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Stigmatization Experiences among People Living with Borderline Personality Disorder in Puerto Rico

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Abstract

The experiences of stigmatization among people living with specific Serious Mental Illnesses (SMI), such as Borderline Personality Disorder (BPD) has not been addressed by the scientific literature. In this study we wanted to explore how people living with BPD experience stigmatization. We examine the experiences of 8 people (7 women and 1 man) living and receiving treatment for BPD in Puerto Rico. We used an exploratory qualitative design with semi-structured interviews. To interpret our data, we conducted a thematic analysis. We discuss three categories that focus on one identified theme: the interpersonal dimension of the stigmatization process. These categories are (a) society's views of people living with BPD, (b) family relationships, and (c) partner relationships. Our findings show that people with BPD experience a high attributed personal responsibility, discrimination, social exclusion, and lack of social support. In addition, our findings suggest that the stigmatization of BPD might be more complex than other mental illnesses as it shares characteristics of both SMI and less severe forms of mental illness. We also discuss the importance for practitioners to address stigmatization in therapy and the importance for research to address other aspects of the stigmatization process such as its structural dimension.

Keywords

Stigmatization, Borderline Personality Disorder, Puerto Rico, Thematic Analysis

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Stigmatization Experiences among People Living with Borderline Personality Disorder in Puerto Rico

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The experiences of stigmatization among people living with specific Serious Mental Illnesses (SMI), such as Borderline Personality Disorder (BPD) has not been addressed by the scientific literature. In this study we wanted to explore how people living with BPD experience stigmatization. We examine the experiences of 8 people (7 women and 1 man) living and receiving treatment for BPD in Puerto Rico. We used an exploratory qualitative design with semi-structured interviews. To interpret our data, we conducted a thematic analysis. We discuss three categories that focus on one identified theme: the interpersonal dimension of the stigmatization process. These categories are (a) society's views of people living with BPD, (b) family relationships, and (c) partner relationships. Our findings show that people with BPD experience a high attributed personal responsibility, discrimination, social exclusion, and lack of social support. In addition, our findings suggest that the stigmatization of BPD might be more complex than other mental illnesses as it shares characteristics of both SMI and less severe forms of mental illness. We also discuss the importance for practitioners to address stigmatization in therapy and the importance for research to address other aspects of the stigmatization process such as its structural dimension.

Keywords: Stigmatization, Borderline Personality Disorder, Puerto Rico, Thematic Analysis

Stigmatization has been recognized as the main barrier for treatment seeking, adherence, and recovery for people with serious mental illnesses, such as Borderline Personality Disorder (BPD) (Aviram, Brodsky, & Stanley, 2006; Beldie et al., 2012; U.S. Department of Health and Human Services, 1999). Recent literature has identified the detrimental impact of stigmatization in the health status of people with serious mental illness perpetuating health inequities among these made vulnerable populations (Hatzenbuehler, Phelan, & Link, 2013; Rivera-Segarra & Ramos-Pibernus, 2013). This current situation worsens for ethnic minorities such as Latinos/as, specifically Puerto Ricans (López, Barrio, Kopelowicz, & Vega, 2012a; U.S. Department of Health and Human Services, 2001).

The prevalence of mental illnesses among the Latino communities in the United States is estimated at 30% (Alegría et al., 2007). Puerto Ricans are U.S. born citizens residing in the Caribbean Island. They represent a group with a prevalence of mental illness estimated at 36%, the highest among the Latino communities (Alegría et al., 2008; Alegría et al., 2007). Also, significant inequities have been found among the Latino communities (López et al., 2012a), especially among Puerto Ricans who have one of the lower rates of treatment seeking (Alegría et al., 2001; Keyes et al., 2012).

Literature has shown that it is critical to understand how socio-cultural factors such as stigmatization shape opinions, beliefs, and attitudes about mental illnesses (Link, 2013; Olafsdottir & Pescosolido, 2009). However, the impact of the stigmatization among specific serious mental illnesses, such as BPD, has not yet been addressed by the scientific literature. Furthermore, research has neglected to address the specific manifestations of stigmatization especially in these made vulnerable populations, such as Puerto Ricans living with BPD (Piza Peluso & Blay, 2004).

