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Disclosure of a Diagnosis of Borderline Personality Disorder

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Objective: **Borderline personality disorder (BPD) is a common psychiatric disorder with a prevalence of 1%–2% in the general population. BPD also has the potential to cause significant distress in the lives of patients with BPD and their families. The diagnosis of BPD, however, is often withheld from patients. The purpose of this article is to explore the history of diagnostic disclosure in medicine and psychiatry and then discuss reasons why clinicians may or may not disclose the diagnosis of BPD.** ***Methods:*** **The authors review medical literature about diagnostic disclosure and other issues that may affect the decision to disclose a diagnosis of BPD.** ***Results:*** **The authors discuss the historical precedents for diagnostic disclosure and reasons a clinician may not disclose the diagnosis of BPD to a patient: questions regarding the validity of BPD as a diagnosis, worries about the stigma of the diagnosis being harmful to the patient, and transference/countertransference issues common in the treatment of patients with BPD. The authors cite factors promoting disclosure, such as the ideal of patient autonomy, possibilities for psychoeducation and collaboration with the patient toward more specific and effective therapies, and the increasing availability of diagnostic information available to patients from sources other than their clinicians.** ***Conclusions:*** **There are compelling reasons to make the diagnosis the subject of open examination and discussion between clinician and patient, and reasons to believe that disclosure would serve to advance the patient in his or her recovery.** (*Journal of Psychiatric Practice* **2003;10:170–176**)

KEY WORDS: borderline personality disorder, disclosure, diagnosis, stigma, countertransference, personality disorders

Borderline personality disorder (BPD) is a common psychiatric disorder with a prevalence of 1%–2% in the general population.[1] BPD is defined by the following symptoms: marked reactivity in mood and affective instability; extreme sensitivity to abandonment; impulsivity; identity disturbance; recurrent suicidal and self-mutilating behavior; unstable interpersonal relationships fluctuating between extremes of idealization and devaluation; chronic feelings of emptiness; transient "micropsychotic" episodes; and difficulty controlling anger.[2] To our knowledge, no studies have yet been published describing how often patients with a sound diagnosis of BPD are informed of their diagnosis in community or academic practices or discussing the sequelae of providing patients this information. Despite the high prevalence of patients with BPD in clinical settings,[3] our experience suggests that clinicians may disclose an appropriate diagnosis of BPD to their patients less often than diagnoses of other psychiatric disorders.

One study published in 1992 by McDonald-Scott et al. assessed the attitudes of psychiatrists toward disclosing a diagnosis of BPD. It asked psychiatrists from the United States and Japan (n = 112 and 166, respectively) to examine hypothetical cases of patients with various psychiatric diagnoses.[4] The psychiatrists read case vignettes of hypothetical patients who had presentations pointing to one of the following diagnoses: schizophrenia, schizophreniform disorder, bipolar disorder, dysthymia, panic disorder, and BPD. They were then asked to indicate whether or not they would provide the patients and/or the patients' families with an accurate diagnosis either actively or if asked. Only 55% of American psychiatrists indicated that they would inform the patients with BPD of their diagnosis without being asked (versus 16% of Japanese psychiatrists) and an additional 16% of U.S. psychiatrists would inform if asked directly (with an additional 16% of Japanese psychiatrists responsively informing). These figures represented the lowest total inform rates (active plus passive)

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for all the disorders, except schizophreniform disorder, which had roughly equal rates.

The diagnosis of BPD is often difficult to make and seems to be confounded by other variables, such as comorbid diagnoses and insufficient historical information. Sometimes, however, the BPD diagnosis is clear. In this paper, we address some of the barriers to informing patients who have a clear diagnosis of BPD of their disorder and also discuss reasons why disclosure of this diagnosis could be in these patients' interest.

