

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

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## 1. 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 part one, 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 part two, 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 such a discussion would be interesting, it is beyond the scope of this chapter to discuss how to develop better scientific policies (or scientific paradigms) involving patients.

## **2. 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 due to 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 Diagnostic and Statistical Manual of Mental Disorders (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” (APA 1994, xxiii; APA 2013, xxvi). 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 United States House of Representatives (APA 1952). 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*. (APA 1952; Greenberg, Shuman, Meyer, 2004).

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; this was published in the 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-20<sup>th</sup> century, many different systems were in use, and there was mounting concern about developing a unifying schema (APA 1952). 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, i.e., it aimed to “to make possible the gathering of data for future clarification of ideas concerning etiology, pathology, prognosis, and treatment in mental disorders” (APA 1952, 9). 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 to adapt to environmental stressors due to 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 (APA 1952). 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. (APA 1952, viii-ix)

The emphasis, it appears, 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 the DSM-I also states that the US Navy made some revisions to the work (APA 1952). 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 the DSM-II.

DSM-I and DSM-II's psychoanalytic orientation was heavily criticized. Critics argued that it was based on theoretical presuppositions about the human mind, e.g., the unresolved sexual tensions of childhood causing adult psychosis. Without observable and measurable evidence, they argued, the categories of mental disorders given in DSM-II failed the standards of scientific validity (Beck 1962; Schwartz and Wiggins 1987a; 1987b; Tsou 2015; Sadler 2005). 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 (Robins and Guze 1970; First et al. 2004).

Thus, two important changes occurred during the publication of the 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, like the American Psychological Association, 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, the American Psychoanalytic Association, and the American Psychological Association. These groups received drafts of DSM-III and were invited to express their concerns (APA 1980). Simply stated, these particular individuals and groups were selected because of their expertise. The introduction to the DSM-III is clear; whenever possible, the creators of the DSM sought the “advice of experts in each specific area under consideration” (APA 1980, 4). Experts were understood as trained researchers or clinicians who investigated mental disorders.

The DSM-IV creation process remained largely identical to that of the DSM-III; the Task Force on DSM-IV and the various work groups 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” (APA 1994, 851). From the publication of the DSM-I to the DSM-IV, patients were never consulted, although there were hints that this might change before the appearance of the DSM-5.

Before the publication of the 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 vested interest in the diagnostic criteria, such as patients and their families (Sadler and Fulford 2004). 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” (Stein and Phillips 2013). 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 the DSM criteria for mental disorders to be finer-grained and more responsive to the real experiences of patients (Flanagan, Davidson and Strauss 2010). Still others argued that the DSM was facing a crisis of public trust and must increase the integration of patients into the DSM revision process to address the issue (Bueter 2018).

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 them 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 (Regier, Kuhl, Kupfer and McNulty, 2010). For example, in response to an article calling for the inclusion of patient-subjective data in the DSM and 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?” (Regier, Kuhl, Kupfer and McNulty, 2010). The second set of worries was more practical in nature. They 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 towards including patient input, in so far as patients are also members of the general public. Anyone, they said, was allowed to comment on the 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 the 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. (APA, 2013b)

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



In the end, the members of the American Psychiatric Association (APA), i.e. 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 to be an objective science.

The explicit calls to include patients in the revision process of the DSM-5 were significant, but the participants in the debate took it for granted that psychiatrists or other professionals trained in psychopathology were the experts, and including patient perspectives was important for reasons of added value (e.g., making the scientific process more democratic, etc.). Their involvement was not considered epistemically necessary 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 (such as in Flanagan, Davidson and Strauss 2010), 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 Section 3. 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. These two connected problems, the critics argue, might end up compromising psychiatry’s status as an objective science.

The notion of objectivity operative in these types of criticisms is insufficiently examined, but tackling it is challenging, given the complexity of the notion (Longino 1991; Douglas 2004). The DSM-5 task Force members seem to be construing objectivity as “impartiality” with objective data on mental disorders coming from third-person observations (of 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” (Regier, Kuhl, Kupfer and McNulty, 2010). Similarly, the rhetorical question asking “Whose subjective experience should serve as a template by which criteria would be developed” (Regier, Kuhl, Kupfer and McNulty, 2010) hinges on the idea that criteria for mental disorders should be based on impartial or third person observations, not “subjective” or first-person perspectives.

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 (Longino 1990; Douglas 2004). However, even though the value neutrality thesis is false, and science is guided by epistemic and contextual values, it 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 (Longino 1990). 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. (Longino 1990, 74)

I would like to respond to the critics who argue 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 different points of view are a 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 patterns, objective patterns of experiences previously missed by the clinically trained experts.<sup>1</sup> Of course, arguing for the indispensability of patients' perspectives in the scientific knowledge production process requires a close assessment of why their point of views are so important; therefore, in the following section I make a case for seeing patients as experience based expert and the epistemic value of their subjective reports.

