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Treatment Experiences of Women with Borderline Personality Disorder

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2009

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A thesis submitted to the Faculty of the
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Abstract

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By Jesse P. Zatloff

Borderline personality disorder (BPD) is a psychiatric illness characterized by emotional lability, behavioral dysregulation, and interpersonal instabilities. Major depression, anxiety disorders, eating disorders, substance abuse disorders, and other psychiatric conditions are common comorbidities. Up to 9% of people diagnosed with BPD commit suicide, with 69-80% engaging in suicidal behaviors (Linehan et al., 2006). Developed in the late 1980s by Marsha Linehan, dialectical behavior therapy (DBT) is a psychotherapy that has been shown to be an effective therapeutic intervention for BPD and suicidal behavior. A form of cognitive behavior therapy (CBT), DBT applies acceptance- based validation strategies to the practice of CBT through the framework of dialectics. This project was a qualitative investigation which aimed to assess common experiences of women with BPD enrolled in DBT treatment. Nine in-depth, semi-structured interviews were conducted with women enrolled in DBT programs in Atlanta, GA and surrounding areas. Topics discussed included treatment histories, experiences with the BPD diagnosis, and engagement in DBT. Interviews were recorded, transcribed, coded, and analyzed for common emerging themes. Findings indicated BPD was a stigmatized diagnosis among the women interviewed but, through various strategies, this stigma was managed. Additionally, DBT was experienced as an effective and superior form of treatment for BPD for reasons including its tangible nature and inherent structure. These key aspects of DBT's benefit can inform the development of future treatment interventions for the disorder.

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CHAPTER ONE: INTRODUCTION

Introduction. Borderline personality disorder (BPD) is defined as a "pervasive pattern of instability of interpersonal relationships, self-image, affects and marked impulsivity…" (Chapman, Specht, & Cellucci, 2005). This psychiatric illness is characterized by strong emotional lability, behavioral dysregulation and interpersonal instabilities (Baer, Peters, Eisenlohr-Moul, Geiger, & Sauer, 2012). BPD is often comorbid with various psychiatric conditions including major depression, bipolar disorder, anxiety disorders, eating disorders and attention-deficit hyperactivity disorder (ADHD) (Goodwin, Brook, & Cohen, 2005; Kasen, Cohen, Skodol, Johnson, & Brook, 1999; Lenzenweger, Lane, Loranger, & Kessler, 2007; Matthies & Philipsen, 2016; Reich et al., 1994, 1994; Zimmerman & Mattia, 1999). While BPD's etiology is not known, it is thought to be a disorder that develops during adolescence or early adulthood, the result of interactions between biological and environmental factors (Lieb, Zanarini, Schmahl, Linehan, & Bohus, 2004; Nehls, 1998; Skodol et al., 2002).

BPD. Few studies have looked at the prevalence of BPD specifically and its demographic correlates. One study put the prevalence at 1.4-1.6% (Lenzenweger et al., 2007), another at 1-2% (Lieb et al., 2004), and in a large-scale epidemiological study, at 5.9% (Grant et al., 2008). Up to 10% of people diagnosed with BPD commit suicide, a rate almost 50 times higher than the general population, with 69-80% of people with BPD engaging in suicidal behaviors (Lieb et al., 2004; Linehan et al., 2006). BPD patients represent approximately 10% of psychiatric outpatients and

20% of psychiatric inpatients, utilizing both psychiatric services (Swartz, Blazer, George, & Winfield, 1990; Torgersen, Kringlen, & Cramer, 2001; Widiger & Weissman, 1991) and medical services more often than people with other psychiatric conditions (Sansone, Farukhi, & Wiederman, 2011). According to a 2006 study, 72% of patients with a BPD diagnosis have had at least one psychiatric hospitalization and a mean of 6.1 past therapists (Linehan et al., 2006).

The demographic data for BPD are lacking. According to the National Institute of Mental Health's (NIMH) website, sex and race categories are not found to be significantly associated with personality disorders in general ("NIMH Borderline Personality Disorder," n.d.). One study of personality disorders found that young men with little education were at the highest risk of Cluster B personality disorders, such as BPD (American Psychiatric Association, 2000), while other studies, both of personality disorders generally and BPD specifically, have found higher rates in men than women and an inverse relationship with age and economic brackets (Grant et al., 2008; Samuels et al., 2002; Torgersen et al., 2001). Despite these findings, BPD diagnoses are far more common in women than in men (Becker & Lamb, 1994; Nehls, 1998). Though particular comorbidities are more common in women than in men, such as eating disorders, and while men have been found to display anti-social and anger management issues more acutely than women, overall rates of BPD have not been found to differ significantly by sex (Zlotnick, Rothschild, & Zimmerman, 2002).

BPD is an illness that is stigmatized by both healthcare providers and society.

this stigmatization has a large influence on both treatment for the disorder and the experience of living with and being treated for BPD (Fraser & Gallop, 1993; Gallop, Lancee, & Shugar, 1993; Nehls, 1998). In addition to being thought of as "hard-to-treat" and intractable, those with BPD are often labeled as problematic patients, often identified as "manipulative," "angry," "difficult," and/or "noncompliant" (Book, Sadavoy, & Silver, 1978; Everett & Nelson, 1992; Gallop et al., 1993; Lewis & Appleby, 1988; Nehls, 1998). These disparaging stereotypes have negatively influenced the treatment received by BPD patients in mental health treatment settings (Gallop, Lancee, & Garfinkel, 1989; Gallop et al., 1993; Lewis & Appleby, 1988) and often lead to a stigmatized sense of self-identity (Nehls, 1998).

DBT. The intense emotional lability at the core of BPD can lead to challenging therapist-patient relationships, often resulting in therapist burnout, high patient dropout rates, and treatment noncompliance (Linehan, 1993; Linehan et al., 1999). Developed in the late 1980's by psychologist Marsha Linehan, DBT is a skills-based approach to treating psychiatric illness that blends key concepts from cognitive behavioral therapy (CBT) with Zen Buddhism (1993).

First developed for use with chronically suicidal patient populations and then expanded to those who met criteria for BPD, DBT has been the most commonly studied form of therapy for the treatment of BPD and has been shown to be an effective intervention (Kliem, Kröger, & Kosfelder, 2010; Lieb et al., 2004; Oldham, 2006). DBT is a year-long treatment modality that has four main defining elements—1) individual psychotherapy, 2) a skills training class, 3) the option of

phone coaching with a therapist, and 4) consultation team meetings for providers (Linehan, 1993). This team-based, manualized treatment approach has been shown to be effective, though little recent research has been done on patient experiences with BPD and DBT, particularly as compared with other therapies.

Theoretical Framework. Behavioral theory, or behaviorism, was first described by John B. Watson in 1924, when he suggested that behaviorism and behavioral intervention should focus on observable behavioral phenomena and not on consciousness (Watson, 1930). Behavioral theory continued to develop through the work of various theorists, and new concepts were added, including an emphasis on cognition (Skinner, 1953) and social learning, or "modeling" (Bandura, 1974). Cognitive behavioral theory broadly posits that behavior is learned through the interaction between external and internal stimuli; within this theory external stimuli are the environment and internal stimuli are cognitions (Gonzalez & Wekerle, 2016). This focus on cognition was a departure from more classic theories of behaviorism (Gonzalez & Wekerle, 2016). CBT, considered to be the second wave of behavioral therapies, was developed in the 1970's by Aaron Beck, which shifted both behavioral intervention and theory (Öst, 2008). Cognitive behavioral theory looks at the ways that negative cognitions and distorted thinking lead to maladaptive behavior and negative affective states (Gonzalez & Wekerle, 2016). Within this framework, behavioral dysfunction results from cognitive dysfunction.

Assessing the ways in which people's behavioral and affective dysfunctions responded to DBT was a primary goal of this project. Cognitive behavioral theory is

useful in understanding how people both respond to a diagnosis such as BPD and their subjective experience of living with that label. Additionally, this framework guided the investigation of the question of how people experience DBT, a therapeutic intervention coming out of the third wave of behavior therapy.

Study Justification. This project was designed to better understand the treatment experiences of patients with BPD who were currently engaged in DBT treatment. It explored patients' experiences of treatment with DBT and how it differed from other treatment experiences in an effort to identify potential mechanisms of change. As previously noted, BPD patients are heavy utilizers of mental health and medical services, often requiring multiple hospitalizations and long-term outpatient treatment regimens. The results of this study may help better direct individuals with BPD toward appropriate treatment and its effective elements, potentially saving large amounts of time, money, and distress.

Research Questions. The two questions that guided this project were:

1) What are typical experiences of patients diagnosed with BPD in outpatient treatment settings?

2) How is DBT experienced compared to other forms of treatment?

