A BPD Teaching Supplement for the Clinical Community

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Remnants of a Life on Paper is the account of a young woman suffering from borderline personality disorder (BPD). The real life unfiltered story is told from the point of view of both the patient and her family. The book illustrates valuable insights that can help us better understand and treat BPD. Identifying how the illness presents, diagnosing it accurately, finding trained specialists, and communicating the diagnosis and treatment plan to the patient, as well as to the family, are some of the crucial steps in treating a BPD patient.

By analyzing the pages of Pamela's copious journals at different stages of her disease, my goal is to teach both doctors and clinicians about the thinking of the BPD patient. In addition, I will highlight the importance of working within the family system, as well as other lessons learned throughout the book that can be used to effectively treat a BPD patient.

THE IMPORTANCE OF AN ACCURATE DIAGNOSIS

An element of Pamela's story that is a feature in many BPD cases is the challenge of accurate diagnosis. Listed here in summary form are the DSM-V criteria for proper diagnosis of BPD. The diagnosis of BPD can be made if a person has five or more of these criteria (American Psychiatric Association, 2013).

- 1. Frantic efforts to avoid real or imagined abandonment (not including suicidal or self-mutilating behavior covered in criterion #5).
- 2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation. This is called "splitting."
- 3. Identity disturbance: markedly and persistently unstable self-image or sense of self.
- Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, promiscuity, substance abuse, reckless driving, binge eating) (not including suicidal or self-mutilating behavior covered in criterion #5).
- 5. Recurrent suicidal behavior, gestures, threats, or 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.

Pamela is initially diagnosed with having a major depressive disorder. While to some degree this diagnosis is understandable, the fact that it was given in Pamela's case demonstrates the existence of a serious gap between the education and practice of mental health professionals. The current educational system for mental health professionals does not pay adequate attention to BPD or other personality disorders. One study has shown (Meyerson

et al., 2009) that there is an average of a 10-year time gap between a borderline patient's initial presentation for treatment and the accurate diagnosis. This time gap leads to unnecessary suffering and wasted treatment efforts, as we observe when *Remnants* describes Pamela's ECT treatments. The time gap in accurate diagnosis can also lead to tragic deaths (10% of cases of BPD end in death) (Stone, M. 1990).

There are several factors that delay the accurate diagnosis of borderline patients, including:

- Psychiatrists' Primary Reliance on Pharmacological Treatments:

Psychiatry's current emphasis is on pharmacological treatments in contrast to more complex bio-psychosocial treatments. The field tends to focus more on symptoms than on the person as a whole. Doing the latter can be complicated but neglecting to do so can lead to unnecessary treatments that can postpone necessary ones, causing harm in terms of side effects or other treatment effects, and possibly leading to a tragic outcome. BPD is the only psychiatric condition for which the official American Psychiatric Association guidelines recommend psychotherapy as the first line of treatment (Oldham 2001). Clinicians who take BPD patients into their care must know this.

- The Desire to Make a "Clear Cut" Diagnosis:

Unfortunately, when attempting to diagnose the BPD patient, clinicians tend to make a clear cut and straightforward diagnosis, which in turn leads to more standard pharmacological treatments. However, the evidence-based treatments for BPD are complex and require special training, skill and treatment over a period of years. In studies, the evidence-based treatments are delivered for a specified length of time: 1-year for DBT and TFP, 18-months for MBT, 3-years for Schema Therapy (Linehan 1993, Fonagy & Bateman 2006, Clarkin, Yeomans & Kernberg 2006, Young, Klosko & Weishaar 2003) and the length of time is highly individualized. Patients may repeat a second or third cycle of DBT. TFP generally continues for a number of years. These treatments have been criticized for taking too long and being too costly. However, the investment of resources is highly cost-effective when patients are helped to move from being a chronic patient at risk of losing their life to living a functioning life. The alternative is most often an unending series of non-specific acute treatments that help a patient survive from crisis to crisis.

- Personality Disorders Not Covered by Insurance:

Some insurance companies have had a policy of not paying for the treatment of personality disorders. There is a good chance that this will be remedied by the Final Rule of the Parity Law, but it is essential that advocates of BPD patients are vigilant

to make sure this is the case. The insurance companies attempted to invoke the idea that personality disorders are not conditions of "medical necessity," distorting the DSM IV distinction between Axis I diagnoses and Axis II diagnoses, and implying that the difference between Axis I and Axis II consisted in the former being biological disorders in contrast to the latter. However, an increasing body of research supports strong biological contributions to BPD. In addition, all psychiatric conditions, whether Axis I and Axis II, are a combination of biopsychosocial features. The insurance companies did not cover personality disorders, large numbers of those suffering from the condition are without coverage, adding immense practical problems to the burden of suffering. BPD is a public health crisis that needs adequate treatment resources. In addition to affecting 1.8% to 6% of the general population (Lenzenweger, et al., 2007; Torgersen, et al., 2001; Grant, et al., 2008), BPD patients represent 10% – 20% of Psychiatric Outpatients (Zimmerman , et al., 2005; Magnavita, Levy, et al., 2010) and 20% -25% Psychiatric Inpatient (Zanarini, et al., 2004).

