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## Features

# Psychiatric Diagnoses and Informed Consent

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### ABSTRACT

Although informed consent for treatment has become a cornerstone principle of psychiatric care, the process of diagnosis has remained largely in the hands of the physician alone. While the conferring of a psychiatric diagnosis has historically not been considered a form of medical intervention, the potential impact of a diagnosis for any particular patient may be substantial. This article explores the challenges involved in balancing respect for patients with the physician's duty of truth-telling and clinical accuracy.

### INTRODUCTION

The doctrine of informed consent for clinical treatment has, over the last half century, been established as a cornerstone of medical ethics. As a result, the doctor-patient interaction has been radically transformed, with both parties now actively engaged in treatment planning and decision making and with the patient's preferences accorded privileged status.<sup>1</sup> The process of diagnosis, however, has generally been seen as separate from medical intervention, and clinicians have largely retained their traditional authority in that arena. Typically, clinicians exercise their expertise through a process of active in-

vestigation and subsequently present the patient with a diagnosis, from which point the two begin to collaborate on treatment planning.

This article explores the idea that, given the potential personal, social, and legal impacts of a psychiatric diagnosis for individual patients, their welfare may be significantly affected by having a specific diagnosis conferred upon them. To the extent that this is the case, it raises difficult questions as to how best to balance respect for patients with clinicians' obligations for accuracy, clarity, and truth-telling as they communicate their diagnostic conclusions.

### PSYCHIATRIC DIAGNOSES

Psychiatric diagnoses, as articulated through the various iterations of the *Diagnostic and Statistical Manual of Mental Disorders* (hereafter, *DSM*), offer phenomenologically based classifications that serve as a useful heuristic, particularly in regard to promoting interrater reliability. Introductory material to the fifth edition of the *DSM* (*DSM-V*) highlights the limits of the diagnostic framework, noting that the boundaries between diagnoses are more porous than had been originally perceived, that symptoms are fluid over the life span of patients, and that not all psychopathology can be captured by a discrete set of diagnostic categories.<sup>2</sup> Rather than mandating a slavish adherence to symptom checklists, the *DSM-V* offers itself as a (hopefully) useful, flexible, and

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at times fallible guide to clinical assessment and treatment planning.

Implicit in the traditional paternalistic approach to diagnosis is the assumption that providing a patient with a diagnosis does not involve a medical intervention in the way that active treatment does, and therefore does not impinge on the patient's autonomy. Although this assumption may be reasonably valid in traditional medical fields, psychiatric diagnoses are often different in kind. Psychiatric diagnoses are highly susceptible to reification, or attributing real world validity to largely heuristic constructs, and may therefore come to play a prominent and unwarranted role in how patients understand themselves and how they are understood by others.<sup>3</sup> As such, a psychiatric diagnosis may become overvalued, stigmatizing, and existentially freighted for a patient, and it may present a misleading label to the world at large.<sup>4</sup> In that sense the diagnosis may pose an even greater risk to the patient than the treatment itself.<sup>5</sup>

The traditional approach to medical diagnosis assumes that a clinician is obligated to employ the specific diagnosis that most accurately represents the underlying disease process and cannot simply select which among many diagnoses to utilize. Psychiatric diagnoses are often different however; hobbled by an impoverished understanding of the underlying pathophysiology and a limited ability to utilize objective data, the psychiatric diagnostician relies to a large extent on characterizing constellations of symptoms as disorders, in a top-down effort to impose a coherence on the vast multiplicity of symptom presentations. As a result, many or most psychiatric disorders fail to demonstrate validity as disease categories, despite their clinical utility, and they lack well-defined thresholds and boundaries.<sup>6</sup> The residual, substantial role of clinical judgment in the diagnostic process, therefore, frequently leaves the psychiatric diagnostician with remarkable latitude in selecting a preferred diagnosis from amongst more than one reasonable candidate.

In practice, many patients may be unaware of or indifferent to the specific diagnoses their clinician has given them, and many clinicians may choose not to address the issue with their patients at all, focusing rather on more global case formulation and treatment planning.

However, patients make meaning of their diagnoses in manifold ways. For many patients the diagnoses seem to tell them something about themselves that they hadn't known before, and in time they come to represent not just a convenient way to think about their symptoms, but a core aspect of their

identity. A person with symptoms of depression, for example, once diagnosed as such, may come to think of him- or herself as fundamentally a depressed person. Diagnoses are regarded in this sense as more akin to the results of a psychological biopsy than to a simple organizational approach for an array of presenting symptoms.