Stigma Definition

Stigmatization has traditionally been defined following the work of Erving Goffman (1963) who stated that stigma should be understood as “an attribute that is deeply discrediting” (p. 3). Nevertheless, Goffman emphasized a fundamental aspect usually not included in stigma related works. He explained: “It should be seen that a language of relationships, not attributes is needed” (p. 3). Link and Phelan (2001) provide an alternate and expanded definition that emphasizes the process of stigmatization, taking into account what Goffman originally proposed. They define stigmatization in the convergence of certain interrelated components. As they explain,

In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them.” In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination. (p. 367)

This definition provides an understanding of stigmatization as a social process where the “elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold” (Link & Phelan, 2001). This allows us to understand that people are not at risk because of an inherent trait or attribute, but because of a changeable, evitable, remediable and preventable social process (Rivera-Segarra & Ramos-Pibernus, 2013). In order to manage the preventable social condition that is stigmatization, it is vital to document how it’s different, yet interrelated, components manifest in people living with mental illnesses.

Stigmatization and Mental Illnesses

Stigma research has documented how attitudes and beliefs about mental illnesses have been developed and maintained based on fear and lack of information (Hinshaw, 2007; Wesselmann & Graziano, 2010). For example, literature has shown how certain sectors of the population see people who live with mental illnesses as incompetent and incapable of maintaining a job (Russinova, Griffin, Bloch, Wewiorski, & Rosoklija, 2011), unpredictable (Angermeyer & Dietrich, 2006), and responsible for their behavior (Markham & Trower, 2003). Furthermore, one of the most prevalent perceptions about people living with mental illnesses is that they are dangerous. Research has shown how the perception of dangerousness has steadily increased in the United States since the 1950s, despite the efforts to educate people about mental illnesses (Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999). These perceptions have also been documented among health professionals, with detrimental consequences for their treatment (Lauber, 2008; Nordt, Rössler, & Lauber, 2006; Polanco-Fronteras, Cajigas-Vargas, Rivera-Segarra, Varas-Díaz, Santos-Figueroa, & Rosario-Hernández, 2013).

Recent research has also begun to document how stigmatization impacts people living with mental illnesses by exposing them to stigmatizing behaviors in their work (Russinova et al., 2011), health care scenarios (Chee, Ng, & Kua, 2005; Verhaeghe & Bracke, 2008) and

with their families and friends (Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). This results in people being socially rejected and excluded because of their health status, which has a negative impact in their quality of life (Martínez, Piff, Mendoza-Denton, & Hinshaw, 2011).

Literature has also pointed out the importance of exploring the experiences of people living with mental illnesses in research agendas to reduce stigmatization (Aviram et al., 2006). Still, research efforts have almost exclusively focused on the opinions, beliefs, and attitudes of the general populations towards mental illnesses (López et al., 2012b; Serra et al., 2013) or among health professionals (Martínez et al., 2011; Polanco-Fronteras et al., 2013; Rao, Mahadevappa, Pillay, Sessay, Abraham, & Luty, 2009). Furthermore, although this research has documented the stigmatization processes outside the US (Baysan Arabaci, & Çam, 2012; López et al., 2012b), developing countries within Latin America and the Caribbean have been neglected (Piza Peluso & Blay, 2004). Although recent literature on the stigmatization of mental illnesses has begun to emerge in Puerto Rico, the focus has been on health professionals in training (Varas-Díaz et al., 2012; Polanco-Fronteras et al., 2013). Moreover, although it is well known that stigmatization varies across different mental illnesses (i.e., depression vs. schizophrenia), this literature has usually used mental illness as an umbrella term without accounting for their differences (Gaebel, Zäske, & Baumann, 2006; Polanco-Fronteras et al., 2013). Thus, the specificities of the stigmatization processes across the different mental illnesses, such as BPD have been neglected.

Stigma and Borderline Personality Disorder

Borderline Personality Disorder is a serious mental illness characterized by a pattern of instability in emotional regulation, self-image, interpersonal relationships, and impulsive behavior. These patterns usually begin to manifest during adolescence and early adulthood and are present in a variety of contexts (American Psychiatric Association, 2013). Lenzenweger, Lane, Loranger, and Kessler (2007) estimate that almost 10% of the general population lives with a personality disorder in the United States. Research has documented that the prevalence of BPD among the general population is at a 6% (Grant et al., 2008). However, these estimates are even higher among psychiatric inpatients with more than 20% (Crowell, Beauchaine, & Linehan, 2009; Holm & Severinsson, 2008)

