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Does “difficult patient” status contribute to functional demedicalization? The case of borderline personality disorder

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Abstract

A diagnosis of Borderline Personality Disorder (BPD) often signals the quintessential “difficult patient” status to clinicians, with at least one scholar arguing the condition itself was created to name and group difficult patients. While patients who are deemed difficult are often dispreferred for care, does this have an impact on their overall status as medicalized patients who have successfully achieved a sick role? This study relies on (n=22) in-depth interviews with mental health clinicians in the United States from 2012 to evaluate how they describe patients with BPD, how the diagnosis of BPD affects the treatment clinicians are willing to provide, and the implications for patients. My findings suggest patients with BPD are routinely labeled “difficult,” and subsequently routed out of care through a variety of direct and indirect means. This process creates a functional form of demedicalization where the actual diagnosis of BPD remains de jure medicalized, but the treatment component of medicalization is harder to secure for patients.

Keywords

USA; Borderline Personality Disorder; Medicalization; Difficult Patient; Mental Health; Access to Care; Doctor/Patient Communication

Introduction

Borderline Personality Disorder (BPD) and “difficult patient” status are intimately linked. One study found that “psychiatrists mentioned the diagnosis of Borderline Personality Disorder up to four times more often than any other diagnosis when asked about the characteristics of difficult patients” (Koekkoek, Meijel & Hutschemalkers 2006:797). Several more have indicated that almost all difficult patients have “borderline personality organization” (See Koekkoek, Meijel & Hutschemalkers 2006, Group for advancement of psychiatry 1987; Fiore 1988; Schwartz & Goldfinger 1981). The very symptoms and behaviors associated with BPD are linked with how providers define the “difficult patient.” Kelly & May (1982) found that behaviors such as mutilation, chronic illness, rule-breaking

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behavior, aggressive, uncooperative or won't accept care, or need too much care, and are destructive, willful, attention-seeking and manipulative have been linked with negative attitudes toward patients. All of these descriptors have been applied to patients with BPD (See Luhrmann 2000; Nehls 1998, Nehls 1999). Manning (2000) has even argued that the category of "Borderline" emerged as a label to group patients perceived as difficult. Research spanning twenty years suggests providers continue to find clients with Borderline Personality Disorder more difficult than other mentally ill populations, including patients with schizophrenia (see Gallop, Lancee & Garfinkel 1989; Treloar 2009). The reasons for this association are generally explained by providers as being a result of patient behaviors.

Under the DSM IV, which was in use during the data collection of this study, to receive the BPD diagnosis, a patient had to meet five of nine criteria that include self-harming behavior, a history of unstable and intense personal relationships and dissociative episodes, or breaks with reality. (The DSM 5 definition incorporates minor wording adjustments). The criteria are (APA 1994:654):

A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

1. frantic efforts to avoid real or imagined abandonment. **Note:** Do not include suicidal or self-mutilating behavior covered in Criterion 5.
2. a pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.
3. identity disturbance: markedly and persistently unstable self-image or sense of self.
4. impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating). **Note:** Do not include suicidal or self-mutilating behavior covered in Criterion 5.
5. recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior
6. affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).
7. chronic feelings of emptiness
8. inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights)
9. transient, stress-related paranoid ideation or severe dissociative symptoms.

Recent estimates suggest a lifetime prevalence of 5.9% of the population or 1.4% at any given time in the United States (Grant et al 2008, Lenzenweger et al 2007). Carefully controlled trials show that patients with BPD are just as treatable as patients with Major Depressive Disorder, the most common diagnosis in the United States (Gunderson et al 2011). Zanarini et al (2010) found at a two-year follow-up 34.9% of patients had achieved

remission (defined as not meeting criteria for a two-year period), and at a ten year follow-up 93% no longer met criteria for the disorder. The most prominent evidence-based treatments for BPD are Dialectical Behavioral Therapy (DBT) (see Linehan 2001, 1987, 1993), Mentalization Based Therapy (see Choi-Kain & Gunderson 2008, Bateman & Fonagy 2009) and Transference-Focused Psychotherapy (see Clarkin et al 2007). Nonetheless, 3–10% of patients with a BPD diagnosis die from suicide (Soloff 2012) and one study found more than 70% attempted suicide (Soloff 2000).

