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Recovered Voices: Experiences of Borderline Personality Disorder

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Abstract

The purpose of this article is to use poetic analysis to present evocative accounts of the lived experiences of individuals who have recovered from Borderline Personality Disorder (BPD). Individuals with BPD suffer from a complex set of clinical issues that may be worsened by stigmatization encountered in their general lives as well as from health care providers. I argue that one method of enhancing clinical service provision to individuals with BPD is to view their behavior within the context that it originally developed. Viewing behavior in context may enhance healthcare providers' abilities to respond empathically and/or to assist clients in generating meaningful solutions to problems associated with BPD. The poems offered here represent six individual stories of the experience of BPD. These poems may serve as a reminder of the painful and often tragic circumstances in which "borderline" behaviors can develop. They may also be useful as tools to assist trainees in developing better understanding of how to work with individuals with BPD effectively and compassionately.

Keywords

Lived Experience, Mental Health and Illness, Borderline Personality Disorder, Recovery

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Recovered Voices: Experiences of Borderline Personality Disorder

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The purpose of this article is to use poetic analysis to present evocative accounts of the lived experiences of individuals who have recovered from Borderline Personality Disorder (BPD). Individuals with BPD suffer from a complex set of clinical issues that may be worsened by stigmatization encountered in their general lives as well as from health care providers. I argue that one method of enhancing clinical service provision to individuals with BPD is to view their behavior within the context that it originally developed. Viewing behavior in context may enhance healthcare providers' abilities to respond empathically and/or to assist clients in generating meaningful solutions to problems associated with BPD. The poems offered here represent six individual stories of the experience of BPD. These poems may serve as a reminder of the painful and often tragic circumstances in which "borderline" behaviors can develop. They may also be useful as tools to assist trainees in developing better understanding of how to work with individuals with BPD effectively and compassionately.

Keywords: Lived Experience, Mental Health and Illness, Borderline Personality Disorder, Recovery

Borderline Personality Disorder (BPD) is a severe mental illness characterized by extreme dysregulation of emotions, behavior, interpersonal functioning, self (identity), and cognition (Linehan, 1993). Individuals with BPD often engage in a variety of risky behaviors (e.g., non-suicidal self-injury, suicide attempts, substance abuse, risky sexual behaviors) that can be understood as both causes and perpetrators of the chaos typically associated with this disorder. An unfortunate consequence of these behaviors is that individuals with BPD are often labeled as manipulative, attention-seeking, or other similarly pejorative terms (see Nehls, 1998; Westwood & Baker, 2010, for reviews). Indeed, Rivera-Segarra and colleagues (2014) investigated stigmatization experiences of individuals living with BPD in Puerto Rico and found that the participants reported experiences related to social isolation, reduced support, discrimination, and a great deal of personal responsibility (e.g., the idea that these individuals just need to try harder to be well) in their everyday lives, by their families, and by their intimate partners. The authors found that the experiences reported were consistent with stigmatization typically associated with severe mental illnesses (e.g., being out of control) as well as that which is associated with less severe forms of mental illness (e.g., over-reacting). These authors uncovered a powerful, dialectical dilemma that individuals with BPD may experience: they are simultaneously viewed as if they are both out of control and as if they can control their behavior. I propose that the continued stigmatization of individuals with BPD may be perpetuated, in part, by faulty assumptions about "borderline" behavior associated with failure to view such behavior within its context. For example, self-injurious behaviors may be interpreted as "attention-seeking" rather than as a maladaptive means of regulating emotions and/or a behavior that has been reinforced over time by an extremely dysfunctional and invalidating environment (i.e., biosocial theory; Linehan, 1993).

Recent literature supports the notion that individuals with BPD are viewed in a particularly negative light, even within the healthcare community. For example, Markham and Trower (2003) found that nurses were significantly more likely to rate examples of challenging

patient behavior as within the control of the patient when the diagnostic label was BPD, as opposed to schizophrenia or depression. The authors investigated sympathy of nurses related to diagnostic label and found that, “staff were not only less sympathetic towards patients with a diagnosis of BPD, they were actually reporting being unsympathetic” (Markham & Trower, 2003, p. 251). The authors also found that nurses reported less optimism related to patient change and more negative personal experiences related to working with patients with the BPD diagnostic label. Similarly, Bourke, and Grenyer (2010) found that therapists exhibited significantly more negative emotional valence in their responses toward clients with BPD as compared with those diagnosed with Major Depressive Disorder. Finally, Bodner, Cohen-Fridel, and Iancu (2011) found that nurses, psychiatrists, and psychologists reported frustration, impatience, anger, and agitation related to treatment of individuals with BPD. They note that these findings were mainly explained by the challenges of managing suicidal behavior, which are perceived by professionals as “risky and dangerous” and potentially infuriating, resulting in “negative feelings towards these patients” (Bodner, Cohen-Fridel, & Iancu, 2011, p. 553).

