co-occur.

▲ BPD affects between 1.5 and 3% of the population (or more). This equals or exceeds the number of persons diagnosed with schizophrenia or bipolar I disorder.

▲ Estimates are that 10% of outpatients and 20% of inpatients of psychiatric inpatients have BPD.

▲ BPD affects men and women, although women are more often given the diagnosis. This may reflect that women more often seek treatment, that anger is more acceptable in men, that men with similar symptoms often end up in prison and receive a diagnosis of antisocial personality disorder.

▲ At least 80% of BPD patients have self-injured.

▲ Ten percent of BPD patients complete suicide.

▲ However, most people with BPD do get better with appropriate treatment.

Services, resources, and research for consumers and families with relatives with BPD are two decades behind those of other disorders. For example, unlike family programs available for other psychiatric disorders (such as schizophrenia and bipolar disorder), until Family Connections was available, there was no standardized family program for BPD. Little was known about how families may be most helpful for BPD, and little was known about the impact on family members prior to the last decade. To date, there are data on long-term course, suicide and suicidal behavior, and preliminary data on some medication effects and treatment outcomes. We will share some of that information in this course.

Research funding for BPD especially lags behind other disorders. A chart from the National Institute of Mental Health (NIMH) says it all!
Despite the low research dollars relative to other disorders, major strides have been made. Over the last two decades, spurred in part by interest in the effectiveness of new therapies and in part by insurance companies' need to justify treatment, a strong focus on evidence-based treatments has emerged. Outcomes of research efforts are widely shared in frequent, worldwide conferences. NEABPD supports and in some cases sponsors these conferences, and participates in symposiums both nationally and internationally. Videos and audios are available at borderlinepersonalitydisorder.com for free viewing.
Different kinds of therapy are effective in the treatment of BPD

Types of Treatment

1. Dialectical Behavior Therapy (DBT)

DBT, designed by Marsha M. Linehan, Ph.D., focuses on regulating emotion through a variety of skills. Individuals work on behavioral change in the context of accepting what is. This is a concept known as Radical Acceptance which we will learn more about later. The treatment targets behaviors in a hierarchy of importance and works on modifying those behaviors that are most life-threatening and life-interfering. The treatment has multiple components: a) weekly individual session; 2) weekly skills group; and 3) telephone coaching as needed. It is important to find a DBT program in which the therapists have taken appropriate DBT training. Many of the DBT skills are thought to be very helpful to most people and are also part of what is taught in this course.
2. **Mentalization** is a program designed by Antony Bateman, MD and Peter Fonagy, Ph.D. in the UK. The treatment is conducted in a day program setting with a length of study of approximately 18 months, followed by another 18 months of outpatient treatment. The overall aim is to develop a therapeutic process in which the ability of the patient to “mentalize” becomes the focus of treatment. The objective is for the patient to sort out more accurately how he thinks and feels about himself and others, how that dictates his responses to others, and how ‘errors’ in understanding himself and others lead to actions in an attempt to retain stability and to make sense of incomprehensible feelings. This treatment is not yet widely available (except in Los Angeles and Boston and a few other locations).

3. **Transference-focused Psychotherapy (TFP)** is the work of Otto F. Kernberg, MD and colleagues. TFP is a long-term psychotherapy that focuses on anger and that is mostly available in New York. The therapy is called “transference-focused” because it is based on the concept that elements of the patient’s internal world are transferred from within the mind and played out, or experienced, as the reality of the current moment.

4. **General Psychiatric Management** is designed by John G. Gunderson, MD. with the belief that most mental health professionals can become “good enough” to help most patients with BPD through mastery of basic principles and approaches. It relies heavily on case management, focusing on the primary goal of success in work and partnerships.

   It is important to ask therapists whether the type of therapy they offer has evidence of efficacy in treating BPD.
How do you know if a treatment works? You look for data that document its effectiveness. According to the BPD Resource Center, DBT is the treatment most sought. It is also the most researched and reported upon treatment of BPD. More than 20 research studies conducted meet what is considered the “Gold Standard” for research (randomized controlled trials). DBT has been shown to reduce self-injury, anger, and in-patient hospital days, as well as to increase social adjustment.

(Linehan et al., Archives of General Psychiatry, 1993)

Bateman & Fonagy’s Mentalization treatment has been researched in three studies for BPD.

(Bateman and Fonagy, American Journal of Psychiatry, 1999).

Other research data are limited –and this is for the preferred treatments. Consider then, the number of BPD patients who are receiving “supportive” therapy in the community limited by managed care restrictions, and you can see why there is often a public expectation of poor outcomes.