This article uses Borderline Personality Disorder as an ideal-type case from which to examine “difficult patient” status as it relates to demedicalization. This article will first explore what the consequences of “difficult patient” status are in terms of care provision and treatment. And second, it will address the linkage between “difficult” patient-hood and de facto demedicalization.

Literature Review

Scholarly discussion of “difficult patients” goes back at least to 1970, when Papper suggested that physicians must work to address their failures with patients they found hard to work with or had trouble treating. While the original scholarship focused on patients as being objectively or inherently difficult, I use quotes around the term: later writers concluded that there was little objective, empirical basis for whom constituted a “difficult patient” or why. Kelly & May (1982) found that much of the literature attributed difficulty to specific patient behaviors. However, they also found that these studies lacked external validity, focused mostly on staff opinions, not actual patient behaviors, and that social structures were absent from analysis. Koekkoek, Meijel & Hutschemalkers 2006:798 presented similar critiques in their review two decades later. “In these studies, professionals were asked to rate the difficulty of certain behaviors, dependent on the patient’s diagnosis. Patients who were diagnosed as having borderline personality disorder were judged more negatively than were patients with other diagnoses—schizophrenia for example—although their difficult behaviors, such as expressing emotional pain or not complying with ward routine, were equal.” Therefore, historical arguments that “difficult patient” status was dependent upon specific patient behaviors have not held up. This has weakened the utility of the “difficult patient” construct in theoretical discussion since why it is attributed or what it fundamentally implies remains unclear. In more recent research, Koekkoek et al 2011:1050 created a model based on survey data suggesting that the primary explanatory variable in describing a patient as difficulty was “professionals’ subjective perceptions of patients.” They also found that patients having a larger number of problems and intensive service use were also important. This suggests that the structures in which patients are treated and clinicians’ ability to effectively help a patient may be closed tied to the “difficult” label. However, this study excluded psychotic disorders, and therefore cannot explain why, for example, patients with Schizophrenia or Bipolar disorder are perceived so differently from patients with BPD, even when they do exhibit similar behaviors.

What does difficult patient status mean then, and how can we best empirically evaluate this meaning? If two patients with different diagnoses can behave in the same way, but one will be labeled difficult, and the other not or less so, then what exactly does the word signify?

Providers say they use the label “difficult” to signal that a given patient is behaving badly, and yet they do not actually bestow the label based on patient behavior, but rather, diagnosis. Since the provider-based explanations do not add up, what purpose does the label serve? By introducing other theoretical perspectives, the *work* of the difficult patient label may become clearer. On the simplest level, diagnoses generally operate to categorize someone as sick, rather than morally deviant—though these may not be mutually exclusive. A diagnosis also generally reduces stigma, by invoking the sick role (Davis 2009). However the sick patient labeled as “difficult” does not receive the benefit of reduced stigma. In fact, it is precisely their “difficult” sick role which stigmatizes them. In the case of BPD this may be particularly salient because stigma related to BPD may be largely contained within the healthcare system (Bonnington & Rose 2014).

The process whereby stigma is reduced (or not) through diagnosis is encapsulated in the literature on medicalization. Medicalization is often described as a mechanism for shifting non-medical deviance to medical deviance, often with an accompanying reduction in stigma (See Conrad & Schneider 1980, Conrad 2005, Conrad 2007). This suggests that one particularly fruitful area for understanding the impact of the “difficult” patient status lies with de/medicalization and the shift from morally deviant to medically deviant. Zola however (1972) viewed the distinction as grey, arguing that patients who might have previously been considered morally deviant may only achieve a tenuous level of morality with their sickness. He suggested that the line between moral deviance or badness, and sickness or madness, are much more fluid than they appear to be in the “badness to sickness” polarity. For patients categorized as “difficult” this may be especially true; they may highlight this fluidity most clearly. The relationship then between difficult patient status and medicalized status bears scrutiny, as they may be linked in important ways.