The Stigma Surrounding Personality Disorders:

There continues to be a shame associated with personality disorders when compared to other psychiatric disorders. The misconception – common to clinicians, patients, and families – is something that we must strive to overcome. Many people feel the person with a personality disorder is somehow responsible for it; nothing is farther from the truth. It is the Tusiani's hope that Remnants will help readers move beyond any stigma they may attach to BPD. The stigma involves at least two factors. One has to do with a misunderstanding of the misconception that a personality disorder reflects a moral failing of an individual in contrast to a "purely biological" condition, such as depression or schizophrenia. As discussed above, psychiatric conditions in general are biopsychosocial conditions involving the individual's biological make-up, and the interaction of biology and environment. As also noted above, there is an increasing body of evidence describing the role of biological factors in BPD. The second factor underlying the stigma has to do with the application of treatments that are not specific to the disorder and that do not address it adequately. Until the advent of specialized treatments, and even now in settings that do not provide them, BPD patients are considered and often referred to as "difficult." However, we now know that within the appropriate treatment setting BPD patients can improve significantly, both in terms of their symptoms, and in the most successful cases, in terms of finding satisfaction in work, leisure activities, and love.

- Improving Skills in Diagnosing BPD:

An early and still valuable effort to focus diagnostic attention on BPD was described in Kernberg's writings about the structural interview (Kernberg, 1986). The field now also offers more programmed diagnostic interviews, such as Gunderson's Diagnostic Interview for Borderlines (DIB) and Zanarini's revised version of it (Zanarini et al, 1989), and Stern et al's Structured Inventory of Personality Organization (STIPO) (Stern et al, 2010).

THE IMPORTANCE OF REFERRALS TO SPECIALISTS

Pamela's experience is a strong testament for the need to refer patients to the specialized treatments that have been developed for BPD. It is unlikely that any of Pamela's inpatient or outpatient clinicians were uncaring. However, her early short-term inpatient experiences reflect a combination of inaccurate diagnosis and treatments that address some of the symptoms (especially depression), without addressing the BPD syndrome in its entirety. In terms of outpatient therapists, the correct diagnosis was made only by the third therapist, who appeared to have a basic understanding of the issues involved, but was not trained in any of the specialized treatments for BPD. A therapist trained in treating more common anxieties or depressive issues should refer BPD patients to a therapist with specialized BPD training.

A summary of the main treatments for BPD is as follows:

- Dialectical Behavior Therapy (DBT): A form of CBT that teaches skills to reverse negative thoughts and behaviors. DBT emphasizes balance between acceptance and change in helping to relieve psychiatric symptoms and improve the quality of life. This type of therapy focuses on the concept of mindfulness (being aware of and attentive to the current situation). There are two components: an individual one in which the therapist and patient discuss issues following a hierarchy (self-injurious and suicidal behaviors take first priority, followed by therapy-interfering behaviors, quality of life issues, and, finally, working toward improving one's life); and a group one, in which clients learn to use specific skills that are separated into four modules: (1) core mindfulness skills; (2) emotion regulation skills; (3) interpersonal effectiveness skills; and (4) distress tolerance skills.
- Dialectical Deconstructive Therapy (DDT): The focus of treatment consists of helping
 patients identify and verbally express their emotions, construct coherent narratives of
 their interpersonal experiences, and integrate polarized attributions about themselves
 and others. Patients are encouraged to both express and think about their emotions and
 interpersonal experiences without resorting to compensatory maladaptive behaviors.
 The therapy involves four distinct phases: (1) therapeutic alliance; (2) identification and

integration of distorted attributions; (3) acceptance of limitations of self and others; and (4) differentiation from the therapist.