HISTORICAL PRECEDENT

The practice of non-disclosure of serious illness to the patient, once common in medicine, underwent a major change during the second half of the last century so that disclosure is now the standard practice. The debate over whether or not to disclose a diagnosis has been documented most extensively in the oncology literature. Arguments against disclosing a diagnosis of cancer were based on the duty to "do no harm"—that is, learning of a cancer diagnosis would cause the patient unnecessary emotional suffering, and perhaps, some argued, a precipitous death.[5] Arguments for disclosure have included the physicians' duty to inform their patients fully of their diagnoses and treatment options, encouraging patient autonomy. Standard of care in oncology has moved toward almost universal disclosure: the percentage of physicians who made disclosure their "general practice" increased from 31% in 1953 to 98% in 1979.[6] According to Goldberg, factors that may have contributed to this change include improved therapy for some cancers, which afford a brighter outlook on the diagnosis; increased attention paid to the subject of death and dying and to palliative care; and "the swing in the pendulum of social values toward consumerism and increasing public scrutiny of the medical profession [which] have altered the physician-patient relationship."[6]

More recently, the question of whether or not to disclose a potentially distressing diagnosis to a patient has been addressed by physicians who care for patients with diseases of the brain, such as dementia and schizophrenia. There are many similar issues at play in discussions about the disclosure of a cancer diagnosis and disclosure of a chronic and debilitating brain illness like dementia. However, as Pinner notes, there are also fundamental and important differences, most notably that "in dementia the illness intrinsically alters the patient's cognition, ability to make judgments and have insight, thus affecting the patient's very being."[7] As with cancer, opponents of disclosure have raised concerns that receiving the diagnosis of dementia could be harmful, and possibly even fatal, to the patient.[8] Another concern has been the potential uncertainty involved in a diagnosis of Alzheimer's disease, since it is a diagnosis that is only certain after autopsy.[7] Advocates of disclosure, like Pinner,[7] however, argue that the diagnosis of Alzheimer's can be made clinically with reasonable certainty, and that the patient should be told early in the course of the illness, if possible, so that he or she can make plans for the future, put legal and financial affairs in order, and communicate desires for future medical interventions.

Informing patients of a diagnosis of schizophrenia has undergone the same examination over the past two decades. In a 1987 survey by Green and Gantt,[9] only 58% of the 246 psychiatrists who responded to the survey "always" or "usually" told patients with schizophrenia their accurate diagnosis; 10%–15% "rarely" or "never" disclosed this diagnosis to patients. Some of the reasons for failure to disclose given to the investigators of this study, and also mentioned in publications elsewhere,[10,11] echoed those arguments given for not disclosing a diagnosis of Alzheimer's disease: uncertainty regarding the validity of the diagnosis and fear that knowledge of the diagnosis would "demoralize" the patient and his or her family. Other reasons offered were fear of stigma and perceived inability of patients to understand the meaning of the diagnosis. Physicians polled in this study who did regularly disclose a diagnosis of schizophrenia indicated that they felt psychoeducation about the nature of schizophrenia shifted blame away from the family and lessened feelings of "anger, helplessness, isolation and stigmatization."[11] They also mentioned the hope that psychoeducation would lead to greater compliance with treatment. Proponents of disclosing this diagnosis have argued that withholding the diagnosis of schizophrenia contributes to the stigma of the diagnosis "by implying that it is too terrible to tell the patient and too awful to discuss."[12] They also argue that disclosure with psychoeducation gives the patient the opportunity to participate in his or her own care and plan for the future.

REASONS PHYSICIANS MAY CHOOSE NOT TO DISCLOSE

Reasons why clinicians may hesitate to inform a patient of a diagnosis of BPD are similar to those cited in the situations above. They include uncertainty regarding the validity of the BPD diagnosis; the feeling that the

diagnosis is too negative to divulge (stigma), and related worries that such a diagnosis would have deleterious effects on the patient's health and morale. Concerns about a patient's transferential rage and the clinician's own countertransference issues may also affect the decision regarding whether or not to disclose.