CHAPTER TWO: LITERATURE REVIEW

BPD. According to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) (World Health Organziation, 1992), BPD is marked by an instability in mood and emotion regulation characterized by a lack of sense-of-self, behavioral impulsivity, unstable interpersonal relationships and a proclivity toward acts of self-injury and suicidality (World Health Organziation, 1992). BPD is typically experienced as a chronic illness and is difficult to treat. Patients with BPD often experience severe fluctuation in mood and affect and are prone to irritability, intense anger, acts of self-harm, low self-image, and frequent crises (Barnicot et al., 2012). The DSM-IV defines BPD as a "pervasive pattern of instability of interpersonal relationships, self-image and affects and marked impulsivity, beginning in 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

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

5) Recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior

6) Affective instability due to a marked reactivity of mood

7) Chronic feelings of emptiness

8) Inappropriate, intense anger or difficulty controlling anger

9) Transient, stress-related paranoid ideation or severed dissociative symptoms"

(American Psychiatric Association, 2000, p.704)

The term "borderline personality disorder" was conceived of by Adolf Stern in 1938 to describe patients thought to have a mild form of schizophrenia; these patients' personality pathologies were believed to be a result of existing on the "border" of neurosis and psychosis (Linehan, 1993; Stern, 1938). Though this theory has long been considered inaccurate, the term is still used by clinicians. While the validity of a BPD diagnosis in adolescents is debated, symptoms of the disorder often present in early-late adolescence or early adulthood (American Psychiatric Association, 2000; Becker, Grilo, Edell, & McGlashan, 2000).

Though the etiology of BPD is unknown, the biosocial theory of BPD has been important in guiding the development of therapeutic treatment strategies along with delineations of the presentation and course of the disorder (Crowell, Beauchaine, & Linehan, 2009; Linehan, 1993). The biosocial theory characterizes BPD as a disorder of emotion dysregulation that results from repeated interactions of biologically vulnerable individuals and an invalidating environment (Chapman, Specht, & Cellucci, 2005; Crowell et al., 2009; Linehan, 1993; Lynch, Chapman, Rosenthal, Kuo, & Linehan, 2006). Within this framework, "vulnerabilities" refer to a predisposition to high and quick emotional reactivity with a relatively slow return to baseline emotional functioning, while an invalidating environment refers to one in which "communication of private experiences is met by erratic, inappropriate and extreme responses" (Crowell et al., 2009; Linehan, 1993, p. 49; Lynch et al., 2006).

Though not always, BPD is often found in individuals who have experienced some type of trauma; one study found that 91% of participants with BPD had been abused and 92% had been neglected (Zanarini et al., 1997), while another study found that patients with BPD were twice as likely to develop posttraumatic stress disorder (PTSD) as compared to a control group (Golier et al., 2003).

Cognitive theorists of personality disorders have characterized BPD traits as products of cognitive schemas that lead to bias in the evaluation and interpretation of environmental stimuli (Barnicot et al., 2012; Beck, Davis, & Freeman, 2015). Studies utilizing this framework have found that individuals with BPD are negatively biased when interpreting interpersonal interactions, leading to increased perceptions of aggression and anger (Arntz, Dreessen, Schouten, & Weertman, 2004; Arntz & Veen, 2001; Barnow et al., 2009), while others have found that those with BPD interpret neutral or ambiguous facial expressions as negatively intended (Mitchell, Dickens, & Picchioni, 2014). Two studies, one conducted in 1997 and another in 1999, found that female patients with BPD had a general deficit when reading facial expressions, particularly when labeling angry, fearful or disgusted expressions (Bland, Williams, Scharer, & Manning, 2004; Levine, Marziali, & Hood, 1997). Cognitive theories posit that certain cognitive schemas lead to particularly negative modes of interpretation and thus heightened negative emotional reactivity within the social context.

Treatment of BPD. People with BPD have been called the psychological equivalents of third-degree burn patients, lacking emotional skin and therefore experiencing life

and treatment in extreme pain (Linehan, 1993). Self-injurious behaviors and suicidality are thought to be behavioral mal-adaptations to this pain, but are often perceived by others, including mental health workers, as acts of manipulation and attention seeking (Fallon, 2003; Gallop, Lancee, & Garfinkel, 1989; Linehan, 1993). There are multiple BPD traits that lead to the labelling of BPD patients as particularly challenging and hard to treat. One common behavioral trait of BPD is "splitting," or adopting a black-and-white, all-or-nothing interpretation of the world and other people. This inclination toward dichotomous thinking often directs patients toward seeing the world and its actors in extremes, while vacillating between identifying others as either all good or all bad (Fallon, 2003; Lynch et al., 2006). This tendency to idealize and then abruptly devalue another individual within a short period of time results in high therapy dropout rates after the devaluation of a therapist and turbulent, inconsistent relationships; these interpersonal challenges lead to general feelings of conflict and, often, animosity toward individuals with BPD (Levine et al., 1997; Linehan, 1993).

BPD is often thought of as a "tough-to-treat" disorder, and the treatment of individuals with BPD often causes great amounts of stress and conflict for both patients and professionals. Typical behaviors, such as self-harming, a tendency toward suicidal ideation, emotional instability and behavioral impulsivity have led to the disorder being highly stigmatized among mental healthcare providers; BPD patients are often thought of as non-responsive, manipulative and feigning illness (Chalker et al., 2015; Linehan, 1993; Verheul et al., 2003). The stigma attached to the diagnosis can lead to negative interactions between patients and mental healthcare

professionals that often further exacerbate symptoms and prevent individuals from seeking out and continuing with treatment (Aviram, Brodsky, & Stanley, 2006; Dickens, Hallett, & Lamont, 2016). Among psychiatric nursing staff and psychiatrists it has been found that there is a greater desire for social distance and less optimism towards patients with a BPD diagnosis as opposed to depression (Hinshelwood, 1999; Markham, 2003). This lack of optimism, or what has been referred to as "therapeutic pessimism" (King, 2014), often leads to a relationship that is exceptionally taxing for providers and exacerbates symptoms for BPD patients (Aviram et al., 2006).

Studies have looked at a variety of different psychotherapeutic approaches to the treatment of BPD. Coming out of the second wave of behavior therapy, CBT is a treatment that aims to change maladaptive or problematic cognitive schemas and behavioral patterns through a systematized and action-oriented therapeutic process (Beck, 1993; Hayes, 2004; Öst, 2008). In one study, treatment as usual (TAU) was compared to TAU combined with CBT in 106 patients with BPD over the course of 12 months; this study found that the combination was effective in reducing suicidal acts, dysfunctional beliefs, anxiety, and distress over psychiatric symptoms, though longer-term follow-up still indicated high levels of dysfunction (Davidson et al., 2006). Another study found that CBT reduced suicidal ideation, hopelessness, depression and dysfunctional beliefs (Brown, Newman, Charlesworth, Crits-Christoph, & Beck, 2004).

Other forms of treatment have been studied with BPD patient populations. A study looking at transference-focused psychotherapy saw promising results, with a

significant reduction in the number of patients who had made a suicide attempt during the year of treatment, though the improvement in the overall number of suicide attempts and the medical risk of these acts was insignificant (Clarkin et al., 2001). A multi-wave study conducted in 2007 compared three different forms of therapy and found that a 1-year course of DBT, transference-focused psychotherapy, or supportive treatment were overall effective treatment options for BPD (Clarkin, Levy, Lenzenweger, & Kernberg, 2007). The study found that, while transference-focused psychotherapy resulted in the greatest improvement, all three manualized, outpatient treatment options were successful in reducing problematic behaviors and affective domains (Clarkin et al., 2007).

DBT. The first DBT manual was published in 1993 by its developer, Marsha Linehan (Linehan, 1993). The manual states that a successful and comprehensive psychotherapy treatment would need to meet the following five functions:

1) Enhance and maintain the client's motivation to change

2) Enhance the client's capabilities

3) Ensure the client's new capabilities are generalized to all relevant environments

4) Enhance the therapist's motivation to treat clients while also enhancing the therapist's capabilities

5) Structure the environment so that the treatment can take place (Linehan, 1993)

Using standard CBT as a foundation, DBT applies acceptance-based validation strategies to the practice of CBT. CBT is a behavioral therapy based on the belief that harmful behaviors and thought distortions play a key role in the development and reproduction of an emotional disorder (Brewin, 1996). CBT works by teaching and integrating new cognitive schemas and healthy coping mechanisms into patients' lives and thought processes (Brewin, 1996). Though originally studied for the treatment of unipolar depression, CBT has also been applied to personality disorders (Beck & Freeman, 1990; Young, 1994), with a CBT manual being developed in 1993 specifically for patients with BPD (Layden, Newman, Freeman, & Morse, 1993). CBT generally consists of weekly individual therapy sessions where behavioral goals are set between patient and therapist and the therapist assists the patient in altering maladaptive thought processes and beliefs (Brown et al., 2004). DBT comes out of the tradition of cognitive and behavioral therapies and is considered part of the third wave of behavioral therapies (Öst, 2008). Similar to CBT, DBT is a goal-oriented and problem-solving-focused form of therapy that emphasizes behavioral modification through teaching individual life skills to regulate emotions and cognitions (Linehan, 1993).