To give context to the frame of medicalization, the definition was crystallized by Conrad in 1975: “defining behavior as a medical problem or illness and mandating or licensing the medical profession to provide some sort of treatment for it,” and drew from Zola (1972) and Parsons (1951). To clarify this distinction, I have named the two components of medicalization using terms familiar to race and legal scholars, the first is definitional (de jure) and the second, treatment-related (de facto). De jure medicalization is *defining* something as medical, and de facto is *treating* something as medical. Beginning in 1992, Conrad introduced a separation between the de jure and de facto components, which he subsequently maintained. Medicalization is “a problem is defined in medical terms, described using medical language, understood through the adoption of a medical framework *or* treated with a medical intervention,” (2007:5; emphasis added). Going forward, definitions and treatment were not both required for medicalization to occur, and many scholars began to focus primarily on the former. Conrad summarized that the “essence of medicalization became the definitional issues,” (2005:3).

This is problematic on a number of levels, with the consequences born out in an increasingly inclusive, yet theoretically weakened medicalization literature (see Halfmann 2006). The result has been a series of case studies that often rely on the presence or absence of a definition as an indication of de/medicalization (See Conrad 2005, Frances 2013) or the presence or absence of a specific treatment as an indication of de/medicalization (See

Williams 2004, Hislop & Arber 2003, Tiefer 2012, Rosenbaum 1995, Salcido 2004, Wikler & Wikler 1991). This past work then also is limited in that de/medicalization is not seen as a process that unfolds over time as medically classified behaviors, attitudes or identities shift into other frames of understanding (such as moral failings). This is the subtle reframing the data in this paper will speak too, thereby addressing micro-level elements of demedicalization.

The separation of medical practice from medical definitions as important markers of medicalization offers a limiting lens for viewing medical power. Davis makes this point succinctly: “medicalization and medical social control involve medical supervision and treatment. This dimension of medicalization has been analytically downplayed in the literature, the definitional issue made primary... However, medicine is an applied field,” (2009:220). Allowing either de jure or de facto evidence to justify the categorization of medicalization misses this important connection. While definitions may inform practices or constrain them, the two are also not interchangeable or inevitably linked. For example, if a condition exists in the DSM but clinicians ignore it and insurance doesn’t provide coverage (such as for caffeine addiction) then the definitional and the treatment components are divorced. Conversely, post-partum depression is widely treated and is not an official DSM category. In this case the treatment component and the definitional component are again distinct---yet both remain important indicators of medicalized status. This distinction between de facto and de jure components of medicalization is salient because demedicalization has not receive the same theoretical treatment as medicalization. For the “difficult” patient these lines may be especially blurry.

When specifically examining the issue of demedicalization, Conrad maintained his earlier requirement of de facto *and* de jure, stating that demedicalization “does not occur until a problem is no longer defined in medical terms *and* medical treatments are no longer deemed to be appropriate solutions,” (1992:224; emphasis added). Demedicalization continued to face a higher bar than medicalization (Davis 2006) and also continued to be viewed as an all-or-nothing category (Halfmann 2006).

Unfortunately, this didn’t lead to conceptual clarity within the demedicalization literature, as the inverse of the medicalization definition was implicitly adopted. Here too is a field of case studies, not always speaking directly to one other despite employing a similar theoretical language. Scholars were unable to agree on whether specific practices or diagnoses, such as sleep or child birth were being medicalized or demedicalized (see Halfmann 2006; Hislop & Arber 2003; Williams 2004).

However, this lack of internal understanding may be explained by the origins of demedicalization research. Even the most well-known example of demedicalization does not technically meet both of Conrad’s requirements. Homosexuality was removed from the DSM-II, making it de jure demedicalized. However, as late as 2003 prominent psychiatrist Robert Spitzer was still researching gay conversions and at least through 2007, homosexuality remained “treated” with medical interventions by some psychiatrists (Conrad 2007). Robert Spitzer, DSM III and IV architect, published a prominent peer-reviewed article about the treatability of homosexuality 30 years after the condition had been removed

from the DSM-II (Spitzer 2003). He has recently rescinded his findings on the grounds of methodological issues (Spitzer 2012). Ultimately, this DSM author did not consider DSM status a compelling indication of what should be considered sickness.

This illustrates the larger point that medical labels and treatments are determined across a variety of sites by a variety of people who are unlikely to be entirely in agreement because medicalization is a *contested process* rather than an absolute category. There are important unanswered questions in Conrad's definition: medical treatments are no longer deemed to be appropriate by whom? And not defined in medical terms by how many and where? If the ideal case example of homosexuality does not strictly meet the definition of demedicalization, surely this is a reason to either reconsider the precision of our definitions as Davis (2009) has proposed, or to recognize that de/medicalization are not absolute states, but partial occurrences as Halfmann (2006) has argued; and perhaps both.

