

### 3 Patients as Experience-Based Experts in Psychiatry: Insights from the Natural Method

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#### Introduction

A primary goal of psychiatric epistemology is to identify the properties of mental disorders that are relevant for developing effective interventions. Sources of information individuating these properties include scientific research on mental disorders (e.g., clinical drug trials), data emerging from clinical settings (e.g., case studies), and first-person reports of those suffering from mental disorders or those who witness or observe such suffering. While dominant scientific frameworks in psychiatry recognize and rely on scientific and clinical data in their efforts to advance the science of mental disorders, they are not similarly committed to directly using the first-person perspectives of patients. More specifically, individuals who suffer from and are diagnosed with mental disorders have not systematically been made part of the scientific inquiry into mental disorders. This chapter calls for this problem to be rectified in scientific psychiatry. I argue that individuals diagnosed with mental disorders are “experience-based” experts on mental disorders and, as such, must be included in the scientific research aiming to expand knowledge in psychiatry. In developing this argument, I challenge the presupposition that individuals with mental disorders lack the expertise to make meaningful contributions to psychiatric epistemology.

In the first section of the chapter I review the history of the creation and revision processes of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* to illustrate how patients have historically been left out of scientific inquiry in mental disorders, tracing it to a presupposition that they lack the expertise required for scientific investigation. In the second section I critically examine the definition of *expertise* deployed by the American

Psychiatric Association (APA), creator of the *DSM*, and develop an alternative definition by identifying patients as experience-based experts. My discussion is guided by Owen Flanagan's natural method and the account of expertise developed by third-wave science studies scholars. My argument for including patients in psychiatric research is primarily conceptual: I challenge the assumption that individuals with mental disorders lack expertise in the scientific investigation of mental disorders. Unfortunately, while a discussion of how to develop better scientific policies (or scientific paradigms) involving patients would be interesting, it is beyond the scope of this chapter.

### **The Presupposition: "Patients Are Not Experts"**

Historically, patients have not been included in the scientific inquiry on mental disorders as "subjects" who produce knowledge. Their role has been constrained to serving as the "objects" of study in clinical trials or clinical case studies. This is largely because of the presupposition that patients lack the expertise required for the scientific investigation of mental disorders. The goal of this section is to illustrate the pervasiveness of this presupposition by reviewing the creation and revision processes of the *DSM*. I focus on the *DSM* because it is the primary classificatory schema used in the United States and around the world to expand knowledge on mental disorders in psychiatry, with a mandate to serve "clinical, research, and educational purposes."<sup>1</sup> I examine the *DSM* creators' conception of what counts as "expertise" in the scientific investigation of mental disorders. As I go on to show, in the various versions of the *DSM*, the notion of "expertise" is limited to those with clinical training in psychopathology; expertise on the basis of experience is discounted.

The primary reason for developing a classification of mental disorders in the United States was the perceived need to collect statistical information on the prevalence of mental disorders. The 1840 census, conducted by the Census Office, recorded the frequency of "idiocy/insanity" in the population, but there were many errors in this preliminary classification, as reported by the American Statistical Association to the US House of Representatives.<sup>2</sup> In response, the Association of Medical Superintendents of American Institutions for the Insane was formed in 1844 to ensure that a classification system for mental disorders was created by medical experts.

The Association of Medical Superintendents of American Institutions, later the American Psychiatric Association (APA), worked with the National Commission on Mental Hygiene (now Mental Health America) to develop a guide for mental hospitals called *The Statistical Manual for the Use of Institutions for the Insane*. Along with the New York Academy of Medicine, the APA also developed the psychiatric nomenclature subsection of the US general medical guide *The Standard Classified Nomenclature of Disease*.<sup>3</sup>

The initial taxonomy for mental disorders was further developed during World War II, when psychiatrists became heavily involved in the selection, assessment, and treatment of soldiers. For example, in 1943, a committee of psychiatrists developed a new classification scheme, Medical 203, which was published in a War Department technical bulletin. Shortly after the war, in 1949, the World Health Organization (WHO) published the sixth edition of the *International Statistical Classification of Diseases (ICD)*. For the first time, the *ICD* included a section on mental disorders.