The trusting relationship between patient and psychiatrist relies upon the physician's capacity to communicate an appreciation of the patient's distress, a recognition of the patient's strengths, and a vision for the patient's future. Psychiatric diagnoses, by virtue of being pathologically oriented, often confusing, and frequently shaming, may be experienced by patients in ways that shake their sense of trust in the clinicians who bestow them, and in the mental health system more broadly. When deciding whether and how to communicate their diagnostic conclusions to their patients, clinicians may struggle therefore to balance the need for diagnostic accuracy and openness against their sensitivity to the patients' experience of being labelled in such a way.

Publicly, psychiatric diagnoses are often the subject of intense social interest and, in our culture, some diagnoses have become near celebrities in their own right. In addition, psychiatric categories often seem to touch on broader issues such as moral worth and personal responsibility. As such, public fascination and familiarity with psychiatric diagnostic nomenclature is remarkably high, and patients often find that the people close to them presume an uncomfortably high level of understanding and insight based on their diagnosis alone. The contrast with medical diagnoses is often striking—while a hypothetical book such as *Are you Married to a Narcissist?* might fly off the self-help shelves, its companion, *Does Your Spouse Have Elevated Cholesterol?* would be more likely to languish.

Although protected by safeguards against indiscriminate dissemination, psychiatric diagnoses can often show up in arenas outside the consulting room, where they are filtered through the ignorance and agendas of nonclinical actors on unfamiliar stages. These include consideration for special education services or academic supports; eligibility for government financial supports; military enlistment; some job applications, such as physician licensing in many states; fitness for duty evaluations; applications for prospective adoptive parents; applications for life or health insurance; and a variety of other civil and criminal legal matters.<sup>7</sup> Certain psychiatric diagnoses, if revealed in particular settings (such as, for example, child custody determinations or the punishment phase of capital criminal cases),

can have substantial deleterious effects for the patient. A psychiatric diagnosis often acts as a label in such circumstances, where it is mistakenly thought to accurately and comprehensively describe the important aspects of an individual's functioning. In addition to the very real risk that a diagnostic label will do harm to patients at some point in the future, patients often harbor well-grounded fears as to the ability of our healthcare systems to truly protect their privacy.

The risks to patients of any particular psychiatric diagnosis, therefore, no matter how accurately it reflects the relevant *DSM-V* criteria, include that it might alter their understanding of themselves in unhelpful ways, damage their trusting relationship with their clinician and with mental health services in general, adversely influence the ways that others understand them, and prove concretely damaging in an administrative or legal forum. It can, in these various ways, do them a great deal of harm.

Psychiatric diagnoses generated in the context of forensic evaluations or research protocols serve purposes distinct from those in the clinical setting and carry their own sets of ethical expectations and challenges. In these settings clinicians are expected, prior to conducting an assessment, to provide clear and informative disclosure around the limits to confidentiality and the risks involved. In clinical settings, however, patients' willingness to be evaluated is usually inferred simply by their physical presence in the examining room. What is also simply assumed is that patients have thereby acquiesced to being given a particular diagnosis and to having that diagnosis enshrined in their medical record, shared with the community of careproviders who access those records, and communicated to third-party payers.

## VIGNETTES

### Case 1

A 26-year-old woman presents to the emergency department, accompanied by her fiancé, after an episode of superficial cutting. She has cut several times before, has felt suicidal at times in the past, and is in long-term therapy due to her difficulties with emotional regulation and maintaining intimate relationships. She is evaluated and cleared for discharge. Her fiancé, who has been fully aware of the patient's difficulties and occasionally present at her therapy appointments, is at her bedside when the emergency room clinician announces that the patient will be discharged with a (new) diagnosis of borderline personality disorder. Both the patient and

fiancé are startled and disturbed by this new diagnosis, and they protest, to no avail. In the days that follow, the patient finds her fiancé to be brooding and distant.

### Case 2

A 52-year-old man is in long-term therapy with a psychiatrist at a major medical center. The gentleman is active in the community, highly religious, and a devoted family man who prides himself on his honor and probity. Having built a trusting relationship with his psychiatrist, the patient one day reveals that he has for years found himself sexually attracted to prepubescent girls, and although he has never acted on those urges in any way, he feels exceptionally guilty and ashamed. He and his wife have struggled with their relationship, largely due to the husband's lack of desire and his emotional distance. After the session the psychiatrist grows concerned about potential future liability and so, after consulting his *DSM-V*, enters the diagnosis of pedophilic disorder into the electronic medical record. The patient returns the following week concerned that he had revealed too much and, after pointed questioning, the psychiatrist reluctantly acknowledges the new diagnosis that he gave. The patient leaves, upset, and the treatment ends.