### **3. Re-evaluating 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 re-evaluate the

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<sup>1</sup> Longino (1990), in her discussion of transformative criticism, argues scientists should be the ultimate decision makers, albeit a diverse community of scientists, representing different viewpoints and schools of thoughts. 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, like patients, who are experience-based experts as I discuss in section 3. The kind of objectivity I envision could thus be labeled Participatory Intersubjective Objectivity. It is beyond the scope of this paper to develop this view.

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” (Collins and Evans 2002). 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 science studies is the situation of scientific expertise in broad social, historical, and philosophical contexts (Collins and Evans 2002). A core question is whether the public, specifically those persons directly influenced by scientific research, should be involved in scientific decision making 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 certification are defined as “experience-based experts” (Collins and Evans, 2002, 251). This enables *pockets of expertise* to be assigned to the citizenry. The goal is to develop a discourse of expertise which will place citizens’ expertise alongside scientists’ expertise. The framework of experience-based expertise can be used to characterize patients’ encounters with mental disorder and their contribution to the

scientific process. This raises the question of what expertise patients have, or what they are experts on.

#### **4. 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 (Poland and Tekin 2017; Tekin 2017; Tekin and Outram 2018). 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 (Tekin 2014). Second, they have knowledge of the various responses to different treatment methods, such as psychotropic medications, psychotherapy, and support groups (Tekin 2017). 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 (Tekin 2011, 2014). 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 etc. 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 (Tekin and Outram 2018). 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, i.e., 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" (Flanagan 1992). 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 the mental types individuating consciousness all 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" (Flanagan 1992; Nagel 1974). To build a theory of consciousness, Flanagan says, 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" (Fireman, McVay, and Flanagan 2003). 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 and first-person reports are the three pillars of knowledge on mental disorders (Tekin 2016). Taken together, these epistemic resources may help to develop 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 first-hand accounts help to assess 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 (Ankeny, 2017). 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 (Flanagan 1992). By "non-standard phenomenologies," 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 (Flanagan 2013; Tekin, Flanagan and Graham 2017). He writes that each of the scientific, clinical, and first-person perspectives contributes to the complete truth of alcoholism or alcoholisms (Flanagan 2013). 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" (Flanagan 2013, 866). Flanagan writes:

[T]he 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. (Flanagan 2013, 867)

Drawing on Flanagan's natural method, we can imagine a trilateral strategy (Tekin 2016) to investigate mental disorders by including patients among the experts on mental disorders. 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 through the natural method may help us understand mental illness and facilitate the DSM development, but does it mean patients themselves ought to be involved in the designing of the DSM? This question is at the heart of my 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 rely 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 healthcare professional and the patient. One suggestion to enhance humanism in medical practice is for healthcare professionals to recognize and engage with patients' narratives. Rita Charon, the founder of Narrative Medicine, argues the clinician must acquire the skills to listen, 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 (Charon 2006). The focus of Narrative Medicine is on the experiences of the patients, rather than 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 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, etc. 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” (Ankeny 2017, p.102). She argues for the inclusion of patient perspectives in clinical studies not just as a source of added value, but as a source of evidence

because patients provide unique details about their illness that may otherwise be overlooked (Ankeny, 2017).

## **5. 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 to establish 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 provide 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.

## **References**

American Psychiatric Association. 2013a. Diagnostic and Statistical Manual: Mental Disorders, Fifth Edition. Washington, DC.

American Psychiatric Association. 1994. Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. Washington, DC.

American Psychiatric Association. 1980. Diagnostic and Statistical Manual: Mental Disorders, Third Edition. Washington, DC.

American Psychiatric Association. 1968. Diagnostic and Statistical Manual of Mental Disorders, Second Edition. Washington, DC.

American Psychiatric Association. 1952. Diagnostic and Statistical Manual: Mental Disorders, First Edition. Washington, DC.

American Psychiatric Association. 2013b. The People Behind DSM-5. Retrieved on 11/29/2018: <https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/dsm-5-fact-sheets>

Ankeny, R.A. 2017. The Role of Patient Perspectives in Clinical Case Reporting. In *Knowing and Acting in Medicine*. Bluhm, R. ed. Rowman and Lilienfeld: Lanham, Maryland, 97-111.

Beck, A. T. 1962. Reliability of psychiatric diagnoses: A critique of systematic studies. *American Journal of Psychiatry*, 119, 210–6.

Bueter, Anke. 2018. Public epistemic trustworthiness and the integration of patients in psychiatric classification. *Synthese*. 10.1007/s11229-018-01913-z.

Collins, H.M.; Evans, R. 2002. The Third Wave of Science Studies: Studies of Expertise and Experience. *Social Studies of Science* 32/2, 235–296.