Good Psychiatric Management (GPM):

GPM (Hopwood et al, in press) is a model developed by John Gunderson for treating patients with BPD whose goal is to provide all mental health professionals who assume primary responsibility for BPD patients with the basic knowledge necessary to treat this patient population. It is usually a weekly individual therapy utilizing both psychodynamic and behavioral concepts. GPM's aim is to communicate what every professional should know about BPD patients and, if necessary, to refer patients who do not improve in GPM to specialists trained in the more specialized treatments listed here. The first basic principle of GPM is psychoeducation. A second principle is the persistent focus on the patient's life outside therapy, linking the achievement of long-term life goals to the need to learn to control emotions or suicidality. A third principle is the therapist's acknowledging and using his dual role as both a professional and a person. In the professional role, the therapist shares his/her knowledge, provides concerned but unemotional responses to a patient's bursts of emotion and works to understand the patient's recurring concerns about the therapist's motives, feelings, and trustworthiness. The person role comes through when the therapist explains what he/she meant, discloses feelings, such as confusion or apprehension, and clearly states his/her wish to help. The fourth principle is the high level of the therapist's responsiveness and activity compared with a traditional therapeutic approach. GPM often includes a second modality (e.g., group, family) in addition to the primary clinician's efforts.

- Mentalization-Based Therapy (MBT): Mentalization refers to the ability to focus and reflect on mental states – beliefs, intentions, feelings, and thoughts – in oneself and in others. This ability is thought to be compromised among people with BPD, in that the capacity to mentalize is highly prone to fluctuation and impairment under stress – particularly the stress of disappointing or rejecting interpersonal experiences. Impaired mentalization is thought to contribute to affect dysregulation, the misreading of interpersonal cues, and impulsive behavior.
- Schema-Focused Therapy: A type of therapy that combines elements of CBT with other forms of psychotherapy that focuses on reframing schemas, (the ways people view themselves). This approach is based on the idea that BPD stems from a dysfunctional self-image—possibly brought on by negative childhood experiences—that affects how people react to their environment, interact with others, and cope with problems or stress. Part of the process of this therapy is "partial reparenting" in which the

experience with the therapist is meant to compensate for flaws in parenting that the patient experienced as he/she grew up.

- Systems Training for Emotional Predictability and Problem Solving (STEPPS): A relatively brief treatment consisting of 20 two-hour sessions, led by an experienced social worker. Emotion and behavior regulation skills are the primary goals of this treatment. In addition, the patient's family members and close friends are taught methods of reinforcing and supporting the new emotional and behavioral regulation skills. This has been proven to reduce the likelihood that the patient will practice splitting (see discussion of splitting below) with those in their social support system.
- Transference-Focused Psychotherapy (TFP): A structured psychodynamic psychotherapy, specifically designed to go beyond surface behavioral change to effect underlying structural personality change. A contracting period sets the frame for expectations of the patient and of the therapist. Contracts focus on individual stated problems, goals, and foreseeable obstacles to the treatment's success. Then treatment involves emotional exploration of the patient's implicit images of both self and others (in the context of the psychotherapeutic relationship). The premise is that the suffering and symptoms associated with BPD are rooted in the patient's lack of a coherent sense of identity. The BPD patient forms extreme mental images of oneself and others that are connected to intense emotional states. The treatment consists of the observation and understanding of these intense mental states as they are "transferred" into the relation with the therapist. TFP focuses on patients' intense feelings of aggression and love, as they learn to verbalize, rather than act out, these feelings. The ultimate goal is to integrate both 'good' and 'bad' aspects of self and others into a healthy and balanced experience.

THE IMPORTANCE OF RECOGNIZING BPD CHARACTERISTICS IN CLIENT'S CLINICIAL PRESENTATION AND HISTORY

BPD Characteristics presented in Remnants

The Internal Reality

"Internal reality" includes a mix of wishes and fears. One of the more poignant aspects of the BPD experience, as seen in both Pamela's appeals to God and in her repeated statements about how much she loves her family, is a strong desire to connect to an ideal experience – an ideal state of love and caring. Unfortunately, the world does not reflect this ideal – every

individual and relationship has flaws. The process of maturing leads psychologically healthy individuals to accept flaws and imperfections in themselves and in others. However, the lack of integration and blending of the extreme positive and negative emotional states in the borderline psyche puts individuals in the position of hoping to find the ideal love, a perfect state in the world – and accepting nothing short of it. When their search is frustrated, they can react in an angry and destructive way.

The Aggressive Affect

Aggressive affect is a universal and complicated feature of the human psyche. While the word has a generally negative connotation, aggression is necessary for the survival of the species and often for an individual. Civilized societies generally prohibit direct, unmediated displays of aggression but provide many outlets for that side of the human psyche, some of which can be beneficial to both the individual and the group: competitiveness in business and sports, ambition and striving, and forms of creativity.

