Does "difficult patient" status contribute to *de facto* demedicalization? The case of borderline personality disorder

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A B S T R A C T

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 de facto or treatment component of medicalization is harder to secure for patients.

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1. 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 et al., 2006:797). Several more have indicated that almost all difficult patients have "borderline personality organization" (See Koekkoek et al., 2006, Group for advancement of psychiatry 1987; Fiore, 1988; Schwartz and 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 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, 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 et al., 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 (APA 2012)). 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.

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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 and Gunderson, 2008; Bateman and Fonagy, 2009) and Transference-Focused Psychotherapy (see Clarkin et al., 2007). Nonetheless, 3–10% of patients with a BPD diagnosis die from suicide (Soloff and Chiappetta, 2012) and one study found more than 70% attempted suicide (Soloff et al., 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.

2. 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 (Papper, 1970). 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 et al., 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 and 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 and Schneider, 1980, Conrad, 2005, 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 (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