Stigma related to BPD also has the potential to impact a therapist’s ability to provide effective treatment. Aviram, Brodsky, and Stanley (2006) note that stigma associated with BPD may interfere with treatment by setting up a self-fulfilling prophecy through which the therapist develops “a priori negative expectations about the course of treatment” (p. 252). Millar, Gillanders, and Saleem (2012) interviewed 16 clinical psychologists about their experiences and perceptions of working with clients with BPD and found both positive and negative themes. Negative themes included negative perceptions of the client (e.g., BPD clients are seen as different, manipulative, and as having limited capacity to change) and negative feelings within the psychologist (e.g., feeling overwhelmed, frustrated, and having a sense of low self-efficacy). Positive themes included positive perceptions of the client (e.g., seeing the client as likeable), desirable feelings in the psychologist (e.g., empathy), and having awareness of negativity and exploring the reasons for it. This research reflects a challenging dialectic experienced by many therapists working with individuals with BPD: Therapists are empathic and like their clients; they also become frustrated, overwhelmed, and confused about how to manage the multitude of issues and crises with which these individuals can present.

Dialectical behavior therapy (DBT; Linehan, 1993) was originally developed for the treatment of chronically suicidal and self-injuring individuals and it is considered to be a best practice for treatment of BPD (National Registry of Evidence-based Programs and Practices, 2006). Linehan’s (1993) seminal text outlining the theory and practice of DBT emphasizes the importance of understanding behavior within context via a variety of strategies (e.g., behavioral chain analysis) and also notes the potential for therapeutic errors to occur when problematic behaviors are not understood and/or therapist judgments and assumptions about behavior take priority over facts. The treatment includes many strategies for managing client and/or therapist behavior that can interfere with therapy. Team consultation, a core component of DBT, is one method of managing therapist reactions to client behavior. The DBT team serves many purposes, including helping therapists maintain adherence to treatment protocols and philosophies, as well as helping the therapist search for non-pejorative interpretations of client behavior (see Phenomenological Empathy Agreement, Linehan, 1993, p. 118). Linehan (1993) advocates for an understanding of BPD that is based on behavioral principles and the importance of “highlighting the basis of the disordered “borderline” behaviors in “normal” responses to dysfunctional biological, psychological, and environmental events” (p. 26).

Although DBT has a strong evidence base as an effective treatment for individuals with BPD as well as many other difficult to treat mental health issues which often present comorbidly with BPD (see Rizvi, Steffel, & Carson-Wong, 2013, for a review), it is unrealistic to propose that all professionals who may interact with individuals with BPD have training in DBT. However, I believe that it is important for healthcare providers who interact with

individuals with BPD to have an understanding of “borderline” behavior that is grounded within context. That is, an understanding of the individual’s behavior that is based upon the experiences throughout his or her life that allowed the behavior to develop and be reinforced over time. Such understanding may facilitate generation of interventions that are more likely to be effective as well as validating of individual experiences. For example, suppose a client has recently ended a relationship and subsequently engages in a suicide attempt via overdose on an over-the counter medication. If her therapist assumes that the client is engaging in this behavior to seek attention, social support, or to get her partner back (as opposed to other functions for this behavior, such as escaping overwhelming negative emotions), the clinician is less likely to select an intervention that will effectively target the behavior and may actually end up inadvertently reinforcing the behavior. It may also be quite invalidating for the client to be labeled as “attention seeking” when she may be quite ashamed of the behavior, which serves a completely different function. Understanding the function of behavior is critically important in reducing dysfunctional behaviors associated with BPD and this can only be accomplished when behavior is viewed in context.

Borba and colleagues (2011) concur with the notion that understanding client experiences in context is important. These authors studied the experiences of women with severe mental illnesses and found that their participants’ reports included several interconnected themes, suggesting “a complex cycle of social disadvantage throughout their lifespan” (p. 288). Borba and colleagues (2011) found themes related to social isolation, fear of hospitalization, moving to different neighborhoods (i.e., having to move frequently to avoid being “found out,” p. 289), loss (e.g., of jobs, custody, relationships), and lack of control over life decisions. With regard to lack of control, the authors note that many of the participants linked their current circumstances to past abuse. For example, some participants became involved in drug or alcohol abuse as a way of trying to avoid abuse by a partner; another fled childhood molestation at home only to find that the man she moved in with also abused her. These findings illustrate the ways in which a variety of tragic circumstances that are beyond the individual’s control can lead to ongoing issues (including mental health, substance use, low social support, or unstable finances) that may restrict the individual’s ability to appear “in control” in the present. Borba and colleagues (2011) conclude that, “mental health care providers may unintentionally contribute to their diminished quality of life by not contextualizing their treatment (p. 290).

