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STATE OF THE ART AND SCIENCE
Patient-Centered Revisions to the *DSM-5*

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The forthcoming fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5* [1]) will mark the first time in nearly 2 decades that the field has overhauled the way mental illnesses are diagnosed and classified. Anticipation of the *DSM-5* has been high, and recent discussions about changes likely to be adopted have focused largely on the manual's increased integration of scientific and clinical evidence in support of proposed revisions [2, 3]. An equally important, though perhaps less frequently heard, voice in this dialogue concerns the potential ethical consequences of the *DSM-5*'s draft revisions.

The therapeutic alliance between psychiatrist and patient is unique and requires constant vigilance on ethical matters of self-harm or harm to others, confidentiality, legal aspects of diagnosis and treatment (e.g., competency), patient autonomy, involvement of third parties, dual agency and dual relationships, and patient stigma. This last issue is of particular concern; perhaps more so than in any other area of medicine, stigma has become a routine aspect of the lived experience for many people with mental illnesses.

While the empirical basis of proposed changes to the *DSM-5* have been discussed elsewhere [2-4], ethical considerations deserve increased attention. Members of the *DSM-5* work groups have discussed the consequences of adopting (or not adopting) changes to the *DSM* concerning public perception, the likelihood of misdiagnosis, the social and cultural implications of having a mental disorder, the impact of diagnostic criteria on treatment access, and more. Hence, attention to ethical circumstances like patient stigma, the pathologizing of normal behavior, and an increased need for patient involvement in the manual's development are reflected in the proposed changes.

Reducing Patient Stigma
Compared to its understanding of general medical illnesses, the public's understanding of and attitudes about mental illnesses are relatively poor, which contributes to patients' experience of stigma. Members of the *DSM-5* work groups have drafted revisions that aim to reduce stigma not only directly (e.g., revising diagnostic labels that have pejorative connotations) but also indirectly, by suggesting changes that will improve medicine's understanding of what psychiatric disorders are and how to diagnose them correctly. Such increased clarity begets the development of more effective pharmacotherapies and psychosocial interventions, as

well as a refined research base of etiological and underlying risk and prognostic factors from neuroscience, neuroimaging, and genetics.

One of the more highly praised aspects of the revisions is the extent to which the manual is grounded in the latest science. Draft diagnostic criteria were developed from extensive literature reviews and secondary data analyses to ensure that proposed changes have a clearly defined and defendable empirical basis. Consultation was also sought from experts in mental health as well as social work, neurology, pediatrics, forensics, and beyond.

By providing a compendium of criteria that universally reflect the most advanced findings from science and medicine, the *DSM-5* arms clinicians to make more accurate diagnoses. Side effects of medications may make patients with certain diagnoses more identifiable to others as having a mental illness, but the adoption of scientifically valid diagnoses may encourage the development of a new generation of psychotropic drugs with, perhaps, fewer side effects and greater efficacy in symptom reduction. Furthermore, improved diagnostic assessments are important in the development and implementation of specific psychotherapies in numerous psychiatric disorders. Finally, the stronger evidence base allows clinicians in training to be better educated about what mental disorders are, how to identify them, and how best to treat them, which also benefits research, industry, and policy.

But what does a stronger scientific foundation mean for patients? Does empirical rigor equal less stigmatization? Not entirely; stigma is a complex phenomenon with numerous sociocultural contributors. But increased awareness—among patients themselves, patients' families and support systems, the health care system, and even the general public—is perhaps our greatest weapon against stigma. Empirical research helps the field better clarify what psychiatric disorders are, how to correctly detect them, and, subsequently, how best to treat them. In this manner, science can serve to combat misperceptions that patients with mental illnesses are dangerous, "strange," incapable, or otherwise insignificant as human beings.

The *DSM-5* work groups have also put forth proposals to address patient stigma issues head-on, particularly through changes in diagnostic labels. The Neurodevelopmental Disorders Work Group has suggested renaming mental retardation "intellectual developmental disorder" partly to bring greater consistency between the *DSM* and the terminology used by the American Association for Intellectual and Developmental Disability. But the work group members were also influenced by recognition that the term "retardation" is often used disparagingly in the American lexicon.

Similarly, extensive analyses of existing literature and previously collected data led the Substance Use Disorders Work Group to propose removal of the term "dependence" from their set of disorders. Used accurately, "dependence" refers to physical dependence, including normal biological reactions of tolerance and withdrawal to, for example, opiate-based prescription medications or even certain

antidepressants. But the labels "dependence" or "drug-dependent" are often interpreted by the public and many in the medical profession as derogatory and implying substance misuse and abuse. So the work group has proposed that the diagnosis of substance dependence be combined with substance abuse to form a single diagnosis called substance use disorder. Elimination of the term "dependence" from the formal diagnosis is considered a step forward in reducing misperceptions of what substance dependence truly means.