### Types of Treatment

In addition to the treatment setting, there are also different kinds of treatment.

1. Dialectical Behavior Therapy (DBT) – (Linehan et al) Empirically supported
2. Mentalization (UK) – (Bateman, Fonagy, et al) Empirically supported
3. “Good” Psychiatric Management – (Gunderson) Empirically supported
4. Many treatments do not work well (all are NOT equal)
5. Specialized treatment always outperform treatment as usual
6. “Treatment as usual”: typically has the poorest outcomes

However, because BPD is a difficult illness to treat, even DBT is not successful one third of the time. The BPD symptoms by themselves are challenging. However, when they exist in combination with other disorders, sometimes undiagnosed, treatment is more complicated and, often times, less effective.

BPD-specific problems are hard to treat, and even more complicated in tandem with co-occurring disorders.

BPD rarely stands alone.
Each of these combinations creates a person with a unique set of behaviors and symptoms.

Which condition to treat first?

Is one condition the cause of another or is it the result of it? Is the predominance of one condition masking the true extent of another one?

Treating co-morbid conditions can be like peeling an onion. As one problem is solved, others can become more obvious.
In interviews of 35 family members of BPD inpatients there was one element that stood out in terms of how patients did over a one-year period.

**Emotional involvement predicted a better clinical outcome.**

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<tr>
<th>Emotional involvement (Page 6)</th>
<th>Expressed Emotion Study</th>
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<td></td>
<td>Higher emotional involvement predicted better clinical outcomes. This means that the more emotionally involved the key relatives were, the better the patient fared (fewer hospitalizations). <em>(Hooley &amp; Hoffman, 1999)</em></td>
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<td>A goal of <em>Family Connections</em> is to teach how to be emotionally involved effectively.</td>
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**Where do Family Members Fit in?**

We know that family involvement is good, but *What Does Emotional Involvement Really Mean?* Emotional involvement means many things and there is no one definition that fits every situation. Simply, it means being there emotionally for our children and relatives. *However*, there are two aspects that need to be acknowledged and highlighted. One important aspect of emotional involvement is when and how it gets expressed. That is something we will learn here.

Another important aspect is that there needs to be a balance so that our lives don’t get taken over and controlled by the BPD symptoms and behaviors. Just as we are told by the airlines to put on our own oxygen mask before helping those around us, so we need to follow the same pattern when trying to help our loved ones.

**Finding a Balance**

We need to acknowledge that there is considerable family burden when a relative has borderline personality disorder. This is often hard for family members to acknowledge, much less articulate. But without recognizing the stress and burden, we can’t deal with them appropriately and still have something left to give our loved one.

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<th>Finding a Balance</th>
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<tr>
<td>Family Member Well-being (Page 6)</td>
<td>Taking care of others and taking care of ourselves</td>
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<td>Family Member Well-being</td>
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<td></td>
<td>Families who have a relative with BPD report higher levels of burden, depression, and grief than do family members who have a relative with schizophrenia. <em>(Hoffman et al., 2004)</em></td>
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<td></td>
<td>How might we understand this?</td>
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<td>What are the sources of stress and burden?</td>
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### Family Member Well-being

Families who have a relative with BPD report higher levels of burden, depression and grief than do families members with a relative with an Axis I disorder, namely schizophrenia.  

(Hoffman et al., 2004)

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<tr>
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<th>BPD Mean score</th>
<th>Axis 1 Mean score</th>
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<tr>
<td>Grief</td>
<td>52.87</td>
<td>49.45</td>
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<tr>
<td>Burden</td>
<td>19.91</td>
<td>16.31</td>
</tr>
<tr>
<td>Depression</td>
<td>26.85</td>
<td>25.08</td>
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How might we, in part, understand this?

### Stressors for Mental Health Care Providers

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

(Hellman, 1986)

### Stressors for Family Members

PTSD (mostly around suicide attempts)

(Hoffman, Harned, Fruzzetti, 2016)

### Etiology

1. People with BPD are likely to have emotional vulnerabilities to the social, cultural and family environments they are born into, making dysregulation more likely.
2. There are factors in the environment that interact with these vulnerabilities that may make dysregulation more or less likely.

(See figure on Page 12, and Fruzzetti, Shenk, & Hoffman, 2005)
**Biological Components**

The biological component of BPD is an innate emotional vulnerability; individuals with high emotional vulnerability tend to have the combination of a very high sensitivity to emotional stimuli, a very intense reaction to those emotional stimuli, and a slow return to the baseline level of emotion. Any one, or even two, of these vulnerabilities by itself is unlikely to cause many problems for an individual, but the combination of all three results in an emotional experience that is very different from most people’s, so it is very difficult for most people to understand, which often results in invalidation.

