



ORIGINAL ARTICLE

Why go to the emergency department? Perspectives from persons with borderline personality disorder

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ABSTRACT: *Through this qualitative study, we explored frequent emergency department use by persons with borderline personality disorder from their perspective. Interpretive description guided the study design, and data were collected through interviews with six individuals diagnosed with borderline personality disorder who had at least 12 emergency department visits for reasons related to their mental illness within a 1-year timeframe. Using thematic data analysis, we articulate the participants' experiences through two broad themes: cyclic nature of emergency department use and coping skills and strategies. Unstable community management that leads to self- or crisis presentation to the emergency department often perpetuated emergency department use by our participants and the ensuing interventions aimed at acute stabilization. The participants identified a desire for human interaction and feelings of loneliness, failure of community resources (such as crisis lines or therapy), and safety concerns following suicidal ideation, self-harm, or substance use as the main drivers for their emergency department visits. Our participants identified several potential strategies to protect them against unnecessary emergency department use and improve their health care overall. More work is needed to explore the viability and effectiveness of these suggestions.*

KEY WORDS: *borderline personality disorder, emergency department, experiences, interpretive description, mental health and illness.*

BACKGROUND

Borderline personality disorder (BPD) is a mental illness characterized by pervasive patterns of instability of interpersonal relationships and difficulty with impulse control and emotional regulation (American

Psychiatric Association 2013; Dickens *et al.* 2016). Persistent suicidality and recurrent thoughts and acts of self-harm are common for persons with BPD (Oumaya *et al.* 2008). Comorbid mood disorders, substance use disorders, eating disorders, or post-traumatic stress disorders are also prevalent in this population (Hong 2016). To address their complex needs, current treatment modalities used for people with BPD include psychotherapies (Biskin 2015). These treatments are useful for reducing acute symptoms, such as suicidality, yet system and patient-level barriers exist that prevent proper access and implementation in the community (Reeves-Dudley 2017; Storebo *et al.* 2018). Persons with BPD requiring community care often describe services as ambiguous and poorly integrated (Lohman *et al.* 2017). Furthermore, they report that stigmatization of the disorder and past negative experiences with

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healthcare providers contribute to their avoidance of certain facilities (Lohman *et al.* 2017). Not surprisingly, persons with BPD present to the emergency department (ED) nearly five times more often than the general population for complaints related to their disorder (Brennan *et al.* 2014). Research suggests that these repeat presentations account for nearly 30% of all ED visits, representing a significant financial and human resource burden on an already overextended healthcare system (LaCalle & Rabin 2010).

Generally, individuals who frequently present to EDs for mental health-related complaints perceive their visits to be necessary and unavoidable (Vandyk *et al.* 2018). Reasons for their visits include needing immediate psychiatric care, lack of timely access to community-based options or satisfactory alternatives, and desiring expedited admission to other services (Wise-Harris *et al.* 2017). As a subset of ED patients with mental illness, persons with BPD appear to seek care for suicidal ideation, self-harm, safety, situational crises, depression, anxiety, and substance use (Lawn & McMahon 2015). These patients are received negatively by hospital staff and treated differently than other psychiatric patients (Hong 2016) – labelled as difficult, manipulative, attention seeking, and self-destructive (Mack & Nesbitt 2016). Rogers and Dunne (2011) found that patients with BPD both perceive these negative staff attitudes and receive suboptimal care because of them. Specifically, the participants in their study encountered healthcare providers who made them feel guilty for being unable to control their behaviours, undeserving of hospital beds, and as though they were less of a priority compared to patients with other diagnoses. While this study helps depict the experiences of this patient population, minimal research exists on the topic. To improve ED care for patients with BPD and ultimately ensure they have access to fair and appropriate healthcare, we must first understand why persons with BPD present to the ED, how they feel about the care they receive, and what is needed to improve their experiences. The purpose of this study was thus to engage in a focused exploration of frequent ED use by persons with BPD.

