University of Tartu
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MEDICALIZATION, VALUES AND PATIENT PARTICIPATION

Master's Thesis in Philosophy

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Introduction

The question whether and how to define something as a disease has been contentious in practice. Should we define chronic fatigue syndrome as a somatic rather than a psychological disorder? Should we lower the diagnostic threshold of hypertension from blood pressure that is persistently ≥140/90 mmHg to one that is persistently ≥130/90 mmHg? Is autism a neurological difference, rather than a pathology? In the thesis, I argue that when deciding whether and how to define something as a disease, values must be relied upon. However, to mitigate their pernicious influence, values should be managed through a negotiation between diverse actors. This includes sometimes patients who as outsiders are particularly well positioned to challenge values within medicine. In this way we improve the chances that disease definitions are epistemically and ethically acceptable. These are disease definitions that support medicine's epistemic and ethical goals. A perfectly epistemically and ethically acceptable disease definition is an ideal, however I do not lay out in the thesis how this ideal could be achieved. The solution I offer should be considered as one part of wider effort to minimize the risk of pernicious value influence in medical taxonomy.

Before outlining the structure of the thesis, a note on why I emphasize both epistemic and ethical acceptability of disease definitions. This will clarify where I stand in philosophy of science regarding values. Among philosophers who argue that science involves values, there are two approaches. First, there is the liberal position, advocated by feminist empiricists like Helen Longino (1990, 2002), which states that while science is value-laden, only those values that threaten science's epistemic integrity are problematic and should be eliminated. We should be strictly impartial towards values that do not threaten the epistemic quality of research, regardless of their social worth. Against the majority view, some argue that science should not just promote epistemic, but also robust ethical goals. For instance, Janet Kourany (2010) advocates for the view that science should be socially responsible, directed towards desirable ideals such as gender equality and other egalitarian values.

By claiming that disease definitions should strive for epistemic and ethical acceptability, my position is both stronger than those of liberal philosophers of science and weaker than those who advocate for research guided by robust values. Undoubtedly, to responsibly manage values in medicalization, we must take

seriously their pernicious influence on medicine's epistemic integrity. However, this is not enough. Medicalization is a long complex process involving points of uncertainty where evidence does not dictate how to proceed. In the face of uncertainty, there may be several competing values, none obviously at odds with our epistemic interests, that influence our decision making. In these moments liberal value-neutrality is undesirable as our choices have consequences to patients. A responsible approach would be to evaluatively weigh the consequences of our decisions, privileging those values that promote medicine's ethical goals. In the thesis I define these conservatively as reduction of harm and respect for patient autonomy. In this way my position is weaker than those who would aim for stronger moral goals in medicine, such as challenging systems of oppression or empowerment of marginalized groups.

The thesis consists of three parts. Chapter 1 argues that decisions about medical taxonomy cannot be done without appealing to values. In Section 1.1 I establish that medicalization has wide ranging consequences. In Section 1.2 I show that despite its significant consequences medicalization has been contentious in practice. This leads to the question: how should we respond to controversies in medicalization? In Section 1.3 I consider an intuitive response that to guard the epistemic and ethical integrity of medical taxonomy we should ban values from decisions about how to define a disease. This view relies on the value-free ideal of science. In Section 1.4 I argue against the view by using a well-known argument against the value-free ideal of science, namely the argument from inductive risk. I establish that medicalization involves inductive risk as well as concept definition and operationalization risk as was proposed recently by Justin B. Biddle and Quill Kukla (2017). To manage both risks in disease definitions we need to rely on values, therefore the value-free ideal is unattainable in medicalization. However, the fact that medicalization is inevitably value-laden does not mean that anything goes in terms of values. In Section 1.5 I elucidate when values are bad for medicine. Based on Elizabeth Anderson's account, I claim that values influence medicine perniciously when they are held dogmatically and/or they contradict its ethical goals. I emphasize that relying on values in disease definitions is always a source of epistemic and ethical risk in medicine. Therefore, if we want to achieve epistemically and ethically acceptable disease definitions, one thing to do is to mitigate the risk of pernicious influence of values.

Chapter 2 argues that to mitigate the risk of pernicious influence of values in medicalization, values should be managed through a negotiation between diverse actors, including sometimes patients who as outsiders are particularly well positioned to challenge values within medicine. In Section 2.1 I propose Helen Longino's transformative intersubjective criticism as a promising value management ideal for medicalization. In Section 2.2.1 I discuss a limitation of Longino's account which is that transformative intersubjective criticism may be less effective against institutionally entrenched values. I propose that to challenge institutionally entrenched values more effectively we need to sometimes include patients in decisions about medical taxonomy. In Sections 2.2.2-3 I argue that patient perspective is both relevant and qualified to do this. It is qualified when it has had the opportunity to develop a standpoint which is particularly good at detecting and correcting deficiencies in the dominant medical point of view.

In Chapter 3 I answer three concerns about transformative intersubjective criticism and patient participation as means to reduce the risk of pernicious influence of values in medicalization. In Section 3.1 I consider the objection that patients do not share the scientific community's standards which are required for effective criticism to take place in science. As a response, I propose to reformulate the standards to facilitate effective criticism between patients and medical experts. In Section 3.2 I consider whether my account leads to the inclusion of controversial patient groups in medicine, such as pro-ana communities and chronic Lyme activists. I argue that it does not. In Section 3.3 I look how well my approach fares against commercial values in medicine. I conclude that it fares as well as or even better than Longino's account.

1. Medicalization is inevitably value-laden

1.1. Medicalization and its consequences

In this chapter, I establish that medicalization is inevitably value-laden. I begin by defining medicalization and describing some of its consequences. I then turn to some controversies in medicalization, both in psychiatry and in other areas of medicine. I argue that the value-free ideal approach to resolving these controversies is unattainable. I show this by considering the argument from inductive risk. Through a critical analysis of recent papers by Justin B. Biddle and Quill Kukla, I conclude that medicalization involves both inductive, and concept definition and operationalization risk that need to be evaluatively managed. Therefore, medicalization is inevitably value-laden. While values are unavoidable when defining a disease, values do sometimes influence medicine perniciously. In the end of the chapter, elucidate when this is the case. I claim that one thing we can do to resolve controversies in medicalization is to reduce the risk of pernicious influence of values.

I begin with a definition of medicalization. Medicalization is a complex social process in which conditions and behaviors previously understood from a non-medical standpoint are redefined and treated as medical problems (Conrad 2007, 5). By medicalizing a condition, we bring it under the control of medical institutions where health care professionals determine its diagnostic standards and treatment. Thus, medicalization expands the medical domain by creating novel disease categories and lowering the standards of diagnosis. Contrarily, demedicalization is the process in which a condition previously understood from a medical standpoint is redefined as non-medical (*Ibid*., 7). An example of medicalization from recent times includes the medicalization of extreme grief as the Prolonged Grief Disorder. The most famous example of demedicalization is that of homosexuality which rather than being seen as a psychiatric disorder, is now understood as a normal part of human sexual diversity.

In practice, medicalization may take decades of specifying and revising different aspects of a disease category before it is accepted in medical taxonomy, after which the diagnosis is still open for revision. In the thesis, I focus on those stages of the process, when experts are reviewing the evidence to decide whether

and how to define something as a disease, what are its boundaries and how to formulate its criteria. The kind of questions that interest researchers at these stages are for instance 'Should antidepressant-induced mania be a criterion of Bipolar II?' or 'Should Internet Gaming Disorder be recognized as a formal mental disorder, instead of a condition under further study?'. As I argue in the thesis, the answers to these questions are inevitably value-laden.