Of primary importance in CBT is change, both behavioral and cognitive. In contrast, through the conceptual framework of dialectics, DBT focuses on the relationship and interdependence of both change and validation, or acceptance (Brown et al., 2004; Lynch et al., 2006). Often associated with Marxist and/or Hegelian philosophies, dialectics refer to the ways the tension between two opposing, polar forces produces reality, or some kind of new truth, often

conceptualized through the triad model of thesis, antithesis, and synthesis (Chapman & Linehan, 2006; Linehan, 1993). Because BPD patients are so often products of invalidating environments, the constant emphasis on change found in CBT often proved challenging or invalidating and led to feelings of rejection and high therapy dropout (Chapman & Linehan, 2006). DBT treatment combines the goal of behavior change (thesis) with the practice of acceptance (antithesis) (Lynch et al., 2006). The DBT treatment protocol consists of four main components: 1) weekly hour-long individual therapy sessions, 2) weekly skills training class, 3) phone coaching and 4) weekly group consultation meetings for therapists and skills class leaders (Chapman, 2006; Linehan, 1993).

DBT therapists work in treatment teams, where ideas and strategies are exchanged and team members can provide both emotional and professional support for one another while enhancing each other's treatment capabilities (Kliem, Kröger, & Kosfelder, 2010). Skills training is broken into four different modules: 1) mindfulness, 2) distress tolerance, 3) interpersonal effectiveness, and 4) emotion regulation, which together last approximately six months (Linehan, 1993). DBT is typically a year-long treatment where patients participate in each module twice. Because patients with BPD have multiple problems and are often being treated for various symptoms and comorbid conditions, DBT utilizes a hierarchy of treatment targets to structure the course and focus of individual therapy sessions: 1) life-threatening behaviors (e.g., suicidal gestures and/or acts of self-harm), 2) therapy interfering behaviors (e.g., cancelling appointments and/or disengaging during sessions), 3) quality of life behaviors (e.g., relationship or financial problems) and 4)

skills acquisition (e.g., replacing maladaptive behaviors with new, learned life skills) (Linehan, 1993). Depending on the week or session, different targets are addressed with an appropriate order of urgency and importance. As described above, comprehensive DBT treatment is devised of five main functions: 1) enhance behavioral capabilities, 2) improve motivation to change, 3) generalize new skills and capabilities to the specific environment(s), 4) appropriate structuring of the treatment environment to the therapist's and patient's capabilities, and 5) enhance therapists' capabilities and motivation to treat effectively (Dimeff & Linehan, 2001).

DBT & BPD. DBT has been the most commonly and systematically researched treatment intervention for BPD, and various randomized, controlled trials (RCT) have shown DBT to be effective (Feigenbaum et al., 2012; Harned, Jackson, Comtois, & Linehan, 2010; Koons et al., 2001; Linehan et al., 1999, 2002, 2006; Linehan, Armstrong, Suarez, Allmon, & Heard, 1991; Linehan, Heard, & Armstrong, 1993; Linehan, McDavid, Brown, Sayrs, & Gallop, 2008; Neacsiu, Rizvi, & Linehan, 2010; van den Bosch, Verheul, Schippers, & van den Brink, 2002; van den Bosch, Koeter, Stijnen, Verheul, & van den Brink, 2005; Verheul et al., 2003). In the first RCT, conducted in 1991, DBT was compared to TAU and resulted in a significant reduction in parasuicidal behavior and medical severity, better patient retention and fewer days of inpatient hospitalization as compared to participants randomized to TAU (Linehan et al., 1991). In 1994, a 1-year follow up of the second cohort in the previous study was conducted, finding that both general and interpersonal adjustment based on Global Assessment Scale scores was greater in those who

received DBT treatment as compared to those who received TAU (Linehan et al., 1993). Other RCTs have found DBT to be effective in reducing suicidal ideation and parasuicidal gestures (Koons et al., 2001) and have even suggested that treatments other than DBT that are not primarily focused on and developed for BPD have the potential for a deteriorating effect (Verheul et al., 2003).

DBT has been shown to be effective for the treatment of BPD in various settings with multiple groups of people, including women veterans (Koons et al., 2001), inpatients (Bloom, Woodward, Susmaras, & Pantalone, 2012) and patients with substance abuse disorders (SADs) (van den Bosch et al., 2002). In a review of studies of the implementation of DBT for individuals with BPD in inpatient settings, improvement was found across multiple domains of functioning, including symptoms of anxiety and depression, violent behavior, suicidal ideation, dissociative experiences, and interpersonal problems (Bloom et al., 2012). Another review found that inpatient DBT programs in the US and in Germany were effective in reducing parasuicide and produced significant improvements in global psychopathology ratings (Robins & Chapman, 2004). Two studies, one a review and one an RCT, looked at DBT treatment with BPD patients with comorbid substance use disorders and found mixed results (Robins & Chapman, 2004; van den Bosch et al., 2002). Both generally found that DBT was an efficacious treatment for SUDs comorbid with BPD, but that the treatment was no more effective than treatments used in control groups. One study recommended that substance use be integrated as a treatment target, directly next to or below suicidal and self-damaging behaviors (van den Bosch et al., 2002). These studies indicate that DBT is an effective treatment option

in multiple settings and with multiple BPD populations, and that the treatment can

be adapted successfully to better target different demographics.

CHAPTER THREE: METHODOLOGY

Design. This research project was a qualitative investigation into the treatment experiences of females with BPD. Information was gathered using semi-structured, in-depth interviews. The study received approval from the Emory Institutional Review Board (IRB).

Participants. Participant recruitment was done by contacting DBT-adherent therapists and mental health treatment programs in the Atlanta Metropolitan Area ("Dialectical Behavior Therapy (DBT) Groups," 2011). Therapists and programs were identified as DBT-adherent via a list of DBT-adherent therapists found on the internet. An e-mail was sent out asking either for permission to come to a skills class and personally recruit or for the therapists to collect contact information from patients for the principal investigator (PI) to contact directly.

In total, nine women participated in this study. All patients gave their therapists expressed permission to give the PI their phone numbers and/or email addresses. Three therapists who were contacted gave permission to enter their skills classes to personally recruit, at which point patients' contact information was collected. All efforts were made to ensure that therapists were unaware of who ultimately participated in the study.

In order to participate, participants had to meet the following criteria: 1) currently enrolled in a module of a DBT skills class, 2) currently under the care of a DBT-adherent therapist, in compliance with the DBT treatment protocol (Linehan,

1993), and 3) self-reported having received a diagnosis of BPD. In addition to these criteria, all participants had to be women of or over the age of eighteen and able to consent and be interviewed in English.

Measures. The interview guide was developed by the PI and approved by the thesis chair (see appendix A). Participants were asked questions related to their previous and current diagnoses, their feelings about and reactions to these diagnoses and their experiences with past and current mental health treatments. Sample questions from the interview guide include: "how helpful and/or effective were past treatment experiences" and "if you were to make recommendations to mental healthcare professionals regarding the treatment of BPD, what would they be?"

Study Procedures. Interviews were scheduled through phone contact or an e-mail exchange between participants and the PI based on a mutually convenient time. Nine interviews in total were conducted.

Interviews took place wherever participants expressed feeling comfortable. Settings included participants' homes, coffee shops or at a local public hospital. Interviews began with a brief description of the project and how the data would be used, including how and when the recording would be deleted. The consent form (see appendix B) was then given to the participant and key points such as confidentiality and PI and Emory IRB contact information was pointed out. Time was given for participants to ask any questions or express any concerns, and once the participant was finished reading the form and asking any questions, the form

was signed by both the participant and the PI.

All interviews were conducted by the PI. The option of a female interviewer was available and offered to each participant, in case being interviewed by a male made them uncomfortable. None of the nine participants chose this option. The interviews lasted between 30-45 minutes and were audio-recorded with the permission of the participant. Participants were given a $20.00 gift card for their time.

Confidentiality. Protected health information (PHI) collected included mental health diagnoses and treatment engagement. A variety of measures were taken to ensure complete confidentiality of both PHI and any other identifying information. All audio files and transcriptions were stored in a password-protected folder on a password-protected laptop, and all signed consent forms were locked in a secured drawer. At all times, either pseudonyms were used or names erased on any written or typed documents to prevent the tracing of identifying information. All recordings were destroyed after transcription.

Data Analysis. Audio recordings were transcribed verbatim by the PI and two transcribers, both of whom were first approved by Emory's IRB. Names and other identifying information were omitted or disguised during the transcription process. © MAXQDA12 software was used to analyze the data using thematic analysis. Once transcripts were uploaded to the software, the transcripts were reviewed and memos were inserted to mark places of importance or interest. After the initial

read-through, a code book was developed encompassing emergent or repeated themes and ideas in relation to the existing literature. The transcripts were then coded by the PI using the developed codebook. Throughout the coding process, the codebook was revised and transcripts re-coded to account for the emergence of new themes and ideas related to the research questions. Once coding was complete, the main themes were organized to answer each of the research questions.

Research Question 1: What are typical experiences of women diagnosed with BPD in outpatient treatment settings?