METHODOLOGICAL CONSIDERATIONS

This paper draws on data from a larger research study about frequent ED use in the context of mental illness (Vandyk *et al.* 2018). For the larger study, we recruited individuals with 12 or more visits to the ED of a university-affiliated tertiary care hospital in eastern

Ontario. The overall objective of the larger study was to explore the experiences of persons who frequently present to the ED for mental health-related reasons. For the present analysis, we focused on the interview transcripts of six persons with a primary diagnosis of BPD. The guiding research question was created in collaboration with an individual with BPD, who advocated that ED use was fundamentally different in the context of BPD compared to other mental illnesses. Each participant was interviewed once using a semi-structured guide in the spring and summer of 2016. Interviews lasted approximately 1 hour. We asked participants to speak about their experiences of using emergency services and explored their reasons for presentation, their impressions of the care they received, and encouraged them to speak freely about anything they deemed relevant to their healthcare use. Interviews were audio-recorded and transcribed verbatim for analysis.

Methodological processes assigned to interpretive description (ID; Thorne 2008) guided this analysis, as well as the larger study. This method of inquiry involves an inductive approach to investigate phenomena relevant to clinical practice in the context of healthcare delivery (Thorne *et al.* 2004). ID uses interpretive naturalistic methodologies and is based on the constructivist paradigm, which assumes the existence of multiple realities. The purpose of this methodology was to produce a coherent conceptual description that advances clinical knowledge through identification of patterns and themes emerging from subjective perceptions (Thorne *et al.* 2004). As with all ID studies, we present both individual variations and commonalities within the phenomenon studied (Thorne *et al.* 2004).

Data analysis

Four team members, including the principal investigator, participated in data analysis. Our process involved two steps. First, to illustrate the reasons for seeking ED care by persons with BPD, we created a flow diagram depicting the common pathways to the ED for the participants. Second, to describe their experiences in greater detail, we conducted a thematic analysis according to Aronson's (1995) method, which included iterative rounds of the following steps: (i) independent initial read of each interview transcript to obtain a general sense of the whole and broad presenting concepts; (ii) independent second read to identify emerging ideas about ED use; (iii) independent extraction of verbatim participant quotes to support the emerging ideas; and

(iv) team meetings to compare ideas and discuss areas of consensus and discrepancy. Once data analysis was nearing completion, we held a final team meeting to discuss the constructed findings, make final adjustments, and agree upon key points for discussion.

Rigour

Research team members have psychiatric and mental health expertise, as well as clinical experience working in psychiatric emergency settings. This enabled an insider perspective to support the understanding of participant perceptions and encouraged thoughtful dialogue between researchers and participants. Following Lincoln and Guba's (Guba & Lincoln 1994; Lincoln & Guba 1985) trustworthiness criteria, during data analysis our team engaged in reflective conversations and met routinely to discuss thoughts and observations. While many of the participants' stories resonated with our understandings and experiences, when we encountered conflicting information, we engaged in disciplined individual and team reflexivity to identify and understand our preconceptions (Thorne *et al.* 2004). When variations in interpretations arose, we explored the logic for these through referencing raw data and discussing our viewpoints. We kept detailed notes of all decisions made during data analysis and included verbatim participant quotes to illustrate the findings. We followed the 21 items suggested in the Standards for Reporting Qualitative Research to guide the development of this article and the reporting of the findings (O'Brien *et al.* 2014).

This study was approved by the University Research Ethics Board and the Research Ethics Board at the participating hospital. Prior to the beginning of the interviews, informed verbal consent was obtained and captured on each participant's encrypted audio file. A protocol was in place in the event that a participant required acute mental health care at the time of – or subsequent to – the interviews (for complete information, please see Vandyk *et al.*, 2018). Only the research team accessed data, which were stored on encrypted devices. Everything study-related is kept in a locked cabinet, in a locked office, and will be retained for a period of 10 years and then destroyed appropriately.

RESULTS

Participant characteristics

There were six participants in this study, five identified as women and one identified as a man. The participant's

ages ranged from 22 to 66 years. All six participants indicated a primary diagnosis of BPD, five reported having a concurrent substance use disorder, and two identified having a history of trauma. During the 12-month period, the participants made between 13 and 27 visits each to the ED. One participant was employed at the time of the study, and five participants reported previous employment or participation in volunteer work. All participants had a family practitioner and three participants received care from a psychiatrist.