In the context of the "difficult patient," this issue is particularly salient. These patients may be canaries demonstrating where physician-based social control is breaking down. It is important to recall that Conrad & Schneider (1980:240) invoke deviance to elucidate how "medicine, especially psychiatry, has replaced religion as the most powerful extralegal institution of social control." As "difficult" patients are functionally removed from medicalized status, they illustrate Zola's (1972, 1975) argument that medicalized categories may only superficially paper-over moral deviance. Since "difficult" patients toe the boundary of patienthood as dispreferred medicalized entities whose stigma is not reduced through the sick role, they offer the opportunity to examine this phenomenon. Given the ongoing classification of patients with Borderline Personality Disorder as the quintessential "difficult patients," BPD represents an ideal case within which to study the relationship between "difficult patient" status and de/medicalization and stigma. First, what are the consequences of "difficult patient" status in terms of care provision and treatment? And second, can "difficult" patienthood be linked to de facto demedicalization?

Data and Methods

Data Collection & Sampling

I conducted in-depth interviews with clinicians to reconstruct their diagnostic process and how they conceptualized the nature of the patient with BPD. I conducted interviews with 22 clinicians or BPD experts: 7 psychiatrists, 8 psychologists, 5 Licensed Clinical Social Workers (LCSW's), and 2 BPD activists. Interviews ranged in length from 30 minutes to three hours, averaging about one hour each.

Clinicians were recruited using purposive and snowball sampling. I solicited participation through my personal and professional network, as well as through referrals from other clinicians. In order to avoid overlapping perspectives from the same reference group, I interviewed up to two additional clinicians from any one clinician referral source. Respondents ranged in career level from clinical residency to nearing retirement and practiced in either public or private in-patient or out-patient settings. Participants included an emergency room intake psychiatrist, a director of a major psychiatric center, a Veterans

Affairs hospital staff clinician, those in private practice, others working in a university hospital setting and more.

All professional interviewees had direct clinical experiences with patients diagnosed with BPD. Areas of clinical expertise or specializations ranged from Cognitive Behavioral Therapy to Jungian Psychotherapy to Dialectical Behavioral Therapy. Interviews took place in person or over the phone. Each interview was recorded and fully transcribed. Interviews included clinicians from Wisconsin, New York, Maryland, New Jersey, North Carolina, Mississippi, Pennsylvania, Alaska, Illinois, and Minnesota. Interviewing continued until no new themes emerged across several interviews, a juncture termed sample saturation in Constructivist Grounded Theory (Charmaz 2006). Written, informed consent was given by all participants. This study was reviewed and approved by the University of Wisconsin-Madison Institutional Review Board.

Interview Content

Interviews were semi-structured and focused on the diagnostic encounter. Clinician training and education were established first, followed by an account of how they first became aware of borderline personality disorder. Subsequent questions focused on how they identified if patients had BPD, what a typical diagnostic encounter was like, and how easy or difficult the diagnosis was to make. Next, they were asked to discuss what steps they took after making a diagnosis, including informing the patient, and filling out insurance or charting forms.

Coding

Interviews were transcribed and coded using an iterative process dictated by Constructivist Grounded Theory (Charmaz 2006, Charmaz 2014). Segments of interviews were sorted into different categories until the categories accounted for all variations in the data. Codes were refined and reformulated through a process of incorporating more interviews into the coding structure. With each addition of data, codes were reconceptualized as needed, or validated by the data at hand, until all of the interview data fit within a clear coding scheme. Data were then organized by codes, such as “clinician perceptions of patient feelings” and “communication of stigma” and I analyzed variations within each code to understand the nuance and range of grouped responses. Some codes were readjusted in this process so that variations were more clearly explained by codes. This process was initiated manually, and ultimately assisted through N*Vivo. For the purposes of this article, I focused exclusively on how providers *described* patients with BPD in order to evaluate clinical perceptions of patients as a general group. Codes were then connected to the broader literature in the course of writing this article.