Although little research on the stigmatization of BPD has been done, some literature has documented how people living with BPD are often viewed in negatively by the general population and health professionals (Aviram et al., 2006; Markham, 2003). For example, this research shows how people living with BPD are described as treatment resistant, manipulative, demanding, dangerous, and attention seeking (Aviram et al., 2006; Markham, 2003; McGrath & Dowling, 2012; Nehls, 1998). Furthermore, BPD can be viewed as less a mental illness than others such as schizophrenia (Shanks, Pfohl, Blum, & Black, 2011), and people who live with it are often seen as in control of the causes of their behaviors (Markham & Trower, 2003). These opinions and beliefs based on the lack of knowledge about the condition are not only held by the general population but also by health professionals who report less sympathy and optimism in their prognosis (Markham & Trower, 2003; Millar, Gillanders, & Saleem, 2012). Recent literature has begun to point out how these elements of labeling, stereotyping, status loss, and discrimination interrelate and impact the health status of people living with BPD. For example, increasing their anxiety levels, guilt, and shame (Rüsch et al., 2007), marginalizing and denying access to mental health care based on their diagnosis (Nehls, 1998), and socially rejecting them (Markham, 2003) which directly impacts their social support network and perpetuates health inequities among these made vulnerable population.

Despite this, the stigmatization of BPD has been overlooked in the scientific literature in comparison to other serious mental illnesses such as schizophrenia or bipolar disorder (Aviram et al., 2006). In Puerto Rico, research on BPD is scarce; however, literature has begun to emerge focusing specifically in the treatment of BPD using Dialectical Behavioral Therapy (DBT; Marqués-Reyes, 2014), exploring the knowledge of families about the diagnosis (Rodríguez-Rosa & Marqués-Reyes, in press), the impact of the diagnosis in their children (Osorio-Mulero & Marqués-Reyes, in press), and the objective evaluation in Puerto Rican's living with BPD (Garrido, 2013). To the best of our knowledge, there is no literature on the role of socio-cultural factors, such as stigmatization in the lives of people living with BPD in Puerto Rico.

Thus, the purpose of this study was to explore the experiences of stigmatization among people living with BPD in Puerto Rico. It is our intention that the results of our work contribute to the literature on stigmatization processes among people living with serious mental illnesses such as BPD, specifically among Latinos/as such as Puerto Ricans. It is our hope that this contribution will foster the development of stigma reduction interventions in order to reduce health inequities among this population.

Our Context

The last author is an Assistant Professor at the Ponce School of Medicine & Health Sciences (PSMHS) in Puerto Rico. He specializes in the treatment of BPD and supervises advanced students from the PSMHS Psychology Program in a clinical practicum focused on using DBT for the treatment of BPD. As part of this practicum experience, the first author (an advanced doctoral student from the PSMHS Clinical Psychology Program in Puerto Rico) gathered anecdotal information about stigmatization experiences among the population he treated as part of his practicum. During his weekly supervision, he brought the subject to his supervisor (last author) and they shared their similar experiences and anecdotes. As we searched the literature on the topic, we could not find literature neither on the BPD stigma subject in general or that which focused on Latinos/as. Because both authors wanted to understand how the stigmatization experiences impacted the people they treated, they recruited graduate students of the PSMHS Clinical Psychology Program (second, third, and fourth authors) to help them conduct the study.

Method

In order to fulfill the objectives of this study, we used an exploratory qualitative design with semi-structured interviews. This type of design was specifically chosen because it is appropriate in cases where literature is scarce and when a description of perceptions, experiences, opinions, and beliefs are needed in order to comprehend a given phenomenon (Denzin & Lincoln, 2011).

Participants

We (the first four authors of this paper) conducted a purposeful sampling of 8 participants (7 women and 1 man). All participants were recruited from two psychology clinics in Puerto Rico that specialize in the treatment of BPD. These sites of recruitment were the Metropolitan Psychology Network and the Psychological Services Clinic from the Ponce School of Medicine & Health Sciences. All participation was voluntary. Participants in the study were

- a) adults older than 21 years of age,
- b) diagnosed with BPD,
- c) receiving psychological services for BPD and
- d) living in Puerto Rico at the moment of the interview.

We chose these selection criteria in order to ensure that the sample represented the population we were interested in, adults living with BPD that were receiving treatment in Puerto Rico. Also, the interviews were conducted face-to-face and the interviewer (first author) lived in Puerto Rico. Table 1 provides a socio-demographic description of the sample.