Pathways to the emergency department

Figure 1 illustrates the common pathways to the ED described by the participants. Based on our analysis, visits to the ED were prompted by three common occurrences: (i) aggressive or disorganized behaviour (leading to police involvement and involuntary presentation to the ED), (ii) medication seeking (leading to self-referral to the ED), and (iii) intense emotions such as loneliness and negative self-perception often triggered by loss. In these latter instances, the participants described progressing through two distinct trajectories. They either attempted to seek support through community-based crisis services or attempted to use self-management strategies. When community crisis services were insufficient to meet their needs, the participants opted to self-refer to the ED for support, viewing this as the only remaining option. Self-management strategies, on the other hand, tended to include risky behaviours such as substance use, self-harm, or suicidal actions aimed at distracting them from their intense emotions. However, these risky behaviours often escalated and participants reported that they frequently resulted in either police or ambulance involvement (and subsequent involuntary escort to the ED) or self-referral to the ED.

Cyclic nature of emergency department use

The participants described their perceptions and feelings about themselves and their lives through their explanations of their ED use. This self-reflection highlighted a pattern of emotional and situational cycles that mirrored their ED visits. While the participants spoke about wanting a more stable life: 'I wish I could live a normal life without feeling like I'm going to whack myself' (2: 327–328), they felt powerless to alter their course: 'But I've lived through it time and time and time again. And I'm sick of doing that, because nothing's better afterwards' (6: 740–743). All

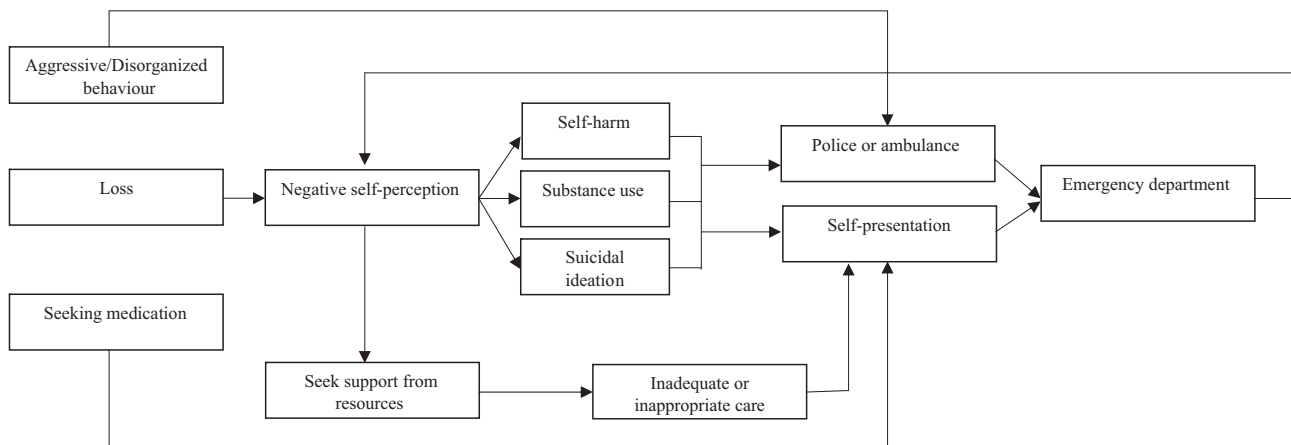


FIG. 1: Pathways leading to emergency department use as described by participants.

participants worried that if they did not change their ways, they would die: ‘I’m actually scared I’m going to end up killing myself one of these days, like I’m actually scared about that’ (4: 736–737).

The participants explained how feelings of loneliness or experiences of loss perpetuated a state of mental deterioration that ultimately led to an ED visit. Feeling lonely, at times, resulted in the participants purposefully connecting with emergency services such as crisis lines: ‘I called 911 and talked to somebody, I wanted to talk to somebody’ (2: 17–18) or the ED: ‘I think that’s why I am going to the hospital. It is because I’m living alone, because I get really lonely at night’. (3: 614–617). Other times, loneliness led the participants to engage in risky behaviour that eventually culminated in a visit to the ED: ‘It’s weird because I’ll start drinking to deal with the loneliness, and then when I get to a certain intoxication point, I’m like “oh my God. This is why I am really lonely”. I freak out and I’m like “oh my God, I’m dying”. And then I’ll call the ambulance’ (3: 493–502). Feeling connected to others insulated the participants from needing emergency care: ‘I find that if I’m around people I’m fine. I mean, I still feel suicidal but it’s not as bad’ (2: 441–442). However, lost relations prompted more intense ED use: ‘I started going more [to the ED] after I stopped talking to my ex because, despite how bad things were, he was my main support for four years. He was like my best friend. We were really close’ (3: 926–930).