As is demonstrated by the studies cited above, viewing client behavior out of context can be damaging for a variety of reasons. Harboring negative attitudes about a client based on his or her diagnosis is likely to affect a clinician’s ability to connect and respond empathically with clients. Linehan (1993) issues this impassioned argument:

It is by making these individuals different in principle from ourselves that we can demean them. And perhaps, at times, we demean them to make them different. Once we see, however, that the principles of behavior influencing normal behavior (including our own) are the same principles influencing borderline behavior, we will more easily empathize and respond compassionately to the difficulties they present us with (p. 26).

The purpose of this research is to present poetic accounts of experiences of BPD as authentically as possible, without separating out pieces (e.g. themes) of narratives that may de-contextualize them. Attending to the lived experiences of individuals with BPD may facilitate deeper understanding and compassion for those suffering with this disorder as well as reduced stigmatization. Additionally, while there is a small body of research attending to the experiences of individuals who are currently receiving treatment for BPD and authors have published powerful autobiographical accounts of their experiences and recoveries from BPD (e.g., Reiland, 2004; Van Gelder, 2010), there are no known studies that focus specifically on individuals who have recovered from BPD through treatment with DBT. Lack of research with

regard to recovery from BPD is unfortunate as it is possible that this furthers the common stereotype that BPD is a chronic and incurable condition.

It is possible that recovered individuals often do not come forward to share their stories because they are now living happy, productive lives and do not wish to expose themselves by publicizing their previous struggles because doing so could open them up to judgment or continued stigmatization. Coming forward as having been previously mentally ill may have real-world consequences such as increased scrutiny of one's emotional state or decision-making as well as potential loss of employment. This study offers an opportunity for individuals who have recovered from BPD to share their experiences with the research community, without fear of continued stigmatization that might jeopardize their current success. This study gives individuals who have recovered from BPD the opportunity to share their lived experiences so that their voices can contribute to a richer and more authentic understanding of BPD.

Method

Reflexivity

I hold a doctorate in Counselor Education and am a licensed mental health counselor specializing in DBT for treatment of individuals with BPD and other difficult-to-treat mental illnesses. I have wondered about a research project including the stories of individuals who have recovered from BPD since I first began to learn about DBT. I believe that individuals with BPD can and do recover; understanding this process was the primary impetus for this research. In addition, I believe that DBT is the best treatment for BPD available at present. As such, the primary theoretical lens through which I approached this research was DBT (Linehan, 1993), which includes elements of cognitive, behavioral, and biosocial theory as well as dialectical philosophy and Zen practice. I present this information to the reader because I believe that it is important to acknowledge my own assumptions and influence on this research and data presented.

As I engaged with the participants and their experiences, I found it increasingly important to work toward setting aside my own objectives through reflexive journaling. I became aware that some of these objectives were to develop poems that present "triumphant" stories of recovery and to highlight the influence of DBT in these stories. In order to subvert these objectives, I decided that once I had completed each poem, I would send it back to the participant with an invitation to edit and to give final approval for the poem to be published as an accurate account of the experience. One technique that was particularly helpful during the interviewing process can be described as "mindfulness of assumptions." I challenged myself to be mindful of times when, as a participant was describing an experience, I made an internal assumption about that experience. When I found myself assuming, I asked a follow-up question and allowed the participant to correct me. For example, one participant noted that her first hospitalization was a particularly significant part of her story. My internal assumption was that this was significant because the first psychiatric hospitalization can cement one's "patient identity" (viewing oneself as a sick or disordered person) and I followed-up by asking what was significant about this event. The participant shared that it was significant for her because it was where she met her first therapist and that it, "got me on the track of healing myself." Although objectivity was not a goal of this research, I have endeavored to be mindful of my own subjectivity and to subvert it where important and possible throughout the research process in order to allow the participants' voices to come through as authentically and unmediated as possible.

Recruitment and Inclusion Criteria

I distributed recruitment messages on two professional listservs for clinicians and researchers interested in DBT. Generally, participants were referred to the study by their former DBT therapists. The inclusion criteria for this study included being at least 18 years old, being willing and able to participate in up to four interviews on the topic of personal experiences with BPD and DBT, and consent to have the principal investigator to contact the current or former therapist to verify that he/she has been diagnosed with BPD, treated by an intensively trained DBT therapist, and is in at least stage three of DBT. This article presents data that is part of a larger project on recovery from BPD through DBT and thus, inclusion criteria related to the type of treatment received and training level of the therapists involved was important. In addition, all participants identified personal and professional sources of support to which they could turn in the event that they found the interviews to be emotionally distressing.