This study has some limitations: it represents a small grounded-theory sample of providers within one national healthcare system. The generalizability of these findings cannot be guaranteed, and these micro-level data cannot by themselves prove a macro-level phenomenon. Additionally, this study does not incorporate data from patient experiences. Explicit comparison of BPD to other personality disorders are missing, but could illustrate to what extent this condition is unique or if these issues relate to personality disorders or other chronic health conditions more generally. Finally, intermediary social structures such as

managed care companies and the availability of pharmaceutical interventions remained outside of this analysis and must be examined more in-depth in future research.

Results & Discussion

Past research indicating that providers found patients with BPD undesirable and “difficult” was consistent with reports in my data (see Manning 2000). As one psychiatrist summarized: “In professional circles, borderline is often synonymous with ‘pain in the ass.’” Another LCSW opined “Well, they’re probably like the least popular patients to work with. Most people don’t like working with them. It’s too much work.” Part of this undesirability is linked to perceptions of how difficult these patients are to treat. One psychologist explained, “I know it’s going to be difficult to interact with them...they’ll probably get on my nerves.” The amount of work treatment involves is also a frequent concern. “They’re very taxing... patients because they call you all of the time,” a psychiatrist said. Furthermore, clinicians referenced the likelihood that treatment would not be effective. A psychologist summarized: “Not a whole lot of rewards come from beating your head against the wall with someone.”

While my interview questions focused on BPD, clinicians often volunteered the impression that this group was harder to treat than others. One provider shared an anecdote that “a schizophrenic³” may throw a chair at you too, but with “the schizophrenic,” it’s not their fault and you have sympathy, whereas with “the borderline,” you think they should be able to control themselves. This connection between behavior and responsibility for behavior linked with this specific diagnosis was found in past research as well (see Nehls 1998, Nehls 1999, Bonnington & Rose 2014). I will more deeply explore this link between patient responsibility and untreatability after discussing the outcomes of this belief-set.

Denial of Treatment

The main outcome of clinician beliefs that patients with BPD were difficult and possible at fault for their behaviors is that they often passively or actively denied care. The refusal of care is one means of denying one of the most fundamental sick role rights: access to treatment. “That’s why I think about that [BPD] as stigmatizing, you know? That others will look at that [diagnosis] and just give you or say, ‘you can’t really do treatment.’” Another echoed “I mean, I have a couple of colleagues who are right in there with me for sure. But they’re hesitant to provide that treatment.” Clinicians linked this back to the “difficulty” of these patients. “I think there’s a lot of misconceptions and again, I think it plays out to how people get treated and makes you look at the other side of that---why so many clinicians will literally tell you they will not treat people with borderline.”

The majority of providers described in my sample openly excluded the BPD patient population from care. “Colleagues don’t touch it,” one provider reported. All clinicians who described seeing these patients had stories of interacting with colleagues who didn’t understand their decision. “I mean, and they [colleagues] literally said ‘I won’t put any borderlines on my case, are you crazy? You treat people with borderline? Are you nuts?’” A director of a major psychiatric center who worked with patients across his career said “I remember when I first started doing this, nobody wanted to work with borderlines at all, and

they'd send them to me because I was okay with working with them... you know this isn't a terminal illness that you're stuck with."

This finding was also found by Bonnington & Rose (2014) who stated "many of those diagnosed with BPD were powerless to resist exclusion from treatment. These beliefs persist despite extensive evidence suggesting that a variety of treatment modalities, including Dialectical Behavioral Therapy (DBT), and mentalization based therapies can effectively treat BPD. Borderline patients retain a reputation for "untreatability," (Gunderson 2008, Bateman and Fonagy 2009). This view that patients with BPD are untreatable continues to be espoused by many clinicians in spite of effective and widely recognized evidence-based medicine. This pattern used to also exist in the UK, but has since shifted to a more evidence-based perspective (see Pickersgill 2012). Importantly, providers are not suggesting that patients will not get better because they will be unable to access care, or because of some structural factor that would prevent them from using evidence-based treatments, or because there aren't clinicians available to provide treatment. Most clinicians reported being familiar with DBT. Rather, these quotes from within my sample are about how despite evidence-based treatments, even if they did have access, patients really don't get "better." This is a discourse of untreatability, which makes sense if patients are perceived as manipulative moreso than mentally ill, a topic that will be discussed at length later.