Professional relationships were also important for maintaining the participants’ community tenures: ‘Yeah, they [community service] forget all the rules and stuff. Their CEO [name], she’ll actually see me in a minute’s notice’ (6: 132–133). Unfortunately, all participants

described how existing services were unable to meet their complex and persistent needs. For some, this was because of the challenges they had managing their concurrent disorders: ‘But the only problem is like when you have concurrent disorders, it’s really hard for them to manage them both at the same time’ (1: 101–104). For others, it was because of the severity of their symptoms: ‘I’ve been at the Centre. They have a group there that I’m a member of. But I have not showed up because, I’m not supposed to walk in there if I’m carved up’ (2: 471–473). These needs, which were too intense for the community care available, led to ED use: ‘I do have my psychiatrist. Well, she doesn’t do emergencies. So she does the trauma clinic and if things aren’t calmed down by the end of my appointment. What do I do? I end up going to the hospital’ (6: 249–255) and ‘So now I’m looking for extra supports and in that time period [when worker is away] I go to the hospital maybe 25 to 35 [times] in that three months’ (3: 634–638). Moreover, the participants experienced lengthy waitlists: ‘So that’s one of the things that I’ve had challenges with and it took me a long time to find the right supports. I’m just finally getting there and I’ve been trying for 4 years’ (5: 95–97), and the persistent nature of their problems meant their supports were often terminated regardless of their ongoing needs: ‘I had a CMHA worker through the outreach program. But that term was only supposed to be ten months and we went fourteen and she couldn’t stay any longer’ (6: 120–121). Finally, half of the participants reported that being well enough to work, go to school, or live in their own homes, also precluded them from accessing community services, thus limiting their options for out-of-hospital support: ‘No links to other

services, because I'm too high functioning; I live in my own house' (6: 1752–1753).

Once in the ED, the participants experienced negative reactions from healthcare providers: 'Anytime that I've come in and I've been intoxicated and I've been hurting myself, I really get treated not very kind. [They] rolled their eyes and like say "why did you do this to yourself? You just took yourself apart so that we'd have to put you back together"' (1: 265–267). For some, simply having a diagnosis of BPD was enough for healthcare providers to dismiss their needs: 'I can't talk about my medical health, as soon as they punch me in the computer, they want to know, most of the time they want to know if I'm suicidal. Yes I'm suicidal all the time' (2: 138–140) and 'Because I find that some nurses all they do is look at my chart and they look back at [psychiatrists] BPD thing and that's how they treat me' (6: 1429–1431). This negative judgement was particularly challenging for the participants, who described themselves as superfeelers: 'So, like really I'm just sensitive to people's emotions and just entering a room, just getting the feel that like, you know, I can sense very quickly like if it's off and I always had that when I was like even younger. And then it just affected my relationships a lot' (1: 79–82). Consequently, the participants expressed intense feelings of shame, resulting from their ED use: 'There's been times when I've felt like the lowliest person in the world. So I'm always there and I'm so apologetic and I'm so embarrassed, you know?' (5: 296–301) and 'It was like more the next day, the shame and the guilt of like having to face people, that was hard' (1: 383–384). At times, these intense negative emotions resulted in a continuation of their distress, ultimately leading them to re-initiate ED care.

Coping skills and strategies

Although the participants described much of their ED use as inevitable, they did employ coping mechanisms to minimize their visits when possible. Some of these coping mechanisms were productive, such as seeking connections: 'I mean I'll go play chess or I'll play crib or I'll play euchre but it's only at certain hours of the day and then they're closed and that's it. If I'm not around people I'm sorry but I'm out to hurt myself' (2: 457–459) and 'If it's might be between Monday and Friday during the day, I can go see the clinical supervisor and they know to engage me in conversation and it distracts me enough' (6: 695–709). Other strategies employed were self-destructive, yet exercised in an attempt to avoid the ED: 'I haven't been there lately

for any suicidal stuff because I just hold that emotion in and do drugs or cut to let it get out' (4: 408–409) and 'I get out of bed, but I just watch TV the whole day. And sometimes people are like "well how can you do that?" I'm like "you know what? I'm safe and that's all that matters to me". And it's like you know what, if me watching TV for a whole day is going to keep me safe, it'll keep me calm and have me feel not afraid, who cares what you think' (3: 547–550). Given their plethoric ED use, the participants explained how, despite their best efforts, their reactions to stressful events were unpredictable: 'I'll either freak out about it or I'll deal with it properly, or I'll go hurt myself' (4: 593–594); thus, they were unable to consistently employ productive coping mechanisms and avoid frequent trips to the ED.

