



## WRONGFUL MEDICALIZATION AND EPISTEMIC INJUSTICE IN PSYCHIATRY: THE CASE OF PREMENSTRUAL DYSPHORIC DISORDER

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### ABSTRACT

*In this paper, my goal is to use an epistemic injustice framework to extend an existing normative analysis of over-medicalization to psychiatry and thus draw attention to overlooked injustices. Kaczmarek (2019) has developed a promising bioethical and pragmatic approach to over-medicalization, which consists of four guiding questions covering issues related to the harms and benefits of medicalization. In a nutshell, if we answer “yes” to all proposed questions, then it is a case of over-medicalization. Building on an epistemic injustice framework, I will argue that Kaczmarek’s proposal lacks guidance concerning the procedures through which we are to answer the four questions, and I will import the conceptual resources of epistemic injustice to guide our thinking on these issues. This will lead me to defend more inclusive decision-making procedures regarding medicalization in the DSM. Kaczmarek’s account complemented with an epistemic injustice framework can help us achieve better forms of medicalization. I will then use a contested case of medicalization, the creation of Premenstrual Dysphoric Disorder (PMDD) in the DSM-5 to illustrate how the epistemic injustice framework can help to shed light on these issues and to show its relevance to distinguish good and bad forms of medicalization.*

**Keywords:** *over-medicalization; epistemic injustice; premenstrual dysphoric disorder; hermeneutical injustice; pre-emptive testimonial injustice; Miranda Fricker*

## Introduction

Medicalization is a controversial topic both within and outside psychiatry, especially since the publication of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5, APA 2013). Several critics have argued that the DSM-5 medicalizes conditions that should only be considered normal life problems (e.g., Lane 2007; Frances 2010, 2013; Horwitz and Wakefield 2012; see also Stegenga 2021 and Murphy-Hollies 2021 in this issue of EuJAP). However, although medicalization in psychiatry is generally discussed from a critical perspective, the term itself is value-neutral: from a sociological point of view, medicalization can bring both good and bad consequences (e.g., Conrad et al. 2010). What appears problematic are the bad forms of medicalization, or what has been called “over-medicalization” (e.g., Conrad 2013; Conrad and Slodden 2013). Regarding the many consequences and implications of medicalization, identifying cases of medicalization from an ethical point of view is a difficult undertaking. Some philosophers and ethicists have recently taken up this ambitious task (e.g., Parens 2013; Kaczmarek 2019), but have not reached a consensus.

In parallel, the framework of epistemic injustices (hereafter EI) as developed by Miranda Fricker (2007, 2017) has proven fruitful in psychiatry and mental health care. EI are the harms suffered by individuals belonging to oppressed groups in their capacities as epistemic agents, due to prejudicial identity stereotypes or to the marginalization associated with these groups. These injustices can arise at various points in the process of knowledge acquisition and transmission, such as interpreting an experience or offering a testimony.

Where medicine is concerned, Kidd and Carel (2017; see also Carel and Kidd 2014, 2016, 2018, forthcoming) have depicted a particular form of EI that concern prejudices associated with the experience of illness, called *pathocentric epistemic injustices*. Pathocentric epistemic injustices occur when

ill persons [are] being ignored, silenced, or dismissed; [are] not being listened to or taken seriously, and [are] being treated as mere sources of information, only able to answer within the defined terms of clinical-epistemic practice. (Kidd and Carel forthcoming)

As some have argued, the risk of encountering this type of EI is even greater in psychiatry because of widespread negative stereotypes associated with mental illness (Crichton et al. 2017; see also e.g., Kurs and

Grinshpoon 2018; Kyratsous and Sanati 2015; LeBlanc and Kinsella 2016). The application of the conceptual framework of EI has thus made it possible to target various ethical problems related to knowledge production and transmission in psychiatry (e.g., Kyratsous and Sanati 2017; Crichton et al. 2017; Kurs and Grinshpoon 2017; Tate 2018; Gosselin 2018; Bueter 2019; Sullivan 2019).

In this paper, my goal is to use the EI framework to extend an existing normative analysis of over-medicalization to psychiatry and thus draw attention to overlooked injustices. Kaczmarek (2019) has developed a promising bioethical and pragmatic approach to over-medicalization, which consists of four guiding questions covering issues related to the harms and benefits of medicalization. In a nutshell, if we answer “yes” to all proposed questions, then it is a case of over-medicalization. Building on the EI framework, I will argue that Kaczmarek’s proposal lacks guidance concerning the procedures through which we are to answer the four questions, and I will import the conceptual resources of EI to guide our thinking on these issues. This will lead me to defend more inclusive decision-making procedures regarding medicalization in the DSM. Kaczmarek’s account complemented with the EI framework can help us achieve better forms of medicalization.

The paper is organized as follows: in section 1, I will first define medicalization and introduce the challenge of “wrongful medicalization”, i.e. the task of distinguishing good and bad forms of medicalization. Secondly, I will critically review previous accounts which have tried to overcome this challenge. I will argue that Kaczmarek’s proposal is a promising one, but needs to be further developed. In section 2, I will suggest that the EI framework draws attention to some overlooked ethical wrongs related to medicalization, if we understand the medicalization process as a transformation of hermeneutical resources implying power relations between different actors. I will then argue that the EI framework should complement Kaczmarek’s account in order to reduce the risk of epistemic injustices induced by medicalization, and therefore the risk of wrongful medicalization. In section 3, to illustrate the relevance of my proposal, I will apply this conclusion to a case study: the medicalization of Premenstrual Dysphoric Disorder (PMDD) in DSM-5. I will then suggest possible improvements based on the findings of Section 2.

# 1. Medicalization in Psychiatry and the Bioethical Challenge of “Wrongful Medicalization”

## 1.1 The Social Process of Medicalization in Psychiatry: Some Methodological Notes

“Medicalization”<sup>1</sup> does not always have the same meaning in the literature (for review, see e.g., Davies 2010; Hofmann 2016; Busfield 2017). In this paper, I will use the following broad definition:

Medicalization occurs when previously nonmedical problems become defined (and treated) as medical problems, usually as an illness or disorder. (Conrad and Slodden 2013, 62)

While this broad definition can encompass a large array of phenomena, I will restrict my analysis to a specific context, i.e. that of North American contemporary psychiatry. In this context, medicalization generally occurs through the revision of the official nosological manual, the *Diagnostic and Statistical Manual* (DSM) published by the American Psychiatric Association (APA). Moreover, in what follows, I will focus on two main actors of the medicalization process: people living with mental illness and the main North American psychiatric institutions by which medicalization occurs, the APA (and the revision structures of the DSM). It is important to recognize that there are other actors involved in this process (e.g., pharmaceutical industries, other healthcare professionals, laypeople, the media, etc.) and other contexts in which medicalization happens (the globalization of medical concepts, the rest of medicine, etc.), but the scope of this paper does not allow me to cover them all in detail.