Participants

A total of nine participants were originally recruited for this study. One participant was excluded because the treating therapist could not be reached to verify that she met the inclusion criteria, a second was excluded due to not meeting all of the inclusion criteria, and a third withdrew from the study prior to participating in the interviews. The final group of participants were six individuals (5 females, 1 male) ranging in age from 30 to 44 years old. Two participants were married, one was in a domestic partnership, one was in a relationship, one was divorced, and one was single. Four participants were employed, two were students, and one was a stay-at-home parent. All participants had been previously diagnosed with BPD. To the extent that it is known, participants also met criteria for the following diagnoses at the time they received DBT treatment (by report of the treatment provider): Mood Disorder (Not Otherwise Specified), Major Depressive Disorder, Post-Traumatic Stress Disorder, previous history of Cannabis Abuse, Panic Disorder with Agoraphobia, Dissociative Identity Disorder, Obsessive Compulsive Personality Disorder, Bipolar Disorder (Type I), Conversion Disorder, and Bulimia Nervosa.

All participants received comprehensive DBT as part of their treatment. Comprehensive DBT is defined as including the four primary components of DBT treatment: (a) individual DBT therapy, (b) group DBT skills training, (c) as needed telephone coaching, and (d) team consultation for the therapists (Linehan, 1993). Participants were also included if they attended a program that offered an adapted version of the original DBT protocol, as long as the program's elements met the functions of the primary components of DBT (e.g., some participants attended a DBT intensive outpatient program). DBT includes four main stages and the primary goals of these are as follows: (1) gaining behavioral control; (2) experiencing a range of emotions without suffering needlessly; (3) managing normal life problems; and (4) building capacity for freedom and joy (NREPP, 2012). I defined "recovery" as being in at least stage three of DBT, as stage four is not always completed in the context of therapy and often includes elements outside of treatment (e.g., developing an increased connection to oneself, others, or one's sense of spirituality).

Data Collection

Participants engaged in three semi-structured interviews, with one interview focused on each of the following topics: experience of BPD, definitions of recovery from BPD, and experiences of the stages of DBT. I provided all participants with interview guides prior to each

interview to ensure that they had time to consider the questions. Generally, the first interview lasted about 90 minutes, with the following two interviews lasting up to 60 minutes. Given the purpose of this study, data from the first interview was analyzed and used to develop the poems. The majority of the interviews were conducted via Skype due to the geographical locations of the participants. I recorded all of the interviews and submitted audio files for transcription. The institutional review board for the University of South Florida approved the procedures for this study; all participants gave informed consent to participate. In addition, all participants provided confirmation that the poem developed from their interview accurately represented their experiences and gave their consent for it to be published.

Data Analysis

I used poetic analysis because the purpose of this data analysis is to offer evocative accounts that communicate lived experiences of BPD. This is consistent with Grbich's (2013) definition of poetic analysis, in which she asserts that researchers must engage creatively with their data in order to "bring the reader as close as possible to the original researcher/participant experiences" (p. 130). In addition to communicating experiences, an advantage of poetic analysis is that it can "present subtle ideas that might be paradoxical or dialectic" (Furman, 2006, p. 561). As the participants in this study were all treated with DBT, which involves learning to think dialectically (e.g., learning that conflicting viewpoints can co-exist as truths, for example, one can feel both love and anger for the same person), it was particularly important that any means used to report the results of the research allowed space for dialectics to exist. Lastly, Pelias (2011) notes that evocative methods of presenting qualitative research are used to "enrich or disrupt normative understanding" (p. 662), which I hope to achieve through this work.

The data analysis process I used closely (but not exactly) mirrored Glesne's (1997) description of poetic transcription or poetic narrative. During the early stages of data analysis, I began by coding each transcript for themes. I reflected on the transcripts as whole narratives, trying to understand the "essence" of what each participant was communicating, and created found poetry using only the words of the participant (although these words/excerpts could be re-ordered as needed; Glesne, 1997, p. 206). I departed from Glesne's (1997) approach in two main areas: I did not require myself to create poetry that mimicked the prosody of the participant and, I used some provisional codes (as defined by Miles, Huberman, & Saldaña, 2014) to guide my coding process.

I elected to use provisional codes because the transcripts were lengthy and I believed that it would be helpful to code them to highlight various sections (e.g., origins, experience of BPD, recovery, etc.) that could later be revisited for poetic transcription. Additionally, as part of the interview, I asked participants to identify what they believed to be the most significant parts of their stories. The aforementioned coding method was quite helpful in allowing me to return to the sections identified by the participants as the significant pieces to emphasize. As the data analysis proceeded and through discussions with my qualitative methods mentor, I came to realize that I viewed the creation of these poems more as (musical) composition or arranging than writing. This is not surprising, as I was previously trained as a classical musician. Upon this realization, I began to rely much more on listening to the data and I used the transcripts much less. I focused on participant-identified sections of significance, listening and re-listening (and/or watching video) to the sections several times over in order to tease out the pieces that were most emphasized by their manner of speech (e.g., volume, tone, word repetition) and physical gestures (e.g., facial expression, hand movements). I found this process to be more satisfying in terms of my desire to present authentic accounts based upon participant experiences and their views regarding the most significant parts of their stories. The iterative

process of data analysis described above resulted in the development of the following method for poetic transcription of participant experiences:

