The Subjective Experience of Women
in Treatment for
Borderline Personality Disorder

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Statement of the Research Problem

Borderline personality disorder (BPD) is a major social problem about which little empirical research has been done. Individuals with this diagnosis, who are approximately 75% female, are highly stigmatized in society, do not readily respond to treatment, and are at very high risk for completed suicide.

It is crucial that society come to better understand individuals with BPD for several reasons. First, these individuals experience are at high risk for suicide; 8 to 10 % of individuals who currently have a diagnosis of BPD will eventually commit suicide (APA, 2000; Oldham, 2006). This mortality rate by suicide is 50 times higher than the rate in the general population (Skodol, 2005).

Secondly, individuals with BPD are highly stigmatized in society. They are usually described in very pejorative terms by even the most well-meaning treatment providers. Thirdly, achieving treatment success with BPD individuals has been so difficult that many treatment providers flatly refuse to treat these individuals. Fourthly, because of the "crisis nature" of much of the treatment for BPD individuals, frequent hospital stays, and because of the length of time required in order to see progress, treatment is extremely expensive.

BPD individuals make up about 20% of all patients in psychiatric hospitals and 8% to 11% of all individuals in outpatient mental health settings. It is evident that they use a significant percentage of all mental health resources (APA, 2000; Linehan, 2008).

What is also not clearly understood is why BPD is diagnosed primarily among females—from 66% to 75% of those diagnosed with BPD are female (Sadock & Sadock, 2004; APA, 2000; Linehan, 1993b).

Similarly to BPD, major depressive episodes occur twice as frequently in women as in men (APA, 2000) and it is believed by some professionals that external social and cultural influences contribute to the greater prevalence of depression among women (Johnson, 1991, p. 242).

This researcher speculated that this could also be true with BPD—that external societal influences may contribute to the greater prevalence of BPD among women. This study, therefore, concentrated exclusively on women with BPD, so that such differences would not confuse the results. A future study could exclusively focus on men with BPD and the responses could be compared.

There is a near-consensus among treatment providers and researchers that BPD is still not well understood and that further research is needed. What research does exist has been almost exclusively from the "outsider's perspective"—i.e., from the perspective of theorists and treatment providers. The "insiders' perspective" has been almost entirely neglected.

The goal for this study was to use both inductive and deductive methods to create a better understanding of the lived experience of women with borderline personality disorder. Since only one previous study had focused on the subjective experience of individuals with BPD (Miller, 1994), this would be an exploratory study with the goal of describing the whole range of responses by women with BPD. These methods would help to re-examine the dominant paradigms about the disorder, and hopefully would uncover new perspectives which would affect how BPD is understood and treated.

The overall aim of this study was to examine how women in treatment for BPD subjectively experience their everyday lives.

To meet this aim, the following three research questions were explored:

1. For women in treatment for BPD, what are their perceptions of "self" and "being" and "personhood"?
2. What are their personal narratives about causality?
3. What are their personal narratives about recovery?

Research Background and Hypotheses

Despite a wide degree of variability in the description of etiology, treatment and prognosis, the theories dominating the professional literature today tend to agree, more or

less, with the description of BPD in the *DSM-IV-TR* (APA, 2000). Thus, this section on current theories will begin with a description of the conceptualization of BPD in the *DSM-IV-TR* (APA, 2000). The diagnostic criteria are listed below.

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Diagnostic criteria for 301.83 Borderline Personality Disorder

A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:
(1) Frantic efforts to avoid real or imagined abandonment. Note: Do not include 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.
(3) Identity disturbance: markedly and persistently unstable self-image or sense of self
(4) Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating). Note: Do not include suicidal or self-mutilating behavior covered in Criterion 5.
(5) Recurrent suicidal behavior, gestures, or 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
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From: *DSM-IV-TR* (APA, 2000, p. 710).
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Four theories dominate the professional literature about treatments for BPD. The following section will describe how those four theories for treating borderline personality disorder address the three research questions of this study.