The emotional systems in the body are highly complex and involve many different components; thus, there is likely not one specific biological cause that underlies BPD. There is probably a range of different biological abnormalities present in different individuals with BPD.

There are three biological characteristics commonly seen in BPD patients. The first is…

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**1. High emotional sensitivity**

a. Immediate reactions- React quickly

b. Low threshold for emotional reaction- React sooner

   - The person is highly sensitive to emotional stimuli.
   - They react quickly and notice emotional things that others don’t notice
   - Big emotional events hurt more
   - Typically, it takes fewer stimuli for them to feel emotions than another person.

   It’s like an open wound on your hand:
   
   It feels the intensity of heat more than the rest of the hand.
Example from an FC Leader: Dialogue and Commentary on Environmental Factors (Pages 18-21)

An example from a leader: It is when we start considering the environmental factors in the development of BPD that we can get derailed in the areas of family dysfunction and self-blame. We don’t want that to be the case, but it is somewhat important that you understand what are thought to be the primary environmental factors. Also, that if there are some factors that may still exist, you want to be aware of them and to be on the lookout for situations which may upset your loved one or “set-off” an emotional response. For example, knowing that the stress of moving always triggers problems for our daughter, we have learned to be proactive and try to take some of the stress out of the situation for her. The last time she needed to move to a new apartment, my husband went to Florida for four days and didn’t leave until shelves were installed, pictures were hung, and the refrigerator was stocked. Although we were delighted that we seemed to get it right that time and she came through in much better shape than usual, we don’t expect we will always get it right. There are no guarantees that we’ll get it right even when we are well informed and plan ahead.

I am a huge reader and have read a massive amount of material about BPD. However, I was told recently that there is a fine line between research and neurosis. Essentially, we want to have enough understanding of the disorder to be able to empathize with our loved one, but we do not want to try to play the expert and draw conclusions that the professionals can yet draw.
Possible environmental factors contributing to the development of BPD include…

➔ 25-60% of BPD patients report having been sexually/and or physically abused, usually by a minor, by a variety of people/relationships.

  " In the non-BPD population, prevalence of sexual abuse in young women before age 18 is thought to be 25% or less, although it is hard to estimate due to under-reporting.

➔ Experiencing a loss or abandonment as a child (perceived or actual)

  " Death, divorce, major illness, frequent and extensive family separations (children of military personnel), multiple or traumatic relocations

➔ Poorness of fit – difficulty - between the child and one or more of their environments. The child experiencing one of these environments as invalidating.

  " By environments we mean any of the places the child spends part of their day, and / or the people that surround them there. There are many possibilities – family, home, neighborhood, schools, peers, childcare settings, etc.

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### Environmental Factors

➔ 25-60% of BPD patients report having been sexually/and or physically abused, usually by a minor, by a variety of people/relationships

➔ Experiencing a loss or abandonment as a child (perceived or actual)

➔ Poorness of fit – difficulty - between the child and one or more of their environments. The child experiencing one of these environments as invalidating.

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### How is an Environment Invalidating?

**De-legitimates one’s experiences, especially private ones (emotions, wants, and desires, thoughts, beliefs, sensations).**

Everyone is entitled to emotions, even when inconvenient or uncomfortable for others - i.e., the family is moving, a child is very upset, and their parent tells them, “I don’t want to hear that. We’re all going to have fun. You’re being selfish.” Vs. “We absolutely have to make this move because of job, money, etc., but we really do sympathize with your unhappiness about it. You’ve loved living here and have so many good friends. We understand how difficult it is for you, and wish you didn’t have to suffer.”

**Invalidates those experiences, ESPECIALLY when they are quite discrepant from other people’s experiences.**

The tougher a parent’s life has been, the more invalidating they may be to their children because everything is seen relative to their own experiences. Another Family Connections instructor told of frequent invalidation by her parents who were Holocaust survivors. No matter what her experiences were, they could simply never compare to those of someone having survived the Holocaust.
**Does not accept or appreciate differences.**

“No son of mine is going to play the piano. In this family, we ALL go to med school.”

**Tries to change or control.**

By this we are meaning a control above and beyond normal parenting and concern for a child’s behavior, choice of friends, etc.

**Ignores or doesn’t pay attention.**

There may be reasons a child feels overlooked – note I said “feels” – It may be only a perception. But in reality, parents and other adults may be consumed with challenges of their own. Someone who is depressed will find it difficult to pay adequate attention to another person’s needs. Someone fighting a serious physical illness may not be emotionally or physically present. A chaotically organized home run by a parent with ADHD can be a tough place for anyone to feel noticed.