Most clinicians describe this as an overt and active pruning process, where the diagnosis was a direct pass out of treatment. "I've known people that were fired by their psychiatrist because the psychiatrist thought they had BPD." Another said patients often come to her primed, announcing "my psychiatrist told me, you know, they were going to fire me because, uhm, I'm too complicated or I'm too difficult." Another clinician reported that in general, many of her patients with BPD had "been rejected for therapy. Gone in and had an initial visit and the therapist had said, 'sorry, no can do.'" Other providers reported doing this pruning themselves: "I have actually cut back on taking a lot of borderlines, just because they're very labor intensive and I'm kind of pulling back a little bit." Or as another joked, "how do I treat Borderline Personality Disorder? I try to find another clinician (laughter)."

A minority of providers described denying treatment to patients as a more passive, or less widespread process. "I don't know of anyone who says 'oh sorry, I can't treat you,'" one provider shared. Yet she also largely didn't treat this population either, saying "it's not really an area that I care to specialize in, and I certainly don't want to open myself up to you know, that clientele." At the time of her interview, she had only had two patients with BPD in memory on her caseload. She went on to add "the ones [colleagues] I talked to were never happy about it [treating BPD]. I don't really know of anyone that enjoys that kind of work." Other providers set inflexible ground rules for patients with BPD or had them sign a behavior contract that was not required with other clients. As one clinician summarized, sometimes therapists will "set up such rigid conditions, and obviously made such rigid judgments about their behavior that they [the patient] felt so insulted," leading to the termination of treatment. This is striking, because whether passive or active, reports of denying care or making care difficult to access were pervasive across interviews, on the basis that patients with BPD were "difficult." Bonnington & Rose (2014:13) found these practices fell into two categories. "a). [patients'] diagnosis was withheld and so was

treatment or b). they were given the diagnosis but told no treatment was (locally) available.” The denial of treatment to patients with BPD is a pattern that has been consistently found in the literature and has not been logically linked to the actual ability to provide treatment (see Nehls 1999, Ramon et al 2007, Stalker et al 2005 and Hyde 2010). The data at hand suggest this is best explained by ongoing debates about the legitimacy of BPD as a sickness, the culpability of patients for their symptoms, and a discourse of untreatability which retracts sick role benefits and can be understood a process of de facto demedicalization.

Care as Contingent: Manipulative Patients Are Not Truly Sick

For many providers, the decision to not provide care was linked to the impression that patients with BPD were manipulative people who feigned sickness to gain access to attention. “Manipulative” was the most-commonly used adjective to describe patients with BPD among providers in my sample. Even clinicians who did not share the perception that patients were manipulative were nonetheless acutely aware that other providers felt this way. Providers who described patients as “manipulative” seemed to believe patients used a high level of intellectual involvement in orchestrating their deviant behaviors, rather than unintentionally acting out of their madness or sickness. Manipulation then operated as a code-word cuing *morally deviant* status.

One psychologist suggested that “maybe [patients with BPD are] so used to getting whatever they need because of their manipulative skills, that they receive the attention they want from people.” In his view, the end goal of exercising “manipulative skills” is time with or attention from clinicians. On one level, these patient behaviors are seen as a way of dominating the clinician, an inversion of the traditional hierarchy in the clinical encounter. These patients “need something to be able to control in their lives...so it comes again with the manipulation,” said another psychologist. On a more implicit level, this is a behavior, or set of behaviors, over which patients are perceived to have control. “Manipulation” is not a sign of sickness, or of needing help from a clinician, but rather an indication of immoral behavior. In this way, the word manipulation functions as a shaming device, framing patient behavior as moral badness rather than sickness and making the patient personally responsible for symptomatic behavior. This is in contrast to a perceived-biological sickness such as Schizophrenia, wherein the patient might manifest similar behaviors, but would be viewed as legitimately in need of medical help.

Taking this logic further, clinicians seem to openly question if patients with BPD are sick at all. According to Gallop, Lancee and Garfinkel (1989:819) “BPD patients are not perceived (by providers) as sick, compliant, cooperative or grateful.” In other words, symptoms that might be identified in the DSM as symptoms (difficulty regulating emotions or a history of intense and unstable personal relationships) are used to reclassify patients as both “difficult,” and not really in need of medical care. These two claims combined are what make “difficult” status link to immoral status, rather than sick status, leading to the effective re-routing out of care. This is consistent with Nuckolls (1992) who presents a cultural history of personality disorders, situating them within a moral discourse. In practical terms, Gremillion (2003) documented that patients labeled with BPD were denied care in eating disorder clinics. After being marginally, physically stabilized, they were removed from the ward in favor of caring

for other patients who were *actually* sick rather than merely manipulative. These patients with BPD met all of the same markers for anorexia as other patients, but their anorexia was labeled as a form of acting out for attention, rather than a form of sickness, as it was for other patients. Despite identical physical markers, patients labeled with BPD were then denied care because they *weren't actually sick*, even though the diagnosis of anorexia was otherwise made based on physical markers. Patients with BPD must meet standards of illness above other patients.