Questions About the Validity of the BPD Diagnosis

Parascandola et al.[13] have described a greater reluctance on the part of physicians to involve patients fully in decisions regarding their care when diagnosis, prognosis, or treatment options are uncertain; such diagnostic uncertainty may affect physicians treating patients with BPD. The diagnosis of BPD can be uncertain both because clinicians may find it difficult to distinguish BPD from other diagnoses (e.g., from bipolar disorder,[14–16] depression,[17] and posttraumatic stress disorder[18]) and because there is still debate as to whether the diagnostic entity itself is a valid one. Although studies have demonstrated that the DSM-IV diagnosis of BPD is statistically valid,[19–21] critics of the diagnosis have argued that there is too much heterogeneity within the diagnosis: individuals who meet different sets of five out of the nine criteria for BPD could appear to have very different illnesses.[22] Moreover, despite studies showing that BPD can be distinguished from other Axis I and II disorders, the frequency of comorbidity with BPD[15] provokes concern that BPD may just be a reflection or variant of the comorbid disorders rather than a discrete entity in itself.

In addition, both Westen[23] and Zimmerman and Mattia[24] have shown that psychiatrists and other caregivers who work in a clinical, as opposed to a research, setting are less likely to ask patients direct questions about Axis II symptomatology. Zimmerman and Mattia additionally demonstrated that providers in clinical settings are much less likely to assign patients Axis II diagnoses. The tendency for providers in clinical settings to overlook borderline symptomatology and avoid making a BPD diagnosis would, of course, make it significantly less likely that these clinicians would disclose to the appropriate patient a borderline diagnosis.

Moreover, some critics of the BPD diagnosis have argued that the diagnosis is inherently sexist: the diagnosis is applied to women far more frequently than to men[25–27] and BPD has come to be known as a "women's diagnosis." Becker and Lamb demonstrated a sex bias in assigning the BPD diagnosis: given case histories identical in every way except for the gender of the subject, clinicians were significantly more likely to assign a diagnosis of BPD to the "female" case and a diagnosis of PTSD to the "male" case.[28] Feminists have raised the question of whether diagnosing a woman with BPD is to ignore the varying social stressors and expectations that women face daily and to which it would be normal to react with distress and, perhaps, anger. However, others have demonstrated a lack of difference in the prevalence of BPD between men and women.[29–31] In addition, Funtowicz and Widiger[32] showed data that contradicted the concern that personality disorders that "may represent maladaptive variants of stereotypic feminine traits." (e.g., histrionic, dependent, and borderline) had a lower threshold of dysfunction required for the diagnosis and thus may be more easily diagnosed than the "masculine" personality disorders. In one study, they demonstrated that patients with BPD and other "feminine" personality disorders were no less impaired than patients with other personality disorders.[33] In a second study, they found that clinicians themselves did not have a lower threshold of patient dysfunction for diagnosing "feminine" personality disorders.[32]

Stigma

Some of the symptoms of BPD which are addressed in the DSM-IV criteria are potentially frightening and frustrating for the clinicians treating them. Impulsivity, self-mutilating behaviors, recurrent suicidal gestures and threats, affective instability, and inappropriate and intense anger can be intimidating and unnerving for clinicians to treat. For these and other reasons, the term "borderline personality disorder" itself has garnered stigma among many mental health care providers,[34] independent of specific patients, possibly secondary to the often intense countertransference feelings of rage, helplessness, or frustration engendered by patients with this diagnosis. This countertransference evoked by some patients with BPD has contributed to a looseness in the way the term is used by some clinicians in mental health fields and elsewhere, who may ascribe the diagnosis to any person who provokes a clinician to anger or frustration. This practice may have contributed to the pejorative connotations associated with the word "borderline."[35] Although other psychiatric disorders also involve behaviors, such as suicidal gestures or ragefulness, that can provoke countertransference, the specific set of symptoms that comprise the BPD diagnosis and the intensely interpersonal nature of their expression set it apart from other psychiatric disorders, particularly Axis I disorders.