Despite the earlier efforts to come up with a common classification system, as these examples suggest, in the mid-twentieth century, many different systems were in use, and there was mounting concern about developing a unifying schema.<sup>4</sup> In response to this concern, an APA Committee on Nomenclature and Statistics developed a system of classification specifically for use in the United States to standardize the diverse and often inconsistent usage of different documents listing the criteria for mental disorders. In 1950, the APA committee undertook a review of Medical 203 by consulting the members of the APA and the Veterans Administration (VA) and created the first edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-I)*, published in 1952. *DSM-I* had clear statistical goals: it aimed “to make possible the gathering of data for future clarification of ideas concerning etiology, pathology, prognosis, and treatment in mental disorders.”<sup>5</sup> It was grounded in the psychoanalytic approach: mental disorders, also called “reactions,” were represented in relation to the psychodynamic causal factors underlying them. These causal factors were characterized as either a dysfunction in the brain or a general difficulty in adapting to environmental stressors resulting from unresolved sexual conflicts of childhood. For example, psychotic disorders were defined as disorders of psychogenic origin or without clearly defined physical cause or structural change in the brain.<sup>6</sup> The following paragraph describes *who* was involved in the development of *DSM-I*:

In April, 1950, the Committee distributed mimeographed copies of a proposed revision of the psychiatric nomenclature to approximately 10% of the membership of the American Psychiatric Association. Addressees were picked from the geographical listing of members, 10% of the members in each State and Canada being selected. In addition, addressees were selected by position held, in order to give complete coverage to all areas of psychiatry. Attention was paid to membership in other organizations (American Neurological Association, American Psychoanalytic Association, Academy of Neurology, American Psychopathological Association, etc.), so that a fair sampling of those groups was included. Members of the staffs of State Departments of Mental Health were included in order to obtain an expression of opinion from such departments concerning the statistical and clinical impact of the proposed revision.<sup>7</sup>

It appears that the emphasis was on bringing together psychiatrists with different specialties to include representatives of all areas in mental disorder research, as well as various interest groups of specialists in mental health. The foreword to *DSM-I* also states that the US Navy made some revisions to the work.<sup>8</sup> In short, the first edition of the *DSM* was the product of collaborations between the members of the APA, various medical professionals (psychiatrists and neurologists), and the military. These stakeholders, except for the military, remained the primary group of experts who revised the *DSM* and published *DSM-II*.

The psychoanalytic orientation of *DSM-I* and *DSM-II* was heavily criticized. Critics argued that it was based on theoretical presuppositions about the human mind (e.g., that the unresolved sexual tensions of childhood cause adult psychosis). Without observable and measurable evidence, they argued, the categories of mental disorders given in *DSM-II* failed the standards of scientific validity.<sup>9</sup> A scientifically valid category of mental disorder required external validators, such as symptoms (experienced by the patient), signs (observed by others), and neurobiological markers, not simply theories.<sup>10</sup>

Thus, two important changes occurred during the publication of *DSM-III*. First, the criteria for mental disorders were atheoretical, based on the signs and symptoms of mental disorders. Second, and more important for the purposes of this chapter, a procedural change made the revision process more collaborative. The *DSM-III* Task Force formed by the APA solicited input not only from psychiatrists but also from scientists in other stakeholder organizations, including the APA, the Association of Women Psychiatrists, the Academy of Psychiatry and the Law, the American Academy of

Child Psychiatry, the American Academy of Psychoanalysis, the American Association of Chairmen of Departments of Psychiatry, the American College Health Association, the American Orthopsychiatric Association, and the American Psychoanalytic Association. These groups received drafts of *DSM-III* and were invited to express their concerns.<sup>11</sup> Simply stated, these particular individuals and groups were selected because of their expertise. The introduction to *DSM-III* makes it clear that, whenever possible, the creators of the *DSM* sought the “advice of experts in each specific area under consideration.”<sup>12</sup> Experts were understood to be trained researchers or clinicians who investigated mental disorders.