I now move on the medicalization's consequences. Medicalization has significant consequences for the patient, both good and bad. I begin with listing some of its benefits. First, medicalization will likely increase awareness and research funding for the condition which may lead to new evidence-based therapies. Secondly, if a condition is recognized as a medical problem it may come to fall under the purview of social benefit programs. Thus, the person with the condition may become eligible for financial or social benefits, therefore saving her from economic anxiety. Thirdly, the objective medical perspective may relieve the patient from seeing their condition as a personal failure. This may further contribute to the de-tabooing of the condition in wider society. (Kaczmarek 2019, 123) In short, medicalization has numerous benefits for the patient.

However, medicalization can also harm the patient. To begin with, medicalization means more, possibly needless expenditure of public and private money and of limited medical resources. Secondly, medicalization may subject patients to unnecessary clinical interventions with many, potentially deadly side effects. Thirdly, instead of seeing people as subjects with agency, medicine tends to look at patients as fixable objects. Furthermore, the focus on suffering bodies can conceal how social structures can contribute to such suffering and, in effect, uphold existing social prejudices by enforcing behavioral standards that are deemed medically normal (e.g., ABA therapy for autism or pharmacological intervention for low sexual desire). (Kaczmarek 2019, 123)

In sum, medicalization can have both benefits and harms for the patient. Some of the harms are inseparable from medicalization. For example, medicalization is objectifying even if we have very good reasons to medicalize a condition. Other harms are related to over-medicalization. It occurs when something is wrongly defined as a medical problem. Needless expense of resources and subjecting patients to unnecessary treatment are examples of harms caused by over-medicalization. Lastly, there are harms that are not caused by medicalization,

but from a lack of it, for instance when a person could benefit from a medical intervention but is barred from receiving it because their condition is wrongly not defined as a disease. In such cases, we can say the condition is under-medicalized.

A separate case of harms stems from instances where a state is rightly considered to be a medical problem but is nonetheless improperly defined. Oftentimes, this happens when a somatic illness is falsely labelled as a psychiatric illness or vice versa. This means that patients will suffer both from over- and under-medicalization by getting unhelpful medical treatment while also being denied of proper available care.

So far, we have considered those consequences that directly affect the patient. Nevertheless, what gets medicalized also determines medicine's knowledge building activities, including what conditions are studied, who studies it using what kind of expertise and tools, what information is accepted as evidence, and what avenues for cure are researched (Biddle & Kukla 2017, 233). For example, since chronic fatigue was defined as a pathology in the 1980s, scientists have pursued diverse research on the causes and treatment for the illness that did not exist prior to its medicalization. Moreover, different definitions of the disease (is it primarily a neurological, immunological, or psychiatric condition?) have determined what kind of knowledge about the illness scientists have sought and produced.

Altogether, the variety and seriousness of consequences that follow from defining something as a disease, means that medicalization is important. However, constructing a classification of diseases has proved to be difficult in practice. In the following section, I explore some controversies related to medicalization. The aim of the section is to establish that medicalization has been contentious both in psychiatry and other medical areas. This sets up the main question of the thesis: given medicalization's importance, what should be done to resolve these controversies?

1.2. The controversies of medicalization

In this section, I go over some examples of controversies in medicalization. I begin by considering cases from psychiatry before moving on to somatic illnesses.

To begin with, since the 1980s with the publication of the third edition of Diagnostic and Statistical Manual of Mental Disorders (*DSM-III*), there have been

attempts to medicalize low libido in women (Brotto 2010, 221). Currently, pathological low libido in women is classified in the *DSM-5* as Female Sexual Interest/Arousal Disorder. The manual lists six symptoms out of which at least three must be present at the time of diagnosis. The symptoms must have persisted for at least six months and cause significant personal distress. (DSM-5, 433)

Two controversies have surrounded medicalization of low libido in women. Firstly, there are conceptual issues which determine the boundary between pathological and non-pathological low libido. How one defines terms such as 'sexual interest/arousal', 'persistent' or 'personal distress' influences what kind of low libido in women is medicalized. For example, by defining all sexual desire as spontaneous, or untriggered, the *DSM-IV* criteria for the disorder might have over-pathologized women who, unlike men, tend to experience more responsive, or triggered, desire (Brotto 2010, 226). Due to these gender differences, the disorder was split into two gender-specific diagnoses in the *DSM-5* to make the diagnosis more accurate.

Secondly, some have raised doubts whether low libido in women should be medicalized at all. Psychiatry's history of treating "frigid" women, increased awareness of asexuality and pharmaceutical companies' attempts to market a Viagra-like drug for the condition all motivate skepticism over the diagnosis' validity (Meixel *et al.* 2015). On the downside, demedicalizing the condition would halt further medical research that might ultimately benefit women with low libido. This would be seen as unfair by some women's advocacy groups who point out that while several approved treatments for male sexual dysfunction exist, no such treatment is available for women (Pollack 2015).

Female Sexual Interest/Arousal Disorder is classified as a psychiatric condition. Indeed, disputes about medicalization tend to revolve around psychiatric classification. Questions whether something should be defined as a normal reaction to life's hardships (e.g., depression, anxiety), a deviance (e.g., alcoholism, paraphilias), or as a non-harmful neurological divergence (e.g., autism, ADHD) rather than a mental disorder are common in psychiatry.

However, it would be a mistake to think that medicalization is not a concern in other medical areas. In fact, drawing the line between health and pathology is also difficult in many cases of somatic illness. For example, it is currently debated whether to redefine hypertension from blood pressure that is persistently ≥140/90 mmHg to one that is persistently ≥130/90 mmHg. The difficulty is that there is no

evidence of a unique biological threshold at which point blood pressure is correlated with cardiovascular mortality. Rather the risk of cardiovascular events rises continuously with increasing blood pressure, which means that any definition of an abnormal blood pressure is open to dispute. Insofar as other biological variables (e.g., cholesterol, blood sugar, bone density) relate to risk in the similar continuous way, hypertension is not the only somatic disease with the issue. (Bolli *et al.* 2007, 581-582)

Furthermore, just like with psychiatric disorders sometimes the problem is not about where to draw the line, but whether to identify something as a pathology at all. This has been the case with infertility. In 2009 the World Health Organization (WHO) defined infertility as "a disease of the reproductive system" and it was shortly after included in the International Classification of Diseases (Adashi 2018). However, infertility's disease status is contested with some arguing that it is a consequence of heterogenous set of biological factors, not a distinct disease, and others arguing that it is a social problem defined by the failure to meet cultural, pronatalist norms (Maung 2018, 44-47; see also Kukla 2017). Indeed, while the medical perspective may see a condition as an organic dysfunction, the critics of medicalization may construe it as an example of normal biological variability that merely deviates from social norms (e.g., deafness, dwarfism).

In conclusion, medicalization has been contentious in practice, and this is the case for many areas of medicine, not just for psychiatry. Due to its social and epistemic consequences we should take these controversies seriously and outline a method to resolve them. The aim of the thesis is to propose a method that contributes to this goal. Before I can do this, I need to consider an intuitive response to controversies in medicalization which is to insist that medical taxonomy should be value-free. This clarifies that what is behind these controversies is a worry about medicine's epistemic and ethical goals that have been imperfectly realized.

1.3. The value-free ideal and medicine

In the following paragraphs, I describe the value-free ideal of science and how it relates to medicine's epistemic and ethical goals.

