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Challenging the *Discourse of Untreatability* for Borderline Personality Disorder: A Call for Comparative Research

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Description

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.

I would like to thank Dr. Koekkoek for taking the time to engage with this work more deeply. I welcome ongoing scholarly discourse on stigma, mental health, and the provision of care, and hope these conversations contribute to an improvement of health delivery systems.

Dr. Koekkoek, offers three major critiques of my paper “Does ‘Difficult Patient’ Status Contribute to De Facto Demedicalization? The Case of Borderline Personality Disorder” (Sulzer 2015). The first is that the mechanisms described in this article likely extend to diagnoses beyond Borderline Personality Disorder (BPD). The second is that this particular article focuses on the interpersonal dynamics between providers and patients, and that there are likely other larger structural forces at play. And the third is a critique of using the demedicalization frame, as it might cause confusion to scholars.

To the first, I respond that I wholeheartedly agree that the routing of particular patients out of care may occur with other diagnoses. This is why I have framed the process encountered by patients with BPD under the rubric of “difficult patients” more broadly. The findings of my study likely extend to other “difficult” populations: “this case suggests that “difficult patients” in general may invoke Conrad’s second criterion related to treatment for de/medicalization.” (Sulzer 2015: 87).

However, I have two reservations here: the first is that comparative analyses are most appropriate for evaluating the extent to which two or more diagnoses are treated in ways that are similar or different. While it is possible to make a rhetorical argument, as Dr. Koekkoek has, that a diagnosis such as depression receives negative feedback from providers, and therefore might be similar, the argument requires a stronger empirical basis before it can be offered as more than a rhetorical possibility. Treating depression certainly may include challenges, but this does not mean that clinicians refuse to treat persons with the diagnosis or question whether depression is a legitimate medical problem. Nor do they evaluate patients as immoral for possessing it—a *discourse of untreatability* is not present in the same way. In fact, a rhetorical argument could be offered in return: much of the clinical struggle with patients who face major depressive disorder centers around keeping them on their medications or in psychotherapy, suggesting the goal of keeping this patient population within the control of the medical establishment is much more salient. And finally, based on the comparative evidence we do have, the intensity and depth of stigma patients with BPD encounter is likely stronger than it is for other conditions (see Treloar 2009 and Gallop et al 1989). Until future research demonstrates otherwise, I would caution against minimizing or generalizing the plight of patients with BPD that is illustrated by this data.

Secondly, it is important to note of course, that this study was conducted in the United States. This is a uniquely American story. There are many other countries which report a greater availability of treatments for BPD, which likely have an altogether different clinical narrative for the condition. Again: comparative research is best-suited to evaluating these critiques, and I am delighted that this article might in some small way initiate these important lines of inquiry.

Regarding the second issue of the critique, that I have treated demedicalization as if it were caused solely by the patient-professional interaction, I wish to make two points. The scope of the paper is limited to the relational component of care by virtue of the research questions: “First, what are the consequences of “difficult patient” status in terms of care provision and treatment? And second, can “difficult” patient-hood be linked to de facto demedicalization?” The first explicitly focuses on care provision and treatment, and sets the bounds for the paper. However, this is only one aspect of salience in the care of any patient with mental illness. Health economics, hospital administration, public health considerations, the sociology of diagnosis, doctor-patient communication, epidemiology and many other perspectives come into play. I sincerely hope readers understand this as a structural limitation to the writing format, not a wholesale minimization of the many other aspects of health services research appropriate to this and other conditions. Secondly, I address some of these considerations in a manuscript currently under review entitled “Borderline Personality Disorder and the Biomedical Mismatch.” This article, undergoing requested revisions, examines issues of payment systems in the United States and may further illuminate many of the specific areas Dr. Koekkoek found lacking in this particular piece. Accordingly, I invite him and other scholars to read this forthcoming article to see if it satisfies these concerns in a more concrete manner. I am optimistic it will extend this conversation into new territory.

The final concern of Dr. Koekkoek is that Demedicalization might not be the most suitable frame for the phenomenon described in this article. He first points to the widely accepted

nature of the biopsychosocial model of mental health as a launching pad for arguing that BPD (an arguably non-biologically based condition) has never been fully medicalized. I think it is again important to note that data for my piece come from the U.S., where the biopsychosocial model is not as widely accepted as it might be in Dr. Koekkoek's home country. The more biomedical orientation in the United States is highlighted by the Director of the National Institutes of Mental Health, Thomas Insel. In 2013 he released a statement signaling that future mental health research must be based on "objective" laboratory measures, not socially interpreted behaviors (Insel 2013). This is just one particularly visible example of how clinicians in the United States may systematically interpret, respond to, and study mental health conditions differently than those in the Netherlands and other parts of Europe. Once again, this is a fruitful opportunity for comparative research, and I would invite future collaborations that could help to address these questions.

Nonetheless, even if the biopsychosocial model were more prominent in the United States, this does not detract from the utility of the demedicalization frame. If patients are indeed routinely routed out of care, as a result of possessing the label, (and to be clear, there was no evidence these patients were being referred to specialized treatment centers of any kind or some other supportive setting), then they are being systematically removed from the purview of the medical profession. That is, by definition, demedicalization. Any condition that clinicians routinely seem to wash their hands of, and to push out of the medical purview, is a perhaps previously understudied, but very pragmatic form of de facto demedicalization.

Implicit in Dr. Koekkoek's critique however is an important point which deserves amplification: BPD may never have been fully medicalized. This study does not purport to evaluate the degree of medicalization across time for BPD, but rather to examine its currently de facto demedicalized status. It is entirely possible, and in no way detracts from the larger arguments, that BPD was never fully medicalized due to a number of factors. Borderline Personality Disorder certainly may meet some criteria for being a contested illness. Importantly though, as I argue in my concluding paragraph, Dr. Koekkoek's concerns point once again to "the importance of considering de/medicalization as contested processes, rather than as absolute categories" (Sulzer 2015: 88). I look forward to scholarly discussions of how we will better parse out these theoretical distinctions in the future.

Works Cited

- Gallop Ruth, Lancee WJ, Garfinkel Paul. 1989 "How nursing staff respond to the label 'Borderline Personality Disorder,'. *Hosp. Community Psychiatry* 40(8), 815–819. [PubMed: 2759571]
- Insel Thomas. 2013 "Director's Blog: Transforming Diagnosis." National Institute of Mental Health <http://www.nimh.nih.gov/about/director/2013/transforming-diagnosis.shtml>. Accessed October 6, 2015.
- Sulzer Sandra H. 2015 "Does Difficult Patient Status Contribute To De Facto Demedicalization? The Case of Borderline Personality Disorder." *Social Science & Medicine*. 142, 82–89. [PubMed: 26298091]
- Treloar A. 2009 "A qualitative investigation of the clinician experience of working with borderline personality disorder. *N.Z.J. Psychol* 38(2), 30–34.