One way for medicalization to happen in North American psychiatry is through the categorization of a condition as a new mental disorder in the DSM. A paradigmatic example is the creation of Post-Traumatic Stress Disorder (PTSD) in the DSM-III (APA 1980). Despite controversies about its existence as a distinct diagnosis, PTSD was introduced in the DSM following pressure from anti-war psychiatrists and Vietnam veterans who were experiencing symptoms of trauma, such as flashbacks and intense anxiety (see e.g., Scott 1990; Riska 2013). Another, more recent example, on which I will return in section 3 of the paper, is the medicalization of Premenstrual Dysphoric Disorder (PMDD), a new diagnostic category

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<sup>1</sup> Although the trend in psychiatry is toward increased medicalization, a condition can, conversely, be removed from the medical field. This phenomenon is called “demedicalization”. For example, homosexuality was excluded from the DSM and thus from the medical field following demands by groups campaigning for homosexual rights (APA, 1973, for a detailed discussion, see e.g., Kirk and Kutichins 1992).

introduced in the DSM-5 (2013). PMDD refers to the distress associated with the menstrual cycle in menstruating women and is considered to be a more extreme form of Premenstrual Syndrome (PMS). Some feminist critics welcomed the new diagnosis with contention, worrying, among other things, about the illegitimate pathologization of women's anger.

Although medicalization generally refers to such a process, i.e. in which a non-medical condition is transformed into a medical category, it can also occur through the revision of already-existing diagnoses. Taken in this latter sense, medicalization happens when individuals who were not diagnosed with a mental disorder become so when the clinical description of the diagnostic criteria changes. That is, when specific diagnostic criteria are modified, when criteria thresholds are revised, or when new age ranges are included in them. Such cases do not involve the creation of new psychiatric categories, but only the expansion of already-existing ones (Conrad and Slodden 2013, 65). A good example of a controversial case of this type of medicalization is Major Depressive Disorder (MDD), and more specifically the debate surrounding the removal of the bereavement exclusion criterion in the DSM-5.<sup>2</sup> In the DSM-IV, people suffering from depressed mood caused by the loss of a loved one were not diagnosed with MDD if the sadness experienced was proportionate to the loss. In the DSM-5, the bereavement clause was removed (APA 2013, 161). A person can now be diagnosed with MDD if she meets MDD diagnostic criteria, despite grief being the cause of her symptoms. According to some critics, this could lead to an increase in the prevalence of the disorder. Worse: it could mean diagnosing people with a mental disorder while they suffer from normal sadness associated with the grieving process (for a more detailed discussion, see e.g., Horwitz and Wakefield 2007; Pies 2014; Bandini 2015).

## 1.2 The Problem of Wrongful Medicalization in Psychiatry

Historically, the term “medicalization” is connected with the work of famous critics of psychiatry and medicine such as Thomas Szasz, Ivan Illich, and Irving Zola, who pointed out the illegitimate hold or social control exerted by medical institutions over “deviance” (or what was perceived as such). However, contemporary critics have recently started to restrict the scope of their criticism to specific diagnoses, arguing that only

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<sup>2</sup> Other instances of this type of medicalization include the diagnosis of Bipolar Disorder in children (BD, see e.g., Healy 2008) or the diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in adults (e.g., Conrad 2007; Conrad and Slodden 2013). In both cases new individuals are medicalized because of a change in age ranges and age-related diagnostic criteria. Another way in which medicalization can happen is via the general definition of mental disorder in the DSM (see e.g., Cooper 2015).

these would be illegitimate forms of medicalization (e.g., Charland 2013; Sedler 2015). Moreover, despite the numerous criticisms aimed at medicalization, most sociologists take the process to be value-neutral. Medicalization is understood as a social process that can bring *both* positive and negative consequences for individuals and society (Conrad 2007). The benefits of medicalization include granting better access to care, motivating people to look for help and resources, decreasing blame associated with medicalized conditions, etc. Disadvantages include depreciating the importance of social context in explications of mental distress, medicalizing all domains of human life to create a unilateral, purely medical understanding of normality, spawning unnecessary clinical interventions, generating high costs in public health care systems, etc.<sup>3</sup> Medicalization is thus neither an inherently negative nor an inherently positive process, making the ethical assessment of it difficult.

Therefore, the literature generally does not discuss medicalization itself, but rather what has been called “over-medicalization” (Conrad and Slodden 2013; Conrad 2013). Over-medicalization usually refers to the process of “altering the meaning or understanding of experiences, so that human problems are reinterpreted as medical problems requiring medical treatment, *without net benefit to patients or citizens*” (Carter et al. 2015, table 1, emphasis added). In other words, “over-medicalization” is often used when conditions are believed to have been unnecessarily, wrongfully, or even harmfully medicalized.<sup>4</sup> However, since medicalization brings both positive and negative consequences, drawing the line between the good and bad forms of this social process is extremely complex. Psychiatry is often faced with practical problems, like whether particular diagnoses should be included in the DSM (e.g., should PTSD or PMDD be included in the DSM?), or whether specific diagnostic criteria for existing diagnoses should be modified (e.g., should the bereavement exclusion criteria be kept or removed from the clinical description of MDD?). The issue here is rather to distinguish cases in which psychiatry expands its domain within its legitimate scope, and other cases in which such expansion proves excessive (see e.g., Purdy 2001; Sadler et al. 2009; Reiheld 2010; Parens

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<sup>3</sup> For a more detailed discussion of the advantages and disadvantages of medicalization, see e.g., Stein et al. (2006), Davis (2010), Reiheld (2010), Bastra and Frances (2012), Parens (2013), Conrad and Slodden (2013), Kaczmarek (2019), and Thomas (2021).