Cooper, J. E., Kendell, R. E., Gurland, B. J., Sartorius, N., & Farkas, T. 1969) Cross-national study of diagnosis of the mental disorders: Some results from the first comparative investigation. *The American Journal of Psychiatry*, 10(Suppl), 21–29.

Darrel A. Regier, Emily A. Kuhl, David J. Kupfer, and James P. McNulty. 2010. Patient Involvement in the Development of DSM-V. *Psychiatry: Interpersonal and Biological Processes*: Vol. 73, No. 4, pp. 308-310.

Douglas, H. 2004. The Irreducible Complexity of Objectivity. *Synthese*, Vol. 138, No. 3, pp.453-473.

First, M. B., Pincus, H. A., Levine, J. B., Williams, J. B. W., Ustun, B., & Peele, R. 2004. Clinical utility as a criterion for revising psychiatric diagnoses. *American Journal of Psychiatry*, 161, 946–954.

Flanagan, O. 1992. *Consciousness Reconsidered*. Cambridge, MA: MIT Press.

Flanagan, O. 2013. Identity and Addiction: What Alcoholic Memoirs Teach. In *The Oxford Handbook of Philosophy and Psychiatry*, ed. K.W.M Fulford et al, 865-888. New York: oxford University Press.

Houts, C.A. Fifty years of psychiatric nomenclature: Reflections on the 1943 War Department Technical Bulletin, Medical 203. *Journal of Clinical Psychology* 56: 935-967.

Flanagan, Davidson and Strauss. 2010. The Need for Patient-Subjective Data in the DSM and the ICD. *Psychiatry*, 73(4):297-307. doi: 10.1521/psyc.2010.73.4.297.

Longino, H., 1990, *Science as Social Knowledge: Values and Objectivity in Scientific Inquiry*, Princeton: Princeton University Press.

Nagel, T. 1974. What is it Like to Be a Bat? *The Philosophical Review*. Vol. 83, No.4, 435-450.

Robins, E., & Guze, S. B. 1970. Establishment of diagnostic validity in psychiatric illness: Its application to schizophrenia. *American Journal of Psychiatry*, 126(7), 983–987.

Sadler, J. Z. 2005. *Values and psychiatric diagnosis*. Oxford: Oxford University Press.

Schwartz, M. A., & Wiggins, O. P. 1987a. Typifications: the first step for diagnosis in psychiatry. *The Journal of Nervous and Mental Disease*, 175, 65–77.

Schwartz, M. A., & Wiggins, O. P. 1987b. Diagnosis and ideal type: A contribution to psychiatric classification. *Comprehensive Psychiatry*, 28(4), 227–91.

Tsou, J. 2015. DSM-5 and psychiatry's second revolution: Descriptive vs. theoretical approaches to psychiatric classification. In S. Demazeux & P. Singy (Eds.), *The DSM-5 in perspective: Philosophical reflections on the psychiatric babel*. Dordrecht: Springer.

Sadler, J. Z., & Fulford. B. (2004). Should Patients and their Families contribute to the DSM-5 process? *Psychiatric Services* 55, 133-138.

Stein, D. J., & Phillips, K. A. (2013). Patient Advocacy and DSM-5. *BMC Medicine* 11, 133.

Tekin, Ş. 2014. Self-insight in the time of mood disorders: After the diagnosis, beyond the treatment. *Philosophy, Psychiatry, and Psychology*, 21 (2), 139-155.

Tekin, Ş. 2017. The Missing Self in Scientific Psychiatry. *Synthese*. DOI.10.1007/s11229-017-1324-

Tekin, Ş. 2011. Self-Concept Through the Diagnostic Looking Glass: Narratives and Mental Disorder. *Philosophical Psychology*, 24:3, 357–380

Tekin, Ş.; Outram, S. 2018. Overcoming Mental Disorder Stigma: A Short Analysis of Patient Memoirs. *Journal of Evaluation in Clinical Practice*, Volume 24, Issue 5, 1114-1119.



Poland, J., and Tekin, Ş. 2017. *Extraordinary Science and Psychiatry: Responses to the Crisis in Mental Health Research*. MIT Press. Cambridge, MA.

Tekin, Ş. 2016. Are Mental Disorders Natural Kinds: A Plea for a New Approach to Intervention in Psychiatry. *Philosophy, Psychology and Psychiatry*. *Volume 23, No: 2*, 147-163.

Tekin, Ş., Flanagan, O.J., Graham, G. 2017. Against the Drug Cure Model: Addiction, Identity, and Pharmaceuticals (with Owen Flanagan, and George Graham). In *Philosophical Issues in Pharmaceutics: Development, Dispensing, and Use*, Ho, D., ed., Springer Press, 221-236.