Object Relations Theory

The first theory about treatment for BPD is object relations theory. There are several theories under the umbrella of "object relations theory" which include much about the description of individuals with BPD, as well as about treatment for these individuals. What these theories have in common is that they theorize that BPD is caused by disruptions in a child's attachment process during the first two to three years of life. They also theorize that, as adults, these individuals have problems in their adult relationships including their relationship with a significant other. And they theorize that one of the most useful tools for learning about and treating an individual's attachment problems is a focus on transference issues in therapy.

One of the best known theorists about BPD is Kernberg, who, together with Yeomans and Clarkin recently developed a relatively brief form of treatment for BPD—Transference-Focused Psychotherapy—and have tested it in clinical trials (Yeomans, Clarkin, & Kernberg, 2002). Kernberg used the term "borderline personality organization" (BPO) to refer to borderline personality disorder and to all "severe" personality disorders", because he believed that they all presented with similar problems in psychological functioning (Yeomans, et al., 2002).

Proponents of TFP theory predict change in some of the serious impulsive behaviors within one year of treatment, but other changes may take many more years of treatment. They exclude certain individuals from TFP treatment on the basis of active substance abuse, active eating disorders and/ or secondary gain as the motivation for treatment. They consider certain other BPO characteristics to be predictive of a poor prognosis (Yeomans et al., 2002). Thus, although proponents of TFP consider BPO to be treatable overall they consider the prognosis for individuals with BPO to be fair to poor.

Trauma Theory

Judith Herman, M.D., considered one of the foremost experts on trauma, proposed what she felt was a more descriptive name for the syndrome (that includes borderline personality disorder and several other diagnoses) that results from "prolonged, repeated trauma" The name she proposed was "complex post-traumatic stress disorder" (Herman, 1992). She wrote that the responses to trauma are a spectrum of conditions rather than a single disorder, and that the PTSD resulting from a single traumatic incident in adulthood differs greatly from the PTSD resulting from prolonged childhood abuse (p.119).

> The earlier the onset of abuse, and the greater its severity, the greater the likelihood the survivor would develop symptoms of borderline personality disorder (Herman, 1992, pp. 125-126).

Herman proposed a model of psychotherapy which assisted BPD individuals to move through three stages of treatment: (1) Finding safety, (2) Remembrance and mourning and (3) Reconnection with others (Herman, 1992, p. 218).

Herman's description of the recovery process implied that it is long, usually taking a number of years (p. 213). She said that clients with complex post-traumatic stress disorder (which includes clients with BPD) do recover to the point where they have a new capacity to take pleasure in life and where they have constructed a coherent system of meaning in all their life experiences (Herman, 1992, pp. 212-213). Still, Herman describes the prognosis for BPD as somewhat guarded. These individuals, she said, do improve with treatment, but recovery is rarely a permanent state (Herman, 1992).

Dialectical Behavior Theory (DBT)

DBT was developed by Marsha Linehan; a psychologist at University of Washington. DBT is based on a "biosocial" theory of borderline personality disorder (Linehan, 1993b). The main tenet of this theory is that the core disorder in BPD is emotion dysregulation. Emotion dysregulation is seen as a joint outcome of biological predisposition and an invalidating environment during childhood.

> DBT was developed in the context of viewing borderline personality disorder as a combination of motivational issues and skills deficits. To address these issues and deficits, DBT is made up of a combination of (1) individual therapy, and (2) a skills training group. . . . The individual therapist is responsible for helping the client reduce their motivation to die and/or to exhibit maladaptive behaviors (Linehan, 1993a, p. 102).

Skills training groups make up the second most important mode of treatment in DBT and were established to address the skills deficits of borderline individuals. Besides their motivational issues, borderline individuals also exhibit maladaptive behaviors. They are unable to inhibit maladaptive behaviors that flow out of strong negative emotions. The skills training groups teach four sets of skills that help BPD individuals to inhibit these maladaptive behaviors and replace them with more adaptive behaviors.

DBT is one of the most effective treatments, along with transference-focused psychotherapy for treating individuals with BPD (Clarkin, et al., 2007). Linehan has recommended one year of treatment for individuals with BPD at the DBT clinic at the University of Washington. However, she admitted that, "Our data do not support a claim that 1 year of treatment is sufficient for these patients. Our subjects were still scoring in the clinical range on almost all measures" (Linehan, 1993a, p. 24).