According to the value-free ideal of science, non-epistemic values, that is values that do not promote science's truth-seeking goals (henceforth values), should

be prohibited from the internal stages of science (e.g., choosing methodology, gathering, and interpreting the evidence). Although values can legitimately influence science externally, e.g., when ethical concerns convince scientists not to research a potentially dangerous technology, research itself should be carried out independently of them. The epistemic worry over values is usually formulated as the problem of wishful thinking: if values are allowed in science, the outcome of research may be more a reflection of a scientist's desire of how the world should be rather than how the world actually is. In this way, values influence science perniciously by interfering with its epistemic goals, such as acquiring reliable knowledge. (Douglas 2000, 559-565)

In medicine, the value-free idealist worries about values' pernicious influence over both medicine's epistemic and ethical goals. Firstly, regarding medical taxonomy there is the epistemic worry that including values may lead to invalid classification of diseases that do not yield successful explanations, reliable predictions nor effective treatment. For example, physician Stanley E. Althof, who opposed the inclusion of personal distress criterion in the *DSM-IV*'s definition of the female sexual disorders, expressed this worry when writing that diagnostic criteria "are not the proper venue for empowering or protecting women; they need to be objective and descriptive" (2001, 125). According to him, any such value-laden consideration "detracts from psychiatry's attempt to maintain scientific rigor" (*Ibid*., 123). In sum, according to the value-free ideal, values undermine medicine's epistemic goals.

However, value-laden medical taxonomy may also be perceived as a threat to medicine's ethical goals. Medicine has many ethical goals, but in the context of the thesis, I take it that at minimum they should include reducing harm and respecting patient autonomy. The defender of the value free ideal accepts that these ethical goals influence research externally, namely by determining that the kind of knowledge medicine seeks is one that is conducive to reducing harm and respecting patient autonomy. In this sense, medicine's ethical goals are constitutive of medical science. Because of this it is also difficult to untangle the epistemic harm of values from the ethical harm as less accurate knowledge automatically undercuts medicine's ability to reduce harm by offering effective treatment. However, there can be additional ways in which values interfere with medicine's ethical goals. For example, there is a worry that if values are permitted in the internal parts of medical

research, for example in how diagnostic categories are constructed, we may unwittingly institutionalize prejudice against certain groups of people leading to discriminatory health care practices. According to the value-free idealist, then, the best way to guarantee medicine's ethical integrity is to refrain from any value judgment in the internal stages of research.

All in all, the value-free idealist worries that values influence medicine perniciously by interfering with its epistemic and ethical goals. This highlights that behind the controversies in medicalization, is the concern that medicine's epistemic and ethical goals are imperfectly realized. Since value-free idealist presupposes that any value influence is bad for science, a logical approach to controversies in medicine is the rejection of values from decisions about medical taxonomy. If we want epistemically and ethically acceptable disease definitions, i.e., definitions that are conducive to medicine's epistemic and ethical goals, we should not rely on values, only on evidence.

I argue against this view. We need to rely on values when defining a disease. In the next section, I establish the inevitability of values in medicalization. The question "Is *X* a disease?", where *X* could stand for distressing low libido or blood pressure that is slightly below 140/90 mmHg, *cannot* be answered without appealing to values. To show this, I use a well-known argument against value-freedom in science — the argument from inductive risk[1]. This has been recently carried over to medicalization by Justin B. Biddle and Quill Kukla. While I agree with the authors that medicalization is inevitably value-laden, I am critical of their view that medicalization entails concept definition and operationalization risk *only*. I argue that medicalization involves both concept definition and operationalization risk *and* inductive risk. However, before turning to their argument, I introduce the standard argument from inductive risk.

[1] The argument from inductive risk is not the only available critique of science's value-freedom. A possibly relevant criticism is based on the idea of thick concepts. According to it, scientists must choose concepts as well as definitions of those concepts to proceed in their subject matter. Some of these concepts are thick, i.e., they are evaluative, not merely descriptive. These may include concepts such as „race", „gender", and possibly „disease". The existence of these concepts undermines the value-free ideal in science. (Betz 2013, example of the argument Dupré 2007) I chose the inductive risk argument due to its recurrent use in analyzing issues in philosophy of medicine, including medicalization.

1.4. The inductive risk and medicalization

1.4.1. The standard argument from inductive risk

In this section, I summarize the standard argument from inductive risk. To begin with, inductive risk refers to the possibility of making an error when either accepting or rejecting a hypothesis: it is possible that we accept a false hypothesis (a false positive) or reject a true hypothesis (a false negative). Because it is unknown how much evidence is needed to accept or reject a hypothesis, scientists must weigh evaluatively the risks of false positives and false negatives to choose a standard for evidential sufficiency. If the harms of the former exceed the harms of the latter, the amount of evidence needed for the hypothesis will be higher and vice versa. The fact that the scientist cannot proceed without such an evaluative analysis of risks means that values have a legitimate role in the internal stages of scientific reasoning. (ChoGlueck 2018, 712-714)

To give an example, consider a scientist who wants to test the hypothesis that breast cancer screening is effective. To begin with, she must decide how much evidence she needs to accept the hypothesis. There is always a risk that she is wrong, and she is aware that being wrong has considerable consequences in practice. If she accepts a false hypothesis she contributes not only to unjustified expenditure of medical resources, but also to the psychological and physical damage to over-treated patients. However, if she rejects a true hypothesis, the lives that could have been otherwise saved will be lost. Since nature does not tell her how much evidence is sufficient for hypothesis acceptance, she needs to make an evaluative choice in a risky situation. Believing that causing avoidable loss of lives outweighs any harms from overtreatment, she may set the standard of evidential sufficiency much lower than a person with opposite values. This decision must occur before the hypothesis can be accepted or rejected.

Philosophers of science have used inductive risk to show how science cannot proceed purely based on epistemic considerations (Churchman 1948; Rudner 1953; Hempel 1965). Heather Douglas is the most prominent recent philosopher to challenge the value-free ideal by utilizing the argument from inductive risk. Her account broadens the argument's scope by claiming that value judgments associated with inductive risk do not occur only when choosing how much evidence is sufficient for a hypothesis but are required at many decision points in research where there is

considerable uncertainty and clear consequences of error. (Douglas 2000, 565; Douglas 2009, 103) For instance, she identifies inductive risk in the characterization of evidence (e.g., when scientists must determine the presence or absence of cancerous growth in rat liver slides to measure the toxicity of dioxins) and the choice of a model for extrapolating data in toxicology research (Douglas 2000). Importantly, she claims that where there is more uncertainty and higher possibility of mistakes, the importance of values to mitigate risks increases. Inversely, when uncertainty is low, the importance of values also decreases. However, according to Douglas, since scientific reasoning is mostly inductive, it is impossible to eliminate uncertainty and, therefore, values. (Douglas 2009, 114) In sum, the value-free ideal of science is unachievable.