Problems arise when one's aggressive urges are not integrated into the rest of their personality and therefore are not under the control of higher level cognitive functions of the brain. This is often the case in BPD. It is an interesting phenomenon that while 80% to 90% of the individuals in clinical treatment settings with BPD are women, overall, 50% of individuals who have the diagnosis are men. How do we account for this apparent discrepancy? Women tend to express uncontrolled aggressive feelings in destructive actions directed toward the self, whereas men are more likely to express those feelings in aggressive actions toward others, and thus end up incarcerated rather than in clinical treatment settings.

The situation is complicated by the role of the aggressive side of the internal world of BPD patients. A combination of temperamental and environmental factors creates a situation in which some patients are burdened with an extreme loading of aggressive affect. This leads to the distinction between higher and lower level borderline (or BPD) patients, and to prognostic factors. Michael Stone, in his naturalistic longitudinal study of 500 borderline patients (Stone, 1990) found the following factors to be associated with poor prognosis:

- A heavy loading of aggressive affect
- •Antisocial features, including dishonesty
- Secondary gain of illness ("fringe benefits" of illness)
- Severely restricted interpersonal relations
- No love life; lack of physical attractiveness
- Low intelligence
- No steady work or study (shifting lifestyle)

•A pattern of negative therapeutic reaction – defeating therapists' efforts, to prove one is stronger and/or to get gratification from frustrating the therapist (this is related to underlying envy).

Impulsivity

There are many examples of Pamela's "acting out" in the book, with regard to self-harm, cutting, drugs, eating, piercing, and tattoos. When she could not tolerate or emotionally regulate her feelings, she acted impulsively to relieve her internal pain. This is vividly illustrated in the book: when she cut, it was a physical release of her internal pain. She knew it was wrong, but found it hard to control. The emotional distress felt worse to Pamela than the self-harming action.

Emotional Regulation

The BPD patient "short circuits" the experience of intense and painful emotions. Successful therapy provides a combination of initially helping the patient develop skills to regulate these emotions, and then sitting with the patient in the presence of these emotions to get to know them better and to integrate them into the full range of the patient's emotional life, leading to an emotional integration and the ability to master the experience of intense emotions. Two essential characteristics of those working with BPD patients are the ability to remain calm and to be accepting in the presence of extreme affects.

Emptiness/Identity Diffusion

BPD patients often report that a sense of emptiness is at the core of their self-identity. Often, at times this can be the most painful aspect of the condition. It is difficult for a person without BPD to imagine the horror of not having a clear and consistent sense of self. Everything in life becomes a challenge if one's values, goals, likes, dislikes, etc. are not clear. It is like going through life without an internal "compass" which often leads to forms of acting out, such as drugs, promiscuity and cutting. On one level, these are attempts to fill the void.

Fear of Abandonment /Over Attachment

Related to the sense of emptiness is a tendency to become overly attached to some individuals, and to desperately fear abandonment. This addresses the issues of trust and mistrust that will be discussed below as part of Pamela's evolution through treatment. The intense attachment and fear of abandonment are difficult for families to understand and deal with. Repeated reassurances of love and devotion have little impact on the patient's fear of abandonment. It is difficult for families to understand the patient's inability to hear their reassurances. An understanding of the bleak internal emptiness of the patient may help the family understand the fear of abandonment, but it remains very difficult to live with. Pamela experienced this kind of attachment in relation to her mother, leading to her mother's difficulty in establishing boundaries with her and sustaining them. A mother's confusion under these circumstances is understandable and one of the reasons that both family education and interventions are essential.

Black & White Thinking – The Manifestation of Psychological Splitting (see below) in the Patient's Behavior

Polarized thinking about people is complex to understand and difficult for families to accept. Pamela saw her mother as "white", her father as "black". Her brother was "white", her sister was "black". Another way of understanding black and white thinking is as the idealizing and devaluing of others. This phenomenon is a principle way in which BPD patients might have a view of others that does not seem realistic, which might involve some psychological contortions. For example, Pamela's idealization of Hank was based on a particular way of denying and/or glorifying his "bad boy" characteristics. This example touches on a frequent, complex relation to aggression in BPD patients. As is clear in *Remnants*, the "black" and "white" perceptions of Pamela's family members were not based in reality: her father and sister loved Pamela and were there for her in important ways. One of the most difficult things for families to understand is the way BPD patients have distorted perceptions of the world around them. Their perceptions are filtered by internal images of self and others, images that are exaggerated and distorted, as well as superimposed on the people in the patient's life, and on the patient themselves. Pamela's frequent devastatingly harsh judgment of herself was not accurate, nor was her criticism of her father.