Table 1: Socio-Demographic Data

	Variable	Frequency
Gender	Women	7
	Men	1
Age	21-25	2
	26-30	1
	31-35	4
	35 or more	1
Marital Status	Single	7
	Married	1
Education	Associate	1
	Bachelors	5
	Masters	2
Employed	Yes	6
	No	2
Considered Religious	Yes	1
	No	4

Note: n=8

Procedure

Before beginning the study, we developed the questions for the interview guide (see Appendix). These questions were developed based on the discussion of the first and last authors about their clinical experiences and anecdotes with this population. Because their experiences were mostly on the relational aspect of stigmatization, most of the questions focused on this aspect. Based on these, the first and last authors developed an initial semi-structured interview guide. This allowed us to gain a better description of the experiences of the participants, while also allowing the researcher flexibility to ask additional questions in order to gain more detail (Roulston, 2010). After this initial interview guide was developed, the team members held a discussion to include everyone's input. After the research team members gave their input and brought new questions and ways to ask them, we finished with our set of final questions. These questions were related to the participant's experiences living with BPD and experiences where they felt stigmatized because of their diagnosis. After this process, we obtained approval from the Institutional Review Board (IRB) of the Ponce School of Medicine & Health Sciences (No. 130116-DM). In order to conduct an ethically informed research project, we all underwent training on responsible research with human subjects. In addition, the first author was trained by the last author on the appropriate ways to conduct interviews about sensitive issues and how to manage them.

The recruitment was carried out with the help from the staff of the two psychology clinics. We obtained written authorization from the two coordinators from the recruitment sites in order to identify potential participants during the recruitment process. Initially, the staff would identify potential participants, inform them about the study, and provide them with the contact information of the researchers. Potential participants then contacted us for further details about the study. We then proceeded to explain in detail the purpose of the study. If potential participants were still interested, we collected their names and contact information, and then coordinated an appointment in the place and hour of their preference to conduct the interview. However, it is important to point out that in all eight interviews participants selected the treatment setting as the appropriate place to conduct the interview.

On the day of the interview, participants signed the informed consent form and completed the socio-demographic questionnaire approved by the IRB. Once this information was collected the interviews began. All interviews were conducted between May and August of 2013 by the first author. The duration of interviews was approximately an hour. Interviews were conducted in Spanish, as it is the everyday language in Puerto Rico. All interviews were audio taped, transcribed, and then analyzed.

Data Analysis

We chose to conduct a thematic analysis because this type of analysis allowed us to explore and better understand the participant's psychological world of beliefs, constructs, and experiences (Saldaña, 2013). Thematic analysis is a technique used to identify, analyze, and report the themes within the collected data (Braun & Clarke, 2006). Our analysis was framed on Braun and Clarke's (2006) recommendations, who identified six phases during the process of analysis (familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report) and which we describe in the following paragraphs.

Process of Analysis

Phase 1

In this phase the authors transcribed the interviews and became familiarized with the collected data in order to engage in the process of analysis. To ensure the confidentiality of the participants, we engaged in a data cleaning process in which identifiers such as names and specific places were changed (Kaiser, 2012). Also, to ensure the trustworthiness of our analysis we began a supervised transcription process to ensure the fidelity of the data. Team members (first four authors) were trained by the last author on the appropriate way to transcribe audio interviews (Rapley, 2012). After transcriptions were completed, we met and read them while listening to the audiotapes to identify possible inconsistencies. After correcting all inconsistencies, we proceeded to the second phase.

Phase 2

After becoming familiar with the data, the team worked systematically through the entire transcripts in order to identify the aspects of the data that were of our interest (Braun & Clarke, 2006). During this process every author independently identified themes that were related to the stigmatization process, for example, the relational aspect of stigmatization. To ensure the trustworthiness of the analysis, the team conducted weekly meetings to discuss their analysis and concerns and to clarify discrepancies across their individual coding. We

also decided not to search for patterns, as they do not necessarily mean that the most recurring themes or codes are more important (Braun & Clarke, 2006). Thus, our focus was on identifying the themes that were related to the theoretical construct of stigmatization we presented earlier. In addition, for this phase we used the qualitative computer software HyperResearch (Davidson & diGregorio, 2011; ResearchWare, 2012). This program allowed us to identify the themes from the transcript readings, which finally helped us move into the next phase, and “build valid arguments for choosing them” (Aronson, 1994).