1. Listen to the recording of the interview without viewing the transcript.
2. Listen to the recording of the interview while coding the transcript.
3. List events or experiences identified as significant by the participants and begin to pull pieces representing these from the transcripts.
4. View and re-view to each specific section of the interview while arranging the participant's words into poetic form (this step was repeated many times).
5. View the poem as a whole without listening to the recording or viewing the transcript; continue to arrange the words as needed to refine the poem into an evocative account of the participant's experiences, as I understood it.
6. Obtain consent from the participant to send him/her a copy of the poem for review, any needed editing, and consent for publication.

Results

The results of this data analysis are poems representing each participant's individual experience of BPD. It is important to keep in mind when viewing the poems that they were developed from a single interview with the main focus of understanding what the experience of BPD is. Poem titles are participant responses to the question, "if your experiences with BPD were written in a book, what would the title of the book be?"

I. BPD Transformation: From Hopelessness to Purpose

When I was a baby and I would cry, she would just not know what to do.

I was always trying to find my way,
 Trying to find love,
 Trying to find stability.
 But there was a lot of crazy stuff going on,
 They did all the stuff that you shouldn't do.
 I was at home all the time by myself.
 Nobody was actually watching out for me.

You have to be the prettiest,
 The smartest (I always got brilliant marks),
 The most talented, hungry, driven.
 And I was a wave of emotion.

I'm ashamed to tell you this but,
 If I threatened suicide she would pay attention to me.

When I got my diagnosis, I felt completely exposed.
 They told my mom that BPD was untreatable,
 And I was not even allowed to be hospitalized there ever again.
 You can't get any validation when people think, "Well, there's no hope for you."
 I felt like I had a terminal illness. Terminal hopelessness.

There's no way I'm going to let this be my legacy.

They are completely wrong.
Nobody will ever understand this but,
It just feels really good to say that I got treatment and figured a way out.

I shouldn't have gotten pregnant, but I did.
My mom told me to give her up for adoption,
there was no way I could keep her.
I'm a fighter, so I said no.

I got in the car, I moved, and,
Told no one.
I got a temp job, a train ticket,
And, I kept my daughter.

Food stamps.
Section 8 housing.
Wanting help but nowhere to go.
I broke down and accepted, but,
It got worse before it got better.

Once you start to get help, people use your diagnosis against you.
My husband had been out drinking for hours,
And I'm driving, frantically looking (I had my daughter in the car).
I called my therapist and I was venting.
I said, "I'm going to jump off the bridge."

The state is taking custody of my daughter.

She said, "I will only work as hard as you work,"
And I took that as a challenge.
She validated her promise every time we met.
I saw how hard she worked for me,
So I wanted to give it to her in return.

DCF told me, "You will never get custody of your daughter back."
I went head in to the situation, with all my skills and would not give up on either of us.
It was not easy, but,
I now have full, legal custody of my daughter.

Now that I no longer meet criteria for any diagnosis and haven't taken anything but vitamins
in three years,
I'm determining what I want out of life,
Where I am currently,
And where I see myself going in the future.
Sometimes I yell at God and sometimes, I'm like,
"I see what you did there."

II. Growing and Changing in a Black and White World

My grandmother died in front of me,

I was 12 and, it messed me up.
There was sexual abuse by my grandfather,
Which went on for 10 years,
Some of it was on a daily basis.

I was depressed, and,
It just got worse and worse.
I was scheduled to go to college; I was enrolled,
And then I just wound up in the hospital.
I was really suicidal.

I started cutting,
I picked it up from another patient there,
It became a daily thing.
But, I met my first therapist,
We started talking about some of the abuse.

In the 5th hospitalization I met my soon to be husband.
He became abusive.
He was controlling and a sex addict.
I feel like I married my father.

I kicked him out.
The thing that got me was,
He was hitting my daughter.
I couldn't stand for that.
The children are the only good that came out of that relationship.

We lived at my job on the sly for several months.
I would get them ready for daycare,
Go all the way back by bus to work; work a full day.
Go back to get them at daycare.
We would wander the street, find something to eat, and,
After the [job] closed we would go back.
I would bathe them and then put them to bed on the floor.

And we would do that every day,
Until we were found out.

We had no where to go and we were homeless,
There were literally roaches crawling down the walls,
I moved the bed into the middle of the room so that the roaches wouldn't crawl on us.

The other mothers told me right off the bat,
that my children would eventually be taken from me.
I didn't believe them, but it came to be true.
I don't know their reasoning,
They just felt like I wasn't in control.

It seemed like every time I would try to get my kids back,

Something would keep them from giving them back to me.
So I was hospitalized over 50 times.