Thus, in Dialectical Behavior Theory also, the prognosis is somewhat guarded.

Neurobiology Theory

The traditional view of BPD in the psychiatric community since its inclusion in the DSM III (APA, 1980) has been that BPD has an environmental etiology.

However, due to new technologies, especially advances in neuroimaging, a growing number of researchers have observed some evidence of brain dysfunction specific to individuals with BPD. This has led to a relatively new conception of BPD which explicitly identifies the core of the disorder as a "neurobehavioral developmental brain dysfunction" (Rosenberg, 1994, p. 59).

Rosenberg (1994) stated that many symptoms of BPD, including lack of impulse control, affective dysregulation, cognitive disability and predisposition to psychotic decompensation suggest orbitofrontal or limbic areas as the center of the brain

dysfunction in BPD. If it is true, he said, that BPD is essentially a brain dysfunction, then it could be primarily treated by pharmacological means. Rosenberg has predicted a day when medication will, indeed, be the primary treatment for BPD (Rosenberg, 1994, p. 59).

The view of proponents of the neurobiology theory of BPD are not specific as to the length of time needed for treatment and recovery, and they report a need for caution because of the individuals' high risk for suicide.

Methodology

This study was a descriptive, non-random, qualitative investigation, which sought to describe the lived experience of women between 18 and 65 who are in treatment for borderline personality disorder (BPD). It was an exploratory study, aiming to simply describe the full range of responses from the research participants and to document the frequency of various themes found in these responses.

The study had a cross-sectional design and an interpretivist perspective. The research protocol was reviewed and approved by the Social/ Behavioral Science Institutional Review Board (IRB) of Case Western Reserve University (Case). The study recruited participants through purposive sampling and consisted of an in-depth interview with each participant.

Sixteen interviews were completed during the months from September 2008 to March 2010. Screening for the inclusion criteria was done during the initial phone call from interested individuals. If the potential participant agreed to be interviewed, she asked to have her therapist fill out a specific form which verified that this individual was, indeed, in treatment for BPD.

One of the sixteen individuals who was interviewed was excluded from the study because the interviewer suspected that she may not have met criteria for BPD.

The interviews were conducted using the McGill Illness Narrative Interview (MINI) (Groleau, Young & Kirmayer, 2006). The MINI was initially developed to explore individuals' illness experience in a community study. It consisted of 46 questions and usually took between one and two hours to conduct (Groleau, et al., 2006).

The guidelines set out by the developers of the MINI were carefully followed when the interviews for this study were conducted. In particular, the interviewer emphasized repeatedly that she was not interested in the treatment providers' perspectives, but in the participants' own perspectives. Due partly to the nature of the responses, which seemed to be quite open and candid, and due partly to subjective observations, the interviewer believed that, in general, the participants seemed to be quite relaxed and to experience some rapport with the interviewer. The participant's responses

provided rich data for the study. Many of them commented that they hoped that their contribution would help other people in treatment for BPD.

Thematic analysis consists of identifying themes within the content of what was said in the narratives and investigating how the themes are distributed among respondents. Riessman (2008) encourages the use of prior theory in order to help interpret the narratives. The Atlas.ti software was used to help with the thematic analysis. The prior theory incorporated into this analysis was primarily from the descriptions of individuals with BPD within the professional treatment literature.

Established qualitative methods were utilized for coding and analysis of the data.

1. ATLAS.ti software was utilized to organize and code the data.

2. A second coder was recruited to read the transcripts of nine of the total of sixteen interviews, and to help identify prominent codes and themes—as described above.

3. The newly-identified themes were compared with the themes identified in the literature review.

The participants' responses to the MINI questions were recorded on a digital voice recorder (DVR), transferred to a computer, then written onto a CD, then transcribed, and the resulting written narratives transferred to ATLAS.ti, a software specifically designed to conduct thematic coding and to manage qualitative data. The data was analyzed thematically; the analytic strategy adhered to Riessman's Thematic Analysis strategy, outlined in *Narrative Methods for the Human Sciences* (2008).

Each of the fifteen interviews was analyzed by the researcher line by line, to uncover concepts related to the three research questions, specifically: (1) What are the research participants' perceptions of self, being or personhood; (2) What are their personal narratives about causality?, and (3) What are their personal narratives about recovery?