This sense of stigma in the diagnosis of BPD fuels the argument behind refraining from disclosure as a way to "do no harm." As with the other diagnoses (cancer, dementia, schizophrenia) discussed above, physicians may be worried that the knowledge that one may have the diagnosis of BPD might engender hopelessness and despair in the patient, given not only the stigma associated with the diagnosis but also the difficulty of treating the illness, which is still often perceived as being untreatable despite promising new therapies. Clinicians may avoid communicating a BPD diagnosis to patients because they fear patients will experience this as a criticism or a conclusion that they are "bad" or "annoying." In her memoir *Girl, Interrupted*, Susanna Kaysen addresses this point:[36]

> What does *borderline personality* mean, anyhow? It appears to be a way station between neurosis and psychosis: a fractured but not disassembled psyche. Thus to quote my… psychiatrist: "It's what they call people whose lifestyles bother them." He can say that because he's a doctor. If I said it, nobody would believe me. (p. 151)

For years, personality disorders in general and BPD in particular were seen by clinicians as distinct from Axis I disorders in their etiology. The conventional wisdom was that Axis I disorders were likely to have biological predispositions and mechanisms, as noted by Silk in his review, while personality disorders were viewed as a response to environmental factors.[37] Recent advances in the understanding of the biological factors at play in personality disorder pathology may over time "supply knowledge that might begin to erode the strong biases and negative labels that for too long have applied to these patients." An understanding of likely biological factors in this population has been slow to spread among clinicians, which may have contributed to stigma and a reluctance to share the BPD diagnosis when appropriate.

For many clinicians, the growing appreciation of the important interplay between childhood trauma and the development of BPD has contributed to a dampening of the stigma attached to the BPD diagnosis. Clinicians, now sensitive to the sequelae of childhood trauma, may be more likely to appreciate the complex, multifactorial etiologies of borderline psychopathology in some of their patients. Given this trend, Gunderson and Sabo noted:[38]

> …it seems safe to conclude that the role of abuse in the pathogenesis of borderline psychopathology, although important, is neither specific nor sufficient. Borderline psychopathology arises out of a history in which abusive experiences join other factors to help shape enduring aspects of character. (p. 23)

The degree to which BPD patients themselves find the diagnosis stigmatizing is unclear. Stigma has been shown to reduce the self-esteem of patients with psychotic and severe affective illness[39] and, in one qualitative study of patients with mental illnesses, some patients with personality disorders said that they felt that the diagnosis was a "label" which they would be reluctant to divulge because of the "prejudice."[40] However, another study reporting life history narratives from patients with BPD indicated that the patients interviewed did not feel that the BPD diagnosis itself was a focus in their self-definition.[41]

Transference and Countertransference

The discomfort involved in treating some patients with BPD, in addition to the field's incomplete success in managing BPD pathology with medications,[37,42] can make work with patients with BPD challenging and often frustrating.[43,44] In addition to engendering the stigma surrounding the diagnosis described above, transference and countertransference with patients with BPD may also complicate the decision whether or not to inform the patient of his or her diagnosis, and make the decision regarding disclosure in BPD different from those regarding disclosure of cancer or even schizophrenia. Patients with BPD can evoke in their clinicians feelings of unusual closeness and sympathy or of hatred and/or fear. These countertransference reactions can affect diagnostic disclosure in a number of ways. They may muddy thinking so that the diagnosis is not made in the first place. In their review of the interface of BPD and PTSD, Gunderson and Sabo cautioned[38]

> Clinicians should be aware that their countertransference reactions may be operative when they use either of these diagnoses. Misuse of either PTSD or borderline personality disorder may reflect sympathy or dislike, respectively, as countertransference problems. (p. 24)

It is clear that the pathology of patients with BPD can also make a physician fearful that a patient will have a rageful or self-destructive reaction upon hearing the diagnosis. In other illnesses, the fear of self-harm or a hastened death has been cited as a reason to withhold diagnoses. Perhaps psychiatrists also fear self-harm or a premature death in their patients who are already prone to self-harm and suicide. Finally, feelings of fear and impotence that may be engendered in clinicians by the elevated threat of self-harm in BPD patients may spur a hateful avoidance[43] of the patient and an ensuing reluctance to

engage the patient in a discussion of the diagnosis and its implications.

REASONS TO DISCLOSE

There are several compelling reasons why a physician should disclose the diagnosis of BPD, when appropriate, to his or her patients.