There has been some criticism of the idea that it is impossible to insulate science from values. For example, Gregor Betz in his paper "In Defense of the Value Free Ideal" (2013) argues that values can be avoided by a careful articulation of uncertainties that accompany hypotheses. Betz differentiates between plain hypotheses that can be accepted or rejected beyond reasonable doubt, and hedged hypotheses that make uncertainties explicit (2013, 211-212). If there is significant inductive risk regarding a hypothesis, the scientist can formulate a hedged hypothesis rather than a plain one by stating the ranges of probability, epistemically qualifying (e.g., it is possible/unlikely that…) or conditionalizing the hypothesis (e.g., if we deem these error probabilities acceptable, then…). A hypothesis can be hedged until the possibility that it is wrong is minimal and thus their acceptance need not invoke values. (*Ibid*., 213)

There are two answers to this defense of value-freedom in science. First, if Douglas is correct and inductive risk is "endemic" (2009, 90) throughout the knowledge building process, it is questionable whether Betz's solution is feasible as it would mean that any point in research where there is substantial risk of error must be appropriately hedged, not just when accepting a hypothesis. Second, even if uncertainties are explicitly articulated in the form of hedged hypotheses, there lies a second-order uncertainty about the accuracy of these uncertainty estimates. Values are then required to weigh whether the accuracy of those uncertainty estimates are sufficient considering some consequences. (*Ibid*., 85) Therefore, Betz's solution does not avoid the necessity of relying on values in science.

In conclusion, the argument from inductive risk is one of the leading arguments against science's value-free ideal. Following Douglas, inductive risks have been identified at various points in research. Could it also be identified in medicalization? The possibility of extending the standard argument from inductive risk to medicalization has been recently challenged by Justin B. Biddle and Quill Kukla who argue that medicalization is not an instance of inductive risk, but concept definition and operationalization risk. In the next section, I present their argument and analyze it critically. Against the authors, I claim that medicalization does involve inductive risk, in addition to concept definition and operationalization risk. This clarification is important to understand how proceeding purely on evidence falls short in medicalization. Either way, both types of risk need to be evaluatively managed which means that the value-free ideal is unattainable for medical taxonomy.

1.4.2. Risks in medicalization

I begin by introducing Biddle and Kukla's position on the inductive risk argument and medicalization. In a series of papers, Biddle and Kukla (Biddle 2016; Kukla 2017; Biddle & Kukla 2017) argue against extending the concept of inductive risk as Douglas did, since many cases of uncertainty in science do not fall easily in the classical framework of hypothesis acceptance and evidential sufficiency. Not all risks in science are *inductive* risks. Instead, Biddle and Kukla offer a taxonomy of epistemic risks in science. An epistemic risk is the risk of being wrong in the knowledge building process. Epistemic risks include inductive, but also other types of risk (Biddle & Kukla 2017, 222). Important for our discussion is that they use medicalization as an example of a non-inductive risk in science. Namely, they claim it is a case of concept definition and operationalization risk (henceforth definition risk). In the next paragraph I explain what definition risk is and how it is different from inductive risk.

Biddle and Kukla distinguish definition risk from inductive risk by pointing out that definitions have a different relationship with evidence than hypotheses. While accepting a hypothesis entails reasoning from evidence to a conclusion, accepting a definition is something that one needs to do to propose a hypothesis and gather evidence in the first place (Biddle & Kukla 2017, 230). For example, to test a hypothesis that a drug *X* is harmful, we must first operationalize the concept 'harm'.

Here, the question "How much evidence is sufficient?" is inappropriate as without a definition of harm we cannot know what the evidence of harm is. However, since there is always uncertainty about which definition to choose in relation to a goal and different definitions carry different consequences, definitions are a source of epistemic risk[2] in science that need to be evaluatively managed. However, unlike in inductive risk where we evaluate the consequences of error when setting the bar for evidential sufficiency, in definition risk values have a more direct role by weighing the consequences of differently defined concepts.

Biddle and Kukla claim that disease definitions are not an example of inductive risk, as proposed by some (e.g., Kostko 2019), but definition risk (2017, 229). Defining a disease "is prior to and a condition for the possibility for hypothesis formation and testing" (*Ibid.*, 233). And while it involves risks due to the uncertainty and the consequences of medicalization there is "no neat way to take these as inductive risks" (*Ibid.*, 232). The relationship between values and evidence to manage risks in medicalization is thus different. Although the authors accept that disease criteria are sensitive to evidence — a diagnostic category is not made up arbitrarily —, Biddle holds that "nature does not dictate how a disease should be defined" (2016, 202). Instead, they emphasize the "significant" and "strong" role of social values and interests in medicalization (Biddle & Kukla 2017, 232). For example, considering the definition of osteoporosis, Biddle notes that the expansion of its diagnostic criteria was not based on evidence, but "on value judgments regarding the costs of living with the condition" (2016, 200). In sum, the definition risk in medicalization is not managed by asking "How much evidence is sufficient?" in relation to costs of error but by weighing the consequences of one definition over another.

I am critical of Biddle and Kukla's view that medicalization is a case of definition risk *only*. My main concern is the authors' simplified understanding of medicalization and its relationship with evidence. I agree that there are aspects of medicalization that exemplify Biddle and Kukla's definition risk, e.g., setting a threshold for a diagnosis for which no natural boundary exists. However, their account fails to consider other aspects of medicalization that are more like inductive

[2] One may question whether definition risk is epistemic risk, i.e., whether you can wrongly accept or reject a definition. Biddle and Kukla suggest that a definition can be wrong in relation to a goal (2017, 229). For instance, if medical taxonomy should be specific for research and diagnosis purposes, it would be a mistake to define a disease vaguely.

reasoning. In those cases, researchers encounter risks that are like inductive risks. These points are not merely pedantic but show different ways in which purely evidential reasoning is insufficient in defining diseases.

To begin with, Biddle and Kukla underestimate the role of evidence in disease definitions. There is a significant difference between defining a concept like harm for a clinical trial and defining a disease category. While the former does occur before any meaningful hypothesis can be formulated and data collected, medicalization has a more complex relationship with evidence which may involve inductive reasoning.

To illustrate, the first evidence for Prolonged Grief Disorder (PGD) as a distinct pathology came in 1995 with the publication of two papers. First, inspired by the discovery that extreme grief does not respond to antidepressant therapy while bereavement-related depression (BRD) does, it was established that the symptoms of grief form a separate psychological response from those of BRD. Secondly, the researchers discovered that the presence of grief symptoms could predict an enduring dysfunction over and above the symptoms of BRD. Thus, the notion 'complicated grief' emerged to describe enduringly debilitating symptoms caused by bereavement that was not attributable to BRD. According to the authors of the studies, these findings were the initial evidence that complicated grief might be a distinct mental disorder. (Prigerson 2021, 8-9) In time, the concept 'complicated grief' was specified and revised based on accumulating data until in the 2020s it was added in the 11th edition of the International Classification of Diseases (*ICD-11*) and *DSM-5*.

The example demonstrates how formulating a disease category is a long process that occurs simultaneously with gathering of evidence and incorporating the evidence to how the category is defined which then shapes further research to the phenomenon (from 'extreme grief' to 'complicated grief' to 'Prolonged Grief Disorder'). It both precedes and succeeds the evidence. Furthermore, researchers generalized from the evidence (that it does not respond to antidepressants and it causes disabling symptoms that cannot be attributed to depression) to a possible explanation that extreme grief is a distinct mental disorder. This is an example of abductive reasoning which is usually classified as a type of inductive reasoning. This means that medicalization, too, can involve inductive risk.