The creation process for *DSM-IV* remained largely identical to that for *DSM-III*; the *DSM-IV* Task Force and the various workgroups encouraged the participation of a wide range of professionals to serve as advisers. These advisers included individuals “from other health associations; clinical practitioners; researchers; forensic specialists; experts on gender, age, and cultural issues; and international experts.”<sup>13</sup> From the publication of *DSM-I* to that of *DSM-IV*, patients were never consulted, although there were hints that this might change before the appearance of *DSM-5*.

Before the publication of *DSM-5*, there were extensive calls to the APA to include patients and other stakeholders in the revision process. These conversations took place largely in response to the *DSM-5* Task Force’s efforts to make the *DSM* creation process more collaborative. Some invoked the need for the process to be democratic, with participants including members of the public with a vested interest in the diagnostic criteria, such as patients and their families.<sup>14</sup> Some approached it from the perspective of patient advocacy and emphasized the need “for scientific experts to review their nosological recommendations in the light of rigorous consideration of consumer experience and feedback.”<sup>15</sup> Others argued that patients bring a different perspective to the conversation on psychiatric classifications because they can report on their subjective experiences. This, they said, would help make the *DSM* criteria for mental disorders finer grained and more responsive to the real experiences of patients.<sup>16</sup> Still others argued that the *DSM* was facing a crisis of public trust and therefore needed to increase the integration of patients into the *DSM* revision process to address the issue.<sup>17</sup>

The *DSM-5* Task Force members responded by acknowledging the benefits of including patients’ perspectives in the *DSM* revision process, but they did not invite patients to join in. Their first set of worries was

primarily epistemic: they raised concerns about the subjectivity of the data in patients' reports and the apparent conflict with psychiatry's desire to establish itself as an objective form of inquiry.<sup>18</sup> For example, in response to an article calling for the inclusion of patient-subjective data in the *DSM* and the *ICD*, they argued that "subjectivity is variable from person to person," making it "impossible to develop definitive criteria that would apply to every disorder." And they rhetorically asked, "Whose subjective experience should serve as a template by which criteria would be developed?"<sup>19</sup> The second set of worries was more practical in nature. The DSM-5 Task Force cited the limited time left in the revision process; there wasn't enough time to include patients. Instead, they suggested the APA's invitation for feedback from the public through an online forum was a positive step toward including patient input, insofar as patients are also members of the general public. Anyone, they said, was allowed to comment on *DSM-5*, including patients, and the task force would take this feedback seriously. To the best of my knowledge, however, no systematic report has detailed how such feedback was integrated into *DSM-5*—if at all. The following statement was released by the APA, in a document called "The People behind DSM-5":

Development of the fifth edition of *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) has been under way since 1999, when the American Psychiatric Association (APA) began recruiting a roster of diverse and internationally-recognized clinicians, scientific researchers and organizations to lend their expertise. Through this wide scale collaboration, the DSM-5 development process has involved not only psychiatrists, but also experts with backgrounds in psychology, social work, psychiatric nursing, pediatrics, and neurology. Participants in this effort represent 16 countries. All are leaders in their fields and are participating on a voluntary basis.<sup>20</sup>

Notably, the statement stresses the ongoing importance of recognized expertise.

In the end, the members of the APA (primarily psychiatrists) were the principal community of experts responsible for determining the criteria for the classification of mental disorders, and patients were once again left out of the process. Underlying this was the ongoing presupposition that patients did not have the expertise to participate in the scientific investigation of mental disorders, even though they might have something to offer as members of the public. Patients' possible contributions were discounted as "subjective" and thus incompatible with psychiatry's goal of being an objective science.