The participants offered several concrete suggestions to improve both their ED use and their healthcare generally. These suggestions included (i) continuing education for healthcare professionals about BPD and the associated care; (ii) increased social interactions with peers who understand their diagnosis; (iii) improved access to available resources, at time when they are most needed – specifically through the night; (iv) access to a self-referral 'safe place' if feeling suicidal, without option for hospitalization or police involvement; (v) opportunities to learn and practice social skills; (vi) an updated, consolidated list of local community resources; and (vii) empathetic, nonjudgmental care that provides validation and understanding.

DISCUSSION

Stigma

Persons with BPD report being stigmatized by healthcare providers and treated differently than others because of their diagnosis (Aguirre 2016; King 2014; Sulzer 2015). Participants of this study echoed these experiences, which caused them distress when seeking ED care. Contrary to expected therapeutic interactions between patients and clinicians, research findings support the notion that patients with BPD are cared for differently. Sulzer (2015), for example, found that most healthcare providers describe patients with BPD as 'difficult' and a 'pain in the ass' (p. 8). According to their findings, many clinicians dread caring for patients with BPD (Hong 2016; Morris *et al.* 2014; Sulzer 2015) and healthcare providers identify manipulating, attention-seeking, and rule-breaking behaviours as traits that make a patient difficult or undesirable (King 2014;

Sulzer 2015). Interestingly, these behaviours are also clinical symptoms associated with BPD. It is important for healthcare providers to understand that these labels, which justify negative impressions of and reactions to these patients, are simply manifestations of the disorder itself (Aguirre 2016; Sulzer 2015).

Persons with BPD have a limited capacity to cope with strong emotions and stressors, and often they struggle to engage in healthy interpersonal relationships. These factors lead to impulsive and destructive behaviours largely outside of the person's control (Aguirre 2016). Despite this, healthcare providers continue to believe that persons with BPD chose their behaviours. This places blame on the patient and perpetuates the stereotypes and stigma experienced by these persons (Sulzer 2015). As indicated by our participants, educating healthcare providers about BPD is important (Aguirre 2016) and research suggests that appropriate clinical knowledge leads to better care for patients with BPD (King 2014). Education interventions exist, and a recently tested anti-stigma continuing education programme, for example, was effective in reducing expressed stigma and improving staff attitudes towards patients with BPD (Knaak *et al.* 2015). Given the volume of ED visits related to symptoms of BPD, educators are encouraged to provide opportunities for learning about the complexity of the disorder and embed evidence-informed practices that remove the use of judgmental language and encourage compassion when caring for these patients.

Strategies to increase connections

Feelings of intense loneliness for persons with BPD is a well-studied phenomenon (Hauschild *et al.* 2018; Liebke *et al.* 2017; Sagan 2017), and our participants reported seeking connections with others through emergency services in response to this emotion. Persons with BPD are more socially isolated; they display fewer diverse roles within their social networks and have lower social functioning than the general population (Liebke *et al.* 2017). Research findings suggest that even after controlling for these factors, persons with BPD continue to feel lonelier than others (Liebke *et al.* 2017). Clearly, this loneliness is a deep-rooted and complex issue and persons with BPD need opportunities to engage in and practice healthy, positive social interactions (Hong 2016; Morris *et al.* 2014). Interventions that aim to improve connections for persons with BPD exist, such as community-based group therapy, peer support, and life-skills programmes. Often, these

interventions target quality of relational interactions by developing stronger interpersonal skills and higher social functioning through psychotherapy (Bowen 2013; Gillard *et al.* 2014). Our findings suggest, however, that strategies to minimize loneliness for persons with BPD should aim to increase both quantity and quality of their connections. Research supports this multipronged approach and highlights the need for multiple opportunities for the person with BPD to engage and re-engage in the available services (Gillard *et al.* 2014). Finally, understanding that persons with BPD experience intense feelings of loneliness that precipitate their ED visits is important when providing care. Nurses, through their therapeutic interactions, should use these opportunities to model communication skills and appropriate social exchanges.