This point is clearer in another paper by the members of the DSM work group for PGD. In it, they admit that there is a "resistance" to pathologizing grief, but that it has been overcome by "sufficiently compelling" evidence that

> certain grief symptoms are distinct from those of bereavement-related depression, have idiosyncratic neurobiological and clinical correlates, can persist unabated for months or even years, prove distressing and dysfunctional, and may only respond to targeted intervention. Thus, there exists *a substantial* and *mounting body of evidence* in support of a psychiatric syndrome of maladaptive grief. (Prigerson *et al.* 2021, 96, my emphases)

Here, researchers inductively infer from the evidence to the conclusion that maladaptive grief is a medical disorder. While the evidence is great, it cannot guarantee the conclusion, only make it more likely. Therefore, embedded in this uncertainty is the risk of being wrong. Moreover, accepting an erroneous conclusion would have had serious consequences. For example, some mental health experts worried that pathologizing grief would lead to over-prescription of medication for the bereaved (Bandini 2015). This controversy was recognized by the work group members who responded by emphasizing the amount of evidence as a reason to accept the conclusion, despite the risks. Thus, the inference from the evidence to the explanation (PGD is a disease) entailed a consideration of costs of error and the question whether the evidence is sufficient. Against Biddle and Kukla, it seems that medicalization does sometimes involve inductive risk.

However, Biddle and Kukla are right in identifying definition risk as a distinct risk in science in which values have a greater role than simply establishing evidential sufficiency. They discuss two examples which I think are good candidates for definition risk in medicalization: (1) lowering the threshold for hypertension and (2) defining intersex anatomy as 'Disorders of Sexual Development'. In both cases, the decisions cannot be based on evidence, but on values.

The first example is related to diseases that have no biologically unique threshold. Besides somatic diseases like hypertension and osteoporosis, many mental disorders like depression or Autism Spectrum Disorder are understood in this way. Without a distinct biological threshold, evidence alone cannot define illness boundaries and as Biddle notes, the question of evidential sufficiency is inappropriate in these cases. To set the boundaries, we must weigh the potential costs of either too broad or narrow disease definitions. For example, *DSM-5* defines

PGD much narrower than *ICD-11* to be "sensitive to the concern expressed in the public commentary about pathologizing normal grieving and diagnosing a grief-related disorder "too soon"" (Prigerson *et al.* 2021, 97). Here, values like respecting societal views on grief and the harmfulness of pathologizing normal grief directly influence the disease category's boundaries.

The same is true for what I will call 'wording decisions' in medical taxonomy. The choice of words defining a disease can significantly affect patients, thus they must be chosen carefully. For example, labeling intersex anatomy as 'Disorders of Sexual Development' rather than 'Differences in Sexual Development' reinforces the idea that deviation from the gender binary needs to be medically corrected. Because wording decisions cannot be decided purely on evidence, values play quite a direct role in considering the possible consequences of different conceptualizations. For instance, to reduce harm from overdiagnosis and -treatment, a recent proposal suggests renaming some early-stage cancers as 'Indolent Lesions of Epithelial Origin' (Esserman *et al.* 2015). Especially controversial are wording decisions in psychiatry. To illustrate, the term 'borderline personality' has been criticized for stigmatizing individuals with the disorder as it implies that the issue is with the individual's personality. An alternative, less stigmatizing label 'Emotional Regulation Disorder' has been proposed to mitigate the harm of the current one. (Bogod 2003) All in all, when medicalizing a condition, we need to make wording decisions that cannot be determined by evidence, hence values are required to make the choice.

In this section, I argued against Biddle and Kukla that, while accepting a disease definition is unlike accepting a hypothesis, it does involve inductive reasoning, in the form of abduction, and consequently, inductive risk. Therefore, medicalization carries definition *and* inductive risks. Both show the limits of purely evidential reasoning when constructing a diagnostic category and how values are needed to overcome them. Sometimes values help weigh the costs of error when we reason from evidence to a conclusion. Other times they help to assess the consequences of a diagnostic threshold or of a particular phrasing. In either way, medicalization is inevitably value-laden.

Returning to the value-free ideal of science, if science is value-laden as the argument from inductive risk shows, the value free idealist can draw two conclusions: (1) all science is bad science; (2) values only sometimes lead to bad

science. Since we do not have any reason to believe (1) (we know good science is out there), this leaves the value-free idealist with (2). Although accepting (2) they would have to abandon the value-free ideal of science, since if values lead to bad science only sometimes, they must at other times be compatible with good science. Relating this back to the issue about values and disease definitions, if values influence medicine's epistemic and ethical goals perniciously only sometimes and if we want to achieve epistemically and ethically acceptable disease definitions, we need to clarify when exactly values have this pernicious influence. Knowing this, we can then think of ways to mitigate such influence of values over medical taxonomy. In this way we contribute to epistemically and ethically acceptable disease definitions.

1.5. The pernicious influence of values in medicalization

In Section 1.3 I stated that values have a pernicious influence in medicine when they interfere with its epistemic (e.g., construction of a valid classification of diseases) and ethical goals (e.g., reduction of harm and respect for patient autonomy). In Section 1.4 I noted that since science is value-laden and there is good science out there, values must only sometimes influence science perniciously. The aim of this section is to specify when exactly they do this. I propose Elizabeth Anderson's view that values are bad for science only when they are held dogmatically regardless of evidence. I begin by outlining her account and then apply it to both medicine's epistemic and ethical concerns.

In her paper "Uses of value judgments in science: A general argument, with lessons from a case study of feminist research on divorce" (2004), Anderson[3] responds to the problem of wishful thinking: not all values in science will lead to predetermined conclusions, but only those which are held dogmatically. She builds her account by rejecting the idea that values lack empirical content — they are not "science-free" (2004, 7). Instead, values entail factual claims which provide support for them. This means that values can be either more or less warranted depending on the accuracy of those claims. Ideally, our values should track evidence. Indeed, most of us have had to revise our values as we gain experience and improve our

[3] After Anderson, more comprehensive accounts of pernicious values that are based on her ideas have been proposed. Most notably Brown (2020). However, as Anderson was the originator of the approach and it adequately serves my needs, I follow her.

understanding of the world. (*Ibid.*, 8) For example, upon learning that animals are not mere automata, but feel pain, have complex cognitive abilities and social lives, our bettered knowledge gives warrant to a new set of normative claims that we didn't have before (e.g., that animals shouldn't be made to suffer gratuitously).

The fact that values are not insulated from how the world is means that there "is body of evidence to which value judgments can and ought to be held accountable (Anderson 2004, 11)". If one encounters evidence that is incompatible with a value, one should adjust it accordingly. The reluctance to do so amounts to dogmatism. Against the value-free idealists Anderson argues that it is not necessarily values, but those that are held dogmatically which drive inquiry to predetermined conclusions and harm the epistemic quality of research. In other words, the pernicious influence of values in science stems from dogmatism, the valuer's stubbornness in the face of disproving evidence (*Ibid.*, 22).

I agree with Anderson that values are not science-free and can be measured against evidence. I also agree, as Anderson emphasizes, that the correct attitude to values is openness to reexamine them. Consequently, if we are worried that value-laden medicalization will lead us to an empirically inaccurate medical taxonomy, we should worry about two things: (1) values that are held stubbornly despite evidence that they are not warranted and (2) unwillingness on the valuer's part to pursue the possibility that the values are not warranted in the first place. Based on this, we have an account of how values can harm the epistemic integrity of medical taxonomy. Values interfere with medicine's epistemic aims if they are held dogmatically, which encompasses both (1) and (2).

Take for example a study that defends the optimal gender approach for intersex individuals. The optimal gender approach defines genital reconstructive surgery as the go-to treatment for infants born with intersex features. In the study the researchers claim that "for physicians it is obvious and unequivocal that a person with CAH-related DSD [Disorders of the Sexual Development] and XX karyotype has a female gender identity" (Binet *et al.* 2015, 465). Embedded in this are values such as 'gender should be determined based on chromosomal sex' and 'if a person has female gender, they should have gender typical anatomy'. These values could be challenged by evidence that gender and chromosomal sex do not always align and not all women have gender typical anatomy. Moreover, these claims were challenged by the study itself by a finding that the patients saw themselves as

considerably more masculine than did physicians (*Ibid.*, 466). Unfortunately, no further discussion of the finding takes place. Therefore, based on (1) and (2) the study entails dogmatically held values. The epistemic costs of this would be that the study falsely concludes that the surgery is effective when it is not.