This process, called "microanalysis" by Strauss and Corbin (1998), is crucial in order to "uncover new concepts and novel relationships and to systematically develop categories in terms of their properties and dimensions" (p. 711). The researcher first assigned in vivo codes, which closely followed the language of the research participants themselves. Next the *in vivo* codes were "dragged" onto a diagram using the Atlas.ti software. This enabled the researcher to look for relationships between the *in vivo* codes, and to assign conceptual codes that grouped several *in vivo* codes together.

The researcher worked extensively with the codes on each diagram (one diagram for each of the three research questions) to make sense of the data. The ATLAS.ti software makes it easy to find all the *in vivo* codes in their original context in the interviews. Sometimes a conceptual code was divided into subcategories. Sometimes,

after reading back over the *in vivo* codes in context, a conceptual code was changed, to better reflect the *in vivo* codes underneath it. Sometimes a conceptual code was deleted entirely, because it was deemed to be not truly supported by the data.

Results

The fifteen research participants (RPs) ranged in age from 23 to 55, for an average age of 37.6 years. All of the participants were, by research design, female. Ten of the RPs identified themselves as Caucasian (67%), four RPs identified themselves as Native American and Caucasian (27%), and one identified herself as African American and Caucasian (6.7%). See Figure 1, below. No participants identified themselves as Hispanic American, Asian American or "Other", which were all options provided on the Demographics Form.

Results indicated that the research participants identified with many of the diagnostic criteria for BPD described in the *Diagnostic and statistical manual of mental disorders,* 4th ed., Text revision (APA, 2000), as well as in other professional literature.

Part of their narrated experience that has been less emphasized by the BPD treatment literature, however, was their subjective experience of shame. Shame has been variously defined in professional literature as "a self-conscious emotion, similar to self-hate, involving a belief . . . that one's own person is immoral or disgusting" (Tangney & Dearing, 2002); and "a physical sensation that occurs when an individual has transgressed societal norms" (Crowe, 2004).

Many participants in this study made statements such as "people think I'm crazy" and "the hospital staff made me feel like I was real dirty", indicating the stigma they felt from other people. They also evidenced self-stigma, with statements such as "I feel like a failure", "I feel worthless", or even, "I hate myself", indicating that they had internalized an extremely negative view of themselves.
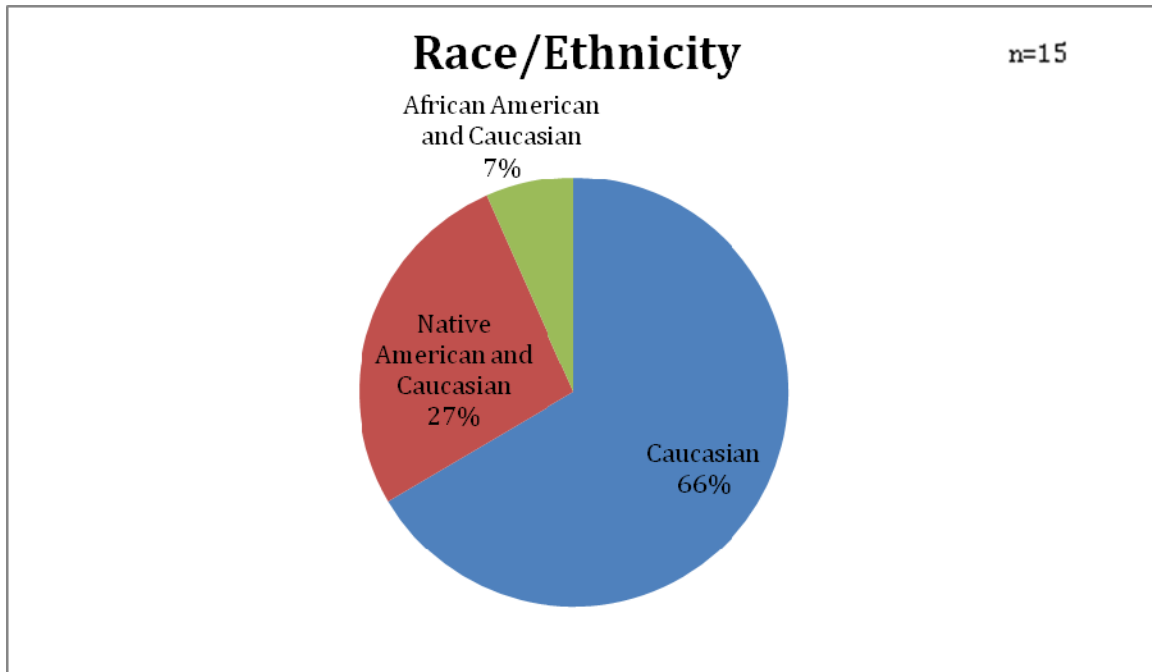
Figure 1: Race/ Ethnicity of Research Participants