She wrote me a letter that said she wanted to be adopted by her foster parents.
I didn't want to go against her wishes, but,
I wanted to fight for her; I wanted her back.
The CPS worker was like, "Well, you'll never get her back, so you shouldn't even try."
One of the worst days of my life was giving up my rights to her.

I met my soul mate.
I meant something to someone.
I was really pushing and pulling,
And it was so difficult we almost didn't make it.

Miraculously, I realized what I was doing, and,
I realized I didn't want to lose him.
I did some major changing, [he] did some changing, and,
We've really got a strong relationship now.

I got a new CPS worker.
As soon as I got a new worker,
He was like, "why are you not reunified?"
I got my son back.

It's so ingrained in me now, the DBT stuff.
Even in the times when it felt like I wasn't,
There was at least a little bit of growth.

III. Misunderstood

I'm adopted.
That primal wound of abandonment,
I've carried with me the sense that
there's something wrong with me.

They didn't want me to be seen as a black person,
Even before I was old enough to *feel* the problems,
I was clearly being invalidated.
I'm looking at myself in the mirror and I'm seeing,
And everybody's telling me, "Oh, but that's not really what you're seeing."

I just remember feeling like I hated myself,
There wasn't anything I could do to fix,
There was something really terrible about me.
It was inherent.

There was this need for me to hurt myself.
I would break my bones.
Fingers were easier to break than wrists, I learned,
So I would take a hammer to my fingers.

I was eight years old.

The man who raped me was the only other black person I ever knew.
I figured he picked me because I was black,
But I probably looked like a good victim,
Vulnerable and lost; an easy target.

I started living with my boyfriend.
After my daughter was born,
I felt like all my insides were on fire and bouncing around,
Burning me.
And then I would down a bunch of pills.
I didn't value myself as a mother,
So it never occurred to me that my life mattered to her.

I remember one night calling my dad and begging him.
Do *anything!*
Put me in a straightjacket and ship me overseas.
Help me! I desperately need *something*.
I went to an outpatient DBT program.
I was trying to use my skills but the pieces weren't falling together.

"I'm not going to take my medicine anymore,
Then maybe I'll be brave enough to jump off of a building."
My mind was telling me that was the right thing to do,
I didn't talk to my doctors – I just stopped.
And coincidentally, it changed everything.
I was actually doing better!

She explained to me that this behavior I have,
Of taking a whole bunch of pills,
Is just a behavior.
All my skills – everything started falling into place.
I still had lots of feelings to work through,
But they were *my* feelings.

I ended up getting strong enough to divorce my husband.
Regardless of how much I loved him,
I knew I couldn't let her see me set this example.
But shortly after that, he died.

I could survive something that terrible and still live through it.
That's when I realized I was gonna be fine.

I understand how to live within these special feelings,
There's something about this that makes me even more powerful.

IV. Out is Through

I was tortured when I was a small child.

Growing up I remember feeling different from everyone else,
My emotions weren't allowed.
I would whip my legs with tree branches,
And pull my eyelashes out.

I did everything I could to be accepted, still I felt so empty,
I was acting my way through life so no one would see me.
I don't know what I was hiding,
But something was very dark.

I had episodes,
Running down the hall terrified,
In the fetal position, screaming.
I decided to go to therapy.

The first therapist I saw abused me.
Unknown to me at the time,
I switched into an alternate personality when he abused me.
I still remember very little.
See, I am DID.

I began having flashes and images of a little girl being tortured and abused.
You can see the movie, but it's jumbled.
Like taking a VHS tape, playing it,
And then pushing fast forward.

I continued with my life,
Not making the connection,
That those images of that little girl were images of me.

I was very successful,
Again, I had to be the best.
It was becoming harder, and it was right there,
Under the surface.

The realization that the movie that played in my head was me.
I would suddenly act like a child or become another person.
I had my psychotic break.

Usually after episodes I could put it away in my box.
My box was too full. Couldn't shake it off.
I went home and told my husband: I quit my job and I'm going into a mental hospital.
He gave me a hug.
I made it a point that I would do everything I could to get better for my [family].

I had to take an eight-hour psychological evaluation.
Borderline Personality Disorder was added to my diagnosis.
Treatment was one year long.
This program saved my life.

I have nine alters that I know of and have met.
I still get triggered, I still struggle.
With hard work, determination, good medication, and,
my [family] to fight for,
I now live a normal life.

The most important part of my story is the ending.

I have accomplished a lot.
I bring a face to mental illness,
Put awareness out there,
Fight the stigma,
And most importantly,
To be an inspiration to others.

V. Sex, Fashion, and Mental Illness

I came from a background of instability.
Fighting, getting arrested for drugs and alcohol, food stamps.
My mom tried to commit suicide several times.
I didn't feel safe.