The explicit calls to include patients in the revision process of *DSM-5* were significant, but the participants in the debate took for granted that psychiatrists or other professionals trained in psychopathology were the experts and that including patient perspectives was important for reasons of added value (e.g., making the scientific process more democratic). Their involvement was not considered epistemically necessary in order to obtain complete knowledge on mental disorders. In other words, the arguments developed in favor of including patients were motivated by social concerns about making science more collaborative rather than epistemological concerns about enhancing the sources of information to develop a more comprehensive understanding of mental disorders. Even if the information patients provided on mental disorders was valued,<sup>21</sup> their perspective remained ancillary to that of trained experts.

Departing from those scholars who defend the necessity of patients' inclusion for social and political reasons, I call for the inclusion of patients in the scientific research on mental disorders for epistemological reasons. Their perspective is indispensable in the creation of knowledge on mental disorders, as I discuss in the third section of this chapter. One worry that must be addressed here is expressed by the *DSM-5* Task Force when they discount patients' perspectives as too "subjective" in a science that aims to enhance its "objectivity." More specifically, the concern is that subjective data are interpersonally variable (not every person's testimony is like another person's), leading to the problem of whose perspective will count in developing the scientific framework for mental disorders. Critics argue that these two connected problems might end up compromising psychiatry's status as an objective science.

The notion of objectivity operative in these types of criticisms has been insufficiently examined, but tackling it is challenging, given the complexity of the notion.<sup>22</sup> The *DSM-5* Task Force members seem to be construing objectivity as "impartiality," with objective data on mental disorders coming from third-person observations (by psychiatrists or other clinically trained experts). The construal of objectivity as "impartiality," possible only when data come from third-person perspectives, can be extrapolated from the assertions that "subjectivity is variable from person to person," making it "impossible to develop definitive criteria that would apply to every disorder."<sup>23</sup> Similarly, the rhetorical question asking "whose subjective experience should serve as a template by which criteria would be developed"

hinges on the idea that criteria for mental disorders should be based on impartial or third-person observations, not “subjective” or first-person perspectives.<sup>24</sup>

The notion of objectivity as impartiality concerns me. It seems to rely on a now dated positivistic notion of objectivity as the “view from nowhere.” Very briefly, according to logical positivists, science is objective to the extent that it is completely free from values. This is possible because, for positivists, justification for scientific evidence is grounded on impartial (third person) observational data that are verified by the world. Thus, objective science is impartial and abides by value neutrality. Feminist epistemologists have challenged the view of objectivity as the view from nowhere; rather, they argue, scientists are people, and science is a community activity.<sup>25</sup> However, even though the value neutrality thesis is false and science is guided by epistemic and contextual values, science can still be objective. The social feature of science is necessary for the objectivity of scientific inquiry. In fact, including a diversity of knowers in the knowledge production process is one way to enhance the objectivity of knowledge.<sup>26</sup> Science is objective to the extent that its methods, especially its criteria for assessing theories, are neither arbitrary nor subjective. In order to ensure objectivity in science, we must consider it as a social activity organized to permit and encourage *transformative criticism*—criticism with the power to change contextual values of scientists, should they be ill founded. As Longino writes:

From a logical point of view, if scientific knowledge were to be understood as the simple sum of finished products of individual activity, then not only would there be no way to block or mitigate the influence of subjective preference but scientific knowledge itself would be a potpourri of merrily inconsistent theories. Only if the products of inquiry are understood to be formed by the kind of critical discussion that is possible among a plurality of individuals about a commonly accessible phenomenon, can we see how they count as knowledge rather than opinion.<sup>27</sup>