<sup>4</sup> “Overdiagnosis” is also used about cases in which an existing diagnosis is applied to a condition with few or no symptoms (e.g., Moynihan et al. 2012; but see Rogers and Mintzker 2016 for distinctions). “Disease mongering” is sometimes used as well to describe situations in which the pharmaceutical industry influences the expansion of the medical field (e.g., Moynihan et al. 2002; Moynihan and Cassels 2005). Overdiagnosis and disease mongering are thus specific manifestations of over medicalization, the latter referring to the more general phenomenon by which the medical field expands (for the opposite view, see Hoffman 2016).

2013; Murano 2018; Kaczmarek 2019; see also Carter et al. 2015, 2016 on overdiagnosis specifically).

One strategy to assess whether a case results from over-medicalization involves arguing that a condition has been wrongfully introduced in medical classification. That is, the condition is not “truly” medical, and has been mistakenly understood as such. I will call this approach the “substantive account”. In philosophy of psychiatry, the work of Horwitz and Wakefield (2007; see also e.g., Boorse 1976 for a similar point), among others, belongs to this approach. Horwitz and Wakefield’s strategy is to appeal to a scientific or objective component to draw the line between good and bad forms of medicalization. According to their account, mental disorders are harmful dysfunctions.<sup>5</sup> They argue that psychiatry should restrict the scope of the concept of mental disorder to harm-inducing deviations from the evolving norms of mental functioning. Within this framework, over-medicalization happens when psychiatry does not refer to the natural and objective definition of mental disorder and extends beyond the scope of this definition. Horwitz and Wakefield focus primarily on the diagnosis of MDD, arguing that the DSM is overly inclusive about some forms of normal sadness. This excess results in the false diagnosis of healthy individuals.

While promising, Horwitz and Wakefield’s strategy is not without problems. Very briefly, their approach is limited by the speculative nature of an evolutionary definition of mental dysfunction and by its vague notion of harm. Although the evolution of the human mind is not what is at stake here, the state of our knowledge about the traits and mechanisms selected for in past human history is too poor to allow us to distinguish mental disorders from normal mental functioning in practical situations (e.g., Lilienfeld and Marino 1995; Murphy and Woolfolk 2000; McNally 2001; Schramme 2010; Bingham and Banner 2014; Faucher 2021). Moreover, although “harm” seems like a good fit here, the notion is underspecified in Wakefield’s definition, since it is not clear how we are supposed to apply this criterion in real-life situations (e.g., Powell and Scarffe 2019 a,b; De Block and Sholl 2021; see, however, Wakefield and Conrad 2019 for a response). In its current state, Horwitz and Wakefield’s account is very difficult to use if we want to identify cases of over-medicalization.

In contrast to “substantive” accounts of over-medicalization—and because of their limitations—many authors have argued that the definition of what constitutes a mental disorder and the establishment of proper boundaries

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<sup>5</sup> Note that this account has been initially developed by Wakefield, see e.g., Wakefield (1992, 1999).

for psychiatry are fundamentally normative issues (e.g., Cooper 2005, Conrad and Barker 2010).<sup>6</sup> The medicalization of health conditions appears as a value-laden process, which is grounded in social institutions and involve multiple interests, values, and goals. Because of the value-ladenness of this social process, we may be more successful in drawing the line between good and bad forms of medicalization if we were to use the tools of bioethics (e.g., Parens 2013; Kaczmarek 2019). In this line, Kaczmarek (2019) has developed a promising proposal that departs from Horwitz and Wakefield's substantive account. She proposes to adopt a more pragmatic and ethical approach when assessing medicalization. Her account consists of four guiding questions that are meant to help us identify cases of over-medicalization:

1. Has X been rightly recognised as a problem?
  - Does X cause or significantly increase the risk of considerable physical or mental discomfort, suffering, impairments or death?
  
2. Does recognising X as a problem not result from unfounded, exaggerated social expectations?
  - Is recognising X as a problem not an example of undue limitation of diversity of individuals for the sake of normalisation? [...]
  
3. Does medicine provide the most adequate methods of understanding X and its causes?
  - At which level (e.g., molecular, mental, social, several levels combined) do main causes of X occur?
  - Are there any alternative, non-medical and more appropriate ways of understanding X and its causes?
  
4. Does medicalizing X ensure the most effective and safest methods of solving it?
  - Are there any alternative, non-medical and more effective ways to solve X or its causes?
  - Does medicalizing X do less harm than good? (Kaczmarek 2019, 122-123)

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<sup>6</sup> Note that Horwitz and Wakefield do not deny the importance of social and cultural values in the determination of what a mental disorder is. Rather, they argue that another component plays a role (or should play a role) in the identification of mental disorder: biological dysfunction. This is the claim that I reject here (at least the claim that biological dysfunction is value-free, see Gagné-Julien (forthcoming)). Without this value-neutral component entering into the definition of mental disorder, it is fair to turn to bioethical approaches to assess medicalization.

Identifying a case of over-medicalization would require positive answers to these four questions. While the answers given can be a matter of degree, answering “yes” to all of them means that X has been rightly medicalized. By contrast, answering “no” to all of them would mean that X has been over-medicalized.

I think the four questions and sub-questions identified by Kaczmarek do a good job of covering the issues that are generally associated with the consequences of medicalization mentioned earlier, and reflect the complexity of the medicalization process as well. That is, the four questions appropriately touch on all aspects at stake in the debate on over-medicalization. For instance, the issue of a unilateral understanding of normality and the risk of medicalizing social deviance is well addressed by questions 1 and 2. Question 3 targets the risk involved in depreciating the external causes (social, environmental) of distress. Question 4 refers to the benefits and potential harms of a medical approach for patients. Moreover, I believe that Kaczmarek’s account can serve as a good alternative to the substantive approach, in that it does not presuppose any conditions to be “real” medical problems, discovered through a “true” definition of mental disorder. Acknowledging that the characterization of these conditions is a pragmatic task rather than a discovery opens up a space for discussion. It opens a space to discuss each of these issues in acknowledging that giving an answer to these is a pragmatic task, not a discovery. On another note, I believe that, while Kaczmarek’s proposal can satisfyingly identify cases of over-medicalization, it could also be used to assess conditions that have not been medicalized yet. That is, despite the fact that the account focuses on over-medicalization, I see no reasons to restrict its use to such cases. For instance, we could use it to assess cases of “under-medicalization”, in which people living with a particular condition—which is not currently understood to be medical—would benefit from medicalization (i.e. cases about which we would answer “yes” to most of the four questions). Kaczmarek’s proposal could then apply to more cases than simply those which are instances of over-medicalization, and more generally instances of “wrongful medicalization”.