The first time I ever got aggressive with a girl was in high school.
My sense of identity was so lost in her,
I was so angry that she had abandoned me.
Things were so uncomfortable at my house,
My only salvation would be through this relationship.

The next relationship was five years,
Of fighting and arguing.
She left me, and I felt that same fear.
Primal fear of the mother leaving a child.

That was the first time that I did any kind of suicide attempt.
It was staged, a cry for help.
But the pain-killers started to feel good.
I almost killed myself on accident.

I can get my needs met by doing this thing!
It was this euphoric moment that turned dark.
This was the first time that I understood,
Something had to change.

The court ordered me to anger management courses.
It wasn't life changing, but,
It felt a little bit more peaceful.
It felt good to have some kind of way to express something.

He planted a lot of the seeds of DBT.
He: "Everything is exactly the way it's supposed to be."

And I: “I don’t fucking understand what the fuck you’re saying.”
He was doing the best he could, but I was still raging.
I started cutting during that time.

Every time something bad happened I would research,
Trying to figure out how I could fix myself.
That’s when I came across something about BPD.
Shit. This is who I am? Great.
It wasn’t very validating for me at the time,
But there’s truth to it.

And then I got into a dark place again.
I didn’t eat for a couple weeks.
All this trauma started coming out,
It was the lowest point.

I found [my DBT therapist].
She was really compassionate, and,
She told me to eat a sandwich.
It was clear that [she] was the teacher.

I was very open-minded going in.
I made progress,
I started feeling like nothing was really happening anymore...
And then [my current girlfriend] enters the picture.
[She] has been an amazing mirror for me.

I would write down the triggers,
Trying to figure out what was causing these rage episodes.
I studied myself like a lab rat, and eventually,
There’s a list! There’s a pattern.
It feels conquerable!

Exposure therapy helped, but there were still these things.
That’s when I started experimenting with psychedelics.
It takes you to a place of pure stillness.
No being, no non-being.
It wasn’t a magic bullet, I was still using skills.

I remember one time,
I realized I was sexually abused,
But I moved through it.
I remember the teaching, “Face the demon and sit with it.”
And I remember going, “Here I am.”

[My DBT therapist] took me up to where she could,
but there was another journey I had to walk,
with a different teacher.
With the Universe.

VI. The Dinner Party¹

My parents weren't really equipped to be parents.
My mom was incredibly volatile.
She would go in the bathroom,
And narrate the fact that she was killing herself.

I got picked on a lot.
I think I used to cut myself a lot.
And then I would not eat for a while.

In high school, I started expressing myself more.
They would have that suicide checklist,
All of a sudden, the tone would change.
I was pretty good at knowing how far to go with what I was saying.

Initially, I was okay in college.
And I started going to see a therapist there.
I was so anxious all the time,
I think it came off as jittery and happy,
Like I couldn't stay in my skin.
I wanted to get out of the situation.

Things started getting really out of control.
I wasn't sleeping; my emotions would flip really rapidly.
I used to think about suicide a lot,
And it would just completely short-circuit all of that emotion.
I would feel fine afterwards.

I accepted that I was going to kill myself at some point,
And I have never felt *so much ecstasy* in my entire life.
It was incredibly hard to hear,
"I don't know how I can help you."
So I ended up going to the hospital.
It made things a lot worse.
The therapy was incredibly condescending.
No one listens to you if you're crazy.

Initially [DBT] was kind of rough.
I honestly couldn't conceive of going to therapy for that long.
I'm desperate and you're giving me homework?

I was just a mess.
I was getting hospitalized all the time,
Yet I was still exceling in my classes.
I still had that illusion that everything was going well.

¹ This title is a reference to the 1962 surrealist film, "The Exterminating Angel," in which several wealthy guests become unable to leave a dinner party at the end of the evening, resulting in increasingly bizarre occurrences.

We talked about the life worth living.
It was beyond my comprehension,
Because my brain had been so inundated with the thought -
I just really want to die.
I just really don't want to feel.

So I finished DBT,
And I was actually more of a mess.
And then I decided,
I'm going to volunteer for six months.

I remember feeling really lonely and just dealing –
It made me deal with my stuff on my own.
I actually used DBT quite a bit.

Eventually, therapy became this crutch.
I was too scared to do it on my own.
What I did was not recommendable,
But for me, it was necessary.
If not, I was always going to act up to get back the support.

I had a clear point of view.
This is what I want to do,
And I'm going to do it no matter what.
Hopefully, to get my self back.

If you were to tape a scene,
And then put two different types of music to it.
One is happy-go-lucky,
And one from a terror film.
That was my experience over all those years.
I would be living in an experience,
But the music to what I was seeing was very different.

