Epistemic Injustice and Psychiatric Classification

Anke Bueter*†

This article supports calls for an increased integration of patients into taxonomic decision making in psychiatry by arguing that their exclusion constitutes a special kind of epistemic injustice: preemptive testimonial injustice, which precludes the opportunity for testimony due to a wrongly presumed irrelevance or lack of expertise. Here, this presumption is misguided for two reasons: (1) the role of values in psychiatric classification and (2) the potential function of first-person knowledge as a corrective means against implicitly value-laden, inaccurate, or incomplete diagnostic criteria sets. This kind of epistemic injustice leads to preventable epistemic losses in psychiatric classification, diagnosis, and treatment.

1. Introduction. Psychiatry and psychiatric classification have a long history of stirring up controversy. With the latest revision of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; APA 2013), skeptical voices have only gained momentum. A plethora of critiques has been formulated within and outside of the scientific community, targeting a variety of issues. For instance, the DSM categories are often rejected as lacking validity, as many diagnoses continue to defy etiological and pathophysiological explanations, exhibit high degrees of comorbidity, and allow for a troublesome amount of symptomatic heterogeneity (see, e.g., Hyman [2010] for an overview). It is often argued that these problems are at least in part due to the DSM's atheoretical, operationalist approach, which classifies mental disorders in terms of polythetic criteria referring to observable behavior, rather than in terms of (theories about) their causes, as it is common in somatic medicine (e.g., Murphy 2006; Tsou 2015).

*To contact the author, please write to: Leibniz University Hannover, Institute of Philosophy, Im Moore 21, 30167 Hanover, Germany; e-mail: anke.bueter@philos.uni-hannover.de.

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In line with this, the National Institute of Mental Health now deprioritizes research based on DSM categories in its funding decisions, focusing instead on its own (continuously developed) theory-driven alternative (the Research Domain Criteria project; RDoC). The RDoC allows for research cutting across the borders of DSM diagnoses and aims at underlying mechanisms of mental dysfunctions (e.g., Insel et al. 2010; Insel 2013). For now, however, the RDoC represents an alternative for research, not all other purposes of the DSM such as guiding clinical practice or informing administrative systems. It remains to be seen whether it will succeed in developing a superior classification.[1] For now and possibly for quite some time, we are thus stuck with the DSM and its operationalist classification, at least in practical contexts, wherefore I will concentrate on the DSM here.[2]

Other critiques of the DSM, which play a more prominent role in public discourse, relate to a perceived lack of credibility of psychiatric research and classification. It is often argued that the DSM tends to pathologize normal behaviors and promotes a troublesome (bio)medicalization of common problems in life (e.g., Lane 2007; Horwitz and Wakefield 2012). Such medicalization critiques are connected to worries about conflicts of interest and the impact of the pharmaceutical industry (e.g., Cosgrove et al. 2006; Cosgrove and Krimsky 2012).

It has been argued that one means against the resulting distrust would be an integration of patients into psychiatric research and classification. For instance, Musschenga, van der Steen, and Ho (2010) point out that most psychiatric research is funded by the pharmaceutical industry. Combined with a biomedical understanding of mental illness, this leads to an exaggerated research focus on drug treatments, rather than on psychological or ecological factors. Regarding such bias in agenda setting, Cooper (2017) proposes an increase in user-led research as one possible remedy. Research initiatives by patients and advocates may provide a helpful counterbalance via the funding or implementing of research on questions that the industry has no interest in pursuing. Similarly, she argues that integrating patients into the process of

1. There are reasons to doubt this, which stem from difficulties in relating the envisaged low-level mechanistic knowledge to such complex higher-level phenomena as human behavior (Hoffman and Zachar 2017). Moreover, even if the RDoC is the decisive step in research on psychopathologies it is hoped for, its implementation in applied contexts comes with further difficulties. A taxonomy for clinical practice has to deal with additional questions that are irreducible to empirical evidence, such as whether a certain (even well-understood) dysfunction is harmful enough to be included as a disorder (see sec. 2). The hoped for "scientification" of psychiatric classification will therefore not resolve all critical concerns regarding the DSM.

2. Outside North America, the International Classification of Diseases by the World Health Organization is more widely used, which is, however, similar in terms of the syndromal classification of mental disorders.