Falling through the cracks – services that do not work

Having a concurrent substance use disorder was a barrier to accessing services and receiving appropriate healthcare for the participants of this study. They desired care that responded to both their mental health and substance use concerns. They articulated, however, that existing services were mutually exclusive, unable to meet their needs, and thus contributing to their prolific ED use. This situation is common, despite evidence that integrated treatments are most effective for concurrent disorders (Drake *et al.* 2008; Samokhvalov *et al.* 2017; Ziedonis *et al.* 2005). Conventionally, clinicians care for either persons with mental illness or addiction, each within their own specialty. This format leads to discontinuous care and poor patient health outcomes (McKee 2017). Given the strong connection between substance misuse and seeking ED care described by our participants, services that allow for both flexibility and compatibility of care for these two interconnected and complex issues are required.

Participants of this study also faced long wait times for services. While estimated wait times differ by jurisdiction, persons with nonurgent mental health needs tend to wait months – not days or weeks – for community follow-up. Persistent, problematic symptoms of BPD, such as mood instability and problems with social functioning, typically fall within this nonurgent category (Storebo *et al.* 2018). Innovative solutions are needed to meet patients' needs while they wait for formal community care. Strategies including the use of eHealth, warrant further exploration, though current evidence of their effectiveness is promising (Kudlow 2013). For

example, in a pilot study of a BPD eHealth tool that provides tailored communication and education through messages and activities, Fassbinder *et al.* (2015) reported a significant decrease in BPD-related symptoms after 6 months of use – though more rigorous testing is required to determine true effectiveness. Furthermore, urgent care facilities for psychiatric needs provide a safe alternative to ED care for patients experiencing acute and persistent psychiatric symptoms. Research findings indicate that patients who utilize urgent psychiatric care are more satisfied and have improvements in their symptom severity, distress, psychosocial functioning, and ED use (Sunderji *et al.* 2015). These services present viable alternatives to EDs for persons with BPD.

Limitations

The credibility of qualitative research findings is dependent on the accuracy and extent of disclosure of participants during the interview process. Given the negative interactions lived by our participants and the known stigma encountered by persons with BPD who present to the ED, it is possible that our participants opted to withhold or modify their recounts regarding their experiences. Secondly, our participants were predominantly Caucasian females, recruited from a small geographic region. This limits transferability to persons with BPD living in other regions or representing other cultures. Finally, inclusion criteria did not demand a set time between ED visits and enrolment in the study. We found that participants with recent ED care focused on their last visit when interviewed while those with a longer gap between the interview and ED care presented a more global summary, though similar patterns were evident in each type of recount.

CONCLUSION

Persons with BPD present frequently to the ED for reasons related to their mental illness. The participants of our study identified a desire for human interaction and feelings of loneliness, failure of other resources such as crisis lines or therapy, and safety concerns following suicidal ideation, self-harm, or substance use as the main drivers for their ED visits. The patterns of ED use by our participants were cyclic in nature involving unstable community management leading to self- or crisis presentation to the ED and the ensuing interventions aimed at acute stabilization. In most cases, participants described being discharged from the

ED without proper or targeted follow-up community care, which inevitably resulted in a continuation of the cycle of repeated ED use. Unfortunately, it appears as though persons with BPD often fall through the cracks of the healthcare system and fail to receive adequate care. Effective community-based strategies aimed at improving connections and decreasing loneliness for persons with BPD might mitigate some ED use for this population. More work is needed to understand the best way to implement these approaches. When in the ED, persons with BPD face stigma from healthcare professionals and experience negative attitudes affecting their care. Better education and training is required for healthcare professionals to reduce the negative connotations associated with this disorder. Finally, the participants provided several concrete suggestions for how to improve their health and ED use. These suggestions should be carefully considered as opportunities to create strategies responsive to the needs of persons with BPD.

RELEVANCE TO CLINICAL PRACTICE

Providing ED care for persons with BPD is complicated, and often visits by patients with this mental illness are perceived as unnecessary and wasteful. Yet, persons with BPD continue to rely heavily on emergency care and are among the most frequent presenters to this service. Our findings shed light on the cyclical nature of their ED use, including key patterns that may form the basis for more tailored and effective community care. Our participants also stressed their desire to avoid the ED because of the stigma they experienced from healthcare providers, which further perpetuated their negative sense of self. While this finding is not novel, it further emphasizes the need to fundamentally shift the perceptions of, and actions towards, persons with BPD to ensure their equitable access to good health care.

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