### Case 3

A 16-year-old adopted boy is brought in for an evaluation by his parents for defiance, dishonesty, fighting, and shoplifting. The parents are highly accomplished, hard-driven professionals who adopted the child when he was five years of age; they express disappointment in his mediocre academic accomplishments, growing frustration with his behavior, and worry that he may be a "bad seed." The boy had early experiences of neglect, and he witnessed his mother die of a drug overdose at four years of age. The boy is very protective and solicitous of his 13-year-old sister, who was adopted by the same family and whose behavior is much less disruptive. At the end of the evaluation the clinician informs the parents (but not the child) that the boy meets criteria for conduct disorder, at which point the father turns to the mother and says, "See, I told you so!"

## LIMITATIONS TO DIAGNOSTIC PATERNALISM

In practice, of course, the skilled mental health clinician will remain sensitive to how the patient might experience being given a specific diagnosis and will take pains to educate and even negotiate

around these matters.<sup>8</sup> Many diagnoses, such as narcissistic personality disorder in the context of long-term psychotherapy, may not be communicated at all. Others, such as schizophrenia, may be offered only after a substantial accumulation of data. In practice as well, however, are clinicians who for a variety of reasons take a more formulaic approach to diagnosis and who accord little weight to the patient's perspective or the possible ramifications of their diagnostic choices. What seems remarkable in any case is how little formal expectation there is for dialogue between the doctor and patient on these matters, how powerless the patient is in times of disagreement, and how much silence surrounds the entire process.

Informed consent for "medical interventions" is codified as a fundamental aspect of ethical practice by the American Medical Association, and, by extension, the American Psychiatric Association.<sup>9</sup> The American Academy of Child and Adolescent Psychiatry *Code of Ethics* calls for consent from the legal guardian before engaging in "actions" involving the child or adolescent.<sup>10</sup> Beauchamp and Childress, in their widely cited textbook on medical ethics, describe informed consent as an "individual's autonomous authorization of a medical intervention."<sup>11</sup> The question, therefore, is whether conferring a psychiatric diagnosis upon a patient constitutes a "medical intervention"; if so, then the relevant ethical codes in regard to informed consent could reasonably be expected to apply in some way. Given the substantial and manifold risks of harm associated with a psychiatric diagnosis, it seems difficult to conceptualize it as anything other than a medical intervention. Another way to address the question is to ask whether patients experience the process of being diagnosed as a substantial "doing to" them of some sort, and whether many of them would wish to have the opportunity to have their perspective and interests meaningfully acknowledged in the process. Unfortunately, there is very little empirical data to help answer that question, and likely a great deal of confusion on patients' part as to the negotiable aspects of the diagnostic process.

To the extent that a psychiatric diagnosis is like a medical diagnosis, there may be little room for dialogue; a kidney stone by any other name is still, irreducibly, a kidney stone. Indeed, many diagnoses widely used in psychiatry, such as Down's syndrome or Alzheimer's disease, do appear to have distinctive and identifiable etiologies, leaving little room for diagnostic hedging. For many patients, however, a psychiatric diagnosis can be thought of as a narrative, built upon a foundation of empirical data,

that the clinician and patient can use together to understand and address the patient's difficulties. If the narrative selected by the clinician is substantially discordant with the patient's experience or with the way in which the patient would like to be able to think of her- or himself, the patient's adherence to treatment may be compromised.

Other cornerstone ethical principles that may be implicated in the psychiatric diagnostic process are those of beneficence and nonmaleficence and the expectation that concern for the patient's welfare is paramount in the clinical encounter.<sup>12</sup> There may be times when skilled clinicians' judgment leads them to protect their patients (and avoid doing harm) by modifying what they record as the primary diagnosis.<sup>13</sup> Certain diagnoses, such as factitious disorder imposed upon another, or antisocial personality disorder, bring with them a host of knotty ethical considerations for the treating clinician who wishes to balance the need for truth-telling against responsibility toward the patient. A paternalistic approach to diagnosis, however, tends to preclude disclosure, and it limits conversations with the patient around such important considerations.