To complicate matters, the images of self and others in the mind can shift. A minor trigger event – for example, a boyfriend arriving late for a date – can "flip" the person from heaven into hell. At first the person might have felt like a princess awaiting her prince charming, but the lateness might provoke images of a worthless loser in relation to a rejecting bully. The development of these intense internal images that sort out into extremely negative and extremely positive ones have to do with the biology of the brain of BPD patients in interaction with the environment. Pamela reacted to the "strong personalities" in her family as the bad, experiencing any shortcoming in response to her needs as callous rejection. This phenomenon reflects two common emotional aspects of BPD: envy and a childish kind of narcissism. If one characteristic of BPD is a sense of emptiness and lack of self-worth, other people are perceived, in contrast, as whole and superior, as "having it all together." This combination can lead to intense envy of others, even others who the person loves on a different level. The envy is often expressed as anger and resentment – and the characterization of others as selfish, antagonistic or even hostile. It is especially hard for families and friends to be the object of these reactions, and therapists are trained to deal with these situations.

Splitting / Alternate Perceptions of Reality

From the start of *Remnants*, we have powerful descriptions of the confusing phenomenon of splitting, the co-existence of two opposite emotional states within the individual. We see Pamela shift from a state of calm to a state of extreme agitation and distress in a moment, with no warning and no transition. A dramatic example is the day a pleasant shopping trip with her mother ended in Pamela cutting herself in her room shortly after they arrived home. These shifts understandably create an anxiety, emotional chaos, and fear of what may happen next, that affect the patient's family as intensely as they do the patient.

Splitting can be understood in terms of the individual's psychological structure. Temperamental and environmental influences can lead to a constitution of the mind that is divided between a segment of all-good, ideal, positive effects and one of all-bad, aggressive, negative effects. Opinions differ as to how much this divided internal frame of mind has to do with biological temperamental factors and how much it has to do with environmental factors, such as a physically or psychologically neglectful or abusive environment. Some authors have considered BPD to be a misunderstood form of post-traumatic stress disorder, and contend that all BPD patients have a history of being abuse victims. However, even though studies have shown that up to 70% of BPD patients have some history of physical or sexual abuse, 30% do not. In addition, studies of non-clinical populations of individuals with a history of being abused physically or sexually have shown that the large majority of them develop into adults who do not have any type of psychiatric pathology. These findings, combined with an increasingly robust literature on the neurobiology of BPD, point to the importance of temperamental factors in the development of the condition.

To focus on clinical issues, the split structure of the mind leaves an individual, and those around the individual, vulnerable to rapid shifts in mood state. The trigger event could be external (something that happens to the patient) or it could be internal (a thought or a memory), and it is not always clear what the event is.

The main point in understanding the BPD experience is that if an individual's mind is populated by internal segments that are extreme and opposite in nature, this mental constitution has an impact on their experience of the world around them. By the process of projection, individuals tend to experience the world around them according to the images, or internal representations, they have of themselves, and of others in their minds. They may perceive people and situations that are benign as threatening and evil. Alternately, they may experience people who appeal to them in some way as being perfect and ideal. In Pamela's story, Hank is an example of this situation. Although Teddy appeared to be a more realistic choice of boyfriend, Pamela held on to a romantic vision of Hank as the idealized, misunderstood misfit – the kindred wounded soul who was somehow superior to the rest.

Because of the split internal psychological structure, the patient's experience of the world is very different from that of others in the patient's life. The perceptions of the same events can

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be so different that the parties involved are sometimes left wondering if they share the same reality. This is why some BPD patients can, in extreme situations, appear to be psychotic – or in touch with a different reality. In a powerful way, the patient's distortions of reality can lead a well-intentioned family member, or even therapist, to question his or her own version of reality – what *was* the real situation? What really did happen? Did I terribly injure my loved one?

This splitting phenomenon is one of the reasons families, as well as patients, have such trouble dealing with BPD, and leads to the question of the appropriate role of the family in relation to the treatment. Families are not equipped to handle splitting, or to understand when it is happening. They do not know how to emotionally interpret the patient's internal reality (viewing relationships in "black" and "white"), or to understand his or her aggressive behavior and inability to regulate emotionally, etc. For all these reasons and more, it is important that the clinical community consider integrating the family into the treatment plan, viewing them as secondary clients.