How about medicine's ethical goals? Firstly, it is clear, even without Anderson's account, that any value employed in decisions about medical taxonomy should be tested against medicine's ethical goals, the reduction of harm and respect for patient autonomy[4]. Is the value conducive to or contradicting them? Sometimes the answer is obvious, e.g., 'the doctor should not tell all the treatment options, but only the one she prefers' is evidently incompatible with respect to patient autonomy and should be excluded from medical science. Other times the answer is elusive, e.g., it might be hard to tell whether the value 'we should not medicalize shyness' is conducive to medicine's goal to reduce harm to patients. In these cases, it is insufficient to merely compare the value against medicine's ethical goals (which due to their generality can be used to justify a wide range of values), one also needs to hold the value accountable to evidence. Therefore, values interfere with medicine's ethical goals if they contradict them and are held dogmatically, which means that (1) they are stubbornly held despite evidence that they do not support medicine's ethical goals and (2) there is unwillingness on the valuer's part to pursue the possibility that the values are not warranted by evidence in view of those goals.

Take again the study defending the optimal gender approach for intersex individuals. The authors of the study, which compared CAH-DSD patients who had early feminizing genitoplasty with those who hadn't, recommend the surgery on the basis that "parental stress and well-being are positively impacted", even though "quality of life and well-being are not significantly different on the long-term evaluation between both groups" (Binet *et al.* 2015, 468). Since children cannot make autonomous decisions about their bodies, medical ethics dictates that parents are required to decide in the child's best interest. While alleviating parental anxiety is often good for a child, it is uncertain whether to go under surgery for this reason is also in their best interest, especially considering the evidence that their well-being

[4] One may wonder whether reduction of harm and respect for patient autonomy are also dogmatically held values in medicine. If so, shouldn't we open them up for the possibility that they are unwarranted? This is not possible if we are interested in discussing medicine. As stated in Section 1.3 these values are constitutive of medical knowledge – without them, we could perhaps talk about an epistemic practice dedicated to the study of human biology, but not about medicine.

is not significantly improved by it. Consequently, there is reason to believe that the value 'alleviating parental anxiety is good for a child' is not conducive to medicine's ethical goals.

In sum, Anderson's account specifies that values influence medicine perniciously, when they are held dogmatically and/or they contradict its ethical goals. The approach is preferrable to Douglas' influential account that values undermine science's epistemic integrity when they are used in place of evidence for accepting or rejecting a claim. As we have seen, in cases of definition risk where there is no empirically inaccurate way to set diagnostic thresholds or to phrase disease criteria, values frequently serve as reasons for accepting one definition over another to achieve ethical acceptability. In this way researchers prevent an epistemically acceptable yet ethically unacceptable disease definition. Since Douglas would prohibit using values in this way, her account cannot guide researchers considering which values to rely on in such decisions. Anderson's account does not share this limitation: researchers should use those values that are supported by evidence.

Before I conclude the first chapter of the thesis, it should be clear that pernicious influence of values is a matter of degree and sometimes it may be difficult to discern it. Hence, it is always possible that values interfere with medicine's epistemic and ethical goals. This means that relying on values in medicalization inevitably involves epistemic and ethical risks in relation to these goals. Sometimes the risk of pernicious influence from values is high, especially if values are held implicitly (although explicitly held values can be just as resistant to scrutiny). Other times the risk is low. While it is impossible to eradicate all value-related risks, we can strive to mitigate them to some extent.

To conclude, in this chapter I introduced medicalization as a controversial issue in practice. I then considered a common response to the controversies which is to insist that medical taxonomy should be value-free. This position is based on a worry that inclusion of values interferes with medicine's epistemic and ethical goals. I argued against this position: medicalization is inevitably value-laden because it involves both inductive and definition risks that need to be evaluatively managed. Against the value-free idealist, I then pursued the possibility that values interfere with medicine's epistemic and ethical goals only sometimes. Following Anderson's account, I concluded that values that are held dogmatically and/or contradict

medicine's ethical goals influence medicine perniciously. However, pernicious influence is often hard to discern which means that there is always a risk that they interfere with medicine's epistemic and ethical goals. Therefore, if we want disease definitions that are epistemically and ethically acceptable, we should find a way to mitigate this risk by managing values that influence decisions about medical taxonomy.

In the next chapter, I use Helen Longino's value management ideal to argue that when deciding whether and how to define a disease, values should be managed through a negotiation between diverse actors, including sometimes patients who as outsiders are particularly well positioned to challenge values within medicine. In this way we improve the chances that our disease definitions are epistemically and ethically acceptable. I begin by outlining Longino's ideal as a promising approach to values in medicalization. I then introduce its limitation which is that it may be less effective against institutionally entrenched values. I argue that including patients can sometimes remedy this limitation.

2. Transformative intersubjective criticism and patient participation

2.1. Helen Longino's transformative intersubjective criticism as a promising value management ideal

In this section, I introduce Longino's critical contextual empiricist approach to managing values in science. According to it, scientific communities governed by the four criteria of transformative intersubjective criticism can effectively sort out biases and improve the epistemic quality of research. I propose that Longino's value management ideal is promising means to mitigate the potential pernicious influence of values in medical taxonomy. I begin by summarizing Longino's account, before considering features which make it a favorable strategy to reduce the epistemic and ethical risks of including values in medical taxonomy.

Like Douglas, Longino contests the value-free ideal of science. However, while Douglas employs the argument from inductive risk, also known as the "error" argument, Longino proceeds from the "gap" argument (Elliott 2011, 62). According to this, there is a logical gap or underdetermination between the state of affairs that is said to be evidence and the hypothesis for which that state of affairs is said to be evidence (Longino 1990, 52). Because of this, we rely on background assumptions that make the evidence relevant to a hypothesis (*Ibid.*, 43). These background assumptions "are a function of consensus among the scientific community, are learned as part of one's apprenticeship as a scientist and are largely invisible to the practitioners of the community" (Longino 2002, 104). The background assumptions can be descriptive, e.g., that substances are composed of smaller elements, or evaluative, e.g., that the simplest explanation is the best one or that women are the weaker sex. Because values can seep into scientific reasoning through background assumptions, scientific practice is not value-free.

To avoid relativism and guarantee scientific objectivity, Longino construes scientific knowledge as a product of a critical social process in which background assumptions are assessed intersubjectively by a diverse community of scientists. Objectivity of scientific knowledge is guaranteed by four criteria of effective critical discourse: (1) recognized avenues for criticism (journals, conferences); (2) shared public standards that critics evoke; (3) uptake of criticism (community's response); (4) tempered equality of intellectual authority (Longino 1990, 76). If a scientific

community is structured according to these criteria the critical discourse will be transformative, i.e., it will be successful at weeding out biases imported to science through background assumptions (*Ibid.*, 70). Objectivity, thus, is a matter of degree depending on how well any given scientific community will fulfill the criteria for effective critical discourse or transformative intersubjective criticism (TIC) (*Ibid.*, 76). Below, I clarify two criteria of TIC, tempered equality of intellectual authority and shared public standards, which will prove to be relevant later in the thesis when discussing patient participation in medicalization.