Despite the fact that Kaczmarek’s contribution is promising, it faces potential problems. First, each of the guiding questions she proposes seems very hard to answer, a problem she acknowledges herself. While Kaczmarek discusses some possible avenues for answers, she does not specify *how* these questions are supposed to be answered and, more importantly, *by whom*. Who is to say, for instance, that seeing X as a problem does not result from an exaggerated social expectation (in response to question 2), or that a non-medical approach would be more effective than a medical one to solve X (in answer to question 4)? Are these answers to

be provided by psychiatrists, bioethicists, patients or citizens?<sup>7</sup> Therefore, even though her account appears to me to be a step in the right direction—because it is not based on a “substantive” conception of mental disorder or on the “true” boundaries of psychiatry—more needs to be said regarding the procedures through which these questions should be answered, and the relevant actors who should express themselves about good and bad forms of medicalization. In the rest of this paper, I will use the EI framework to specify Kaczmarek’s pragmatic account. This will lead me to defend an inclusive account of the manner in which the four questions she proposes should be answered.

## 2. Epistemic Injustices and Problematic Forms of Medicalization

### 2.1 Epistemic Injustices

I believe that the EI framework as it has been developed by Fricker (2007, 2017; see also e.g., McKinnon 2016; Kidd, Medina, and Pohlhaus 2017) can help us expand and specify Kaczmarek’s account, which will allow for a better distinction of good and bad forms of medicalization in psychiatry. This is so because it gives us a better grasp on some forms of injustices that can be created by the process of medicalization, injustices which are often overlooked in the bioethical literature on medicalization. In what follows, I briefly describe the EI framework and state the reasons why it can prove fruitful concerning medicalization in psychiatry. I then present recent work in which these conceptual resources have been applied to medicalization or medicalization-related processes, and show how it could be applied to Kaczmarek’s account as well.

EI are wrongs related to the production and transmission of knowledge. The literature generally identifies two types of EI: testimonial injustice and hermeneutical injustice.<sup>8</sup> Testimonial injustice occurs when a hearer deflates the credibility of the speaker because of a negative identity prejudice. In other words, the speaker is not taken seriously by the hearer, not because of her lack of expertise, but because of negative stereotypes related to her belonging to a socially subordinated group (such as in the cases of racism, sexism, classism, etc.—note that these social identities can intersect) (Fricker 2007, 16-17). In the case of testimonial injustice, an epistemic agent is undermined in her capacity to share knowledge. Pre-emptive testimonial injustice is a particular form of testimonial injustice

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<sup>7</sup> This point is raised in the debate surrounding the definition of overdiagnosis by Carter et al. (2018). I think it can be applied to Kaczmarek’s account as well.

<sup>8</sup> See also e.g., Dotson (2011, 2014) and Berenstain (2016) for more recent work going beyond these two notions.

that occurs when epistemic agents are not solicited in the process of knowledge production, and therefore do not even have the chance to produce their testimony, when such testimony could be relevant. Their testimony is therefore discredited in advance because of a devaluation of the credibility of members of a group which is socially stigmatized or subordinated by the group in power. It is an injustice if their perspective would be relevant to the knowledge-production process, but because of social identity prejudice, it is not even heard (Fricker 2007, 130).

In contrast, hermeneutical injustice happens “when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences” (Fricker 2007, 1). In the case of hermeneutical injustice, epistemic agents are wronged in their capacity to understand and/or participate in the collective understanding of the social world. This type of injustice happens to individuals belonging to marginalized social groups, those groups being disadvantaged regarding the availability of or their access to means of creating interpretive resources (e.g., concepts, social schema, etc.) which can make particular aspects of their lived experience intelligible to themselves and others. Testimonial and hermeneutical injustices are injustices because of their discriminatory nature and because of the harmful consequences that they cause to wronged individuals (e.g., loss of confidence as an epistemic agent, feeling of isolation or confusion, etc.).

## 2.2 Assessing Wrongful Medicalization within an EI Framework

Recall that the main limitation of Kaczmarek’s account so far is the vagueness of the procedures through which we are to answer the four suggested questions. Applying EI to her account can prove fruitful for at least two reasons. First, because medicalization is a process of meaning transformation, EI gives us the resources to identify injustices that can happen in relation to this kind of knowledge production. As mentioned earlier, medicalization is the social process through which non-medical phenomena are reinterpreted as medical problems, often as “pathologies” or “disorders”. Understood as such, medicalization has an “epistemic tone” (Wardrope 2014). Since it implies the transformation of collective hermeneutic resources to make sense of specific phenomena, here mental distress as a medical problem, and the development of epistemic tools to approach the medicalized conditions,<sup>9</sup> it can be seen as an epistemic process. Therefore, EI could well apply to medicalization and help identify ethical harms that can be created during medicalization, understood as an

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<sup>9</sup> Epistemic tools such as concepts, models, and theoretical frameworks (here e.g., the biomedical model of psychiatry, etc.).

epistemic process. This is important for Kaczmarek's account, since answering the four questions—and therefore determining whether a condition should be medicalized or not—is an epistemic process that could create epistemic injustices.

The second reason why EI can prove useful is that it is a good framework to identify injustices that involve social subordination in an epistemic context. For EI to happen, there must be power relations at play: a group is socially subordinated, and such subordination impacts access to knowledge, knowledge creation and/or knowledge transmission. As medicalization scholars have already pointed out, medicalization implies different actors which do not have the same status and level of recognition (here I focus on people living with mental illness versus psychiatrists and psychiatric institutions, see e.g., Reiheld 2010; Wardrope 2014). As Wardrope argues (2014), patients are a marginalized social group during the medicalization process, and medicine (and psychiatry) has excessive power over the construction of conceptual resources related to medicalized phenomena. In other words, medicine has an epistemic privilege regarding the conceptualization of “life problems” (see also Carel and Kidd 2014 for a similar point), while people living with mental illness are underprivileged in that regard. EI can thus help identifying the wrongs associated with social subordination during the medicalization process. So far, because Kaczmarek's account is underspecific about the procedures through which the four questions are to be answered, it cannot keep such power relations from harmfully impacting the medicalization process. But do these EI actually happen during medicalization?