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DSM revisions may enhance public trust in the classification. Cooper takes this to be a point in favor of the operationalist approach of the DSM, as it makes it easier for laypeople to participate than the resource- and technology-intensive RDoC.

Proposals to integrate patients and advocates into DSM revisions have been discussed before. They have been dismissed as "politically correct nonsense" (Spitzer 2004) or been supported in terms of democratic representation in policy-relevant taxonomic decision making (Sadler and Fulford 2004; Sisti and Johnson 2015). Others have argued for a need for patient perspectives as input regarding the accuracy of diagnostic criteria (Flanagan, Davidson, and Strauss 2010). The latest revision of the DSM has proven responsive to these concerns, insofar as one patient advocate has been included in the task force and all proposals for how to revise diagnoses were published online at several points, calling for comments by the public (eliciting about 13,000 responses). It has mostly been left unclear, however, how the workgroups and task force have actually reacted to these comments. Future revisions therefore should increase and improve the integration of patients by being more transparent or inviting advocates into the actual work groups. Bueter (2018) argues that this can enhance the public epistemic trustworthiness of the DSM.

My aim in this article is to support calls for an increased integration of patients into revision processes of psychiatric classifications by arguing that this integration is a matter of epistemic justice. To be more precise, excluding patients and advocates from the revision process is a case of *preemptive testimonial injustice* in which the perspectives of patients are not sought even though they are epistemically relevant. This undermines patients in their capacity as knowers, and it leads to epistemic losses. The purported relevance of patient perspectives is based on two aspects of psychiatric classifications: (1) the role of values in taxonomic decision making in this context and (2) the importance of first-person accounts as a corrective means in operationalizing mental disorders. I start by explicating these two points. Afterward, I provide an analysis of the special kind of epistemic injustice involved here.

2. Value Judgments in Taxonomic Decision Making. Many of the decisions to be made in revising the DSM involve value judgments (see Bueter [2018] for this section). Psychiatric classification aims to categorize and operationalize highly complex entities: mental disorders usually involve a range of interacting biological, social, and psychological factors. As pointed out above, these interactions and the relevant causal pathways are in most cases not yet well understood. There is still a lack of etiological explanations as well as laboratory measures or biomarkers of most psychopathologies; in addition, symptoms of such disorders often (although not always) depart from "normal" behavior only in degrees (e.g., depressed mood, trouble concentrating,

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excessive worrying). Yet, DSM revisions cannot just wait until more evidence or better understanding has been gained: the DSM is not only a scientific document but also (or even primarily) a manual to be used in clinical practice—guiding current diagnoses, treatment regimes, reimbursement policies, and education. Therefore, the DSM has to make decisions that are affected by considerable uncertainties and exceed the available data. Many of these decisions are thus at least transiently underdetermined by empirical evidence.

Reporting from their service in the DSM-5 workgroup on obsessive compulsive spectrum disorders, Stein and Phillips (2013) list some questions on which the workgroup consulted with the public feedback on their online drafts. In general, they emphasize that this feedback has provided helpful inputs and led to some reevaluations of the workgroup's first proposal.

The first issues they mention were *naming conventions*. Patients were concerned about, for example, the 'mania' in "trichotillomania" as being inaccurate and pejorative. It was discussed to replace it by "hair pulling disorder," which, in turn, was rejected by other advocates as too colloquial and therefore underselling the condition's medical significance. As a compromise, the workgroup went for "trichotillomania (hair-pulling disorder)" in the end (Stein and Phillips 2013, 3). Further examples of advocates arguing for different names include the replacement of "mental retardation" with "intellectual disability (intellectual development disorder)" (Regier, Kuhl, and Kupfer 2013, 97) or worries about the use of "psychotic" as pejorative and misleading, possibly to be replaced by "salience dysregulation" or "salience syndrome" (George 2010, 281).

The wording in a classification of mental disorders (relating to names and criteria of diagnoses)—and their stigmatizing potential—seems a rather uncontroversial issue on which to include patient perspectives, as it is patients who have to live with the name and experience such stigma firsthand. Another reason this is usually considered unproblematic is that it may be perceived as a trivial or at least peripheral question to scientific concerns, since it leaves untouched the operationalization and classification of the named conditions as such. However, even if such wording questions might seem inconsequential to the very heart of science, ignoring input by patients and caregivers in such matters is a serious issue. First, it can constitute cases of *willful hermeneutic ignorance*. This is a type of epistemic injustice in which knowers in powerful positions (e.g., medical scientists) ignore epistemic and linguistic resources that have been developed by marginalized knowers (e.g., patients or their caregivers; Pohlhaus 2012). Second, it may be argued that some terms (e.g., "retarded") are so thoroughly embedded in a certain sociopolitical context of power relations that there is no way to overcome their semantic value ladenness by a neutral scientific operationalization (see Dupré [2007] on semantic value ladenness in other contexts).