Discussion

The poems presented here offer deeply personal, moving accounts of the life experiences of individuals who have recovered from BPD. Although I had originally set out to understand what the experience of BPD was, what I found was that these experiences are described in a wholly different manner from that which I had become accustomed to using in my clinical work. Specifically, what I was expecting was a great deal more discussion and description of experiences that corresponded relatively closely with the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (APA, 2013) criteria for BPD. Although there were certainly references to symptoms, there was also significant attention to early childhood experiences, abuse, trauma, self-hatred, and a sense of being unheard. It appears that dialectical tension exists between the utility of viewing a disorder as a collection of symptoms (which facilitates referral for appropriate treatment) and the potential for harm (de-contextualization, stigmatization) that may come to a person when the challenges she presents with are reduced to a collection of symptoms or diagnostic criteria. In addition, the particular problems associated with BPD can make balancing this dialectic very

difficult. For example, Aviram, Brodsky, and Stanley (2006) suggest that “because of the unpredictability of behavior and the intense range of emotion associated with BPD, it may be challenging for clinicians to maintain a view of the problems that emerge as reflecting “nature of the pathology” and not the “nature of the individual” (p. 249).

A metaphor may be useful in further illustrating the importance and process of developing contextualized understanding. In the field of classical music, teachers sometimes have the habit of assigning a very advanced student a classic, but not extremely technically challenging piece of music that the student learned at an earlier point in his or her education. The point of such an exercise is to move beyond the technical capacity to play the notes, in order to develop artistry. Similarly, Faye-Ellen Silverman (a contemporary composer and professor at Mannes College, The New School for Music, NY, NY) uses the technique of introducing very difficult pieces of music to freshman conservatory students and again, when the students reach their junior year. In discussing this method, she notes that, “some of them hated the work as freshman but understood it as juniors, so going back creates a new level of understanding” (F.-E. Silverman, personal communication, April 6, 2015). She explains that her own perspective of these pieces is also constantly evolving and that each encounter with a piece helps her to further her understanding of the piece, its details, and the composer’s intentions.

In the field of counseling, understanding the client’s subjective experience is regarded as one of the very first and most central tenants of the profession. Phenomenological understanding of client experiences may not always occur the first time we hear a client’s story, just as playing a piece of music with true artistry does not usually happen during the student’s first encounter with the piece. With regard to working with individuals with BPD, I have observed that the focus on client experiences and the willingness to hear something new in a story I may have already heard many times can sometimes be overshadowed by the need to manage crisis or protect the client’s safety, as well as my own fears and insecurities about whether I will truly be able to help the client build a life worth living. It takes considerable effort for me to turn my mind back toward the tasks of listening and understanding in the face of these challenges. However, I believe that the act of returning our focus to understanding client experiences and responding with phenomenological empathy is both beginning and end. It is the primary foundation on which everything else is built, and it is a means through which we continuously develop our understanding and the artistry of helping.

As academics and educators in the helping professions, we plant the seeds of this artistry for future generations of counselors, social workers, psychologists, nurses, physicians, and many other professionals. The experiences detailed in these poems give important insight into the differing ways that BPD and treatment via a variety of interventions (e.g., hospitalization) can be experienced (sometimes quite negatively) by the individual client. It is critical that we help students develop the self-awareness and professional skills to intervene when clients are having harmful or ineffective treatment experiences due to inaccurate or ineffective formulations of presenting problems based on judgment (of the therapist or other treatment providers) rather than contextualized facts. Doing so requires the ability to look beyond stereotypes, assumptions, biases, and one’s own reactions to client behavior that can be quite aversive, anxiety-provoking, and frustrating at times. It is important to encourage students to accept that we are all fallible human beings and thus, prone to moments of less compassion, less positive regard, and of lowered energy and tolerance and, to push past these moments to see individuals as they really are rather than as a diagnosis or a collection of problems to be solved. Seeing clients as they are, with all of the unique experiences that have lead them to a particular moment, facilitates not only more compassion and understanding (Linehan, 1993), but a more contextualized view of client difficulties that may reduce the

negative biases and stigmatization that have been documented to occur among healthcare workers and clinicians (e.g., Millar, Gillanders, & Saleem, 2012; Markham & Trower, 2003).

It is my hope that these poems will serve, in part, as a call to mindfulness. The purpose of mindfulness is not to reach a point where we can do something perfectly – we will never understand and respond perfectly to our clients. Rather, there is great value in our moments of non-understanding because these give us the opportunity to develop awareness of those times when we are off track and have become unmindful. These poems may be used as a way for students and professionals to continue to work on the ability to become mindful of times when their compassion for BPD clients is lowered. They may also be useful as a method of assisting students and professionals in learning the value of viewing individuals and their behavior within context. Ultimately, I hope that the poems presented here will promote more awareness of the seemingly insurmountable challenges and suffering faced by those with BPD and, the incredible strength, resilience, and humanity that these individuals possess. Even when things seem hopeless, there is hope.

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