Phase 3

During this phase, the authors extracted from the transcripts the texts that evidenced each theme. This process took place during weekly meetings where the research team discussed the appropriateness of each selected text for the specific theme. Because several verbalizations were coded for more than one theme, the team discussed which one was more appropriate. Only those verbalizations in which all team members agreed were included as part of our data (DeCuir-Gunby, Marshall, & McCulloch, 2011). After the authors gave their input, we finished with a collection of several candidate themes with their respective verbalizations to support them.

Phases 4 and 5

In these phases, we engaged in the refinement of the identified themes. During this process we identified that several themes needed to be broken down as they comprised several categories within the theme. Thus, the group engaged in weekly discussions to

- a) review the coded extracts,
- b) develop categories that were coherent with the identified theme,
- c) develop definitions that accurately reflected the proposed category and capture the essence of the theme, and
- d) review that the verbalizations accurately reflected the categories.

After this process we reviewed the categories and their respective verbalizations and those in which all team members agreed that accurately reflected the category generating an inter-reliability of 100% for the analysis (DeCuir-Gunby et al., 2011).

Phase 6

During this phase we began to write the research report. In order to do so, we referred to the literature in order to formulate interpretations, inferences, and statements about the data (Aronson, 1994). Because of the importance of providing a concise, coherent, and logical account of the story the data tells and the interpretations we formulated, we decided to present the results from one of our identified themes: the relational aspect of stigmatization. Thus, the results are organized in the following manner. First, we present each category and definition. Second, we provide the textual evidence for this category. Third, we provide a brief analysis of the data. Finally, we provide our analyses and interpretations in light of previous literature on the subject. We also include the agreements and discrepancies of our findings with previous literature.

Results

For the purposes of this paper, we will only discuss three categories that we identified in our analysis that focus on the relational aspect of the stigmatization process:

- a) Society's views of people living with BPD,
- b) family relationships, and
- c) partner relationships, and representative verbalizations for each one of them.

In Table 2 we present a description of each one of these categories.

Table 2: Description of the Categories of Analysis

Category	Description
1. Society's views of people living with BPD	Includes verbalizations about the participant's opinions, beliefs and experiences on how the general society sees people living with BPD.
2. Family relationships	Includes verbalizations of participant's experiences within their family context.
3. Partner relationships	Includes verbalizations of participant's experiences in their sentimental relationship context.

Society's Views of People Living with BPD

In this category we found verbalizations related to the participant's perceptions about the views that the general society holds about those living with BPD. One of the first issues to be pointed out by participants was the lack of knowledge about the condition, which they see as linked to the particular views about it.

In the case of borderline, because I believe that the condition is less known than others; it is easier for others to assume things about it like what is a borderline or what is not a borderline. Is borderline the same as bipolar? Borderline is like something very bad because people don't know what it is, they assume the worst. [*En el caso de borderline, pues como creo que la condición es menos conocida que otras, pues se presta más para que se asuman cosas como qué es lo que es un borderline o que no es un borderline. ¿Borderline es lo mismo que bipolar? Borderline es como que algo bien malo porque como la gente no sabe lo que es pues asumen que es bien malo.*]

Linked to this lack of knowledge about BPD participants expressed several views:

- a) being out of control; "they think that one is out of control, or that one is going to commit a violent act or something [*piensan que uno está fuera de control o que va a hacer un acto violento o algo*]",
- b) making a big deal of things; "one of the things that bothers me most is when they say "you make a mountain out of a molehill"...because for the other people it is not something that one has to worry [*una de las cosas que más me molestan es cuando dicen 'tu te haces una tormenta en un vaso de agua'...porque para la otra persona no es algo por lo cual uno tenga que preocuparse*]", and

- c) not doing enough; “people say ‘if you don’t do your part you won’t get better’...they already think you are not doing your part [*la gente dice ‘si no pones de tu parte no te vas a mejorar’...ya piensan que tu no estás poniendo de tu parte*]”.

Another dimension expressed, as deeply-rooted among the general society was the perception of BPD as a myth, unlike other health conditions. This was also linked to the view of people living with BPD as not doing enough.