Treatment Histories. A central goal of this research was to gain a better understanding of the lived experiences of women with BPD. While restricted in scope, there were common themes and patterns that emerged from the interviews, many of which were consistent with the literature. Five out of the nine women interviewed reported having experienced some form of abuse, neglect and/or trauma in the earlier parts of their lives. Participants discussed experiences including childhood molestation, physical and emotional abuse by alcoholic parents, rape, domestic abuse as adults, and kidnapping. Though no specific questions were asked related to the abuse or neglect, during five out of the nine interviews these types of stories were spontaneously shared:

> So, it was from, um, childhood, from my father being an alcoholic, and then my brother molested me, and then rapes and having to, running away from home. And then the huge one was being kidnapped... (Participant #9)

> I had all these, like, I was molested as a child, so it's like I have all these dark secrets that I felt like I couldn't tell anybody and they were eating me up, making me feel really terrible about myself. (Participant #8)

Consistent with the literature (e.g., Chapman, Specht, & Cellucci, 2005; Lieb, Zanarini, Schmahl, Linehan, & Bohus, 2004), all of the women interviewed had long

and varied histories of symptoms including depression, anxiety, anti-social

behavior, self-harm and substance abuse:

> Um, the symptoms leading up to it? I was severely depressed. Um, like, it got to a point I didn't want to get out of bed. Um, I would just, like, I didn't want to go to work, I didn't want to do anything except hanging out with all my friends. Um, I had a lot of negative self-talk, beating myself up constantly. And, um, on-and-off suicidal tendencies throughout the years for a long time. So, that was mainly, it was, my life had just got to a point where I couldn't really, like, I felt like I wasn't functioning in life. And I knew I needed to do something. It had gotten to a point where it was just outta control, so. I was doing a lot of drinking and stuff, too. (Participant #5)

> And also drug use. Um, you know, at that point it was, like, pot and pills. Um, you could still get, what do you call them? Um, they were made by [inaudible], it starts with an 's,' I can't remember what they're called. Um, the most recent, when I was forty-years-old, I tried heroin, and I'd never tried it before because I knew I'd like it too much. It's exactly what happened. I became a junkie. And so that lasted about, maybe three years or so, and I had, I was being hospitalized during that period. I don't remember ever detoxing because I was in the hospitals when it happened. Um, and I would detox and go back to it, and that was during the period that I was also, you know, there was a couple years of being a junkie and then starting to go back-and-forth between the different hospitals and stuff. So, um, I don't remember detoxing at all. (Participant #3)

> I have bad anxiety. Um, sometimes it's worse than others. I really, I don't like big crowds of people. Um, I remember times that my anxiety has been so bad, like, I would go into the grocery store and couldn't even concentrate and would have to just leave…My anxiety has been so bad, like, I just couldn't concentrate at all. (Participant #6)

In addition to these symptoms, four participants described behaviors that could be

defined as attention-seeking, manipulative and/or passive-aggressive. As one

woman put it:

> Because, I get, it seems to fit, right? Like, the whole idea that the world needs to revolve around me kind of. And I need to make

everybody do what I want them to do and, um, pitching a fit if I don't get my way and, woe-is-me type of behavior as well, and um, yeah. I don't know. It's just, I remember reading the, the DSM, it was 4, criteria. For once I was like, 'oh yep, yep, yep...' (Participant #2)

In the words of another:

I misinterpret things. And get in trouble over it. Like, I used to get really angry and bitter at people because I'd hear – I was paranoid –and I'd be mean and very passive-aggressive... (Participant #4)

Along with their past symptoms, participants brought up suicidality. Suicide attempts, often resulting in bodily injury and hospitalization, were reported by four out of the nine women as a major aspect of their history with BPD. The methods of suicide attempts included overdosing on pills, attempting electrocution, and severe self-mutilating behavior. One participant described her drug addiction as a form of suicide and included it in her history of attempts:

But again, I was 40 years old, I walked into it with my eyes wide open. So, um, at this point, at that point, I said, 'no, no, the drugs have nothing to do with my depression.' Um, it was, I look at it now and see that it was slow suicide. Um, I've made many suicide attempts. Um, some of them were very serious. Um, and fortunately I never completed. I don't like it when they say succeed. Nobody succeeds when you commit suicide. You either complete it or you don't. (Participant #3)

Another participant discussed her suicidality as a major reason for her first hospitalization:

So, uh, and then hospitalized, on all different kinds of medications. So, the fear, the greatest fear was that I was very suicidal, these thoughts, and the triggers. I don't know if that makes sense but that's pretty much. So, I have to constantly stay in therapy, any kind of counseling. (Participant #8)

Consistent with the literature (e.g., Linehan et al., 2006), psychiatric

hospitalizations had played a part in the lives of most of the women interviewed.

For two of the women interviewed, their hospitalizations were where they first

learned about DBT and had their BPD diagnosis conferred. Most of the women

interviewed who had been hospitalized were admitted due to a suicide attempt, a

suicide threat, or because of other acts of self-harm. The experiences they expressed

regarding time on inpatient units of psychiatric hospitals were mixed. While there

were participants who described their hospitalization as being a positive step,

others had more negative or ineffective experiences. One participant had a

particularly negative experience in a hospital setting, where she was forcibly

medicated and physically abused. Some felt that their hospitalization had afforded

them a needed respite from the world and had provided them with a safe space and

an insular environment. As one woman put it:

> And I did. I went to the hospital for about two months and it was a
> safe place. I just really needed a break from everything. I just
> needed a break from stress and worrying about, you know,
> everything. So, it really helped in a way. But it didn't really help
> psychologically because, like I said, they didn't really address the
> issues that I was having, probably because they didn't really know
> what was going on besides that I was depressed. (Participant #8)

Another woman described her experience as follows:

> Yeah, the, um, the first time I went I felt pretty good about it. Like, it
> was the first one. That was the time that they were all kind of like,
> 'you know, we really think you need to get some DBT help' and
> whatever. Um, and they just seemed really knowledgeable and kind
> and caring and it was, I don't know, it was just, it was a good
> environment. I felt safe in there. Um, and by the time, I think they
> kept me like four or five days. When they let me out I felt like, I was

scared but I felt like I was okay to leave. (Participant # 5)

While there were some positive experiences of hospitalization, other women described their time in the hospital as an unproductive and ineffective use of time. When asked about her time in a hospital after a suicide attempt, one participant expressed feelings of not fitting in:

> It was horrible. It was just for the quick… I mean it was like a two-week-stay place…yeah, and, um, I didn't fit in. I find often where I am I don't fit in. It's hard for me to connect with someone. (Participant #4)

Another participant, also describing her experience in the hospital as "horrible," said the following:

> Because I just, like, I was still in that, like, 'woe is me, everybody is out to get me, I hate everybody, I'm not cooperating with this,' being impetulent about that whole thing. So, making me stay there and making me wear socks, like, I was walking around barefoot and they were like, 'you have to put socks on!' Stupid! So, [that] was not productive. Like, that did not help me. The only thing I got from that was a sort of wake-up call, like, 'oh, I need to be serious and do something different with my life.' Trick is, it took four more years for me to figure out the right 'different,' so. (Participant #2)

All but one of the participants in this study had long and varied outpatient treatment histories. The types of treatment included different forms of psychotherapy, psychiatric medication management, partial hospitalization programs (PHP), electroconvulsive therapy (ECT) and inpatient hospitalizations. Some patients also had been in DBT prior to the treatment they were taking part in at the time of the interview. While specific forms of psychotherapy were mentioned by two participants, the rest of the participants were not aware of the exact forms of

psychotherapy they had received in the past. Psychotherapy in which they engaged prior to DBT was often described as or identified in vague terms such as "talk therapy" or simply "therapy," without a cohesive description of what that meant. When asked what specific form of therapy they were referring to, most were unable to identify it. A common feature among all the participants was that past therapies described as "talk therapy" or simply "therapy" were experienced as ineffective. One participant described "talk therapy" as follows:

> So, just general, like, I would go in and talk. And not get homework, not get structure, not get, you know, 'this is a conversation you should go have with your husband,' or, 'we need to talk to him about this.' It was literally just me, just venting and talking to a listening ear that could sometimes help guide me to a little bit more insight. But almost always, and I think because I'm, was, a raging borderline, I could recruit people to my side and then just sit there and bash on [husband's name] for an hour and pay for it. So, that's also what it was. Quite ineffective. (Participant #2)

Another participant had the following to say:

> ...when I look back at talk therapy and drugs, I tend to have, I'm where I have a pretty negative bias against it. You know, if I'm to be really blunt with you, I think talk therapy is a waste...was a waste of time for me, 'cause I feel like for me to have ever had the talk therapy work with me I still had to be in touch with my emotions and still not be invalidating myself all the time. When you're validating yourself all the time and there is somebody validating you, you're so invalidating that whenever they say something validating to you, you can't really let it sink in and I don't think talk therapy helps. There was always the thought in the back of my mind, 'you don't really know me and I don't know if you can keep up with my thoughts, and I don't know if you're intelligent enough to follow the metacongnitivness of my thoughts.' (Participant #1)

Another participant, when probed for a more detailed account of past therapies she had engaged in, responded in the following manner:

> Um, well, I mean, usually just, um, medication and therapy. The therapist that I think I went to the longest, um, it was just, I mean,

straight-out therapy, you know? I'd go in, we'd talk about what was going on. Um, I don't think she was like a specialist in anything, she was just a licensed social worker. (Participant #3)

Histories of Diagnoses. When discussing their histories with diagnoses, it became

apparent that BPD was rarely an initial diagnosis. The women interviewed reported

diagnoses of major depression, generalized anxiety disorder, bipolar disorder,

attention deficit hyperactivity disorder (ADHD), post-traumatic stress disorder

(PTSD), multiple personality disorder (now called dissociative identity disorder,