I would like to respond to the critics who argue that the inclusion of patients in the *DSM* revision process will compromise psychiatry’s goals as an objective science by evoking Longino’s response to positivists. Patients must be included in the knowledge production process for epistemic reasons; their inclusion will not compromise psychiatry’s goal to be an objective science. The subjectivity of their experience with mental disorders and their perspectives on the diagnostic criteria are assets, not impediments, in the scientific process. Their direct encounter with mental disorders is an



experience unknown to clinical or scientific experts. Including patients in the knowledge production process will allow transformative criticism by ensuring that different points of view are part of the scientific decision-making process. This, in turn, will lead to procedural objectivity, as the clinically trained experts and the patients can subject each other's hypotheses and evidential reasoning to critical scrutiny, thereby limiting the intrusion of individual subjective preferences into scientific knowledge. In the process, the subjective experiences of patients may create objective patterns of experiences previously missed by the clinically trained experts.<sup>28</sup> Of course, arguing for the indispensability of patients' perspectives in producing scientific knowledge requires a close assessment of why their points of view are so important; therefore, in the following section, I make a case for seeing patients as experience-based experts and for the epistemic value of their subjective reports.

### Reevaluating Expertise in Psychiatry

As I explained in the previous section, the notion of expertise used in the psychiatric context is limited to those with training in psychopathology, but we need to reevaluate the epistemological question about who is qualified to conduct research and thus expand knowledge in psychiatry. I challenge the dominant notion of expertise in psychiatry. Patients, I argue, have a special kind of expertise when it comes to mental disorders, and they could contribute to psychiatric epistemology as "experience-based experts."<sup>29</sup> In addition, taking them as experience-based experts and including them in the knowledge production process in psychiatry overcomes the challenge of "subjectivity" put forward by the creators of the *DSM*. It is precisely these patients' subjective experience with mental disorders that makes them experience-based experts, and this perspective allows them to make a unique contribution to the understanding of mental disorders.

An important topic in philosophy of science and in science studies is the situation of scientific expertise in broad social, historical, and philosophical contexts.<sup>30</sup> A core question is whether the public, specifically those persons directly influenced by scientific research, should be involved in making scientific decisions or whether this should be left to the experts trained in the relevant sciences. A significant contribution to this debate has been the introduction of categories of expertise in science. The value of scientists'

and technologists' knowledge and experience has been compared with others' knowledge and experience. In this new understanding, members of the public with special technical expertise by virtue of experience that is not recognized by degrees or other certifications are defined as "experience-based experts."<sup>31</sup> This enables *pockets of expertise* to be assigned to the citizenry. The goal is to develop a discourse of expertise that will place citizens' expertise alongside scientists' expertise. The framework of experience-based expertise can be used to characterize patients' encounters with mental disorders and their contributions to the scientific process. This raises the question of what expertise patients have.

### Patients as Experience-Based Experts: Insights from the Natural Method

First-person reports of individuals with mental disorders offer unmatched resources for psychiatric epistemology, especially in the context of the current crisis and controversy in mental health research.<sup>32</sup> Before continuing, let me first list a few aspects of mental disorders on which patients have expertise. First, patients, especially those who have been dealing with a chronic mental disorder for a long time, have a robust understanding of the orientational challenges associated with mental illness, such as psychic pain or other symptoms and signs of the illness.<sup>33</sup> Second, they have knowledge of the various responses to different treatment methods, such as psychotropic medications, psychotherapy, and support groups.<sup>34</sup> Third, they understand how mental illness affects other aspects of their lives, such as interpersonal relationships, their treatment within the community, and the reactions of others to their illness.<sup>35</sup> Fourth, they understand how the scientific framing of their mental disorder (e.g., their *DSM* diagnosis) affects the kinds of accommodations they receive in their jobs and other aspects of their lives. Finally, those who have been successful in sustaining a good quality of life despite their illness have a good grasp of the sources of courage and strength they need to cope with disruptions in their daily lives.<sup>36</sup> Given their wealth of understanding, the inclusion of patients (i.e., those most directly influenced by scientific research programs and clinical treatments) can only benefit the process of knowledge production in medical epistemology.