### **2.3 Hermeneutical and Pre-Emptive Testimonial Injustices Induced by Medicalization**

Recent work done in an EI-informed perspective has shown that medicalization can create *hermeneutical* injustices. Fricker has already acknowledged that the medical lexicon and categorization process constrain our collective understanding of what is medically normal and abnormal (Fricker 2007, 163-167). Usually, the hermeneutic resources we draw on to understand phenomena associated with (mental) disorders are forged by medical language. Our collective understanding of mental disorders—because it is developed primarily through psychiatric discourse—masks or dims other dimensions that may be associated with the experience of mental illness. For instance, patients' experiences may be understood only in biomedical terms because of the dominance of hermeneutic resources created by neuro-oriented psychiatry over other, marginalized conceptual models, such as phenomenological approaches (see also Charland 2004, 2013; Conrad and Barker 2010). Wardrope

(2014) explores this further by arguing that medicalization can bring about hermeneutical injustices because patients' experiences are construed *solely* through the discourse of medicine. Because of the power of these medical concepts, patients might not be able to adequately understand what they are experiencing, making it a case of hermeneutical injustice. Despite the occurrence of these epistemic harms in some cases of medicalization, Wardrope adopts a nuanced stance toward the medicalization process. He argues that medicalization can also *provide* hermeneutic resources for patients to report their experiences (for a similar point, see Reiheld 2010). When we look at personal experiences of medicalization, we find that testimonies include a great variety of responses to the process, ranging from positive to negative attitudes (more on this in section 3). Therefore, medicalization in itself does not necessarily create hermeneutical injustices. Only when it deprives patients of access to conceptual resources, or of the means to create hermeneutical tools allowing them to make better sense of their experience, can it be said to create hermeneutical injustices.

Moreover, some recent work by Bueter (2019) on the DSM revision process has revealed a particular form of testimonial injustices. Bueter's analysis does not target the medicalization process itself, but I believe that many aspects of her analysis can fruitfully apply to it. She argues that patients' perspectives are given little consideration when decisions are made about naming conventions, inclusion or exclusion of a condition as a mental disorder, determination of diagnostic thresholds for particular categories, and choices of diagnostic criteria. However, there are good reasons to believe that patient input would be relevant, as in the case of first-person experiences provided by patients about the effects and appropriateness of a particular diagnostic classification (Bueter 2019; see also Carel and Kidd 2014; Scrutton 2017; Drożdżowicz 2021 for patients' particular knowledge and epistemic injustices, but also see Tekin 2020 for the idea of patients' expertise).<sup>10</sup> Patients can provide relevant input regarding how particular conditions are described, and draw attention to overlooked symptoms (Bueter 2019).<sup>11</sup> Patients can also be aware of what is best for them when it comes to the harms and benefits the creation of a

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<sup>10</sup> Bueter argues that patients are excluded from the DSM revision process not because they belong to the social group of "patients," but to the social group of "non-experts" (Bueter 2019, 1071). The social identity prejudice at play here would be the negative attitude of experts toward non-experts. While this point is interesting, here I am more interested in epistemic injustices done to patients *qua* belonging to the social group of "patients."

<sup>11</sup> Note that Bueter's argument is in line with the literature about community-based participatory research and, more generally, with situated epistemologies in medical and scientific contexts, even if it has been developed in parallel with them (see e.g., Hill Collins, Harding, Code 2006; Wylie 2014; McHugh 2015; Scheman 2015). That is, marginalized communities can contribute relevant input to knowledge production because their perspective is external to the dominant framework.

new diagnosis might bring about, and report their actual needs concerning the conceptualization of particular conditions. And they can draw attention to the positive value of a “pathological” experience which the medical profession might see only in a negative light (Scrutton 2017). Not considering these forms of knowledge would entail epistemic losses (Drożdżowicz 2021) and create pre-emptive testimonial injustice. Since the two main ways through which medicalization occurs in psychiatry are the creation of a diagnostic category and the modification of diagnostic criteria in the DSM (see section 1.1), it is fair to say that Bueter’s analysis can well be applied to the medicalization process. Because patients’ perspectives about the DSM revisions are not heard enough, and because their perspectives would be relevant to assess medicalization, patients are wronged as epistemic agents. The fact that the DSM revision process does not provide enough spaces for the inclusion of patients’ voices about the creation and modification of psychiatric diagnoses means that medicalization can also create pre-emptive testimonial injustice.

These previous results show that medicalization taking place via the DSM revision structures can create hermeneutical injustices and pre-emptive testimonial injustices. These types of injustices have generally been overlooked in the bioethical literature aiming to distinguish good and bad forms of medicalization. They are nonetheless real injustices that should be avoided, especially since medicalization can be interpreted as an epistemic process. Moreover, the previous analyses imply that the way medicalization occurs in current medical practice and in institutions such as the APA and the DSM revision structures leads to epistemic injustices *usually because people living with mental illness are not heard enough in the process*. The DSM revision process causes EI mainly because patients are excluded from decision-making structures (or plainly not heard enough). Even if the DSM revision process were to adopt Kaczmarek’s pragmatic model, it would still need to acknowledge the occurrence of EI during medicalization and the necessity to overcome these harms. While I agree with Kaczmarek’s pragmatic proposal and the associated four guiding questions, I think that using an EI framework forces one to advocate that medicalization should be done following an epistemic justice ideal, with the goal of avoiding the creation or perpetuation of epistemic injustices which would impair the epistemic legitimacy of people living with mental illness. Kaczmarek’s model has so far proposed no procedures to avoid the epistemic harms actually involved in the medicalization of particular conditions in the DSM.

One way to overcome this deficiency is to argue that—if Kaczmarek’s model was implemented in the DSM revision process—answers to the four proposed questions should take patients’ voices into account—and take

them seriously. This would make epistemic resources related to medicalization more accessible, and therefore reduce hermeneutical and pre-emptive testimonial injustices. Moreover, even if I believe that Kaczmarek's proposed questions satisfyingly cover the problematic issues related to medicalization which have already been pointed out by medicalization scholars, including patients' perspectives could lead to the realization that other questions need to be asked, specifically where the needs and interests of people experiencing medicalization are concerned. Therefore, I believe that if one is to adopt a pragmatic approach like the one put forward by Kaczmarek, the occurrence of EIs should be taken into account, and mechanisms should be developed to fight them. This would call for the consultation of people living with mental illness on the answers to Kaczmarek's four proposed questions (and even for their assessment of the proposed questions, including the possibility to add more questions or to reformulate existing questions if needed).