DID) and intermittent explosive disorder. These diagnoses were often given by

multiple mental health professionals and were contradictory and rapidly changing,

leaving participants confused as to how to label their illnesses. When asked about

past diagnoses, one participant offered the following:

> Um, you know, even though the symptoms have stayed the same, different doctors have given me, there was one time inside of three months that I got three different diagnoses. So, none, you know, what they call it doesn't make a difference. And, like I said, I don't really know what it means. (Participant #3)

As noted above, certain participants felt apathetic about their varied and fluctuating

diagnoses and were more concerned with treatment options, symptoms, and

symptom alleviation rather than diagnostic labels. Often referring to a diagnosis as a

"box" or "number" for insurance or classification purposes, participants were much

more interested in feeling better. When asked about her diagnosis history, one

participant put it the following way:

> So, from my perspective, I don't care. I could not care less what those words are and what that number is, I don't care. Um, I never have and I really don't really think I ever will, just because, like I said before, it helps me get what I need to feel better. (Participant #2)

Another participant shared the following:

> I haven't seen any, like, paperwork or anything for an official
> diagnosis. And I was offered the opportunity to just have it down
> on paper, but that was by the receptionist, the DBT center, for the
> sake of insurance purposes. I don't use insurance on this so I didn't
> need to get a diagnostic…you know, the way they treat everyone at
> the DBT center is just, like, they don't care what you have.
> (Participant #1)

At the same time, the inability of doctors to provide a clear and consistent diagnosis

was of concern to two participants who expressed feeling frustrated and confused.

As one participant stated:

> I just, I always thought that it was something wrong with me and
> that I was never going to figure out what was wrong with me. That
> was just my thing. I was like, 'I've gotta be crazy because there's no
> reason for why I can't work and I can't, you know, have a
> relationship and I can't, you know, do these things that I want to do
> so bad unless there's something wrong with me. Besides just being
> depressed.' So, but I just never could figure it out, you know?
> (Participant #8)

As noted, however, while two of the women interviewed were frustrated at the lack

of clarity they had been given in the past regarding their diagnoses, for most of

those interviewed it was of little importance.

Responses to BPD Diagnosis. The reactions to the diagnosis of BPD varied among

the nine women interviewed, and many of their opinions and initial reactions had

changed over time. Two women expressed their initial concern that the diagnosis

conveyed a fundamental flaw in their character. The term "personality" seemed to

evoke a sense that the illness was something that was innate. As one woman put it

when referring to what the diagnosis meant to her, "is, like, something's wrong with that." When asked about how she felt upon first being diagnosed with BPD, another woman recalled:

> Um, I remember being extremely ashamed. Um, extremely ashamed that they put me on this personality disorder. Ashamed, depressed and hopeless is how I felt. Borderline encompasses everything. So I felt that borderline was telling me, 'you, as a core person, are horrible.' (Participant #6)

Another participant expressed her initial fear that the illness was going to be a life-long burden that would hinder her ability to reach particular life goals:

> I mean, just because I was afraid that, that that meant I was never really going to be truly able to control my emotions and the way I always felt so volatile all the time and, um, that my relationships were always going to suffer. And admitting that I might never have, like, a normal marriage or, you know? Having kids, that I still have concerns. But um, yeah, it was just the fear of wondering would I ever be able to have a normal life. (Participant #5)

Another participant recounted her initial rejection of the diagnosis as follows:

> Well, nobody wants to accept that there's something wrong with you, that you actually have a personality disorder, cause that means there's something you're going to deal with the rest of your life. And of course I want to be ok. I want to be normal, at least once. You know? After a while. So, I really rejected it. (Participant #8)

A lack of understanding of what BPD was or meant was common among participants. One patient asked me during the interview what BPD was. When asked what her psychiatrist and/or psychotherapist told her about the disorder, her response was, "nothing;" while she had a vague understanding that her symptoms of dissociation may be part of the disorder, her understanding of BPD was lacking. Similarly, three other participants explained to me that at the time of, and subsequent

to, their diagnosis with BPD no one had tried to explain to them what it meant. This lack of understanding led to fear and a negative perception of the illness. One participant, when asked how she felt about her diagnosis, expressed both a lack of knowledge regarding what BPD was and a fear of what it could possibly mean. As she recounted:

> Well, I read about it once, and it was very frightening to me because people can get really violent or, um, what? Hurt other people, or, um. But to me, I don't know what, it just means extremes, which is me, but I don't really know. (Participant #4)

Six of the participants interviewed recounted stories of perceived judgment and criticism by family, friends, or providers upon their initial diagnosis. Whether it was family referencing a participant as "crazy" or "defective," or the perception that a provider was labelling them with a personality disorder because they were "difficult," the diagnosis carried with it negative connotations and/or consequences. One participant recounted the tension between herself and her daughter regarding her mental illness as follows:

> Well she just, no she just would get angry and say, 'you can just get a job,' like over and over as though I'm normal but I was lazy. Or you know, what's the word... hiding out, or not wanting responsibility. (Participant #4)

Another participant described the reason she has not told her family about her diagnosis and how she anticipated they would react based on their treatment of other mentally-ill family members:

> Because people don't accept mental illness. And even though I came from a family that had a lot of mental illness, the way that they look at you, treat you, is just like, you're crazy. That's it. 'Ok,

she's one of the broken ones. Let's put her over here and let's just
try to deal with the ones that are not broken.' (Participant #8)

Some participants, even some with initial negative reactions, were not particularly

bothered by the diagnosis at the time of the interview. One conceptualization of BPD

that was expressed was that it is simply a label attached to a group of symptoms, not

something to base an identity on. One participant, who first suspected she had BPD

during her psychiatry rotation in medical school many years ago and was only more

recently diagnosed, described the BPD label in the following way:

> Like, I've never really, I don't really care what the number is that
> gets attached to my diagnosis code. I care what gets me the
> medicine and the treatment that helps. I never really put up a fight
> on any of that. (Participant #2)

For this participant, BPD was a diagnostic category that served its purpose but was

not a definitive aspect of how she identified herself. Another woman compared her

diagnosis of BPD with having a physical ailment that one just has to accept and live

with. While she simultaneously expressed concern about what others may think, she

also had managed to figure out a way to prevent the fear of stigma from defining her

life:

> …it's just, it's one of those things, like, people have diabetes or they
> have whatever. I've got borderline personality disorder but there
> are things that I can do to, that I can…I can still live a happy life, you
> know? So I'm okay with it. Every once in a while, like I said, it, you
> know, I wouldn't just go around parading to everybody just yet. but
> there's, all my friends and family know, but I'm not gonna like walk
> up to a stranger, 'hey, guess what?!' But, um, yeah, I'm pretty okay
> with it. (Participant #5)

Two other participants attributed their acceptance of and their attitudes toward their diagnosis of BPD to DBT. One participant, who was receiving DBT through a private treatment center, credited her provider with helping her to not dwell on the label, to simply use it as a descriptor but not an identity, and therefore, not something to feel stigmatized by. Referring to her therapist, she said:

> ... she's just, like, the way [therapist's name] said was, 'honestly, it doesn't matter if you have it or not, it's just, you know, that you have all these symptoms that happen to be classified in the DSM IV under this category, this box, and all you're trying to get rid of is how it just gets in the way of your life. Who cares if you're borderline or not? You're just dealing with these trust issues, this inability to,' you know, whatever my problems were. (Participant #1)

Another participant expressed a similar sentiment, stating that "the therapists at [name of DBT center] make it seem so, they minimize it to such a degree that you don't feel like such a weirdo."

Research Question 2: How is DBT experienced compared to other forms of treatment?

DBT vs. Other Psychotherapies. DBT is a form of psychotherapy designed to be administered in stages. This allows patients to learn new life skills and coping mechanisms prior to and then concurrently with exploring past trauma and/or current difficulties. This treatment progression grants patients the opportunity to discuss painful and potentially traumatizing topics only after they have begun to learn new ways of handling negative and disturbing emotional states. One complaint

that two participants brought up regarding past psychotherapy that they described

as "talk therapy" was not being emotionally able to handle what was being asked of

them by their providers. One participant who was under supervision by the local

drug courts and the Georgia Division of Family and Children Services (DFCS) had the

following to say about her experience with therapy prior to DBT:

> Cause there's this one counselor in drug court, and her name is
> [name of counselor], and we have to see her one time and, like, she
> just, like, dug, dug, dug. Like, it was a thirty-minute session and she
> just started digging, digging, digging in our first session. And I mean,
> I shut completely down after, like, ten minutes. I'm like, 'put on a
> happy face, whiten my teeth, and I'm great.' And I didn't have to see
> her again. (Participant #7)

For this participant, the idea of revealing and sharing right away with someone she

did not know caused her to shut down and, in effect, leave therapy before it really

began. Another participant, when discussing her experience with a previous

therapist, shared a similar story:

> So, at that point, that's when everything, like, really, they got me
> starting to talking about stuff that was painful, and I didn't have the
> knowledge of how to deal with it... I just felt like going in and
> talking to him and him, like, digging at stuff that was so painful and
> me already being unstable was not at all helpful because, you know,
> I coped by, you know, escapism and, like, trying not to deal with
> those things because I couldn't handle it. And so, it's like, when you
> come ripping all of that stuff up, out, and don't give me any way to
> know what I'm supposed to do with it, it's like, it wasn't pretty, you
> know? It made me want to just die. (Participant #5)

For this participant, it was not so much that it was too early in the relationship for

her to begin sharing with a professional, but rather that she felt she did not have the

tools necessary to handle the process. She described feeling that the way the process

was handled was dangerous, and she credited her second hospitalization that same

year to this handling. While the stories were unique, the common experiences that people shared about what they described as "talk therapy," or at times simply regular "therapy," were generally negative or unhelpful. For participants, what were understood to be traditional forms of therapy involved conversing in an unstructured and undirected fashion. One participant described "talk therapy" as paying to have a friend.