**Is critical or judgmental.**

School bullies, aggressive coaches, overly demanding teachers – It’s sad to say that there are more negative people in our children’s lives than we may be aware of.

**Does not communicate acceptance and caring, even if that acceptance and caring exists.**

Some children feel that there was no one who really understood how they felt – as if they were the proverbial black sheep. Again, the adults in their lives may be emotionally unavailable for a variety of reasons. In some cases an extended family member can fill that gap. A favorite aunt or grandmother may be a perfect fit with a child who has difficulties with their immediate family. Having close access to extended family members is no longer the norm for many families - another negative factor in our fast-paced society.

**Hinders problem solving, problem management, and coping.**

If a child is not encouraged and helped to work through difficulties, but rather is shut down or has all problems taken care of for him/her, the child may end up feeling unable to cope.

### How is an Environment Invalidating?

- De-legitimizes one’s experiences, especially private ones (emotions, wants, and desires, thoughts, beliefs, sensations).
- Invalidates those experiences, ESPECIALLY when they are quite discrepant from other people’s experiences.
- Does not accept or appreciate differences.
- Tries to change or control
- Ignores or doesn’t pay attention.
- Is critical or judgmental.
- Does not communicate acceptance and caring, even if that acceptance and caring exists.
- Hinders problem solving, problem management, and coping.

**List 2-3 invalidating AND validating environments your family member experienced growing up.**
So What Goes Wrong? Nearly anything!

One of our former students said, “No matter what, I believe our daughter would have found some environments to be invalidating.”

Obviously almost all children experience stressful events - relocation, loss of a parent, divorce, etc. - and yet almost none of them suffer severe life-altering consequences. If your BPD child has healthy siblings who grew up in the same environment, that’s a prime example. It’s doubtful that your family situation was much different from anyone else’s. It is that your child had the pre-disposition to interact with that environment differently than most children. So what makes one child’s experience so different?

- A child may be particularly difficult to “read.”
- There can be a real mismatch in personalities between a child and a parent or caregiver. Obviously, not everyone is attracted to the same spouse, and so why do we expect that all children can live in harmony with the adults around them? The parent who makes a joke out of everything may be a favorite of one child and an incredibly hurtful, invalidating parent to their sibling.
- Remember that children themselves are the biggest factor in how the world treats them. We can easily forget the importance of that direction in the relationship. Some children’s biological emotional reactivity, temperament, and/or personality, often cause them to be much more difficult to parent than the child with the sunny disposition. Some teachers have a strong preference or bias - girls vs. boys or the reverse. The predisposed behaviors of each sex will bring out different teaching styles and impact their success in the classroom.

To the contrary, we’ve all met people who appear to be incredibly resilient. They’ve faced extreme trauma and hardship in life – perhaps far worse than our relative - yet they are emotionally very healthy. They obviously were not born with this emotional vulnerability.

This is all a very long way of saying we don’t know the answers and that all of our ideas and thoughts as to possible causes may be right – or none of them may be. I believe that in coming years, after more research is done, the list of possibilities will not be shorter, but even longer.

But by being aware of some of the early childhood experiences that may have contributed to the development of BPD, and remembering that for them perception is reality, it can be helpful to understand them better and lay the foundation for improved communications with them in the future. But no matter what happened in your relative’s environment, we want to stress that this is not about blame. By the very fact that you are making the time and effort to attend this class, we know that you love your relative dearly and want the best for them, and we applaud your efforts.

And like any disorder or illness that becomes better known, not all information is positive. Personally, we’ve never felt any “surplus stigma” except from professionals. We’re more concerned about the stigma being given to the disorder by the media and some of the books that take a run-for-your-life approach – “You’re in a relationship with a borderline? Get out fast for your own safety!” Borderlines are being stereotyped in ways that aren’t always accurate. Is more information leading to more or less stigma?
Stigma

In general, there is stigma about families of persons with mental illness.

However, there also seems to be “surplus stigma” around BPD in part because of the issues of abuse.

What is the stigma with this disorder?

What stigma have you or your family member encountered?

Practice Exercises

1. What was your relative like when he/she was a child?
   a. What adjectives best describe his/her temperament? (one word)
   b. What was he/she like to “soothe”? (one sentence)

2. What is your relative like now?
   a. What adjectives best describe his/her temperament? (one word)
   b. What is he/she like to “soothe”? (one sentence)

3. Bring in two examples of your own emotional reactivity patterns tracking each of the following:
   a. High reactivity
   b. High intensity
   c. Slow return to baseline

4. Think about your relative now in terms of emotional reactivity patterns:
   a. High reactivity
   b. High intensity
   c. Slow return to baseline

5. What environmental factors do you think were present for your relative when he/she was growing up? (one sentence)
The following two articles are written by two psychiatrists very involved in BPD research. They were asked to share with Family Connections participants their thoughts on the disorder, its etiology, and the importance of family involvement.