The Role of the Family

In most cases of mental illness, psychiatry and psychotherapy have long respected a tradition of focusing on the individual, with limited or no contact with the family. The ethics and laws of patient confidentiality have contributed to this position. However, the field is increasingly recognizing the importance of family involvement in severe cases of BPD. There may be cases of relatively high-functioning BPD patients whose therapy is best conducted in the traditional "individual therapy-only" model of therapy (readers of *Remnants* may not be aware that some BPD patients can function at a high-level professionally (e.g., lawyers, doctors), but still be plagued by the emotional storms and interpersonal chaos of BPD). However, a large number of BPD patients are adolescents or young adults, who, as in the case of Pamela, are very involved with, and dependent on, their families. There are also many cases of BPD patients in their 30's, and sometimes their 40's, who remain very dependent on their parents or a partner/spouse.

Because of the unique psychological characteristics of BPD patients, clinicians can treat these patients from a family-systems perspective as well, recognizing the family as the secondary client. As the field learns more about successful treatment of BPD, an increasing emphasis is now being placed on the role of the family. Since every case is unique, it is best for the therapist to adapt the nature of the family involvement to the specific case, while applying the following general principles:

GENERAL PRINCIPALS FOR WORKING WITH FAMILIES OF BPD PATIENTS

Remnants provides many examples for the need of these principles.

1) Families should be included in the initial evaluation. Involvement of the family serves a number of purposes:

- a. It adds a source of valuable information regarding the patient's history and clinical presentation.
- b. It provides the opportunity to inform the family about the nature of the diagnosis. The concept of BPD is complex and needs to be discussed with families so that they have a realistic understanding of the condition and of treatment options.

2) Psycho-education

The therapist's discussion of the condition, and also referral to informational resources, is critical during the evaluation phase. The therapist is the expert on the condition and should keep in mind that the better informed the family, the more they will be able to help the treatment effort.

- a. The psycho-education should include discussion of the nature of the condition and the nature of treatment options. The former, the nature of the condition, should include a clinical description what to expect in terms of clinical manifestations of the illness and how best to respond to them as well as information regarding the biology and the psychology of the illness and how they are related.
- b. This process of psycho-education includes an understanding of the complex nature of BPD and an explicit avoidance of any tendency to blame the family. Families often blame themselves and adequate psycho-education can alleviate that burden and help them embark on a more productive way of thinking about the illness, the situation, and the path ahead.
- c. An important corollary of informing the family about the patient's diagnosis is providing a sense of realistic expectations of treatment. A realistic appraisal can help families be prepared for what is ahead. While there is no quick and easy treatment for BPD, specialized treatments now have a proven track record. In the best outcomes, patients move beyond the borderline state and eventually manage to deal with the pressures of life much like the rest of us. Nonetheless, since statistics show a 10% fatality rate, the message to the family should be to have guarded optimism and patience when they participate in the treatment process as described below.

d. A discussion of the role of the family in the patient's life is essential. Some families with the best intentions act in ways that are not therapeutic. For example, they might provide financial support without guidelines. A skilled clinician can help the family determine what degree of support is realistic and is an appropriate balance between helping the patient and also encouraging the patient's strivings toward autonomy.

3) A good communication plan

- a. A system of communication should be agreed upon as part of the initial treatment arrangement. The general rule applies that the patient's communication with the therapist is regarded as confidential with the exception of life-threatening material. However, the arrangement should allow family access to the therapist to communicate concerns that the patient might not bring into sessions either because the patient is not aware of its significance, is ashamed of it, or prefers not to mention it because of feared consequences.
- b. The nature of the family communication should be tailored to the specific case. Sometimes it is in the form of the family having the option of calling the therapist if they have concerns; sometimes it is more formalized in the inclusion of monthly family meetings in the treatment plan.
- c. To facilitate communication with the family, in most cases the patient should be asked to sign a consent form for release of information to allow communication between therapist and family, as it has been worked out in the initial discussions with all parties.
- d. As the communication system is discussed and developed, it is important to encourage the patient and family to communicate as openly as possible with each other. A misuse of therapy would be for the therapist to become the conduit of information between the patient and the family.

4) Consider the family the secondary client

a. The family's own needs should be assessed as they can be considered a "secondary client". The therapist should be aware of the impact and needs of the entire family system. First, the family contact with the patient's therapist can provide the information and support that is necessary to help the family in their long and confusing exposure to this devastating medical condition. Second, the therapist's communication with the family can help structure certain aspects of the patient's life in ways that enhance the patient's progress and over all treatment.