The other, specific forms of psychotherapy that were mentioned by name were CBT and psychoanalysis. While the participant who mentioned psychoanalysis did not remember much more about the experience than that it had happened, feelings about CBT were expressed. One participant felt that CBT had been helpful and compared its structure and emphasis on problem solving and behavioral modification to DBT:

> ...but anyways, every time you went into a session before, while you were in the waiting room, you just filled out this Scantron, answering questions about like, oh, 'how are you feeling from this week from a scale of 1-10, how did you feel in these different areas of emotions?' And then they tracked it. I liked it way more than talk therapy because they actually tracked everything, like, metrically. I just felt like there was a concrete sense of improvement. It wasn't just like, 'oh, talk your feelings' bullshit, whatever, and you don't really know if you're improving or not but then you're just...but with CBT you're practicing skills and implementing them. (Participant #1)

Another participant had also been engaged in CBT, and while she did not feel like it was the treatment she ultimately needed, she was more positive about it than she was other past therapies. Yet another participant recounted her experiences with what she remembered as CBT:

> The therapist I saw during 2 years in college was probably cognitive, I would guess. But he was a total idiot. He never diagnosed my

depression or anything. Then, um, when I went to the hospital and I came out, I had a therapist through them, still think he was cognitive. Um, I saw him for five years, you know, he was somewhat helpful but not all that helpful. (Participant #6)

Introduction to DBT. The women I interviewed were introduced to DBT in various ways and for various reasons. Two of the women began DBT through a study they were part of, after which the researchers asked if they'd like to participate in a DBT group that was starting that might benefit them. Some women had family members who, through their own research, suggested DBT. Others were referred to DBT treatment by previous psychotherapists or psychiatrists. While not specifically asked how they felt about the idea of DBT prior to beginning, those who knew something about this form of psychotherapy prior to beginning expressed feeling what they read and/or were told about the process seemed like a good fit for the problems with which they needed help. Those who were unfamiliar with DBT were more than willing to try anything that might help them feel better. The exception to this was one participant who was in psychotherapy through a court order after having her children taken away by the state.

Barriers to Receiving DBT. When asked about accessing DBT treatment, participants told me about financial and geographic barriers they faced, although the fact that they were participating in this study indicates they were able to overcome those barriers. Speaking about her experience with past DBT treatment, one participant mentioned that, when she first tried DBT, it was not available in Georgia and she had to commute three-and-a-half hours each way to South Carolina to receive treatment:

> Well, in 2003, there was no DBT program in Georgia. So, my father paid for a driver to pick me up once a week at six in the morning, drive me three–and-a-half hours to South Carolina. I would take a class and have a therapy appointment. And this person would drive me back. (Participant #6)

Other barriers involved transportation. One woman who did not drive was limited to one provider because the others that she was aware of were outside the city.

Financial barriers were problematic for two participants. Both had heard about DBT, either through a recommendation by another provider or through their own research, but were unable to start treatment for some time because of the considerable cost of treatment and lack of insurance coverage.

Perceived Effectiveness of DBT. Participants were asked if they felt DBT was an effective form of treatment and, if so, which symptoms they felt were being alleviated and/or how did they know it was effective. Overall, the experiences that the study participants were having in their current DBT treatment were overwhelmingly positive, and the sentiment was common that everybody, regardless of mental health diagnosis or status, should give DBT a try. One participant stated:

> Because I'm less, I make better decisions now. I definitely don't make decisions based on my emotions anymore, and I'm actually able to cope with a lot of things that come up easier and more without having to, you know, it's just like, without having to think about it so hard. You know? It's just, like, becoming normalized, you know? I can deal with whatever life throws at me now. (Participant #5)

Another participant, discussing how her thought processes and interpersonal relations had changed for the better, offered this summary:

> So, since I started, so when I started, I would get mad and I would
> shut down, or I would be upset and stressed and I would shut down
> and do nothing and ignore the world. But since then I don't get mad
> and throw things. I don't, you know, shut down and do nothing, I
> don't, um, pick fights for no reason or I mean, it's, it was always for
> a reason but for a less than stellar reason. Um, so, I'm less
> catastrophic in my thinking, I just sort of go with it and most of the
> time it works out a lot better than it did before. (Participant #2)

When asked about specific symptom alleviation participants' answers and

experiences varied; some were able to say that symptoms such as depression or

suicidality were decreased or completely gone, while others were not as certain that

DBT had, as of yet, eradicated particular behaviors. However, common among the

participants was a general sense that the treatment had altered their attitudes

towards themselves and others. Decreased anger, along with the ability to control

mood fluctuations, were also noted by participants as positive changes they have

seen in themselves since beginning DBT. As in the above interview excerpts, an

increased feeling of control over one's life was expressed by more than one

participant, as well as increased and improved interpersonal skills. A participant put

it this way:

> But, you know what, it is really helpful, it's helping me…um, kinda, I
> guess, be mindful of what I'm thinking and what I'm saying and
> how I'm acting. Although I'm not at the point where I can really
> control what, before it happens, you know what I'm saying? I feel
> like it's helping me grow. Like, it's helping me mature. (Participant
> 6)

Still another woman said the following while recounting how her life had changed

through DBT:

> Um, so we were just talking in class a little bit ago about how it's
> about learning to think dialectically. It's not about using the skills
> perfectly or walking the middle path perfectly all the time, but
> being able to think dialectically and see where you're at on a

spectrum at any given moment and if you want to change it, being able to change it. I can do that. Like, I can look at myself, I can look at the situation, and much more efficiently and quickly than I used to. Being able to say, 'alright, this is what I need. Here's my vulnerabilities, this is, this is what I need to have happen to be where I want to be.' So, it's, yeah, it's night-and-day, I think. I feel my, and I understand that some of my behavior still isn't exactly where I want it to be, but it's a process. (Participant #2)

In response to a question asking how she felt about DBT, a participant stated that DBT helped her expand her mind about her disorders and changed the way she relates to her family:

And that's another thing that DBT has taught me, um, how to understand, and to not hate my family for, because I walked around with resentment for so long because of them. So, um, they're very judgmental…And that's rewarding. And I don't, I come in here one way, and when I leave out, I'm better. And it's like, I hope that it never die, the groups never die, because they're life-saving. This, they're so life-saving, to understand the borderline personality and all other, the PTSD and, it helps to under-, it helps the mind. It helps so much and I don't know who ever thought of this, they're like Einstein to me. (Participant #9)

What Makes DBT Effective. When asked about why they considered DBT to be an effective treatment and how it differs from past treatments, two major themes were common. One theme had to do with the ways in which the treatment emphasized learning skills and methods of handling life and its inevitable challenges. Participants spoke about how they were able to develop new ways of thinking and viewing themselves, and how the combination of introducing new thought processes along with tangible actions worked together to effect positive change. As one woman put it:

And going through DBT and rewiring the way I think about things has made all the difference in the world. Um, it was like my sister

said, 'there is no medication, there is no procedure, you need to learn a different way to live.' And it includes things like meditating a couple of times a day, and you know, using the half-smile while you're meditating. Because that affects the amygdala which affects the hippocampus, you know, that there are actual things, physical things, that affect the way your thinking goes. (Participant #3)

Another participant pointed to the ways in which the skills she had learned and the emphasis on particular ways of thinking were interconnected:

I had to ultimately validate myself at that very deep level. I had to have that self-acceptance, to even make it this far, where I could even start noticing that my connections are starting to, my emotional memory is starting to be retained. And I could not have reached that point of self-sympathy and self-acceptance had I not been in DBT learning these skills, because they all build-up together, like grains of sand. They just build up constantly until it comes around full-circle. (Participant #1)

The second way in which DBT was distinguished from other psychotherapies was in its structured and manualized format and delivery. In discussing DBT, and which aspects of it worked best for them, participants often cited the large amount of structure, while differentiating it from other types of "talk therapy" that were seemingly more fluid. Multiple times, the fact that the treatment involved worksheets, manuals, homework and a relatively rigid curriculum was regarded as valuable and seemingly legitimizing. One participant discussed some of these aspects of the treatment:

So, I think it's better because I have homework. We were actually talking about this, too. Talk therapy, and cognitive behavioral therapy, and things like that, are, CBT is more structured than talk therapy. But where you just go in and you talk and somebody sort of helps be a sounding-board to you, then they can tell you things like, 'oh, just sort of, you know, you gotta feel your way through your depression, you've just gotta experience it and let it go.' Well, DBT gives you a way to do that. (Participant #2)

Another participant said the following:

> Just having these tangible things, and that's what DBT does, too.
> They give you a lot of sheets, they give you homework, and to keep
> your mind going. (Participant #3)

All the women interviewed viewed DBT as a successful and effective form of

treatment, particularly compared to past treatment experiences. Whether they were

receiving care through a program within a public hospital, a private provider or a

mandate by the state through DFCS, DBT was overwhelmingly discussed in a

positive way.