In order to reduce the risk of EI, I have argued for the consultation of people living with mental illness in the medicalization process associated with the DSM. This does not amount to the exclusion of psychiatric expertise or of the expertise of other relevant experts in such a decision-making process. The perspectives of patients and of various experts are both relevant on this issue, and the implementation of decision-making structures compatible with diversified views would be ideal. Multiple models exist in the literature on participatory sciences—such as community juries, deliberative opinion polls or consensus conferences following the Danish model, where each member comes from a different perspective and tries to find a viable solution to a controversial issue (see e.g., Fung 2003; Smith 2009; Solomon 2015). The assessment of each of these structures in relation to the ideal of epistemic justice advocated here would require more analysis. But, for now, let us say that inclusive decision-making structures would be a first step toward such an ideal, since they allow for negotiation between divergent views, such as between mental health professionals, other relevant experts and patients. Therefore, arguing in favour of the inclusion of patients' voices in the medicalization process does not entail the exclusion of other types of expertise, but rather makes room for the expertise of patients as well.

### **3. Problematic Medicalization and PMDD**

#### **3.1 A Brief History of the Controversy**

To see how rewarding it can be to use EI to expand on Kaczmarek's approach in order to distinguish between good and bad forms of

medicalization, I will use the much-debated case of Premenstrual Dysphoric Disorder (PMDD). My goals in this section are to explain how and why PMDD was included as an official mental disorder in the DSM-5, and to briefly assess this decision in accordance with the conclusion of the previous section. This will draw attention to overlooked epistemic injustices and allow me to suggest possible future improvements.

PMDD has been added in the DSM-5 (APA 2013, 171-175) as an official diagnosis and is now classified as a Depressive Disorder. The main criteria for diagnosing PMDD are “mood lability, irritability, dysphoria, and anxiety symptoms that occur repeatedly during the premenstrual phase of the cycle and remit around the onset of menses or shortly thereafter” (APA 2013, 172). It is also associated with physical symptoms such as breast tenderness, joint or muscle pain and weight gain. The prevalence rate is estimated at between 1,8% and 5,8% among the menstruating women<sup>12</sup> population. Before the introduction of PMDD in the DSM-5, premenstrual psychological distress had already been named in the manual. It was first classified in the DSM-III-R (APA 1987) under the name “Late Luteal Phase Dysphoric Disorder” (LLPDD) and added to Appendix A: “Proposed Diagnostic Categories Needing Further Study.” In the DSM-IV-TR (APA 1994), LLPDD was renamed “Premenstrual Dysphoric Disorder” (PMDD) and was included in Appendix B: “Criteria Sets and Axes Provided for Further Study.” It could also be diagnosed as “Depressive Disorder Not Otherwise Specified”. With the publication of the DSM-5, PMDD was given its full diagnostic status, and was considered to be an official mental disorder (see e.g., Zachar and Kendler 2014 for a more complete history).

The creation of PMDD (and its previous existence as a non-official diagnosis in the DSM) has been criticized from a feminist point of view. The main criticisms concerning PMDD target the illegitimate pathologization and stigmatization of the physical and behavioural changes experienced by women during the premenstrual phase. Moreover, it has been argued that PMDD wrongfully medicalizes the normal distress or anger related to social circumstances such as toxic relationships, history of abuse or social inequalities affecting women (see e.g., Offman 2004;

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<sup>12</sup> Note that the DSM and many studies on PMDD refer to “menstruating women” as the only individuals affected by the condition (e.g., APA 2013, 173). However, it should be noted that AFAB (assigned female at birth) individuals can suffer from PMDD. This does not only include cisgender women, but also transgender men, and transmasculine and non-binary individuals. Therefore, when I refer to the way the DSM conceptualizes PMDD, I will use “women” only, and when I talk about PMDD in general, I will use “AFAB individuals” to include cisgender women, transgender men, and transmasculine and non-binary individuals. I take this failure to mention AFAB individuals who are not cisgender women to be a problematic assumption in the DSM’s account of the disorder.

Hartlage et al. 2014; Chrisler and Gorman 2015; see also Browne 2015 for a good review).<sup>13</sup> Given the outcry among feminist critics, it might be relevant to investigate the rationale behind the decision to move PMDD to the official list of diagnoses in the DSM-5 in order to assess it.

During the DSM-5 revision process, the Mood Disorders Work Group, in charge of PMDD, mandated a panel of experts specializing in women's mental health to formulate recommendations about PMDD. Epperson and colleagues, members of the panel, published a report in which they explain the reasons motivating the official inclusion of PMDD in the DSM-5. They write that the panel was in charge of

- 1) evaluat[ing] the previous criteria for premenstrual dysphoric disorder, 2) assess[ing] whether there is sufficient empirical evidence to support its inclusion as a diagnostic category, and 3) comment[ing] on whether the previous diagnostic criteria are consistent with the additional data that have become available. (Epperson et al. 2012, 465)

All of the eight members of the panel represented a different country, and six of them were experts of PMDD or reproductive mood disorder. The panel conducted a review of the literature on PMDD. Based on this review and on their discussions, they ultimately recommended that PMDD be moved from the appendix to the Mood Disorders section of the DSM. This decision to include PMDD in the official list of disorders was based on the *Guidelines for Making Changes to DSM-V* produced by Kendler et al. (2009) and used by the different Work Groups assigned to specific revisions. These guidelines are in line with the long-standing wish of the APA to enhance the role of empirical validation in the DSM-5 revision deliberative process (see e.g., Kendler 2013). The document produced by Kendler and colleagues is therefore an overview of qualitative guidelines to advise specific Work Groups in their evaluation of empirical support for proposed modifications to diagnostic categories. It prescribes distinctiveness of diagnosis, and three types of validators: antecedent (e.g., familial aggregation such as family or twin studies), concurrent (e.g., biological markers, patterns of comorbidity) and predictive (e.g., diagnostic stability, course of illness and response to treatment). If a condition meets the validation standards and shows sufficient distinctiveness from other diagnoses, then it can be included in the official nosology.