(Pages 10-11)

**Families Cannot Go It Alone**

**Joel Paris, MD**

Families have long been the mainstay for their relatives with mental illness. Families impacted by borderline personality disorder (BPD) are no exception. However, their plight is three decades behind families whose lives have been altered by other psychiatric illnesses. What was once the horror of being vilified as a schizophrenogenic mother was replaced then by being a victim, a parent with a brain disordered child.

BPD parents are not so fortunate in that respect. Often portrayed as individuals high in affectivity, high in borderline traits, high in substance use disorders with their own suspected levels of pathology, parents of BPD sufferers are often described as perpetrators of verbal, emotional, sexual abuse, and/or of neglect. Certainly we cannot summarily dismiss all allegations and, surely, in some families, great injustices to say the least, were done; in many others there is relatively little evidence of malevolence. Just as the illness of BPD is heterogeneous from many aspects, so are the families of BPD sufferers. Rather than continually pointing a finger of blame, we need to find a balance as we invite families to engage in the recovery of their relatives. Family matters!

Conversely, due to the severity, symptomatology, and high rates of co-occurring disorders, BPD not only affects the diagnosed but also affects family members and others in their social environment. Families cannot go it alone. Fortunately, relatively few professionals have included family members in the treatment process.

**Etiology of BPD**

**John G. Gunderson, MD**

Like other major psychiatric disorders, the etiology of the borderline personality disorder (BPD) involves both genes and environment. The genetic component, which has been underappreciated, is substantial. It is not, however, the disorder itself which is inherited. Rather, what are inherited are forms of temperament that predispose a child to develop this disorder. The predisposing temperaments (*aka* phenotypes) for BPD are *Affective Instability, Impulsivity, and Needy/Fearful Relationships.*
Each of these temperaments predisposes to other disorders as well as BPD: Affective Instability also predisposes to mood disorders; Impulsivity also predisposes to substance / alcohol abuse, bulimia, and conduct disorder; and Needy/Fearful Relationships also predispose to histrionic, dependent, and avoidant personality disorders. The presence of these inherited temperaments helps explain why patients with BPD are often co-morbid with these other disorders.

Still, these predisposing temperaments do not by themselves explain the etiology of BPD. They make it possible for someone to develop this disorder. To develop BPD also requires unfortunate environmental conditions. Most theories believe that early caretaking experiences are very important. Here, patients who have BPD will often report that their parenting was inconsistent, neglectful, or even malevolent.

This perspective is deeply distressing to parents. Some parents will feel deeply guilty as they review the past and elaborate on their failures. Others will dismiss the accusations, deny having any role, and thereby add to their borderline offspring’s alienation.

Early caretaking relationships are significantly shaped by the child. This contrasts with the more widely recognized belief that parental interactions significantly shape the child. Thus, the easily upset, needy/fearful, hyperactive child who possesses the predisposing temperaments for BPD will pose special problems for parents. Such a child will benefit from forms of parenting that may not come natural to their parents.

The easily upset child may need an unusually calm and patient caretaker. In its absence their emotions may be poorly integrated and disturbing to them. The needy/fearful child may require a consistently involved, reassuring caretaker. In its absence, their fears of abandonment may become unrealistic. An impulsive child may need parenting marked by predictability and non-punitive limit setting. In its absence, they may not develop self-controls.

Regardless of the early childcare, the child with predisposing temperaments for BPD will be far more easily undone by traumatic events. Most children with trauma grow up without sequelae. Those who suffer enduring consequences from trauma have both a predisposing temperament and -- perhaps due to problematic early caretaking -- will often have failed to disclose and process the event with their caretakers.

It is not easy to develop BPD. I expect that only a small fraction of the people who have the genetic disposition go on to develop it. Parenting is sometimes dysfunctional, but villains are truly rare. We need far more research to understand the contributions of both genes and environment.
Transactional Model of the Development of BPD and Related Disorders

Emotion Vulnerability
(current biology, baseline, AND temperament, such as sensitivity, reactivity, slow return to baseline)

Pervasive History of Invalidating Responses

Event

Judgment

Heightened Emotional Arousal
(leading to emotion dysregulation)

Inaccurate Expression & Out of Control Behavior

Invalidating Responses
(From Yourself and Others)

Adapted from Fruzzetti, Shenk, & Hoffman, 2005