- b. In other situations, where the condition takes a particularly hard toll on family members, ongoing family therapy may be recommended. It is important that the family therapy engage all parties as participants in resolving communication difficulties and other stresses within the family system, without creating an "us" (patient and therapist) vs. "them" (rest of the family) atmosphere.
- c. In certain situations, family members may be referred for their own therapy. An additional type of support is provided by family support groups. Two principle models are those of TARA and the NEABPD Family Connections System. The former consists of psycho-education for families, including an in-depth understanding of BPD, current treatment models, and aspects of those treatment models that can be applied to family communication. The latter helps families achieve an understanding of BPD that stems from the DBT model and helps them learn some DBT skills to use in their communication with the patient.
- d. More general resources for families can be obtained by accessing the BPD Resource Center website (www.bpdresourcecenter.org). Contact with others who are experiencing the same intense stress can help families who might otherwise feel that they are the only ones living in this extreme situation. In addition, the Borderline Personality Resource Center <u>www.bpdresourcecenter.org</u> provides a trained specialist available to answer questions as well as provide information and additional resources.

5) Set expectations

- a. It is important that all parties understand that the course of treatment can be intense and can include very difficult moments. These moments are sometimes created by outside events (for example, the tragic rape that Pamela endured), and sometimes occur for reasons that are not clear at the moment. It is essential that the "team" – therapist, patient, and family – continue to work together during the most difficult times with honest communication.
- b. Therapists who enter into work with this patient population need be able to weather intense emotional moments in the treatment without either overreacting or retreating.
- c. The therapist must be able to "contain" intense affects, and to show the patient and family that these emotions which the patient tends to discharge in actions can be experienced, reflected upon, and mastered. If the patient's condition worsens in the course of treatment, it is important to have outside consultation, with an expert, to determine if another type of treatment might be more helpful. But in most cases, the best strategy for the therapist

during the "stormy" times is to continue with the patient, the treatment, and the family. A good structure for communication can help avoid the mutual "finger-pointing" that tends to lend to setbacks.

6) Assist families to monitor medications

- a. While therapy is recommended as the first line of treatment for BPD, medication is usually part of the broader treatment plan. Doctors have a responsibility to help BPD patients and their families monitor medications. The increasing availability of specialized therapists is helping to avoid the unfortunate practice of "medication cocktails." Psychiatrists and, sometimes, other doctors who are not adequately educated in the treatment of BPD can get involved in an endless search for the right combination of medications that can be a distraction from the importance of other therapeutic interventions.
- b. In fairness to providers, the patient, and sometimes the family, may exert great pressure to find a "magic bullet". This is another instance in which state-of-the-art information is essential. There is no medication for the BPD syndrome as a whole, but two meta-analyses of studies of medications for symptoms of BPD provide practitioners with the most up-to-date guidelines (Stoffers et al, 2010; Ingenhoven et al, 2010).
- c. Pamela's story illustrates, at points, the use of medication, and ECT, in a way that reflects the grasping of some clinicians to treat BPD without an adequate knowledge of the specialized treatments available.
- d. In addition to side effects that can negatively impact a patient's physical state and health, some medications have potentially lethal effects. In particular, monoamine oxidase inhibitors (MAOI's) need to be prescribed and monitored with expertise. It is the responsibility of the prescriber to be aware of the special precautions involved with this type of medication. The prescriber must carefully educate both the patient and the family about the potentially lethal food interactions with MAOI's, must carefully assess the patient's ability and willingness to comply with the recommendations, and must be prepared to act immediately if there is any evidence of a negative drug-food interaction. Because these elements were not in place in Pamela's treatment, she lost her life.
- e. If family members are part of the team, they should be fully informed about medications: the specific target symptoms, the expectable symptom changes from the medication, the potential side effects to watch for, and the actions to take in case of emergency.

7) Incorporate specialists in the treatment plan

- a. In the course of treatment, it is not infrequent that patients with BPD need referral to additional care providers – to add a treatment targeted to a specific problem (such as substance abuse) or to refer the patient to a different level of care (such as inpatient, residential, or day hospital).
- b. It is the responsibility of the clinician to be informed about and, if possible, connected to treatment resources that are fully credentialed and experienced in treating patients with BPD. While this may seem self-evident, it is possible that referrals could be made to individuals, or institutions, that are not adequately qualified to treat those with BPD. Pamela's story provides an example of this.
- c. A related issue has to do with the economics of health care. While most individuals become therapists because of a strong commitment to help relieve suffering, some individuals and institutions may put greater emphasis on profit over quality of care. This is an intricate issue. Those who are best at treatment are not necessarily best at promoting their services, and vice- versa. Family members need to be as informed as possible about what is the best level of care, at any given time, for the patient's current condition. A general rule is that the patient is best off in the least restrictive treatment setting possible. This allows the patient to work on increasing his or her autonomy as treatment proceeds. The person to make these decisions is an individual therapist who specializes in treating BPD and who can provide consultation about what treatment is right at what moment including providing for outpatient therapy when that is the right level of treatment.