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<sup>13</sup> Note that I cannot do justice to the full and complex history of the controversy surrounding the medicalization of the menstrual cycle. For a more detailed presentation of some of these issues, see e.g. Offman and Kleinplatz (2004), and Chrisler and Caplan (2002).

According to the panel in charge of PMDD, the diagnosis meets all validation requirements. In short, it first appears that PMDD is at least partly heritable. Second, while not associated with a clear biomarker, it appears that the symptoms of PMDD are correlated with menstrual cycle-related hormone fluctuations. Third, PMDD symptoms are generally stable in that they are recurrent at every menstrual cycle (Epperson et al. 2012; Epperson 2013). Moreover, the panel reports that PMDD can be seen as a distinct diagnosis, mainly because of the key correlation between phases of the condition and the menstrual cycle. PMDD seems to be distinct from other diagnoses such as Major Depression (MD) or Bipolar Disorder (BD) since its symptoms are related to the late luteal phase (Epperson et al. 2012, 466-467). Therefore, the main rationale for the inclusion of PMDD as a new diagnosis in the DSM-5 follows the more general empirical turn taken by the DSM during its last revision process, which requires a careful review of empirical evidence to justify the inclusion of new diagnoses.

Nonetheless, in addition to these empirical concerns, it is worth mentioning that the panel reports discussing the feminist worries mentioned earlier concerning the pathologization of women's reproductive cycle and the correlated risk of stigmatization. However, the panel ended up dismissing these worries given the benefits allegedly incurred by the creation of the diagnosis (Epperson et al. 2012, 470; Gotlib and LeMoult 2014). These benefits take into account the decreased functioning of women with PMDD symptoms and include the expected development of therapeutic resources associated with its inclusion in the DSM (Epperson et al. 2012, 470). Studies suggest that the quality of life of women living with severe forms of PMDD were comparable to the one of patients living with MDD (Pearlstein et al. 2000; Halbreich et al. 2003; Rapkin and Winer 2009; Pilver et al. 2013; Osborn et al. 2020a, b). The benefits of including PMDD in the DSM for mental health was held to outweigh the risk of stigmatization and pathologization of feminine anger, especially because the description of the diagnosis made it clear that PMDD concerned only a small minority of women with severe symptoms and could not apply to all women. Thus, despite the fact that there has been no unanimous agreement on the creation of PMDD, it was justified by the panel with arguments about the empirical validity of the disorder and the benefits of this inclusion in terms of future research opportunities and access to clinical care for women with severe symptoms of PMDD.

### **3.2 Assessing the Medicalization of PMDD in the DSM**

I will now turn to the use of Kaczmarek's account and the EI framework to assess the medicalization of PMDD in the DSM-5. I will briefly discuss how the rationale behind the panel's recommendations can be interpreted

as a good fit with Kaczmarek's four questions, but then I will quickly move to the assessment of the creation of PMDD using the tools of EI. I proceed in this manner because I want to focus on how importing an EI framework into Kaczmarek's model can help it shed light on overlooked ethical issues related to the medicalization process in the DSM.

A first thing to note is that the panel in charge of revising the status of PMDD discussed many of the issues covered by Kaczmarek's model. For instance, in discussing the empirical validity of the diagnosis, they addressed question 3 (at least partly), pondering the most adequate methods for understanding a condition and its etiology. For the panel, findings about the empirical validity of the diagnostic category are in favour of its medicalization. Moreover, the panel was concerned with the impact the official inclusion of PMDD in the DSM would have for people living with associated symptoms, especially in terms of access to clinical care. The perceived benefits of the introduction of PMDD as an official diagnosis were seen as an additional argument for its validity—which can be related to questions 1 and 4 (the recognition of a condition as a problem, in terms of suffering or impairment, and the positive effect of medicalization). The risk of harmful pathologization and stigmatization associated with the medicalization of PMDD has also been discussed, in relation with question 4 (Does medicalizing X do less harm than good?). But some sub-questions have also been left unaddressed, such as some sub-questions to question 3, concerning mostly the possible existence of non-medical frameworks to conceptualize and address the condition. Nonetheless, if we interpret the panel's decision within Kaczmarek's framework, it could be argued that the panel asked many of the relevant questions, and that they judged that the medicalization of PMDD would lead to more positive answers than negative ones. Even if the discussions among members of the panel could have gone deeper to address overlooked aspects of medicalization, it could be suggested that including PMDD as an official diagnosis in the DSM is legitimate since Kaczmarek's framework had been applied (recall that this is a matter of degree, and that while medicalizing PMDD can bring about negative consequences, it can still be seen as a legitimate decision given that more questions can be answered by “yes” than by “no”).

While it seems that the panel did address many of the core issues of medicalization identified by Kaczmarek, I believe that the PMDD revision process is guilty of creating two types of EI: pre-emptive testimonial injustice and hermeneutical injustice. Looking at the panel's report, AFAB individuals living with PMDD have been left out of the decision-making process. Pre-emptive and hermeneutical injustices occurred because the decision-making process associated with PMDD was not inclusive enough.

As seen in section 2.3, using the EI framework to assess problematic cases of medicalization requires us to make room for consultation and critical discussion involving individuals who will be affected by the process. Within the framework of EI, if individuals with PMDD had been included in the process, and their voices and reports about their lived experience truly heard, epistemic injustices would have been reduced.

Because the consultation with people affected by PMDD did not take place, it is difficult to know precisely what would have been the result of an inclusive process of decision-making grounded in EI. However, recent investigations on PMDD have looked into the narratives of women with specific PMDD symptoms (in contrast with reviews including both PMDD and its milder form, PMS), and studied the impact of this diagnosis on their experience (see e.g., Usher 2014; Hardy and Hardie 2017; Osborn et al. 2020a, b). What these studies reveal is a positive attitude toward the creation of the diagnosis in women living with PMDD. Being diagnosed with PMDD (instead of receiving another diagnosis or no diagnosis at all) was perceived as a relief by most women, who felt that their experience was finally rightfully described:

I also feel like now I know why, like I know why I feel so anxious sometimes and why I feel so sad. I know it's not my fault, which is probably the main thing, I know it's not my fault now, I'm not just a bad person. (Participant 3) (Reported in Osborn et al. 2020a)

Women diagnosed with PMDD reported feelings of recognition, and of being really heard. They also detailed how the diagnosis transformed their identities and self-understanding, a transformation some described as life-saving. A negative attitude on their part was rather directed toward their “lost years”, during which they were not recognized as suffering from PMDD.