Medicalizing Normal Variation?
Among the more prominent criticisms of the *DSM-5* is that of its potential to pathologize normal human experiences. It is understandable that critics would question the *DSM*'s sensitivity to the medicalization of human behaviors and emotions, especially given psychiatry's somewhat checkered early history. However, members of the *DSM-5* work groups have made concerted efforts to assess the possible effect of proposed changes on prevalence rates and the potential public health fallout of excluding existing diagnoses and including novel diagnoses, like Internet addiction and hypersexual disorder. For example, although its inclusion could yield greater research and treatment, some have complained that the proposal to include premenstrual dysphoric disorder as a new psychiatric diagnosis demonstrates that the field is placing a mental health label on a normal variation of biological experience. However, work group members have reiterated that diagnosis would require symptoms to be severe enough to cause distress or to disrupt functioning. Further, epidemiological and clinical data indicate that women with this condition exhibit a distinct pattern and severity of symptoms that differs from those of other mood disorders and those more commonly experienced by women before or during their menstrual cycles. Inclusion in the *DSM-5* may afford women with the premenstrual dysphoric disorder diagnosis better access to treatment.

In another notable proposal, the Mood Disorders Work Group suggested that the bereavement exclusion be removed from the diagnosis of major depressive disorder. This exclusion holds that it is normal for a person in mourning to exhibit depressive symptoms and therefore such people should not be diagnosed with depression. The suggestion has drawn ire from those who claim that the experience of intense, entrenched sadness following the death of a loved one (an experience that is felt to be normal and expected in our society) should not be considered the same as clinical depression—i.e., that the exclusion should remain.

Neglected in this argument are the findings from large-scale clinical and epidemiological studies that clearly demarcate a difference between bereaved people who exhibit major depressive disorder-like symptoms and bereaved people who simply experience grief. Moreover, depression that arises in the context of bereavement appears to be nearly identical to major depressive disorder resulting from other significant psychosocial stressors, like job or relationship loss. For the bereaved person whose symptoms mirror clinical depression, diagnosis can mean access to treatment and a better, faster chance for recovery. And because the symptoms may include suicidal ideation, access to services is vital.

In a more general sense, the *DSM-5* will seek to avoid overpathologizing by more actively addressing contextual issues—such as explicating the effects of age, gender, and culture on symptomatology—that may counter, mitigate or, in some cases, confirm the diagnosis of mental disorder. For instance, the diagnostic criteria for attention deficit/hyperactivity disorder provide examples of how symptoms may manifest differentially in older adolescents and adults than in children. Where available, text within each diagnostic chapter also contains important descriptive information about gender, culture, age, functional consequences, associated features, and more. Cumulatively, these details will provide a clearer picture of psychiatric diagnoses and help clinicians better understand and interpret patients' symptoms to narrow the likelihood of improper diagnosis.

Greater Patient Involvement
Ensuring high-quality care is an ethical imperative, and one of the most innovative and anticipated proposed changes to the *DSM-5*—the integration of dimensional assessments and patient- and clinician-completed questionnaires on symptoms and functioning with the current categorical classification—could improve the quality of care by offering a greater opportunity for patients to actively participate in their own diagnosis and treatment planning. Psychiatric disorders frequently occur in patterns or clusters (e.g., depression with anxiety, and vice versa), and diagnoses are often unstable and change over the course of a patient's lifetime. These can make determining the thresholds that separate clinical from nonclinical conditions perplexing at best and near-impossible at worst. Patterns of excessive comorbidities also suggest the presence of a complex genetic or neurobiological underpinning to many if not most disorders, which belies the neat, clean boundaries implied by the *DSM-IV*'s categorical system. Supplementing binary diagnostic categories (in which the diagnosis is either present or absent) with dimensional quantitative rating scales (in which symptoms are measured along a continuum) will better capture the nuances of mental illnesses, including co-occurring conditions and disease severity, and could result in earlier, more accurate identification of psychiatric illness and provision of care.

How do patients themselves fit in with this new integration? The inclusion of diagnostic dimensions across the manual would be effected through patient-reported measures, like the Nine-Item Patient Health Questionnaire for depression, which have been long supported by clinical research yet remain noticeably absent from routine clinical practice. Patient-completed measures not only contribute a quantifiable aspect to psychiatric diagnosis, tracking of illness course, and treatment planning, they encourage solicitation of patients' perceptions of symptoms, functioning, health status, and treatment that are free of interpretation (or misinterpretation) by the clinician.

The broadest dimension proposed for the *DSM-5* is cross-cutting assessments— psychiatry's version of general medicine's "review of systems"—that call attention to areas of functioning likely to "cut across" diagnostic boundaries (e.g., mood, anxiety, cognitive status, sleep, psychotic symptoms, suicidal ideation) and may be

of clinical relevance. Items endorsed on this "review of systems" would trigger more specific assessments. A patient who indicates that she has been experiencing moderately depressed mood for the past 2 weeks, for instance, would be given a corresponding assessment for depression (in the case of the *DSM-5*, the depression module from the National Institute of Health's Patient Reported Outcome Measurement Information System [PROMIS] initiative).

