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Changes in the Diagnostic Criteria for Autism in DSM-5: Controversies and Concerns

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The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was published by the American Psychiatric Association (APA) in May 2013. The new edition introduced major revisions to the diagnostic criteria for autism spectrum disorder (ASD). These changes could have a significant impact on patients and families affected by ASD, as well as mental health providers and researchers working in the field of autism. In this article, we will review the changes and the rationale behind them. We will then discuss the concerns that have been raised about the new criteria and the evidence that relates to these concerns.

Revisions and Their Rationale

Before discussing the specific changes, it is important to note 2 overarching conceptual shifts in DSM-5. One is the elimination of "subthreshold" categories, such as pervasive developmental disorder not otherwise specified (PDD-NOS), throughout the manual. This decision, understandable particularly from the point of view of more specific and research-based criteria sets, also poses some practical challenges for DSM-5. Historically, DSM has been used for both research and clinical purposes; this differs from the current ICD-10 approach, which has separate manuals for research and clinical work. A second shift in the DSM-5 has been the focus on the use of relevant dimensional and other assessment instruments. The use of such instruments for research is well known, and often, as in autism, these have been explicitly "keyed" to categorical diagnostic criteria. This approach, while both cost efficient and research focused, comes at the potential price of some loss of "ecological validity." In other words, in real-world settings, clinicians do not have the time to take weeks of training on a panoply of research instruments. Furthermore, the applicability of items and concepts taken out of context and without formal training in the assessment processes from which the items are derived may create some significant issues.

With regard to the diagnosis of pervasive developmental disorders (PDDs) (the categorical title used for the "autism spectrum disorders" in DSM-IV DSM-5 has introduced several major changes, which include (1) converging the diagnostic groups previously subsumed under the category of PDDs into a single diagnosis of ASD; (2) merging the social and communication impairment symptom domains required for the diagnosis of autism into a single domain, thus reducing the symptom domains involved in diagnosis from 3 to 2; (3) expanding the "restricted, repetitive behaviors" symptom domain to include abnormalities in sensory processing; and (4) relaxing the age at onset criterion.

For autism and related conditions, the most significant and controversial revision in DSM-5 is the merging of 4 disorders that were distinct under DSM-IV criteria into a single diagnostic category. The DSM-IV diagnoses of autistic disorder, Asperger's disorder, childhood disintegrative disorder, and PDD-

NOS have been brought together under the single diagnostic heading of ASD, effectively eliminating the Asperger's disorder, childhood disintegrative disorder, and PDD-NOS diagnoses.

The merging of diagnoses under the single category of ASD has been introduced in response to concerns about the diagnostic reliability of DSM-IV subtypes, which has been shown to be weak,1–3 particularly with regard to the distinction between Asperger's disorder and "high-functioning" autism.4,5 On their Web site describing the revisions, the APA states, "A single spectrum disorder is a better reflection of the state of knowledge about pathology and clinical presentation; previously, the criteria were equivalent to trying to 'cleave meatloaf at the joints.' "6

A second major shift in the DSM-5 criteria is in moving from the 3 major symptom domains in DSM-IV, namely social impairments, communication impairments, and restricted, repetitive behaviors, to 2 domains. Social and communication impairments have been merged into a single symptom domain, while restricted, repetitive behaviors have remained distinct. The shift from 3 to 2 symptom domains in the definition of ASD was proposed because, as stated by the APA, "Deficits in communication and social behaviors are inseparable and more accurately considered as a single set of symptoms with contextual and environmental specificities."6 It was felt that under the DSM-IV definition, a single symptom could meet criteria in both of the distinct domains of social impairment and communication impairment, giving undue weight to that symptom.

The category of restrictive, repetitive behaviors has been expanded to include sensory symptoms, which have long been observed in individuals with autism but were not part of the diagnostic criteria under DSM-IV. This new criterion describes hypersensitivity or hyposensitivity to sensory input or an unusual interest in sensory cues. Under the new criteria, 2 or more restrictive, repetitive behavior symptoms must be present, instead of a single symptom as required under the DSM-IV definition. This change is intended to improve the specificity of the diagnosis.

Under the new DSM-5 definition, the age at onset criterion for the diagnosis of ASD has been relaxed to state that symptoms must be present in early childhood. This shift is a departure from DSM-IV, in which the criteria for autistic disorder require that symptoms be present before the age of 3 years. The diagnoses of Asperger's disorder and PDD-NOS in DSM-IV did not include an age at onset criterion.

Concerns About Decreased Sensitivity

Several concerns have been raised about the proposed changes to the ASD criteria in DSM-5. One major concern is that many individuals who were diagnosed with PDD under DSM-IV criteria would not meet criteria for the ASD diagnosis under the DSM-5 criteria, potentially resulting in loss of services for a number of these individuals. While the APA has expressed the intention to improve the specificity of the ASD diagnosis, concerns have been raised that this will come at the cost of decreased sensitivity.