As Osborn and colleagues suggest, the positive attitude seen in diagnosed women could be explained in large part by the severe psychological distress associated with PMDD. Participants report:

All of a sudden it went pitch black, my emotional mood changed drastically and I could never see any outside things, like things had happened that made me upset or made me dark, so as a very young woman I was wondering why I felt that darkness. I felt like there was no point in living.

I couldn't control the way that I was feeling, I'd cry at the drop of a hat and I'm not particularly a cry, a crying kind of person. It takes quite a lot to get me upset, erm, I just literally could not function. I couldn't, I didn't want to get out of bed in the morning, couldn't sleep at night, erm ... just doing stupid things like ripping wallpaper off because I couldn't cope with the anxiety, the feeling of the anxiety. (Reported in Osborn et al. 2020a)

Of course, more research needs to be conducted before we are able to conclude (or overrule) that the medicalization of PMDD is unanimously or mostly welcomed by individuals living with associated symptoms.<sup>14</sup> But these findings suggest that if individuals with PMDD were included in the discussions related to the introduction of PMDD in the DSM-5, they could have asked for its introduction. This would mean that patient requests are in part compatible with the decision of the panel in charge of PMDD.

However, what needs to be emphasized here is that within the EI framework, this does not make PMDD a perfectly good form of medicalization in terms of epistemic justice. This is so because people living with PMDD have not been properly consulted. Despite the fact that patients seem to favour the introduction of PMDD in the DSM-5, their narratives have been collected *after* the inclusion of the diagnosis. During the DSM revision process, these findings were not known. Official structures of consultation and inclusion during the revision process would have *made sure* that the diagnosis as it is described in the DSM meets the needs of people living with PMDD symptoms and matches their interests. It would also have contributed to a more egalitarian access to the creation of hermeneutical resources. One potentially overlooked aspect in these studies is the possibility that, while people living with PMDD symptoms are in need of recognition and care, they might not want their condition to be viewed as a *disorder*. That is, they might want medicalization of PMDD without its pathologization (see e.g., Browne 2015 for a similar point). In another research about PMS more generally, women report hypersensitivity to environmental changes and a “deep feeling of vulnerability, a desire to protect themselves from the assaults of everyday life, and of the demands of others; of wanting to turn inwards” (Usher 2014, 318). These types of narratives could help shape the clinical description of PMDD to make sure that people living with associated symptoms recognize themselves in the diagnosis as they would express it,

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<sup>14</sup> For instance, only English speaking women over 18 years old who had already received a diagnosis of PMDD were included in Osborn and colleagues' study. But this is a first step toward understanding the attitude of women living with PMDD symptoms toward their diagnosis.

and that the diagnosis is a hermeneutical tool that can really make sense of their experiences. In addition, while it appears clear that most women wish that their symptoms be alleviated, the available treatments tend to focus on medication and, when medication proves ineffective, total hysterectomy combined with bilateral oophorectomy. Women might also want recognition and care, but not necessarily medication or invasive procedures (especially if medication is ineffective for some and if infertility brought on by total hysterectomy is unwanted for many, see Osborn et al. 2020). The treatments developed could be more diversified, and include psychologically based interventions (Usher 2002; see also Usher et al., 2002; Hunter et al., 2002). These are all unexplored possibilities so far. Nonetheless, they point to the epistemic injustices at play in medicalizing PMDD, and to the need for a more inclusive approach to decision-making in the DSM revision process. If such a process were implemented, it would be possible to obtain a medicalized description of PMDD that would reduce epistemic injustices, because it would have been developed in collaboration with people living with PMDD.

Adopting the EI framework shows that it might not be enough to adopt Kaczmarek's pragmatic proposal for identifying good and bad forms of medicalization. The inclusive manner in which the process of medicalization is conducted is relevant to reduce epistemic injustices and to achieve better forms of medicalization. Despite the fact that there is a clear need for recognition and care on the part of people living with PMDD symptoms, further consultation and discussion is needed before we can see PMDD as a fully legitimate form of medicalization. Using the EI framework allows us to pave the way for these possible future improvements.

#### **4. Conclusion**

The goal of this paper was to explore the ways in which the EI framework can serve to expand on Kaczmarek's bioethical account, which attempted to distinguish between good and bad instances of medicalization. Kaczmarek's proposal is promising, but it lacks guidance on how the four questions she proposed should be answered, and by whom. Building on the EI framework, I have argued that medicalization in psychiatry can create at least two types of EI: hermeneutical injustice and pre-emptive testimonial injustice. I have then argued that, if Kaczmarek's account was to be implemented, inclusive procedures should be established when debating the medicalization of particular conditions through the DSM in order to address these injustices. This means that individuals living with mental illness should be involved in the discussions and decisions about

the medicalization of their conditions. This is so because medicalization is essentially a process of hermeneutical transformation and comes with power relations between psychiatrists and patients. I have used the controversial case of PMDD to briefly illustrate how using this framework could help make the medicalization of this particular diagnosis more ethical.

What I have proposed here is a first step toward a broader analysis of EI and medicalization in psychiatry. I do not claim to have offered a comprehensive analysis. For instance, a separate analysis drawing on the EI framework would be required to address the role of the pharmaceutical industry as a major driving force of medicalization (e.g., Moynihan and Henry 2002; Moynihan et al. 2013; Musschenga et al. 2010). Moreover, recent work suggests that EI can also occur among patient advocacy groups (Jongsma et al. 2017; Jordan et al. 2020; Matthew et al. 2020), raising the question of how to prevent EI coming from patients' organizations themselves.

In addition, I will signal several questions which I have left unanswered in this paper: How to ensure that patients' voices are truly heard in an ethical medicalization process? How should critical discussions with patients be conducted? And how to deal with serious disagreement between participants (e.g., between patients and psychiatrists, or between patients)? What this list of questions suggests is that research needs to be urged further in order to better map the many power relations at play in the process of medicalization and the exact ways EI can occur in the DSM revision process. Nonetheless, I do believe that more interaction is required between EI literature and the research on wrongful medicalization. I hope I have been able to contribute to this nascent dialogue.

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