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Value judgments also affect traditionally more controversial questions, which relate to the very content of psychiatric taxonomy. A first example here is the *exclusion or inclusion of conditions as disorders* in the DSM. To be newly included, conditions need to have demonstrable validity and clinical utility, while excluding former diagnoses requires a demonstration of their lack of validity and utility (Kendler et al. 2009). However, respective empirical data cannot determine whether a condition actually is a disorder or whether it is helpful for affected persons to be diagnosed as suffering from such a disorder.

Regarding the latter, the benefits of having an official diagnosis depend on many features of the social context that need to be balanced, such as resulting stigma versus access to health care. Regarding the former, whether a condition actually is a disorder or disease is a challenging question even in somatic medicine. Naturalist positions aim to ground disease or disorder status on descriptive criteria for dysfunctions (e.g., Boorse 1976, 1977). Problematic for naturalists are, for instance, difficulties in determining whether differences with regard to certain functions are in fact pathological or just present normal variations (e.g., Cooper 2002). Based on this and similar critiques, normativist positions hold prescriptive judgments about the (un)desirability of certain behaviors or conditions to be essential to disease or disorder ascriptions. Strong normativist positions have been most relevant with regard to mental disorders. Especially in the antipsychiatry movement of the 1960s–70s, it was worried that diagnoses of mental disorder were primarily an instrument of social control, lacking a scientific basis (e.g., Laing 1967; Szasz 1974).

At least in the psychiatric realm, a hybrid position that combines descriptive and prescriptive aspects is currently most popular. Wakefield (1992) argues that mental disorders necessarily presume dysfunctions. Yet, these are only sufficient for disorder status if their consequences are also evaluated as harmful. Even if one accepts the possibility of a value-free determination of (mental) dysfunction,[3] normative evaluations of the harms involved thus remain crucial.

Accordingly, deliberations about the inclusion or exclusion of putative disorders can benefit from the perspective of affected persons and caregivers and their own evaluations of harmfulness. For example, Stein and Phillips (2013) note that the decisions to include excoriation (skin picking disorder) and

3. This seems particularly questionable on Wakefield's own terms, as he adopts an etiological notion of *function* as resulting from evolutionary selection processes. This brings up questions about how to identify such functions; i.e., on the basis of what kinds of evidence (as fossils of mental functions are rather rare and leave lots of room for speculation and—possibly value-laden—interpretation). Thus, even if one grants the ontological point of a clear distinction between function and dysfunction, it leads to problems on the epistemological level.

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hoarding disorder have been supported by feedback from the public, which they took to underline the clinical utility and significance of these diagnoses. Other examples of patient advocates lobbying for the inclusion of diagnoses into the DSM are posttraumatic stress disorder or (so far unsuccessful) body identity/integrity disorder. On the other side, there are also many examples of activists arguing against the inclusion of conditions such as premenstrual dysphoric disorder (PMDD) or hyposexual desire disorder in women (HSDD).

Once a condition has become an official DSM diagnosis, a further issue is the setting of *diagnostic thresholds*. Most DSM diagnoses are based on polythetic criteria; that is, there is a list of possible symptoms, a certain number of which are sufficient for diagnosis. Usually, individual criteria are not necessary. This results in considerable heterogeneity in the phenomenology of diagnosed cases. Moreover, deciding how many symptoms out of a certain list are required for a diagnosis cannot simply be read off the empirical data. For instance, a diagnosis of HSDD requires the presence of three out of six signs. In response to worries about disease mongering in this case, it was discussed during the latest revision of the DSM whether to raise the bar to four out of six (Brotto 2010; see also Bueter and Jukola 2019). With regard to such questions, input by advocates and patients, who can give feedback on the pros and cons of medicalization as well as the clinical significance of their symptoms, can be valuable in ethical and epistemic hindsight.