CHAPTER FIVE: DISCUSSION

Experiences of Women with BPD. The women interviewed for this study described histories that were largely consistent with the literature. Many of these women had histories of trauma including rape, childhood physical abuse, childhood neglect and childhood molestation, among others. Studies comparing BPD with other psychiatric conditions such as depression (Ogata et al., 1990), other personality disorders (Zanarini, Tilla, Frankenburg, Hennen, & Gunderson, 2000), and childhood BPD (Goldman, D'Angelo, DeMaso, & Mezzacappa, 1992; Zelkowitz, Paris, Guzder, & Feldman, 2001) have found that patients with BPD have the highest rates of childhood sexual abuse, physical abuse, and emotional and physical neglect (Bandelow et al., 2005).

As stated earlier, the etiology of BPD is thought to be the interaction of a biological predisposition and an invalidating environment (Linehan, 1993). Biosocial theory is a framework that describes mental illnesses and personality disorders as biologically-determined personality traits reacting to environmental stimuli (Matson, 1985). Based largely on work done by Marsha Linehan, the biosocial theory of BPD is the predominant theoretical model for understanding BPD (Linehan, 1993). Within this framework, there is a dialectical relationship between the individual and the environment over time, and for BPD specifically, the environment is thought to typically be, above all else, invalidating.

In addition to trauma histories these women had also experienced a range of psychiatric symptoms and comorbidities including depression, self-harm, anxiety

and suicidality. In addition, they had exhibited behavior they identified as "manipulative" or "acting-out." As noted, mood instability and a proclivity towards acts of self-injury are common parts of BPD (American Psychiatric Association, 2000; World Health Organziation, 1992). Psychiatric hospitalization had played a role in most of the women's lives because of these serious symptoms and dysfunctional behaviors. These experiences of hospitalization, though sometimes helpful, were largely ineffective and at times counterproductive. Their outpatient experiences included varied forms of psychotherapy, including psychoanalysis and CBT. While some of the women expressed having had helpful therapeutic experiences prior to DBT, for the most part these therapies were also experienced as ineffective, with the women expressing a clear and often emphatic preference for DBT.

Stigma. The diagnosis of BPD often took many years of treatment and evaluation by mental health professionals to be reached. Once the diagnosis was received, the nine women in this study had varied experiences related to stigma, both before and after beginning DBT treatment. Participants discussed feeling ashamed of the diagnosis when they first heard it, being afraid that personality disorders were life-long illnesses and rejecting the diagnosis for fear of how they would be treated by their friends and family members. Participants who stated that they were accepting of or indifferent to the diagnosis of BPD mostly followed-up that sentiment by explaining that they still would not tell many people, if any.

In 1963 sociologist Irving Goffman wrote about stigma and described it as a strong and discrediting social label that radically alters the impression of a person, both for society and the stigmatized individual (Goffman, 1963). Within this conceptualization, the stigmatized person is reduced to an undesirable individual, based on a particular set of behaviors and attributes that are deemed deviant from social norms (Goffman, 1963). Illnesses can be stigmatized in different ways and for different reasons; some are stigmatized because of the behaviors that produce the illness (e.g., HIV), and others are stigmatized because of the deviant behaviors produced by the illness (e.g., mental illness, epilepsy) (Conrad, 1986). For the women in this study, the stigma they had to negotiate was produced by behaviors that were or could be perceived by others as deviant. All except one of the participants had at least one story to tell of discrimination or mistreatment because of their BPD, and all in one way or another expressed concern either about other people finding out and/or what the disorder might mean to their self-identity. Though the stories of, degrees of, and perceptions of stigma differed among the women, there were common themes of managing that stigma.

Invisible stigmas, like those associated with mental illnesses such as BPD, can be managed in a variety of ways and tend to fall into the categories of either "revealing" or "passing" (Claire, Beatty, & Maclean, 2005; Joachin & Acorn, 2000). Participants generally managed their stigma through a combination of the two categories or styles and used the strategies of concealment or discretion (passing strategies) and normalizing (revealing strategies) (Claire et al., 2005). Some participants chose to conceal their BPD diagnosis entirely from family and friends,

while others carefully chose who they would tell and who they would not, utilizing discretion in their disclosures. Others, who were more open about their diagnosis deployed normalizing strategies in an attempt to transcend either internal or external stigmatization, through either comparing BPD to a medical condition or reducing it to a less personal, bureaucratic number or "box."

The lived experiences of the women interviewed were influenced by forms of stigmatization or its threat. Even when stigma was not specifically brought up or even when it was denied, issues and experiences of stigmatization, discrimination, shame and fear of being labelled were expressed throughout the interviews.

Experience of DBT Treatment versus Other Treatments. All of the nine women interviewed for this study spoke positively of their treatment in DBT. When asked about DBT in relation to past psychotherapies they had experienced, all but one of the women felt that DBT was a superior form of treatment for their particular challenges. There were multiple reasons participants preferred DBT over previous forms of treatment such as hospitalizations and different psychotherapies. One of the reasons centered around the ways in which DBT offered pragmatic and tangible suggestions and goals, as opposed to previous psychotherapies in which participants expressed the feeling that they were "simply" doing a lot of talking. DBT is problem-focused and, when done correctly, develops treatment goals based on a hierarchy of behavioral and cognitive targets (Linehan, 1993). This aspect of the treatment was well received by the women interviewed. Cognitive behavioral theories prioritize solving problems over understanding their origin, and this

prioritization of direct problem-solving was something that many participants both valued and felt set DBT apart from previous forms of treatment. Homework, manuals, clearly defined skills and a set curriculum were also aspects of DBT treatment that were valued.

Cognitive behavioral theory emphasizes changes in both behavior and thought processes and, broadly, brings together both cognitive and behavioral theoretical frameworks to look at the ways behavioral patterns are engendered through particular cognitive schemas and core beliefs (Gonzalez & Wekerle, 2016; Young, 1994). The focus on learning how to re-conceptualize specific situations, relationships, and life more generally was another area of DBT treatment that was discussed by many of the women. Developing the ability to relate and effectively interact with family who had, in the past, been disapproving or unsupportive was brought up by two of the women interviewed. This process was facilitated by learning new interpersonal skills, but also by learning how to think about their family members in a different way.

Learning how to manage the BPD diagnosis was another area in which the modifying of thought processes in DBT was beneficial for participants. Participants who had negative associations or reactions to the diagnosis of BPD were able to minimize or re-frame the diagnosis in ways that de-stigmatized the label and guided treatment. Through anecdotes and personal reflections, the women interviewed identified ways in which DBT had modified or eradicated problematic or harmful behaviors through altering their processes of thought.

Implications. The findings from this study corroborate previous research indicating that DBT is an effective form of treatment for BPD when compared to other forms of psychotherapy. Manualized delivery, tangible goals and skills acquisition, and outlined, personalized treatment objectives were seen as key aspects of DBT's benefit and can inform the development of future treatment interventions for the disorder. Also, public health interventions that aim to eradicate or minimize mental health-associated stigma may benefit from utilizing specific cognitive behavioral techniques to address both managing and coping with stigmatization.

Limitations. The present study had some limitations. This study had a relatively small sample. Nine participants were included in the study, and future research would benefit from a larger selection of experiences and thought. Time and resources limited the number of participants who could be recruited, although a larger sample would be preferable.

One of the two main goals of this study was to gain a better understanding of the lived experiences of women with BPD. While questions were asked regarding past and current symptoms, no questions were asked specifically about past and current behaviors, such as self-harm or substance abuse. While these behaviors often came up through participants' answers to the questions regarding symptoms, it is very possible that valuable information regarding behavioral patterns that may have added to an understanding of the experience of BPD, and subsequent behavioral changes that may have spoken to the response to DBT, were missed. Related to this, questions were asked about experiences and feelings toward DBT

but not about specific modules, skills or components. Future research, particularly

research looking at the mechanisms of change in DBT and reasons DBT may be

effective, should take a more detailed look at specific aspects of the treatment.

Finally, this study only included data from participants who were actively

engaged in DBT therapy, who agreed to discuss DBT, and who did not drop out of

the project or therapy during the course of this project. These characteristics of the

participants may, in part, possibly explain the overwhelmingly positive experiences

and perceptions of DBT treatment garnered from this study. Future research would

benefit from including experiences and opinions from individuals who are no longer

engaged in DBT therapy.