The methodology proposed here, taking patients as experience-based experts to enhance knowledge on mental disorders, follows Owen Flanagan's

natural method of solving what he calls the “puzzle of consciousness.”<sup>37</sup> The natural method corrals consciousness by paying attention to its phenomenology (how consciousness seems), its psychology (what the mental labor of consciousness does), and its neurobiology (how consciousness is realized). In Flanagan’s view, consciousness is a superordinate term for a heterogeneous array of mental state types. Adopting Thomas Nagel’s description of the phenomenal character of consciousness from his seminal article “What Is It Like to Be a Bat?,” Flanagan argues that all the mental types individuating consciousness share the property of “being experienced” or “being experiences,” or, in other words, of there being “*something that it is like for the subject* to be in one of these states.”<sup>38</sup> Flanagan says that, to build a theory of consciousness, we must deploy “the natural method” of coordinating all relevant informational resources at once, especially phenomenology, cognitive science, neuroscience, and evolutionary biology. By being responsive to both scientific findings and first-person experiences, this picture of consciousness is grounded on actual human selves as we encounter them.

In his later work on the problems associated with self-consciousness, dream interpretation, and narratives, Flanagan further develops the natural method, calling it “the expanded natural method.”<sup>39</sup> In addition to looking at phenomenology, psychology, and neurobiology for insights into human consciousness, the expanded natural method draws insights from religion, literature, and other disciplines in the humanities. Such a multidisciplinary approach to human consciousness, Flanagan insists, demands constant vigilance against privileging or diminishing the value of any one approach.

My claim that patients are experience-based experts applies the natural method to psychiatric epistemology. In this trilateral strategy, scientific and clinical work involving individuals with mental disorders are the first two pillars of knowledge on mental disorders, and first-person reports are the third.<sup>40</sup> Taken together, these epistemic resources may help in developing effective interventions into mental disorders, as they disclose, respectively, the underlying causes of mental disorders, their effective treatment, and what it is like to have a mental disorder. The latter epistemic source can guide interventions in psychiatry, because firsthand accounts help in assessing therapeutic successes and failures. The information obtained is not exhaustive; rather, it is complementary to the information obtained from clinical and scientific research. Nonetheless, the inclusion of patient perspectives allows us to engage with different types of evidence that might

be overlooked in conventional case-reporting scenarios.<sup>41</sup> Simply stated, their inclusion is necessary if we want to obtain a complete understanding of mental disorders.

The outcome of Flanagan's natural method to understand human selves is the embracing of human variations. Flanagan introduces the concept of "non-standard phenomenologies" to capture this diversity.<sup>42</sup> By that he means the wide range of capacities and limitations of human selves, some of which point to the distortion of the bonds connecting a person to her cognitive, bodily, social, and agential experience. His rich account of selfhood recognizes the existence of those with mental disorders and other cognitive diversities and includes them in the philosophical contemplation of how human selves should live their lives. Flanagan puts his naturalistic research program on human selves to the service of ethics and human flourishing. The recognition of the complexity of the psychological capacities and limitations of human beings by taking the scientific scrutiny of the actual lived world as simply one reference point results in naturalistic ethics.

Flanagan's recent work on addiction showcases the pertinent role played by the first-person perspectives of those with addiction in enhancing our understanding of this condition.<sup>43</sup> He writes that each of the scientific, clinical, and first-person perspectives contributes to the complete truth of alcoholism or alcoholisms.<sup>44</sup> Paying attention to all perspectives is necessary to understand any "psychobiosocial phenomenon, a social kind, not a natural kind, which has phenomenological, behavioral, social, cultural, genetic, and neurophysiological aspects or features."<sup>45</sup> Flanagan writes:

The alcoholic who attempts to speak truthfully about what being in the grip is like, even if he does not get it exactly right even about himself, deserves a say in determining what alcoholism is because alcoholism is a complex psychobiosocial disorder with an irreducible first-person what-it-is-to-be like-ness. DSM-IV, and the soon-to-be-fully-unveiled DSM-5, speak truthfully, as far as we know, about the general contours of alcoholism and alcohol abuse given the data. But if one wants to know what it feels like to be an alcoholic, one is much better off reading, say, Charles Jackson's *Lost Weekend* (1944), the best description ever of the phenomenology of alcoholic craving, scheming, the multiple kinds of alcoholic forgetfulness, forgetfulness of what one said and did, of the alcoholic's self-degradation, self-loathing, of the abject awfulness of his predicament, the suicidal despair.<sup>46</sup>

Drawing on Flanagan's natural method, we can imagine a trilateral strategy to investigate mental disorders by including patients among the experts

on them.<sup>47</sup> This will have scientific significance because of its ability to capture mental disorders in their full complexity. At the same time, it will have ethical implications, affecting how we treat those with mental disorders and contributing to their flourishing. The inclusion of patients will result in scientifically grounded ethical and policy-related initiatives that can improve the lives of those suffering from mental disorders.

Looking at patient reports by using the natural method may help us understand mental illness and facilitate *DSM* development, but does it mean patients themselves ought to be involved in designing the *DSM*? This question is at the heart of this chapter. As I see it, any reporting on the first-person perspective by others will necessarily be selective and representative and will not capture the full fabric of what the patients themselves are reporting. For example, when clinicians report on what their patients' experiences are like, they are selective; they are necessarily influenced by their own perceptions of the patients and their theoretical orientations. What we get directly from the first-person reports, in the *DSM* designation process, is raw input reflecting patients' standpoints. This would be missed if we relied on others' reports of first-person perspectives.

A second question is whether my view of including patients in the knowledge production process in psychiatry applies to other areas of medicine. I say it does. We already see examples of this line of thinking in all areas of medicine; there are many, but let me give two here. First, in the last few decades, an important topic for proponents of humanistic approaches to medicine has been the nature of the relationship between the health care professional and the patient. One suggestion to enhance humanism in medical practice is for health care professionals to recognize and engage with patients' narratives. Rita Charon, the founder of the narrative medicine approach, argues that the clinician must acquire the skills to listen to, interpret, and reflect on the patient's stories with an "engaged concern" to achieve therapeutic outcomes, because this is the fundamental way in which the patient learns to trust the clinician.<sup>48</sup> The focus of narrative medicine is on the experiences of the patients rather than on the generalizable propositions about them produced by logicoscientific inquiry. Giving uptake to patients' narratives is considered necessary not only to build trust between clinicians and patients but also to give physicians the means to improve the effectiveness of their work with patients, themselves, their colleagues, and the public. Active research and clinical programs in various

hospitals is testing the fundamental tenets of narrative medicine in medical practice. My proposal to include patients in the knowledge production process in psychiatry is developed in a similar spirit of humanism: one of the best ways of enhancing psychiatric epistemology and practice is to give a voice to those directly affected by mental illness.

The second example of recent advocacy for the direct inclusion of patients' perspectives in the medical knowledge production process is the current discussion of the nature of clinical case studies in medical epistemology. A clinical case study, as a research methodology, is an empirical inquiry that investigates a medical phenomenon within its real-life context. Clinical case studies are based on in-depth investigations of individuals' illnesses to describe the details of a case, explore its underlying causes, study its unique aspects, create effective interventions, and so on. Rachel Ankeny recently noted that most clinical case studies are only presented from the physician's point of view, in which "the doctor's voice becomes authoritative, even though in a sense his or her version of the events could be seen as a mere interpretation of the 'real' case as narrated by the patient."<sup>49</sup> She argues for the inclusion of patient perspectives in clinical studies not just as a source of added value but also as a source of evidence, because patients provide unique details about their illness that may otherwise be overlooked.<sup>50</sup>