Understanding that this is a condition, that it is not a myth; it’s not that the person says...I don’t know...‘it’s something from her personality, a misbehaving girl,’ because they minimize it ‘ah, it is because she is not doing what she’s supposed to do.’ No, it’s a condition. [*Entender que es una condición, que no es un mito, que no es que la persona...que se yó... ‘es algo de personalidad, es una niña malcriada’ porque lo minimizan ‘ah es que no está haciendo lo que tiene que hacer’. No, es una condición*].

Another participant also shared the perception that others view BPD as different from other health conditions:

For me it’s something that’s very infuriating because everyone can understand cancer, everyone can understand heart attacks, diabetes, all conditions. . . . You could be limping for 10 days and I understand, because ‘oh you poor thing, your leg!’ But if you have...you know, your heart broken, and you feel that you are in the dirt...and you are working, even though you are dragging yourself with all you’ve got, people don’t see that; people don’t feel that. They can understand physical pain you know, but emotional, psychological pain, they can’t and don’t want to accept it [*Para mí eso es algo que es bien “infuriating” porque todo el mundo puede entender los cáncer, todo el mundo puede entender los ataques al corazón, la diabetes, todas las condiciones...Tu puedes estar ‘limping’ 10 días y yo te entiendo porque ‘hay bendito pobre, la pierna’ pero si tú tienes, tu sabes el corazón partió y te sientes que estás por el piso y estás trabajando aunque tú estás arrastrándote con to’ lo que tú tienes, la gente no ve eso, la gente no siente eso. Tu sabes el dolor físico lo pueden entender, pero el dolor emocional, psicológico no lo pueden entender y no lo quieren aceptar*].

Family Relationships

In this second category, we found verbalizations in which participants expressed differences in how their families dealt with their diagnosis. In this first example, a participant explains how the family dealt with the recent diagnosis.

That was the feeling in the family; it was like this is very dirty underwear, and this is washed in the house and stays in the house because no one can know and if “What Sonia [fictitious name] does in Boston [fictitious name of the city]?” Oh, studying...always inventing and making up excuses, no one wanted to talk about the issue [*Ese era el “feeling” de la familia era como que esto es un panty bien sucio, esto se lava en la casa y se queda en la casa porque nadie puede saber y si “¿qué hace ‘Sonia’ [nombre ficticio] en Boston [nombre*

ficticio de la ciudad]? ah estudiando...” siempre inventando y poniendo excusas, nadie quiso hablar del tema].

In the case of this verbalization, the family considered the diagnosis as something secret and dirty that no one else besides them should know. Furthermore, if someone asked about the absence of the participant in the home (she had moved to Boston [fictitious name of the city] to seek specialized treatment for BPD) they would make up a cover story.

In the case of this other participant, family members—in this case, a sister—also experienced a sense of embarrassment because of the diagnosis. This next verbalization is the verbalization of the sister as the participant recalls it.

I don't know how to tell my roommates why you are here, because this is very embarrassing that you have put me in this situation, you know, I have to deal with you because you can't deal with yourself [Yo no se cómo decirle a mis 'roommates' porque tu estás aquí, porque esto es bien bochornoso que tu me hayas puesto en esta posición, tu sabes de que yo tengo que bregar contigo porque tu no puedes bregar contigo misma].

Some participants also recalled experiences from their childhood, which they now see as linked to their BPD diagnoses. For example, this participant said, “I remember my father telling me I was a hysterical. I remember my mother telling me I was a clown. . .hearing those words made me feel like I wasn't normal. [Yo recuerdo a mi papá diciendo que yo era una histérica. Recuerdo a mi mamá diciendo que yo era una payasa. . .el escuchar esas palabras me hizo sentir que yo no andaba en la normalidad]”.

Another opinion related to dealing with the family was the complexity of the Puerto Rican context. As one participant states, in Puerto Rico the relationship with the family is one of the most difficult things for people with BPD: “I believe that in Puerto Rico it's more difficult [referring to living with BPD]. . .there's a lot of family here and the family gets into everything. . .there are no boundaries; the family meddles, you know. [Yo creo que en Puerto Rico es más difícil todavía [refiriéndose a vivir con BPD]. . .aquí no hay 'boundaries', la familia se mete tu sabes].”