Conclusion. This study investigated the lived experiences of women with BPD and

their experiences with treatment, in particular their experiences with DBT. Through

nine semi-structured interviews it was found that women with this disorder utilized

particular cognitive and behavioral strategies to manage stigma associated with

their diagnosis. It was also found that individuals responded well to DBT and that

this form of treatment was perceived to be more effective than other forms of

psychotherapy. Consistent with previous research on personality disorder

treatment, the women in this study cited the structured, manualized, and problem-

focused nature of the treatment as key elements of its efficacy. Given the chaotic

lives often led by individuals with BPD, the value placed on a treatment that

provides structure makes sense, and future treatments designed for BPD should

take this into account.

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History of past mental illness/treatment
1) What diagnoses have you received from previous professionals?
> -What are symptoms you've exhibited in the past?
> -What have previous professionals told you, "you are?"

2) What form(s) of treatment, if any, have you received in the past?
> -Have you sought out types of therapies other than DBT?
> -Any in-patient or partial hospitalizations?
> -Have you been under the care of a psychiatrist?
> -What types of medications have you been on in the past?

Current mental health diagnosis/treatment
3) What is your current diagnosis?
> -(if BPD)-who told you you had BPD?

4) What form(s) of treatment are you currently engaged in?
> -(if DBT)-how did you find your current DBT treatment team?
> > -How did you hear about DBT?

Feelings/attitudes about past diagnosis/treatment
5) How do you feel about your past diagnoses?
> -Do you feel you were diagnosed correctly?
> > -Why do you feel you were diagnosed correctly or incorrectly?
> > -What impact on your life did these correct and/or incorrect
> > > diagnoses have on your life?

6) How helpful and/or effective were your past treatment experiences?
> -How well would you say they worked?
> -What were some positive and negative experiences you have had in past
> > treatments?

Feelings/attitudes about current diagnosis/treatment
7) How do you feel about your current diagnosis?
> -Who has given you your most recent diagnosis?
> -Do you feel your current diagnosis is accurate/appropriate?
> -(if BPD)-do you feel your diagnosis has any connotations?
> > -Have you been treated differently after being diagnosed with BPD by
> > > professionals?
> > -How do others (family, friends, co-workers, etc.) react to your
> > > diagnosis?

8) How has your experience been in your current form of treatment?
> -(if DBT) How in general do you feel about DBT?

-Would you say DBT is "working?" How or why not?

Differences in process and outcomes of current treatment
9) How is your current treatment compared to your previous treatments?
-Are your symptoms being alleviated?
-Which ones and how?
-How do you interact with your treatment team now compared to how you would have in the past?
-Is DBT more or less effective than past treatment experience? Why or why not?
-Do you feel differently about your diagnosis now that you are receiving DBT? How?

Recommendations based on personal experience for professionals
10) If you were to make recommendations to mental healthcare professionals regarding treatment of BPD, what would they be?

Emory University
Consent to be a Research Subject

Title: Treatment Experiences of Patients with Borderline Personality Disorder

Principal Investigator: Jesse P. Zatloff

Introduction
You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. You can skip any questions that you do not wish to answer.**

Before making your decision:
- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

Study Overview
The purpose of this study is to gain a better understanding of the types of treatment people who have been diagnosed with Borderline Personality Disorder (BPD) receive and how they experience those various forms of treatment. In addition, this study aims to better understand the role of Dialectical Behavior Therapy (DBT) in the treatment of BPD. This study will aim to include 15 participants.

Procedures
Participation in this study will involve a one-on-one interview with the researcher. If you choose to take part in this study the interview should last about 30-45 minutes. The researcher will ask you questions regarding your mental health status and history, your past treatments, your current treatment, and your experiences and feelings regarding these topics. Please inform me at any point during the interview if you would like the tape recorder to be turned off.

Risks and Discomforts
Participation in this study poses some risks, mainly stress, embarrassment, and/or overall discomfort revealing information regarding you mental health and your experiences in treatment. Breach of confidentiality is also a potential risk with participation in this study. All information revealed during the interview will remain strictly confidential; no real names will be used on transcriptions or any other written materials. All materials will be

kept securely locked and only me and my co-investigator Dr. Nancy Thompson will have access to any materials and identifying information.

Benefits
This study is not designed to benefit you directly. This study is designed to learn more about BPD, DBT, and the experiences that patients have with their treatment. The study results may be used to help others in the future.

Compensation
You will be given a $20.00 Gift Card for participation in this study.

Confidentiality
All efforts will be made to keep your information and identity confidential at all times to the extent that the law mandates. Your name will never appear if the results of this study are published or presented, and all transcriptions of this interview will use a pseudonym to protect your identity. Transcripts, consent forms, and all other potentially identifying information will be kept in a secured location and materials will be destroyed within the time frame set by the Institutional Review Board.

Voluntary Participation and Withdrawal from the Study
You have the right to leave a study at any time without penalty. You may refuse to do any procedures you do not feel comfortable with, or answer any questions that you do not wish to answer.

The researcher also have the right to stop your participation in this study without your consent if:
- He/she believe it is in your best interest;
- You were to object to any future changes that may be made in the study plan;
- or for any other reason.

Contact Information
Contact Jesse P. Zatloff at 973.943.2082
- if you have any questions about this study or your part in it,
- if you feel you have had a research-related injury, or
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:
- if you have questions about your rights as a research participant.
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Authorization to Use and Disclose Protected Health Information

The privacy of your health information is important to us. We call your health information that identifies you, your "protected health information" or "PHI." To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and

Accountability Act and regulations (HIPAA). We refer to all of these laws as the "Privacy Rules." Here we let you know how we will use and disclose your PHI for the study.

PHI that Will be Used/Disclosed:
The PHI that we will use or share for this research study includes:
- Your self-reported mental health diagnoses

Purposes for Which Your PHI Will be Used/Disclosed:
We will use and share your PHI for the conduct and oversight of the research study. We will use and share your PHI to provide you with study related treatment and for payment for such treatment. We will also use and share your PHI to conduct normal business operations. We may share your PHI with other people and places that help us conduct or carry out the study, such as laboratories, data management centers, data monitors, contract research organizations, Institutional Review Boards (IRBs) and other study sites. If you leave the study, we may use your PHI to determine your health, vital status or contact information.

Use and Disclosure of Your Information That is Required by Law:
We will use and disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or abuse of elderly or disabled adults. We will also comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

Authorization to Use PHI is Required to Participate:
By signing this form, you give us permission to use and share your PHI as described in this document. You do not have to sign this form to authorize the use and disclosure of your PHI. If you do not sign this form, then you may not participate in the research study.

People Who will Use/Disclose Your PHI:
The following people and groups will use and disclose your PHI in connection with the research study:

- The Principal Investigator and the co-investigator, Dr. Nancy Thompson, will use and disclose your PHI to conduct the study.
- The Principal Investigator and co-investigator, Dr. Nancy Thompson, will share your PHI with other people and groups to help conduct the study or to provide oversight for the study.
- The following people and groups will use your PHI to make sure the research is done correctly and safely:
    - Emory offices that are part of the Human Research Participant Protection Program and those that are involved in study administration and billing. These include the Emory IRB, the Emory Research and Healthcare Compliance Offices, and the Emory Office for Clinical Research.
    - Research monitors and reviewer.
- Sometimes a Principal Investigator or other researcher moves to a different institution. If this happens, your PHI may be shared with that new institution and their oversight offices. PHI will be shared securely and under a legal

agreement to ensure it continues to be used under the terms of this consent and HIPAA authorization.

Expiration of Your Authorization
Your PHI will be used until this research study ends.

Revoking Your Authorization
If you sign this form, at any time later you may revoke (take back) your permission to use your information. If you want to do this, you must contact the study team at: 225 Briarvista Way NE, Atlanta, GA 30329 or 973.943.2082.

At that point, the researchers would not collect any more of your PHI. But they may use or disclose the information you already gave them so they can follow the law, protect your safety, or make sure that the study was done properly and the data is correct. If you revoke your authorization you will not be able to stay in the study.

Other Items You Should Know about Your Privacy
Not all people and entities are covered by the Privacy Rules. HIPAA only applies to health care providers, health care payers, and health care clearinghouses. If we disclose your information to people who are not covered by the Privacy Rules, including HIPAA, then your information won't be protected by the Privacy Rules. People who do not have to follow the Privacy rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them.

To maintain the integrity of this research study, you generally will not have access to your PHI related to this research until the study is complete. When the study ends, and at your request, you generally will have access to your PHI that we maintain in a designated record set. A designated record set is data that includes medical information or billing records that your health care providers use to make decisions about you. If it is necessary for your health care, your health information will be provided to your doctor.

We may remove identifying information from your PHI. Once we do this, the remaining information will not be subject to the Privacy Rules. Information without identifiers may be used or disclosed with other people or organizations for purposes besides this study.

Consent and Authorization

TO BE FILLED OUT BY SUBJECT ONLY
Please **print** your name, **sign**, and **date** below if you agree to be in this study. By signing this consent and authorization form, you will not give up any of your legal rights. We will give you a copy of the signed form to keep.

_____

Name of Subject

_____

Signature of Subject (18 or older and able to consent)   **Date**
Time

_____

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TO BE FILLED OUT BY STUDY TEAM ONLY

_____

Name of Person Conducting Informed Consent Discussion

_____

Signature of Person Conducting Informed Consent Discussion   **Date**
Time