## Conclusion

In this chapter I have argued that patients have experience-based expertise on mental disorders and thus must be included in the scientific research programs advancing knowledge about these disorders. Patients' involvement as contributors to research has been minimal because of the presupposition that they lack the technical expertise required to make meaningful contributions to psychiatric science. Acknowledgment of their possible contribution has been limited to their position as members of the general public with a certain vested interest in the research. All they can offer is subjective information, however, and this is incompatible with psychiatry's goal of establishing itself as an objective science. Partially inspired by Flanagan's natural method, I argue that the very subjectivity of the experience of patients makes them experience-based experts on mental disorders and provides indispensable resources for establishing psychiatry

as an objective science. The first-person reports of those suffering from mental disorders represent a pillar of psychiatric epistemology, right beside those of scientific and clinical research, and should be acknowledged as such. The stakes are high, not only in scientific and medical terms but also in ethical terms.

### Notes

1. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, xxiii; American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, xxvi.
2. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, First Edition*.
3. *Ibid.*; Greenberg, Shuman, and Meyer, Unmasking forensic diagnosis.
4. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, First Edition*.
5. *Ibid.*, 9.
6. *Ibid.*
7. *Ibid.*, viii–ix.
8. *Ibid.*
9. Beck, Reliability of psychiatric diagnoses; Schwartz and Wiggins, Diagnosis and ideal type; Tsou, DSM-5 and psychiatry's second revolution; Sadler, *Values and Psychiatric Diagnosis*.
10. Robins and Guze, Establishment of diagnostic validity in psychiatric illness; First et al., Clinical utility as a criterion for revising psychiatric diagnoses.
11. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Third Edition*.
12. *Ibid.*, 4.
13. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, 851.
14. Sadler and Fulford, Should patients and their families contribute to the DSM-5 process?
15. Stein and Phillips, Patient advocacy and DSM-5.
16. Flanagan, Davidson, and Strauss, The need for patient-subjective data in the DSM and the ICD.

17. Bueter, Public epistemic trustworthiness and the integration of patients in psychiatric classification.
18. Regier et al., Patient involvement in the development of DSM-V.
19. Ibid.
20. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*.
21. For example, see Flanagan, Davidson, and Strauss, The need for patient-subjective data in the DSM and the ICD.
22. Longino, *Science as Social Knowledge*; Douglas, The irreducible complexity of objectivity.
23. Regier et al., Patient involvement in the development of DSM-V.
24. Ibid.
25. Longino, *Science as Social Knowledge*; Douglas, The irreducible complexity of objectivity.
26. Longino, *Science as Social Knowledge*.
27. Ibid., 74.
28. Ibid. Longino, in her discussion of transformative criticism, argues that scientists should be the ultimate decision makers, albeit a diverse community of scientists, representing different viewpoints and schools of thought. Longino herself therefore may not advocate including patients in the scientific decision-making process, as they are not scientists. In defending patients' inclusion in the knowledge production process from the standpoint of feminist epistemology, I invite readers to think of transformative criticism as a process that includes not only technically trained scientists but also other kinds of experts, such as patients, who are experience-based experts, as I discuss in the third section of this chapter. The kind of objectivity I envision could thus be labeled participatory intersubjective objectivity. It is beyond the scope of this chapter to develop this view.
29. Collins and Evans, The third wave of science studies.
30. Ibid.
31. Ibid., 251.
32. Poland and Tekin, *Extraordinary Science and Psychiatry*; Tekin, Flanagan, and Graham, Against the drug cure model; Tekin and Outram, Overcoming mental disorder stigma.
33. Tekin, Self-insight in the time of mood disorders.



34. Tekin, The missing self in scientific psychiatry.
35. Tekin, Self-concept through the diagnostic looking glass; Tekin, Self-insight in the time of mood disorders.
36. Tekin and Outram, Overcoming mental disorder stigma.
37. Flanagan, *Consciousness Reconsidered*.
38. Ibid.; Nagel, What is it like to be a bat?
39. Fireman, McVay, and Flanagan, Introduction.
40. Tekin, Are mental disorders natural kinds?
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