Discourse of Untreatability

This subtle shift allows clinicians to then operate within what I call a *discourse of untreatability*, since it frames issues with these patients in terms of their morality, rather than their sickness, removing them from the purview of reasonable medical intervention. This absolves clinicians of working with them, and reframes the discussion of what constitutes a mentally ill patient. As one ER psychiatrist described how he thought of a typical patient: “there’s a young female who comes in and she took five aspirin, six Benadryl and put a very superficial cut on her wrist because her boyfriend broke up with her.” In his mind, the typical patient with BPD does not truly need his medical help, because she is not really sick. Once it is called into question if the patient has achieved the terms of the Parsonian sick role (Parsons 1951), he or she may no longer be entitled to the benefits that follow, such as sympathy or health care. Clinicians then may wash their hands. And, as I presented above, many try to. Patients are routinely routed out of care, and their difficulty is marshalled as justification. “Difficult” operates as the code word to legitimize clinicians dismissing some patients. The sum effect of these practices is that many patients are denied care, which has been documented in reports of broader data and scope such as the 2010 Report to Congress on Borderline Personality Disorder (Hyde 2010). However, the logic behind this reluctance to treat based on the claims that patients are manipulating providers for attention remains suspect.

One clinician shared a story of an archetypal patient he had known. As he reported, this woman had been claiming to be suicidal for two years, calling the hospital every single day. The fact that she was still alive indicated to him that she wasn’t suffering from suicidal ideation, but rather was seeking attention, and keeping him from people who were, as he put it “really sick.” This echoes the research of Nehls (1999) who found that clinicians conceptualize cutting and suicidal behaviors among BPD patients as manipulative, whereas patients classify them as a temporary coping method for intense emotional pain. While it is possible that this provider was correct about this patient, another interpretation is that she remained suicidal, because she had not yet received effective treatment, despite ongoing efforts to seek help. The effective suicide rate among persons with BPD is between 3–10% making them one of the most suicidal populations of all mental illness categories (Soloff & Fabio 2008, Linehan et al 2006, Soloff et al 2012). It is hard to reconcile how they could both be the most suicidal patient group, and yet simultaneously perceived as presenting their suicidality as a means to attention. However, with the “difficult patient” label, this discourse of untreatability has a foundation in that suicidal and other behaviors ordinarily related to sickness can be recategorized as moral failings, falling under the umbrella of “manipulation.”

Disrupting the Discourse: Patients as Complex, Pleasant, Treatable

By highlighting providers who do not participate in the dominant discourse, I will demonstrate how this untreatability discourse operates. The above sections depict the stereotypes of a borderline patient, but there are clinicians who have mixed reviews of them as well as positive or constructive perspectives. These less-common clinician constructions of BPD patients as treatable, or even wonderful patients, which challenge the dominant discourse provide an important counterpoint.

Some clinicians valued these patients. As one psychiatrist explains:

I work with a whole group that specializes in [BPD]. We all find it a very interesting and challenging patient population who we like to work with. When I talk to colleagues who are back in the hospital or you know, just general psychiatrists, they often still have this attitude ‘ah, it’s a bad Borderline.’ You know, it’s pretty bizarre.

Several providers insist this population is skilled in different life areas. An activist revealed “any borderline you know is high-functioning. They are emotionally low-functioning.” One LCSW said “a lot of the borderline patients I’ve worked with have been higher level functioning and they’ve usually had, as I mentioned, some talent, whether it be musical or literature or that type of thing.” A psychiatrist agreed that “many of my borderline patients are professionals or successful in other areas.” This way of describing patients was not common, but demonstrates the social-constructedness of their undesirability.