3. First-Person Accounts as a Corrective Means. Taxonomic decision making in psychiatry, at least for now, requires value-laden judgments with regard to striking a balance between different risks, such as under- versus overdiagnosis, stigmatization, medicalization, lack of access to health care or reimbursement, and so on. Concerning such questions, patients' perspectives are relevant and should be represented in the revision process. This can be seen as a matter of social justice. Yet, it also has epistemic impact, insofar as incorporating different perspectives is a means to detect value impacts in the first place and put them out for debate (Longino 1990). In addition to the issues discussed above, patient perspectives, and the first-person knowledge on mental disorders involved in these perspectives, provide a corrective means against implicit value ladenness, inaccuracies, or incompleteness with regard to the operationalization of mental disorders.

First, consider the issue of a potential *value ladenness of diagnostic criteria*. For example, Hawthorne (2010) has convincingly argued that the criteria for attention-deficit/hyperactivity disorder (ADHD) are informed by ideals of academic success particular to a certain cultural context. For instance, current criteria include possible symptoms such as "often fails to give close attention or makes careless mistakes in schoolwork, at work, or during other activities"; "often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace"; "often leaves seat in situations

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where remaining seating is expected" (e.g., in the classroom; APA 2013, 59–60). Hawthorne argues that such behaviors constitute problems and thus qualify as symptoms of a disorder only relative to a certain sociocultural environment (which is, however, compatible with the possibility that ADHD does in fact result from a certain dysfunction or pathology). Comparably, the criteria of female sexual dysfunctions such as HSDD or PMDD have been said to incorporate certain norms of gendered behavior and female sexuality (e.g., Chrisler and Johnston-Robledo 2002; Tiefer 2006; Brotto 2010). The integration of patients and advocates can help to detect such value influences and provide input on stigmatizing diagnostic criteria (at least until more conclusive laboratory measures or biomarkers are available; Bueter 2018).

Similarly, patients can provide helpful input on the *accuracy of diagnostic criteria*. Stein and Phillips (2013) report patients' criticisms of the draft proposals arguing that the criteria for trichotillomania were based on a problematic understanding of it as impulse-control disorder, as well as that some criteria did not apply to a significant amount of patients. As this was in line with the evidence, the diagnostic criteria have been changed accordingly.

Another point is the possibility of an *incompleteness* of diagnostic criteria. For instance, Flanagan et al. (2010) argue for an increased inclusion of first-person narratives in the development of diagnostic criteria. As they point out, the DSM's operationalized diagnoses mostly rely on observable behavior as well as self-reports elicited by structured questionnaires. As the outward appearance of symptoms may differ from their subjective phenomenology, this might not offer enough room for patients' actual experience and lead to a loss of valuable information. For example, the authors maintain that this has led to missing criteria in some diagnoses, such as a "disrupted sense of self" in schizophrenia, as well as to misinterpretations of symptoms, such as the criterion of "identity disturbance: markedly and persistently unstable self-image or sense of self" in borderline personality disorder, which should better be replaced by "sense of flawed self" to accurately represent patients' experiences.

These arguments fall in line with critiques that the DSM's diagnostic criteria fail to sufficiently represent the clinical reality and phenomenology of mental disorders (e.g., Parnas and Sass 2003; Andreasen 2006; Kendler 2016), which leads to a lack of clinical utility and has negative impacts on the treatment of patients (e.g., Sadler 2005; Tekin 2015). First-person accounts of the phenomenology of mental illnesses can therefore provide a helpful means against an unacknowledged or one-sided value ladenness of diagnostic criteria, inaccurate criteria, or incomplete criteria sets.

4. Preemptive Testimonial Injustice. The perspectives of patients and their representatives are relevant to a wide array of questions in psychiatric classification, in particular because of the current syndromal approach and

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the role of values in taxonomic decision making. Questions on which patients' input might be helpful include the setting of diagnostic thresholds, the ascription of disorder status, naming conventions, and the accuracy of diagnostic criteria.

An exclusion of patients from the respective process of decision making is, in turn, epistemically detrimental in several respects: it is harmful on the level of epistemic practices such as classifying mental disorders, as it leads to epistemic losses by failing to represent all relevant perspectives and to employ a worthwhile corrective means. Moreover, it constitutes an epistemic wrong. I understand epistemic wrongs as relating to the level of (groups of) individuals. The exclusion of patients' perspectives represents such a wrong, because it is a special case of *testimonial injustice*.