A study by Mattila and colleagues7 applied an early draft of the proposed DSM-5 criteria to a population of children diagnosed with a PDD under DSM-IV criteria and found that 54% of these children did not

meet criteria for an ASD diagnosis under the new criteria. Subsequent studies8,9 have supported this finding, with estimates of 24%–39% of patients who fit DSM-IV criteria for a PDD failing to meet criteria under the proposed DSM-5 definition. Patients diagnosed with Asperger's disorder and PDD-NOS were the least likely to meet criteria for ASD under DSM-5 in these studies.8,9 Young children might also be less likely to meet the new criteria, with one study showing as many as 48% of toddlers who met DSM-IV criteria for a PDD not meeting ASD criteria according to DSM-5.10

Findings in this area have been conflicting, however. A recent article by Huerta et al11 showed that, consistent with the purpose of the revision, application of the DSM-5 criteria in a clinical population improved the specificity of diagnosis without significant reductions in sensitivity, with 91% of subjects in the study who met criteria for a PDD under DSM-IV criteria meeting criteria for ASD under DSM-5. The DSM-5 criteria had greater specificity than the DSM-IV criteria and were better able to identify subjects who did not have a clinical diagnosis of PDD. The authors speculate that the discrepancies between their findings and those of previous studies are due to the fact that the earlier studies used previous drafts of the DSM-5 criteria that were more stringent, with more symptoms required for diagnosis and a fixed age at onset criterion of 36 months.

This possibility is supported by a study by Frazier et al12 which demonstrated that the sensitivity of the DSM-5 criteria improved from 85% to 95% when the stricter criteria of the early draft were relaxed to require 1 fewer symptom criterion, which is more consistent with the DSM-5 criteria. It should be noted, however, that in the study by Huerta et al11 the sensitivity of diagnosis fell if both of the study's diagnostic instruments (a parent report measure and a clinical observation instrument) were not used. The sample analyzed was very highly and well assessed and may not represent a "real world" approach. As Tsai13 pointed out in an editorial accompanying the Huerta et al article, the actual sensitivity and specificity of the new approach remain unclear.

The findings of Huerta et al11 and Frazier et al12 appear to be consistent with the APA field trials that suggested that the overall prevalence of the disorder would not change significantly.14

Other Concerns

In addition to decreases in sensitivity and the attendant apprehension about potential loss of services for those who no longer fit the criteria for diagnosis, additional concerns have been raised about the change. In a recent letter to the editor published in the Journal of Autism and Developmental Disorders, Ritvo15 questions the potential cost to research and clinical programs involved in retraining clinicians on the use of the new criteria and applying the new criteria to existing patients or research subjects, who will need to be "rediagnosed." He also points out the likely disruption to research on developmental disorders, particularly ongoing longitudinal studies, as, in his words, "The vast body of research data and results published since 1994 using the DSM-IV criteria and the screening instruments based on them will not be straightforwardly compatible with the data or results produced using the new DSM-5 criteria." In other words, significant changes to the criteria may impair our ability to generalize findings and may particularly complicate longitudinal and epidemiologic studies that are currently underway.

Patient advocacy groups have raised concerns about the impact that lumping the diagnoses together and losing the Asperger's diagnosis will have on public understanding of developmental disorders and the sense of community for patients and families. For example, in a petition to the APA, the Asperger's Association of New England, a prominent patient advocacy group, argued that the Asperger's diagnosis should be preserved "to help ensure clinical continuity and the established sense of community precious to already diagnosed individuals and families, and to maintain the hard-won understanding of the label in the population at large."16

Conclusions

It is clear that the revision to the diagnostic criteria for developmental disorders will have a significant and broad impact on research and clinical practice. It is hoped that the changes in criteria will better reflect current scientific understanding of developmental disorders, particularly with regard to evidence suggesting poor diagnostic validity for the current DSM-IV diagnoses. The studies of the new criteria that have been conducted thus far have suggested that the specificity of diagnosis is likely to improve under DSM-5, but this might come at a cost of reduced sensitivity as well. On the other hand, recent studies have suggested that the reduction in sensitivity will be smaller than initially feared with the less stringent criteria included in the final version. Given the conflicting results and the difficulty in predicting how these results from academic medical centers will translate into "real world" clinical settings, it is hard to know how many patients and families will be affected by the changes. It is possible, however, that there may be patients with a diagnosable illness under DSM-IV who fail to meet the new DSM-5 criteria, and these patients may risk losing eligibility for services. The full impact of the new criteria on ongoing research studies, clinical practice, and patients' sense of community and identity may not be fully appreciated until long after the new criteria have been implemented.

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