Particularly relevant to Longino's critical contextual empiricist account of knowledge is the understanding that TIC requires pluralism. According to Longino, "A diversity of perspectives is necessary for vigorous and epistemically effective critical discourse" (2002, 131). The criterion of tempered equality of intellectual authority upholds this vital critical resource by prohibiting unequal share of intellectual authority due to differences in political, social, or financial power. This ensures the participation of scientists with diverse backgrounds which means that the range of criticism to which background assumptions are subjected to is broader than it would have otherwise been. (*Ibid.*, 131-132; Longino 2004, 133) Because not incorporating alternative viewpoints renders criticism less effective the criterion also imposes duties of inclusion and cultivation of alternative, dissenting voices in science. By stating that equality of intellectual authority is tempered Longino emphasizes that there may be differences in authority based on the level of expertise. (Longino 2002, 132)

For Longino, to avoid cacophony or anything goes relativism, the shared public standards criterion limits the sorts of criticism the scientific community must respond to. Shared public standards are substantive principles, epistemic or social norms held by members of the practice and against which all aspects of scientific activity are evaluated. Criticism, which does not appeal to standards, does not require a response from the scientific community. In this way, the shared public standards delimit the critical discourse. (Longino 1990, 77-78; Longino 2002, 130-131)

I now turn to features which make Longino's account a promising value management ideal for medicalization. Most generally, it is promising since it accepts the inevitability of values, while also offering a method — TIC — to reduce the risk of pernicious influence from them. A more specific advantage is that it guides how

values should be managed in a scientific community, not in the head of an individual researcher. This is the appropriate level of analysis in medicalization because decisions about disease definitions are not made by individuals, but collectively, oftentimes in consensus conferences by a specially assigned work group. Because of this, we are interested in how to organize these groups to minimize the risk pernicious influence of values. Longino offers guidance in this regard.

Furthermore, her solution captures the simple and intuitive liberal belief that pluralism — scrutiny from multiple angles — is a good thing epistemically, but also ethically[5]. By subjecting claims to diverse range of criticism we are more likely to challenge values that influence decision-making in science. While Longino concern is only with the epistemic integrity of science, TIC can uncover and disqualify values which are incompatible with medicine's ethical goals, thus guarding its ethical integrity.

All in all, the ethos of TIC parallels the concern that it is the dogmatically held values that render disease definitions less epistemically and ethically acceptable. Similarly, its duty to include and cultivate dissenting perspectives complements Anderson's view that the correct attitude towards values is openness to consider they are not warranted. Based on Longino's ideal, epistemically and ethically acceptable disease definitions could then emerge from a scientific practice (e.g., diagnostic manual revision process) which is governed by the four criteria of TIC. Epistemic and ethical acceptability would then be a matter of degree depending on how well the criteria for TIC are fulfilled.

I want to underline that my interest in Longino's approach is in the method she uses for sifting values in science — the TIC and its facilitating criteria. While Longino applies her method to values in background assumptions that link observations to hypotheses and is concerned with scientific objectivity, my focus lies elsewhere: a transformative critique of values that are used to balance risks that arise in constructing a diagnostic category. I am not interested in questions of objectivity, but how to reduce the chances of having a medical taxonomy that involves dogmatically held values that interfere with medicine's epistemic and ethical aims.

[5] In the classical example of the argument, John Stuart Mill not only relates plurality of opinion to truth but argues that diversity ("different experiments of living") improves our understanding of what it means to live a good life (2003, 122).

To conclude, Longino's TIC is a promising method to combat pernicious influence of values in medicalization. Nevertheless, TIC as proposed by Longino has an important deficiency: by limiting participation in the critical discourse to those perspectives that appeal to shared public standards it is less effective against or even oblivious to institutionally entrenched values. To deal with the problem, I propose that sometimes we should involve patients in the critical discourse. Patient perspectives can be both relevant and qualified to participate in decisions about medical taxonomy making TIC more effective against institutionally entrenched values. This is the topic of the next section.

2.2. Patient participation against institutionally entrenched values

2.2.1. The problem of institutionally entrenched values

I begin by considering the question who belongs to a scientific community as another instance of epistemic risk in science. When setting the criteria for membership, it can go wrong in two ways: we either eliminate voices that would have contributed positively to the community's epistemic aims or sabotage the knowledge production process by including irrelevant or unqualified perspectives. In other words, it is always a tug-of-war between, on the one hand, pluralism as a prerequisite for effective criticism and, on the other hand, cacophony as an obstacle for effective criticism. Longino balances these risks by arguing for the inclusion of minority perspectives that have been historically excluded from science. At the same time, she constrains pluralism by insisting that participants need only address criticisms that are based on the public standards which are shared by the scientific community.

The problem with insisting on shared public standards is that it restricts criticism from outside of the scientific community, especially from non-scientists. If criticism from the outside is significantly limited, it raises the risk that institutionally entrenched values — values that are held uniformly by the members of the scientific community — are largely closed to TIC. Especially at risk at becoming invisible for criticism are values embedded in the shared public standards. If community members are unaware of values, they cannot pursue the possibility that they are unwarranted, threatening the epistemic and ethical integrity of science. According to Biddle and Kukla, institutionally entrenched

values are widespread in science, embedded in guidelines and rules that ultimately constrain decision making — including decisions on how to balance risks — in research (2017, 224). If institutionally entrenched values are indeed ubiquitous, the epistemic and ethical acceptability of disease definitions is seriously at risk.

To give an example of an institutionally entrenched value, take for instance the debate over the status of autism as a disorder which has been construed as a conflict between the pathology and the disability paradigm (Chapman 2019). According to the pathology paradigm, divergence from "normal" amounts to deficiency and the harm stemming from the divergence is internal to the patient. This stands in contrast to the alternative, disability paradigm, advocated by the disability rights advocates. According to it, "normal" is a social construct and disability is external to the individual, resulting from social structures and attitudes. The disability paradigm states that the focus should be on changing society, rather than bodies. The pathology paradigm — seeing divergence first and foremost as a deficiency — is a candidate for an institutionally entrenched value in medicine. It is likely that for the most part, medical scientists are incognizant that they are relying on the paradigm, that the paradigm is value-laden or that there are alternatives. This means opening it up for criticism for any condition is difficult from inside the biomedical community.

Instead, we need outsider perspectives to make entrenched values, like the pathology paradigm, open for criticism. Longino herself notes this by writing that universally held attitudes "do not become visible until individuals who do not share the community's assumptions can provide alternative explanations of the phenomena" (1990, 80). This leads her to emphasize the importance of pluralism within the scientific community. For example, the duty to include and cultivate marginalized and dissenting voices in science may lead to the involvement of disabled scientists or scientists who dispute the appropriateness of pathologization in a case. Afterall, a pivotal moment in demedicalization of homosexuality was a speech given by John E. Fryer, under the pseudonym Dr. Henry Anonymous, at the 1972 APA annual conference on his experiences as a gay psychiatrist.

However, Longino also admits the limited effectiveness of diversity within the scientific community against taken for granted ways of thinking by conceding that "for the most part" they remain immune to criticism (*Ibid.*). This is particularly likely considering how apprenticeship — learning to see the world through the

professional lens — diminishes diversity of thought within the scientific community, even if scientists themselves come from different backgrounds (see also Kourany 2010, 58-62).