Other clinicians focused on how treatment is effective and possible. Demonstrating not only an awareness of effective treatment options, this psychologist also reframed “manipulative” behavior as a symptom of BPD. “There’s an effective treatment. And most individuals with BPD really, they’re not affecting people’s lives negatively because they want to, or because they’re trying to be manipulative, they just want the pain to go away.” There is a link between seeing patients as both treatable and as sick, rather than as untreatable and morally deviant. While these kinds of statements were relatively less prevalent, they demonstrate that the prevailing view of BPD is not inevitable. The very pieces of evidence which most clinicians in my sample used to categorize patients as not sick, such as suicidality, self-harming behavior and “manipulation,” could also be used to defend patients’ legitimate occupation of the sick role.

And yet, clinicians who consistently described clients with BPD as mentally ill persons who were *not* bad represented only a handful of members of my sample. This is telling, because clinicians willing to be interviewed arguably were more specialized in treatment of BPD than the average clinician, so my sample is likely skewed towards providers who enjoyed patients with BPD. Clinicians who did not interact with these patients at all declined to be interviewed. They providers rebut the dominant untreatability discourse and were among the relatively rare few in my sample who elected to treat this patient group. They rejected the idea that patients with BPD were inherently more “difficult” than other patients, and were more likely to describe patients as both sick *and* treatable. This suggests that the dominant practice of denying care is very likely linked to perceptions of clients as morally at fault for their behavior, while the removal of these stereotypes is linked with successfully treating

persons understood to be patients. In this way the “difficult patient” stereotypes of patients with BPD are recruited in defense of the status quo of the current unavailability of care. When “difficult patient” status is removed from the equation, providers also are more likely to provide treatment – some, enthusiastically. There is a clear relationship between the stigma of “difficult patienthood” and the de facto or treatment component of medicalized status.

Conclusions

Though not previously deconstructed in the literature, demedicalization requires both a de facto and de jure component within Conrad’s framework. A discourse of untreatability may trigger treatment-based demedicalization. If clinicians can be engines of de/medicalization, just as activists and other actors can be, this is significant. The availability of treatment options or clinical training is less relevant if clinicians are reluctant or decline to provide care in the first place, and otherwise normalize denying care through the use of words such as “difficult” and “manipulative.” In this way, clinicians, through their preferences, may be initiating a, perhaps incomplete, process of de facto demedicalization for Borderline Personality Disorder. As the case of homosexuality demonstrates, nuanced and partial examinations of de/medicalization are essential to advancing our theoretical understanding of mechanisms, as well as clarifying the significance of de/medicalized status. In this case, I would argue there is clear evidence of de facto demedicalization for patients with BPD, and that - given the particular quality of the ‘difficult patient’ discourse within my data - this could be widespread.

Secondly, this case suggests that “difficult patients” in general may invoke Conrad’s second criterion related to treatment for de/medicalization. In general, patients whom clinicians disprefer and are less eager to treat may be more likely to slip through the cracks of the system, less likely to receive the personal investment of their providers, and overall receive worse care, even when treatment may be technically or theoretically possible. Even as their condition may be de jure medicalized and considered a valid condition, these patients may face real barriers to receiving effective care due to clinician arguments that “difficult patients” shouldn’t be patients at all, because they are more appropriately classified as morally suspect people. The interpersonal component of care provision should not be underestimated as a necessary condition for treatment (see Charles, Gafni & Whelan 1997, Duggan 2006, Sleath et al 2014).

Overall the word “difficult” operates as a code-word linked with other associations such as manipulative and untreatable, which operate to rhetorically justify the re-routing of these patients from care through direct and indirect means. Thus, despite a de jure medicalized status, patients with Borderline Personality Disorder face barriers to de facto medicalized status. The longer term outcomes of this reluctance or refusal to treat may have long-lasting implications for patients who may give up seeking care, as well as for their families, and the criminal justice system. Importantly, the sick role does not guarantee a reduction of stigma, and may not be more humanitarian, particularly in cases such as this where patient-status is routinely questioned. Ultimately, the example of Borderline Personality Disorder illustrates

the importance of considering de/medicalization as contested processes, rather than as absolute categories.

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Research highlights

Borderline Personality Disorder and “Difficult” Patient status are tightly linked
Demedicalization includes both labeling (de jure) and clinical (de facto) components
“Difficult” Patient status may initiate a process of de facto demedicalization A *discourse of untreatability* provides moral authority for de facto demedicalization