Partner Relationships

This third and last category shows verbalizations about the difficulties encountered in the participants' sentimental relationships because of their diagnosis. In this next example, a participant explains the reaction of the partner when knowing about the diagnosis and the implications for the relationship in the future: “The last thing he said to me was that he couldn't marry me because of the problem I had, my condition, he couldn't marry someone like that. . .because what kind of family we would have? [Lo último que él me dijo fue que él no se podía casar conmigo porque como la problemática que yo tenía de mi condición, esto, que él no se podía casar con alguien así. . .porque ¿qué clase de familia íbamos a tener?]

Another participant narrates the verbal and emotional abuse she received by her boyfriend because of her BPD diagnosis.

I had a boyfriend and I tried to explain...he treated me like shit and abused me emotionally, and when we had fights he started 'ah you weak, you cut yourself'...And then, 'ah sorry'...but you stay, because you believe that he is the only person that has given you love, because all your family loves you, but

they don't want you like that...[Tuve un novio que se lo traté de explicar...y él me trató como mierda, abusó emocionalmente de mí y teníamos peleas y él empezaba 'ah you weak y tú te cortas'...y después 'ah perdón'...pero tu te quedas porque tu crees que es la única persona que te ha dado amor por que toda tu familia te quiere, pero no te quiere así...]

These types of manifestations from the partners towards the person living with BPD were shared by several participants. One of them shares the feelings of fear and frustration this kind of behavior from the partner produces in her: "To be honest, one of my biggest fears is that I won't be able to have a partner and I'm not going to have a family because of the condition. . .It's like fuck, will I be normal some day? [Realmente, uno de mis miedos más grandes es que yo no voy a poder conseguir una pareja y no voy a tener una familia por la misma condición. . .como que puñeta ¿algún día voy a ser normal?]"

Discussion

Stigmatization is a social process that is comprised of several dimensions. In this paper, we presented three categories related to the interpersonal dimension of the stigmatization process in people living with BPD. These verbalizations show how stigmatization processes impact the lives of people living with BPD in their everyday interactions with family members, their partners, and society in general. These processes have a negative impact on their social support networks, self-esteem, and quality of life, which leads to a high risk of suffering from a myriad of other health conditions (Rivera-Segarra & Ramos-Pibernus, 2013; World Health Organization, 2003).

Although our research focused on the perspective and experiences of people living with BPD, these findings share some commonalities with previous results from mental illness stigma research. For example, our findings show how people living with BPD are also linked to undesirable characteristics such as being out of control, "making a mountain out of a molehill," or not doing enough to get better. In addition, participants expressed an attributed personal responsibility from society and family, which contrasts markedly from those ascribed to other health conditions. These findings from the perspective of the person living with BPD are congruent with literature that documents how society views people with serious mental illnesses as unpredictable (Angermeyer & Dietrich, 2006), an aspect that leads to fear, social rejection, and exclusion (Martínez et al., 2011). Also, literature has documented how high levels of attributed personal responsibility are associated with higher stigmatization and ineffective treatment (Bos, Pryor, Reeder, & Stutterheim, 2013; Pickard, 2012). Our results support these past research findings from the perspective of those who experience this stigma. However, it is important to mention that these findings have been documented separately among different types of mental illnesses.

An interesting finding that seems to be divergent from previous literature is the fact that most verbalizations seem to support characteristics usually ascribed to Serious Mental Illnesses as well as less severe forms of mental illnesses. For example, unpredictability has been linked to Serious Mental Illnesses such as schizophrenia, but not Depression. On the other hand, the idea of not being ill at all, "making a mountain out of a molehill," and personal responsibility has been documented in Depression but not in Serious Mental Illnesses (Gaebel et al., 2006). This has detrimental consequences for people living with BPD, who have to face a stigmatization process that goes beyond the ones associated with other mental illnesses (Aviram et al., 2006). It also poses a serious challenge for research and anti-stigma campaigns that will need to tackle this particularity in their future endeavors.

Another element of the stigmatization process as proposed by Link and Phelan (2001) is the loss of status and discrimination that leads to unequal outcomes. Verbalizations from our participants seem to support this assertion when referring to the rejection of their partners to marry them, which leads the person to feel less normal and discriminated against because of the condition. All these results are intertwined with the lack of knowledge about the condition in the general population; something that markedly contrasts with other conditions such as depression or schizophrenia, which have been the main focus of many anti-stigma campaigns (Stuart, Arboleda-Flórez, & Sartorius, 2013).