Testimonial injustice is analyzed by Fricker (2007) as a case of *epistemic injustice*, which consists in undermining someone in her capacity as a knower. Testimonial injustice occurs when someone's judgment or testimony is assigned less relevance and credibility than it actually deserves because of prejudices against the speaker's social group and identity (e.g., if one's testimony is not fully taken into account because one is a woman, belongs to an ethnic minority, etc.). While testimonial injustice typically relates to a speaker's given testimony, it can also take a *preemptive* form, in which such testimony is never even solicited because of its presumed irrelevance or unreliability: "This kind of testimonial injustice takes place in silence. It occurs when hearer prejudice does its work in advance of a potential information exchange: it pre-empts any such exchange" (130). Excluding patients from revising authoritative psychiatric classifications constitutes such a case of preemptive testimonial injustice. It might be objected here that mentally ill patients and their caregivers vary widely with regard to their social backgrounds and identities and therefore do not qualify for an injustice that is essentially defined as an effect of prejudices against someone's social identity. However, social identity and location is to a certain degree context dependent, which also holds for stereotypes and prejudices; for example, I might encounter prejudice because of my gender or ethnic background in some contexts, because of my dialect in others, and so on. In the case at hand, patients are excluded from participation in virtue of belonging to the group of laypeople, who are taken to have nothing competent or relevant to contribute to scientific practices. Patients' input is undervalued because they do not qualify as scientific experts, even though many of the questions at hand are either irreducible to empirical evidence or can profit from additional first-person knowledge.

Others have argued that (mentally) ill persons suffer from epistemic injustice in virtue of their being patients or being (mentally) ill, a status that often comes with certain prejudices about patients being too emotional and unstable

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for fully rational discourse (e.g., Kidd and Carel 2017). Mentally ill persons certainly often suffer from epistemic injustice because of their status as mentally ill. This results from their stigmatization in society, leading to a low credibility of their testimonies in all kinds of informal (e.g., Kurs and Grinshpoon 2017) or formal contexts (e.g., being considered an unreliable witness in court; Melamed 2008). In particular, it can occur during diagnostic and therapeutic processes in psychiatry (e.g., Crichton, Carel, and Kidd 2017; Scrutton 2017).

I fully agree with these observations. Yet, I think in this specific context, exclusion and credibility deficit relate more to the status of layperson than of ill person. However, the respective prejudices and versions of epistemic injustice may and probably will often interact. If one does consider lay judgments as unreliable, the judgments of allegedly irrational, emotionally unstable laypeople will not fare much better. And excluding patients from taxonomic decision making in virtue of being laypeople can reinforce prejudices and low credibility ascriptions regarding their testimonies in virtue of being mentally ill, by perpetuating the assumption that it is not worth listening to them. As Fricker (2007) points out, the effects of such repeated testimonial injustice can be very pervasive for the epistemic subject who threatens to lose her epistemic self-trust. This, in turn, may even lead to a lack of conceptual resources and hermeneutic marginalization of mentally ill persons in the long run.

5. Conclusion. In this article, I have supported calls for an increased integration of patients and advocates into taxonomic decision making in psychiatry, in particular into DSM-revision processes, by arguing that their exclusion constitutes a case of epistemic injustice. To be precise, it is a case of preemptive testimonial injustice that precludes the opportunity for testimony because of a presumed irrelevance or lack of expertise. This presumption is misguided for two reasons in this context: the role of values in current psychiatric classification and the potential function of first-person knowledge as a corrective means against implicitly value-laden, inaccurate, or incomplete diagnostic criteria. Here, patients' perspectives are relevant and contribute valuable viewpoints. The epistemic injustice they suffer in this case mainly affects them in virtue of being laypeople, not of being mentally ill. It interacts, however, with testimonial injustices mentally ill people suffer from in other social contexts and, in particular, in health care contexts, and it perpetuates a lack of conceptual resources for the experience of mental illness and thus connects to hermeneutic injustice as well. The exclusion of patients from psychiatric classification therefore constitutes a wrong against mentally ill individuals. At the same time, it constitutes a harm on the level of epistemic practices such as psychiatric classification (and, based on this, diagnosis and treatment), because it risks epistemic losses by failing to engage with valuable viewpoints and thereby misses a worthwhile corrective means.

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