Pamela's story provides a real life account of the intensity of trying to live with and help someone, with BPD, and a family's struggle to find the right BPD treatment option. The course of the illness is rarely, if ever, one of simple linear improvement. The frequent alternation between moments of progress and setback is emotionally draining for everyone involved. Pamela's story illustrates some of the factors that contribute to progress and some of those setbacks that can undermine progress. Her first treatment experiences were with inpatient and outpatient clinicians who did not make the correct diagnosis, and therefore did not provide an appropriately targeted treatment.

When the right diagnosis was made, referral to a residential treatment setting led to improvement in some areas. A stable setting with staff familiar with the disorder, and a community of other empathetic patients were positive elements. The patient community is mostly beneficial but can also be a "double-edged" sword. For example, contact with fellow patients can provide mutual support, or can provide temptation that leads to destructive behavior. Thus there is a need for careful staff monitoring and limit-setting in relation to the community of patients.

The most unfortunate event in Pamela's story is the rape that occurred in the course of her treatment at the residential facility. Difficulties with trust play a fundamental role in BPD patients. People with BPD generally have great trouble feeling comfortable in close relationships. And it is a hallmark of BPD to desperately seek closeness and then to experience anxiety and fear as a close relation develops. A fundamental element of treatment is to explore the mistrust and help the patient move beyond it, even though the fear of possible betrayal is intense. At a time when Pamela was making progress, the rape occurred. To Pamela, the rape represented a betrayal by the world, and a confirmation of her fear that it is not safe to begin to trust others.

Another factor that interfered with Pamela's progress was substance abuse. This co-morbid condition worsens the prognosis of anyone with BPD. Any substance abuse problem should be diagnosed and treated as soon as possible. Attempting to help a patient improve psychologically when their ability to function is a daunting challenge.

The referral to the Malibu facility had a tragic end due to the inadequate professional level of that facility – most glaringly evident in their prescribing an MAOI without the necessary precautions. As we read this part of the story, an element emerges that is one of the most negative prognostic factors: dishonesty. Pamela's allegations about her father were not based in fact, and we can only speculate about the reasons behind the false accusations. Perhaps it was an effort to situate the "badness" outside of her. BPD patients are often plagued with a sense of being "bad" and have guilt related to difficulty managing angry and aggressive feelings, which are not well integrated into the rest of their personality, and thus not well controlled. It can provide some relief from the sense of "badness" to find an external "enemy." The emotional tragedy is that, due to the splitting phenomenon described above, the "enemy" may simultaneously be a loved one. The managing of allegations, such as Pamela's lie about her father, requires very delicate and tactful clinical work. The way this issue was addressed, or not addressed, in Malibu is another example of the inadequacy of their treatment of BPD patients.

A final comment about Pamela's path involves her experiences at work. A period of hope was followed by self-castigation and despair. Moving into a work setting is a major achievement. It is a moment in a person's treatment evolution that must be handled with the utmost care, and it is a time when adequate care and support are often lacking, as in Pamela's case. As the patient begins to transition from the clinical world to the "outside" world, his/her way of thinking plays an important role. Even if the patient has made considerable gains modulating his/her extreme emotional reactions, there are inevitably moments of regression to old ways of thinking and feeling at times of stress. The "black and white" thinking and the tendency toward self-castigation can re-emerge. If the patient can call on a combination of what he/she has learned from therapy and external support, he/she may be able to regain their

footing. However, it is easy for patients to perceive any shortcoming as evidence of total inadequacy and worthlessness and to give up. It is tragic that many people with BPD continue to suffer and fall back because they can never be comfortable with themselves and instead continue to treat themselves with a level of expectation that is harsh and aggressive.

There are many lessons to be learned from Pamela's diary and the family narrative provided by her mother. The circumstances that ultimately led to her death offer insight for psychiatrists and medical professionals in the field of BPD. Her journals help us understand the trademark characteristics of BPD, while her mother's narrative highlights the importance of integrating the family experience into the treatment process.

Suggestions for Medical Professionals in Light of Remnants

1) Become trained on BPD diagnostic criteria and improve the rate of proper diagnosis.

2) Increase training in medical schools on BPD treatment and therapy modalities.

3) Make referrals if the client's case is too complex, and publicize a resource list of trained BPD clinicians.

4) Involve the family as a secondary client, because they may be assets in the client's recovery and may be directly affected by how BPD personality traits manifest themselves in the client's clinical presentation and history.

5) Draw on the client's strengths, not negative characteristics associated with BPD, because strengths are the starting point for recovery.

6) Provide long-term, supportive care for the client through ups and downs of the BPD trajectory.

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