The experience of shame often has destructive consequences including: a sense of isolation; inability to trust others; impulsivity; refusal to seek or follow through with treatment; self-mutilating behavior; and, most importantly, suicidal behavior (Crowe, 2004). Indeed, at least three studies have shown that a significant proportion of deliberate overdoses have occurred while the individual was experiencing shame-related thoughts and emotions (Hastings, Northman & Tangney, 2000; Lester, 1998; Brown et al., 2009).

Thus, the professional literature on stigma and shame has linked the following characteristics of shame to the experience of individuals with BPD: (1) expressions of anger, as a way to re-direct the feelings of shame out toward others; (2) feelings of self-hatred—because these individuals see themselves as immoral or disgusting; (3) self-harm behaviors, as a way to punish oneself for being "bad"; (4) suicidal ideation, because suicide would be a way to escape from the terrible feelings of shame, (5) feeling the need to hide from others, in order to conceal one's badness. All of these are clearly characteristics of individuals with BPD.

The research participants in the current study expressed shame in their responses—in ways that closely paralleled the definitions of shame in the stigma literature. See Table 1, below, for a summary of these parallels.

Utility for Social Work Practice

The professional literature has suggested a significant relationship between BPD and shame. Theory does suggest a correlation between the experience of shame and the symptoms of BPD (Crowe, 2004).

There is also some empirical evidence for the relationship between shame and BPD, as reported above. For example, three studies have found that current and future suicidal ideation is associated with shame (Hastings, Northman, & Tangney, 2000; Lester, 1998; Brown, et al., 2009). This finding is fairly robust and could confidently be related to the suicidal ideation of individuals with BPD.

However, more research is needed to understand the connections between shame and the other symptoms of BPD and to obtain more empirical support for what is so far mostly theory and anecdotal evidence.

Interventions must be developed to more directly address this experience of shame among individuals with BPD for at least five reasons, below.

1. Individuals who feel shame may be less likely to engage in treatment initially.

A major characteristic of shame is that it leads to a person's hiding their behaviors and thoughts from others. Thus, individuals who feel shame are less likely to enroll in treatment initially, and even once they have begun treatment, they are less likely to trust the treatment providers in order to create an effective working relationship.

2. Individuals may be less likely to complete treatment if their intense feelings of shame are not addressed.

BPD individuals who feel intense shame will need to feel a lifting of their shame in order to feel that the treatment is "working". Their intense feelings warrant attention in order to help these individuals feel that the treatment holds promise for them. Indeed, individuals with BPD are known to drop out of treatment before its completion; lack of attention to their intense negative feelings towards the self may be one reason.

3. Shame appears to be associated with higher risk for suicide.

A number of studies have linked suicidal behavior to feelings of shame; this suggests that shame must be addressed in order to decrease individuals' suicide risk. This association with suicidal behavior is probably the most important reason for why feelings of shame must be addressed.

4. Shame may also be associated with other BPD symptoms.

As described above, a number of authors have speculated that shame may also be associated with many BPD symptoms besides suicide attempts and self-harm behaviors. Alleviating the feelings of shame may be a key to treating many of the symptoms of BPD.

5. Research is needed on the effectiveness of interventions for alleviating feelings of shame.

Finally, the effectiveness of various interventions for alleviating shame must be tested. Strategies from adult attachment disorder could be studied for their effectiveness in treating shame (Gormley, 2005).