Patient Autonomy

Respect for patient autonomy has become a standard of care among physicians in all fields.[13,45] Including the patient in decision-making regarding his or her care and respecting the patient's values have become widely held ideals, and, although self-determination and physician beneficence (the ideal of wanting to do "what is best" for the patient) sometimes diverge, it is now generally accepted that patient autonomy is primary.[37]

Psychoeducation

A patient (or the family of a patient) who has been experiencing distressing symptoms without a name might feel a sense of relief once the constellation of symptoms has been named. Even more comforting may be the information that BPD is an illness that affects many and that there are BPD-specific treatments with proven efficacy. Bolton and Gunderson have written of how "relieved" the patient and his or her family are at hearing the diagnosis, "understanding that there are others who struggle with it and that there are effective, albeit time consuming, treatments available."[14]

Once a patient has been informed of his or her diagnosis, valuable education regarding the diagnosis can take place that can provide the patient with a greater sense of empowerment and mastery—the patient will know better what to expect from his or her illness and how to intervene when symptoms develop.[46] Moreover, family psychoeducation can provide important support to the patient and his or her family and can lead to increased communication between the patient and family.[47] The website of the National Alliance for the Mentally Ill (NAMI) cites education as a primary activity of the organization.[48] Groups like the National Educational Alliance for Borderline Personality Disorder (NEA-BPD) and the Treatment and Research Advancements National Association for Personality Disorder (TARA) are devoted to advancing knowledge and fostering understanding in the scientific and medical community as well as among patients with BPD, their families, and the general public. These organizations are excellent resources for psychoeducation. ***(Editor's note: A Patient and Family Guide concerning BPD is provided on p. 204.)***

Accurate Diagnosis Can Guide Treatment

Psychoeducation can also provide both the patient and the physician with a shared concept of treatment options, both psychological and pharmacological, and suggest what kind of results can be expected from each option. As stated above, pharmacotherapy for BPD is less likely to be globally effective than pharmacotherapy for less complicated Axis I disorders. Developing a common vocabulary that one can use to discuss symptoms with patients and then discussing target symptoms for particular medications with the patient will lead to less disappointment when a medication fails to fix all of a patient's symptoms (but does succeed in treating the target symptom).[49] Alerting a patient to the reality that any modality of psychotherapy for BPD will require an investment of time and effort prevents feelings of frustration and blame directed at self and treaters. Not disclosing the diagnosis also limits the psychosocial therapeutic options open to the patient. For instance, a patient could not join either a Dialectical Behavioral Therapy group as outlined by Linehan[50] or a Systems Training for Emotional Predictability and Problem Solving group as outlined by Blum[51] without knowing his or her diagnosis, and psychosocial treatments such as these are often the cornerstone of effective treatment for BPD.

Self-Discovery of the Diagnosis

Finally, in practical terms, even if their physician does not inform them directly, many patients will come to suspect or know their diagnosis, whether through researching their symptoms, hearing about the diagnosis in the media, or reading an insurance form. With the increased availability of medical information on the Internet, it is now common for patients to bring in information to an office visit with questions about how it applies to them. The clinician is then faced with a potentially compromised therapeutic relationship, and the patient is left wondering what was so bad about the diagnosis that he or she could not be told in the first place.

CONCLUSION

The pathogenesis, treatment, and prognosis of BPD are still subjects of active debate and are therefore difficult to explain to patients. Patients with BPD can engender many strong feelings, both positive and negative, that may impede a clear discussion about diagnoses. Despite the recommendation in the APA *Guideline*[42] to inform patients with BPD of their diagnosis, our observation has been that, for the reasons discussed above, clinicians can be reluctant to disclose the diagnosis of BPD to patients, their families, and, at times, other treaters. There are many compelling reasons, however, to make the diagnosis the subject of open examination and discussion between clinician and patient, and many reasons to believe that disclosure would serve to advance the patient in his or her recovery.

There are facets of this issue to be explored further and quantified through research. For instance, there is no quantitative research concerning the prevalence of disclosure of BPD in the community, or whether disclosure of the BPD diagnosis is associated with more appropriate care. Also, research following patients after they were informed of their diagnosis could be valuable to clinicians working with patients with BPD. Finally, the public health implications of having a subset of patients with a persistent and potentially severe illness, who are high utilizers of psychiatric[52] and medical services, being unaware of their diagnosis, and therefore impaired in finding appropriate care, should be kept in mind for future study.

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