Many of the proposed dimensional assessments for the *DSM-5* are drawn from existing tools (e.g., PROMIS measures) while others were generated by the *DSM-5* work groups based on findings from the literature. These measures are not intended to be screens that take the place of categorical diagnoses but to be supplements that bring attention to areas of treatment need, subthreshold conditions, and co-occurring symptoms that might impact prognosis.

A second type of proposed assessment is aimed at helping clinicians document clinical change within each individual disorder. These diagnosis-specific severity measures are rated on a quantitative scale, though the scales themselves are not universal in content or format: some measures rate illness severity based on symptom count, while others use such ratings as symptom frequency, duration, or intensity. All severity measures, regardless of their quantitative approach, are designed to help clinicians track course of illness and response to treatment.

Dimensional approaches have also been embedded in the criteria themselves of select disorders, most apparent in the proposed revisions to the diagnosis and classification of personality disorders [5, 6]. The current model of personality disorders requires clinicians to fit patients into specific personality disorder types (i.e., categories) while individuals who present with personality-related dysfunction but do not meet strict criteria for an existing personality disorder are given a diagnosis of personality disorder not otherwise specified (NOS)—a vague distinction that does little to help clinicians (or patients) understand their constellation of symptoms and how best to treat them. Furthermore, personality disorders in the *DSM-IV* have arbitrary threshold cut points and, over long periods of time, patients may not consistently meet criteria for diagnosis.

Members of the Personality Disorders Work Group have proposed a hybrid approach that uses separate dimensional ratings of core aspects of personality functioning (of self and, interpersonally, with others) and personality traits, which map onto explicit personality types and allow clinicians to make categorical determinations of diagnosis (e.g., is a personality disorder present? yes or no?) while recognizing the continuous and heterogeneous nature of personality dysfunction.

In place of the current personality disorder NOS diagnosis, the work group has proposed a new disorder, "personality disorder trait specified," wherein clinicians can diagnose patients who meet the general criteria for a personality disorder but whose traits do not match onto any of the six defined personality disorder prototypes (e.g., borderline personality disorder, antisocial personality disorder, narcissistic

personality disorder, avoidant personality disorder, obsessive compulsive personality disorder, and schizotypal personality disorder). Theoretically, this would allow psychiatrists to document limitless variations in personality by providing dimensional ratings of personality traits, domains, and facets; this level of specificity should make a designation of personality disorder trait specified more clinically meaningful than the *DSM-IV*'s personality disorder NOS in terms of better understanding patients' symptom presentations and treatment needs.

Lastly, it is worth noting that this is the first time in the manual's history that revisions to psychiatric diagnoses and their classification are being integrated with patient and public input. Over the past 2 years, the American Psychiatric Association has twice solicited comments, questions, and concerns about proposed revisions to the *DSM-5* from patients, their loved ones, and the general public through the APA's *DSM-5* web site (www.dsm5.org). The initial commenting period (February-April 2010) garnered more than 8,000 comments and questions from Web site visitors, and a second commenting phase (May-July 2011) produced approximately 2,000 responses—all of which were systematically reviewed by the respective work groups and considered in their decision making about proposed revisions.

Feedback played a central role in subsequent revisions, such as the decision by the Child and Adolescent Disorders Work Group to revise the terminology for temper dysregulation disorder with dysphoria (currently proposed as disruptive mood dysregulation disorder), and the Sexual and Gender Identity Disorders Work Group clarifying the criteria for nearly all of the disorders in the paraphilias chapter. Given the high utility of patient and public feedback in drafting revisions thus far, a third open commenting period has been scheduled to take place in 2012, following completion of the *DSM-5* field trials.

What Lies Ahead?
The degree to which the *DSM-5* will adopt proposed changes is unknown at this time. Much of the decision making will be predicated on outcomes from the *DSM-5* field trials [7], which are testing draft revisions—including those to diagnostic criteria, as well as proposals for dimensional assessments and severity ratings—in large-scale medical-research settings and in smaller, routine clinical care settings. Although field trial analyses will provide some immediate answers about whether the diagnostic criteria and dimensional changes are reliable, useful, and feasible, questions about changes in prevalence, impact on clinical research (including drug development), public health implications, and patient perceptions will require greater scrutiny once the manual is released and can be studied in larger community and clinical populations. In this respect, assessment of the *DSM-5*'s ultimate impact on patients will be an ongoing endeavor, just as the manual itself will be continuously updated in concert with advances in the mental health field and likely in more frequent iterations than before. With each revision, we expect to move closer to a diagnostic and classification system that reflects the science of psychiatry with the same authenticity with which it reflects the needs of the people it serves.

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