Also, large-scale, randomized studies could be done on the effectiveness of "opposite-action", a technique from Dialectical Behavior Therapy (Rizvi & Linehan, 2005) to see if it would, indeed, weaken the shame response, and strengthen more adaptable feelings and actions.

There are many other possible approaches for targeting the feelings of shame. Treatment providers could use insight therapies to help individuals recognize the impact of shame in their lives. Providers could help individuals recognize maladaptive methods of coping with shame, such as displacement of their anger onto others and self-harm behaviors.

Professionals could help individuals learn to substitute positive messages about self for the shame-filled messages they may often give themselves, as in cognitive therapy (Beck, 1996). Treatment providers could help individuals to become empowered and focus on seeking the most effective health care for themselves. Indeed, research suggests that some individuals, in response to stigma, become empowered, begin to help others in similar situations and even become powerful advocates for people with mental illness in general.

Conclusion

In conclusion, findings from this study are consistent with the claims of the stigma literature about the experience of shame in many individuals with BPD. Findings also support the association of shame with many of the symptoms of BPD from a theoretical perspective. Given the intensity of the feelings of shame experienced by these individuals, it is speculated that treatments that do not address these feelings will not be entirely effective. Much more research needs to be conducted this area, in order to further understand the experience of individuals with BPD; in order to find treatments to help alleviate their intense, maladaptive feelings of shame; and most importantly, to reduce the high suicide rate within this population.

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Table 1. Definitions of Shame
Compared with Quotations from Research Participants

*Definitions of Shame from Professional Literature	*Quotes from Research Participants (Interviewee Number)
Stigma referred to blemishes of character . . . usually inferred from a person's record and history . . . including a person's record of mental disorder (Goffman, 1963).	"People think we're crazy" (Int #2, 3, 8, 9, 10, 11, 12, 13) "People think we're not normal" (Int #2, 3, 4, 9)
Self-stigma often includes failing to pursue school, work and/or housing opportunities. . . . This kind of self-stereotype will significantly interfere with a person's life goals and quality of life (Corrigan & Kleinlein, 2005).	"It's sad because—look at me! Nobody in the world is going to want me" (Int #15). "I don't have a job because [my illness] interferes with everyday things. I need to be mentally stable before I can hold down a job" (Int #3). "I don't see a [future for myself]. I just live one day at a time. I try not to plan nothing . . . because if I do, it never goes through" (Int #8).
Feeling more isolated and less as though they belong with others (Crowe, 2004).	"People think we're dangerous" (Int #9, 13). "People don't like us" (Int #3, 11). "Some professionals don't want to work w/us" (Int #2). "People look at me like I'm at a distance, I'm detached" (Int #4). "Not very many people want to be a friend when They find out that I have that diagnosis" (Int #2).
Feeling devalued as a person (Tangney et al., 1996) Feeling one's sense of self worth fading. . . A sense of disgrace (Crowe, 2004).	"I feel like a failure; I feel like I'm worthless" (Int #2). "I hate myself" (Int #8). "I feel like I'm not going to get into heaven" (Int #12).

Table 1, cont.

*Definitions of Shame from Professional Literature	***Quotes from Research Participants (Interviewee Number)**
Belief that one's own person is immoral or disgusting (Tangney & Dearing, 2002).	The hospital staff "made me feel like I was real dirty" [because she had to be in treatment] (Int #11).
Suicidal behaviors & threats may occur because Suicide represents the "fantasized destruction" of the person's self image (Crowe, 2004). Three studies have found that current & future suicidal ideation is associated with shame (Hastings, Northman & Tangney, 2000; Lester, 1998; Brown et al., 2009).	"I want to get out of here [to die]. It's very hard to hate yourself so much. . . " (Int #15). "I'm at very high risk for self harm" (Int #2) "I just started getting feelings of wanting to kill myself" (Int #4).
When an individual's feeling of being immoral becomes too strong, the self-hatred can lead to self-punishment, in the form of self-inflicted injury (Brown et al., 2002).	"I have self-mutilated" (Int #4, 9, 10, 16) "I used to self-mutilate. I have scars on my arm" (Int #10).

*Quotes from both the professional literature and from the research participants were edited slightly for brevity.

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