Finally, these results show the impact of the process of separation (“us” from “them”) in the social support network of people living with BPD. As family members experience emotions such as embarrassment and partners distance themselves from a more formal form of commitment, the social support network for people living with BPD shrinks. This has direct consequences in their health status as social support has been identified as a social determinant of health (Mikkonen & Raphael, 2010; World Health Organization, 2003). This process of separation from the person echoes previous literature that has documented how the lack of social support is also linked to lower levels of recovery and quality of life (Chronister, Chou, & Liao, 2013; Corrigan & Phelan, 2004). This is especially worrisome in the context of the Puerto Rican culture, where family is an important source of support (Varas-Díaz, Serrano-García, & Toro-Alfonso, 2005).

Limitations, Implications for Practice, and Future Research Efforts

There are some limitations in this study. First, the recruitment was only carried out in two psychology clinics in Puerto Rico. Both clinics are the only ones specializing in the treatment of BPD in Puerto Rico, using DBT specifically. Thus, the participant’s experiences and coping strategies might have been different from those who do not receive treatment for their condition. Future efforts should also include participants who receive other treatments (i.e., psychodynamic or Cognitive Behavioral Therapy) or no treatment at all.

Second, all eight interviews were conducted in the same setting where the participants received treatment. Although we selected a different room from the ones they usually use and scheduled the interview on a separate day from their usual appointments, participants might not have been as open as they would outside this setting. Also, because of the context, they might have seen the researcher as a therapist, which would also have impacted their narratives.

Third, we are aware of the different positions regarding how much a researcher should be engaged with the literature on a subject before the beginning of the study. Thus we acknowledge that some might see our involvement with the literature before the study as a limitation, arguing that it narrows our analytic field of vision.

In spite of these limitations, this study represents a preliminary effort to gain a deeper understanding of how stigmatization processes impact the lives of those who live with BPD in Puerto Rico. These results have several implications for practitioners who work with this population. It is fundamental that practitioners working with people living with BPD take into account the interrelational aspects of stigmatization when working with them in therapy. This is important at least in two particular instances. First, practitioners should explore how stigmatization processes have impacted the person as they would do with any other aspect of their developmental history in order to understand if in their case they are related to the existence of particular symptoms. Second, it is important for practitioners to be aware of their own views about BPD in order to avoid reproducing society’s view in therapy which could lead to detrimental consequences in their health.

In terms of research implications, these results provide evidence of the need for further studies addressing the different manifestations of stigmatization, specifically in other contexts and scenarios. Because of this we recommend that future research efforts address the following topics:

1. Explore the manifestations of structural stigmatization in people living with BPD.
2. Explore the internalized stigma among people living with BPD.
3. Explore the knowledge of BPD among the general population and health professionals.
4. Explore stigmatization experiences among the family members and partners of people living with BPD.
5. Document stigmatization management strategies used by people living with BPD in order to develop effective stigma reduction interventions.
6. Evaluate the impact of stigmatization in their treatment and health.

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Appendix

Interview Questions

- 1) ¿Desde hace cuanto tiempo sabes que vives con el Trastorno de la Personalidad Limítrofe?
[How long have you lived with Borderline Personality Disorder?]
- 2) ¿Consideras que tu vida ha cambiado por que vives con TPL?
[Do you think your life has changed because of your condition?]
- 3) ¿Cómo ha cambiado?
[How has it changed?]
- 4) En general, ¿qué opinión crees que tienen las personas en la sociedad sobre aquellas que viven con TPL?
[In general, what do you think is the opinion of people in society about those who live with BPD?]
- 5) Alguna persona ha discriminado contra ti o te han hecho sentir mal debido a tu condición?
[Has someone discriminated against you or has made you feel bad because of your condition?]
- 6) Completa la siguiente frase: “La sociedad rechaza a la persona que vive con TPL por que...”
[Complete the following phrase: “Society rejects people living with BPD because...”]
- 7) ¿El vivir con TPL ha impactado tus relaciones con tu familia? ¿Cómo?
[Has living with BPD had an impact in your family relationships? How?]

- 8) ¿El vivir con TPL ha afectado tus relaciones con tu pareja? ¿Cómo?
[Has living with BPD had an impact on your partner relationship? How?]
- 9) ¿Cómo describirías las consecuencias de vivir con TPL?
[How do you describe the consequences of living with BPD?]
- 10) ¿Existen otras dimensiones de tu vida que sientas que han sido afectadas por el TPL?
[Is there any other dimension in your life that you feel has been affected by BPD?]

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