Rather than being a simple, by-the-book exercise in checking lists of symptoms, the process of psychiatric diagnosis may in fact be a more ethically complex endeavor than is often appreciated. Very little attention has been given, however, to questions of how to think through the difficult issues that arise in the process and how best to engage patients in diagnostic decision making. The unexplored ethical and practical challenges surrounding shared authority for psychiatric diagnoses are similar in many ways to those regarding treatment decisions 40 years ago. Jay Katz, in his classic book on informed consent for treatment decisions, wrote, "The insistence on authority has stifled any serious exploration of whether physicians and their patients could interact with one another on the basis of greater equality. Thus, the idea of informed consent—of mutual decision making—remains severely compromised."<sup>14</sup>

#### **SHOULD PATIENTS HAVE THE RIGHT TO REFUSE PSYCHIATRIC DIAGNOSES?**

One somewhat radical approach to engaging patients in the process of psychiatric diagnosis would be to fully extend the concept of informed consent to include both diagnosis as well as treatment, in an acknowledgment that the two processes are interrelated and that both implicate patients' right to self-determination. In this model, patients

would have the right to refuse a psychiatric diagnosis (even if it were fitting), just as they have the right to refuse lifesaving treatment (even if it were medically indicated). And, in the same way that patients cannot choose just any treatment plan, patients here would not have the right to simply choose a diagnosis for themselves. Although the clinician might not believe it to be in the patient's best interests to reject an apt and informative diagnosis, the competent patient's preferences would be the final determinant.

One objection to a strong right-to-refuse-diagnosis approach is that some psychiatric patients lack insight due to their illnesses and therefore might be likely to reject an accurate diagnosis. Even in the absence of clear risk to patients, allowing delusional, irrational, or cognitively compromised patients to dictate their diagnoses would seem to offer little benefit, and would be a concession not to the patients' autonomous interests, but rather to the limitations associated with the disorder. To avoid this situation, clinicians would need to be able to ascertain that patients were not competent due to an inability to understand or rationally think through the ramifications of the diagnosis and then override the stated preferences on that account.

A second objection to allowing patients to refuse psychiatric diagnoses is that it might jeopardize reimbursement from third-party payers, either if no diagnosis were given or if a more anodyne diagnosis than was warranted led to a more restrictive reimbursement schedule. This speaks, perhaps, to yet another of the various burdens that have been piled upon the narrow shoulders of the diagnosis, and it may represent a quite valid, if unfortunate, real world concern.

The most troublesome objection to this approach, though, is that the diagnosis is not only something that happens between a clinician and a patient; it is also a primary mode of communication among clinicians. As such, it is expected to reflect an accurate recording of the clinical encounter. The clinician and the patient each have ownership of the diagnosis in different ways, with the clinician responsible for its accuracy and thoroughness and the patient the one who has to live with it. A clinician's diagnosis is an attestation that the important aspects of a clinical encounter have been articulated, and, in many circumstances, a clinician's silence would be misleading and potentially dangerous for a patient. For example, a psychiatrist who evaluated a patient in the emergency room for alcohol intoxication and a suicide attempt would be professionally obligated to communicate that informa-

tion in the diagnosis, even in the face of the patient's objections. In circumstances such as these, clinical care would be compromised at the patient's expense if the given diagnoses were not forthright, which might justify overriding the patient's preferences. More broadly, clinicians' trust in the accuracy of the medical record might be seriously eroded if it was understood that critical conclusions could be withheld at a patients' behest.

### **PATIENTS' ASSENT FOR PSYCHIATRIC DIAGNOSIS**

If full informed consent (with its accompanying right to refuse) is overly broad, and if traditional diagnostic paternalism is too narrow, is there a Goldilocks framework whereby a patient's agenda and interests could begin to be invited and considered in a meaningful way? I would suggest that the concept of assent, particularly as has been developed and articulated with pediatric populations, would be a workable and reasonable approach.

Although pediatric patients are typically not legally empowered to give informed consent for medical interventions, children of a certain developmental level are able to offer their perspective, articulate their interests, and agree or disagree with a treatment approach. The process of assent for children involves a developmentally appropriate explanation of the options available, an invitation for them to ask questions and express concerns, and an opportunity for them to express a preference. While it is the adult guardians of children who provide the legally and administratively mandated permission for a treatment, the process of assent is more than just a pretense, in that children's wishes carry real weight. Although children may not have full veto power in all cases, their preferences matter, and their opposition to a particular treatment plan may well be enough to scuttle it, depending on their developmental level and the gravity of the clinical problem at hand.<sup>15</sup>

The model of assent would set an expectation that clinicians have a meaningful discussion with patients prior to giving a psychiatric diagnosis and make a good faith effort to consider and give weight to the patients' preferences. It would, no doubt, call for a certain amount of explanation as to the meaning of any particular diagnosis, as well as about the limitations of the *DSM-V*-based nosological approach. At the same time, it would ultimately allow clinicians to select the diagnoses that they felt were indispensable for accurate communication and good patient care.

An assent model for psychiatric diagnoses would not require clinicians to provide a misleading diagnosis in the medical record. Rather, clinicians might at times defer making a particular diagnosis in the face of patients' resistance, choose a more benign or acceptable diagnosis from among a few reasonable options, or utilize one of the many unspecified diagnoses offered in the *DSM-V*.

In addition to demonstrating respect for patients' autonomy, engaging with patients around diagnoses might well enhance clinical care. Patients who appreciate the significance of their diagnosis and who feel they have made a meaningful contribution to the diagnostic decision are more likely to sustain participation in treatment. And, to the extent that such a collaborative process helps to reduce patients' sense of stigmatization, it would promote care-seeking behavior on their part.<sup>16</sup> Given the enormous challenge of treatment avoidance and treatment non-adherence for serious mental illness, any lowering of the barriers to treatment would be likely to pay substantial public health dividends.<sup>17</sup>

#### **POSSIBLE OBJECTIONS TO PATIENTS' ASSENT FOR PSYCHIATRIC DIAGNOSIS**

One possible objection to incorporating patients' preferences into diagnostic decision making, as in the assent model, is that it would undermine the reliability of psychiatric diagnosis and thereby impoverish the communication between patients' various treating clinicians.<sup>18</sup> Even if the most critical diagnoses were retained, this argument goes, more subtle modifications in diagnosis (such as putting persistent depressive disorder in place of major depressive disorder) would hamper collaborative care and might distort treatment plans in unhelpful ways. However, the utility of psychiatric diagnoses for communication between clinicians has long been compromised by problematic reliability in clinical practice, episodic changes in diagnostic criteria, the perverse influence of third-party payers, and the everyday, thoughtful deviations from diagnostic orthodoxy made by clinicians as they diagnose patients. For many patients with a lengthy psychiatric history, their medical records contain a motley array of diagnoses, made with varying degrees of rigor at different points in time. As such, the actual loss of accuracy involved in according patients more involvement in the diagnostic process may not be as great as might be feared. Secondly, it may well be that in primarily relying on a *DSM-V*-based diagnostic category to effectively and comprehensively communicate individual patients' circumstances, we are

asking too much of it. The primacy and assumed authority of the diagnosis has perhaps overshadowed the critical role that the clinical formulation should play in collaboration among careproviders.

A second possible objection to allowing psychiatric patients a role in their diagnosis is that it would set psychiatry apart from other fields in medicine. An obstetrician does not invite lay opinions on an ectopic pregnancy, and an internist has no use for patients' thoughts as to whether or not they may have hypertension. After working so hard to establish itself as a legitimate branch of medicine with a scientific foundation, why should psychiatry veer away in this manner, acknowledging in effect that its diagnostic systems lack genuine validity? The answer is that psychiatric diagnoses at this point in time are indeed different from medical diagnosis in any number of ways. Not only are psychiatric diagnoses largely heuristic, but they frequently contain much greater value complexity than do medical diagnoses.<sup>19</sup> As such, it is only appropriate that they be addressed differently. Further, it is not necessarily the case that allowing patients to have meaningful input around their diagnoses reflects the developmental immaturity of the field of psychiatry; it may well be that certain medical diagnoses carry their own underappreciated ethical complexities and that the field of psychiatry could take the lead in acknowledging and addressing the issues involved.

#### **CONCLUSION**

Current psychiatric nosology represents an effort to impose coherence on the confusing particularities of patients' distress, much as celestial constellations attempt to make sense of the starry night skies. Psychiatric diagnoses, however, are highly prone to reification and can have substantial and harmful impacts on patients in a variety of ways. The paternalistic approach to psychiatric diagnosis, in which clinicians retain full authority in the diagnostic endeavor, leaves patients powerless and largely silent in the process and appears to take little regard for their autonomy. At the same time, clinicians bear responsibility for accurately documenting their clinical impressions and would be remiss in allowing patients to simply dictate their preferred diagnoses. An expectation that clinicians seek patients' assent before bestowing a psychiatric diagnosis upon them would encourage a meaningful dialogue, demonstrate respect for patients, and likely reduce patients' sense of stigma, while still allowing clinicians the latitude necessary for accurate recording.

NOTES

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