If institutionally entrenched values become visible only when individuals who do not share them bring forth alternatives and if it is more likely to find such individuals from outside the scientific community, it is important to ask whether we could improve TIC by including outsider perspectives, thus making the critical discourse more pluralist. Longino seems to be open to the idea, writing that one remedy against universally held values in an epistemic practice is "openness to criticism both from within and from outside the community" (Longino 2004, 134). Of course, per her account, a productive intracommunity dialogue requires that at least some public standards are shared so that criticism made by one group can be made relevant to the other (Longino 2002, 130). Still, Longino withholds explicit support for the idea and does not openly discuss the possibility of including non-scientists in the critical discourse in science. I think this is a mistake on her part considering the problem of institutionally entrenched values.

In the following sections, I explore the possibility of including outsider perspectives in decisions about medical taxonomy to improve criticism against institutionally entrenched values. I claim that if we are interested in epistemically and ethically acceptable disease definitions, sometimes patients should be involved in the critical discourse over whether and how to define a disease. I argue that patient perspective can be ethically and epistemically relevant in tackling the threat posed by institutionally entrenched values. Besides being relevant, patients can also be qualified to contribute to taxonomic decision-making when they have had an opportunity to develop a standpoint. In this way we make the inquiring community more pluralist without sabotaging the knowledge production process through cacophony. Instead, we facilitate TIC by opening institutionally entrenched values to the possibility that they are not warranted. This contributes to epistemically and ethically acceptable disease definitions. In the next sections, I clarify how patient perspective is relevant and how it can be qualified.

2.3.2. Patient perspective is relevant

I have stated that the outsiders we should include in the taxonomic decision-making are patients. But why not, say, medical sociologists or concerned taxpayers?

Do they not also increase pluralism in the discourse? As stated in the previous section, there is a tension between pluralism and cacophony that must be balanced. Hence, we must wisely decide which perspectives to include to scientific practice in the name of pluralism. One approach is to claim that some perspectives are more relevant than others. When worrying about institutionally entrenched values in medical taxonomy, I claim that patient perspective is both epistemically and ethically relevant.

I begin with ethical relevancy. When researchers are faced with the risk that certain values, like the institutionally entrenched values, may influence disease definitions perniciously, they are interested in avoiding the possibility that those values interfere with medicine's ethical goals to reduce harm and respect patient autonomy. A relevant perspective in relation to this interest is one that can say whether these fundamental ethical values are respected. In this regard, patients are uniquely positioned to provide this insight. While it could be that a medical sociologists may help to gauge how well the ethical goals are met, the relevancy of their input still hinges on how well they are able to take patient perspectives into account. Therefore, if we are interested in the task of finding out whether values perniciously harm medicine's ethical integrity, patient perspectives are relevant.

Researchers also have an epistemic interest in avoiding bias in medical taxonomy. To confront the problem of institutionally entrenched values, a relevant perspective is then also one that can detect and correct bias in institutionally entrenched values by offering, as Longino put it, "alternative explanations of the phenomena" (1990, 80). Again, patients may be in a good position to do this making their perspective also epistemically relevant. However, what makes their perspective qualified to be epistemically relevant? Their outsider status? If so, any outsider would be qualified. Instead, I claim that their perspective is qualified when it has had the opportunity to develop a standpoint to analyze and dispute the biomedical point of view as it relates to their own lived experience. I specify this in the next section. Right now, it suffices to say that incorporating patients with such a perspective would reduce errors in our medical taxonomy caused by institutionally entrenched values, thus making their perspective epistemically relevant.

In summary, if outsider involvement helps to critique institutionally entrenched values, it is the patient perspective, given its ethical and epistemic relevancy, that should be included. It was however revealed that while the patient

perspective is always ethically relevant, it is only contingently epistemically relevant. I now turn to explain this point further.

2.3.3. Patient perspective is qualified

I have argued that to challenge institutionally entrenched values more effectively in medicalization we need an outsider perspective, and that the relevant outsider perspective belongs to patients. However, I have not yet clarified what exactly makes the patient perspective qualified to tackle institutionally entrenched values and contribute positively to TIC. In this section, I propose that a convincing explanation of how a patient perspective can be qualified to do this comes from feminist standpoint theory. I begin with an overview of feminist standpoint theory and then carry it over to the context of patient participation and values in medicalization.

The central tenet of feminist standpoint theory is the idea that knowledge is a product of a particular standpoint which emerges from one's social position and relationships with other knowers. However, a standpoint is not just an accumulation of experiences from a specific social location but is constituted through a reflective critique of how power structures and social conditions shape knowledge production. (Intemann & de Melo-Martin 2014, 10) For instance, Alison Wylie defines standpoint as "a critical consciousness about the nature of our social location and the difference it makes epistemically" (2003, 31).

Specifically, feminist standpoint theory describes how a knower's location in a hierarchy of power relations shapes the availability and creation of hermeneutical resources, i.e., shared meanings that are used to understand one's lived experience and communicate this to others. Similarly situated knowers may find that the dominant hermeneutical resources either capture, neglect to capture or even distort their lived experiences depending on whether their social position has enabled them to influence those resources. Marginally situated knowers will more often find that the socially prevailing tools used to interpret the world are inadequate for their lived experience. This may spur the creation of new resources that are more aligned to their needs. (Wylie 2015, 206)

Marginalized knowers create new hermeneutical resources collaboratively through critical reflection. This process may occur separately from or in opposition to the dominant culture. In the end, through this collective critical effort

participants gain a standpoint equipped with better hermeneutical resources to make sense of one's experiences and relationships with other knowers. (Intemann & de Melo-Martin 2014, 10; Wylie 2015, 206) An example of such collaboratively evolved hermeneutical resource could be spoon theory which was developed to explain how people with chronic illnesses must ration limited energy for daily activities[6].

The standpoint which a marginalized group acquires through collective critical reflection gives its members an epistemic advantage referred to as "double-consciousness" by W.E.B. Du Bois. This is the capacity to not only navigate one's own non-mainstream social experience, but also that of the dominant group. By interacting with both social realities, marginally situated knowers gain a heightened ability to detect gaps and distortions within the prevailing hermeneutical resources. Privileged knowers often lack this as they needn't be aware of the deficiencies in the dominant resources to comprehend their own experiences. Thus, they are epistemically disadvantaged and would epistemically benefit from adopting the hermeneutical resources developed by marginalized knowers. (Wylie 2015, 206)

I suggest that the tension between the prevailing hermeneutical resources suited for the needs of the dominant group, and the lived experience of marginally situated knowers who often find themselves in the "gaps" of these resources which leads to the development of a standpoint, can explain how patients are sometimes qualified to challenge entrenched values. To begin with, there is an asymmetric power relation between the patient and the medical professional, which leads to the marginalization of patients in medicine (Kidd & Carel 2016). Patients as marginally situated knowers may often find that the prevailing resources offered by the dominant biomedical viewpoint are inadequate. For example, individuals with chronic fatigue syndrome may discover that the prevailing understanding of their illness as primarily psychological falls short, while those with diseases without a natural boundary may perceive a disconnect between their own acceptance of risk and that of the medical consensus. Through a critical interaction (frequently on online platforms) with others who face similar challenges, patients can acquire a critical consciousness — a standpoint — especially calibrated to notice the gaps and

[6] In spoon theory, a specific number of "spoons" represent the limited energy reserves a chronically ill person has each day, with each task costing one "spoon". As a hermeneutical resource it helps to communicate the invisible challenges of managing daily activities with a chronic illness.

distortions in the biomedical framework and to formulate better alternative hermeneutical resources. A standpoint gives patients an epistemic advantage over the members of the biomedical community and this advantage can be used effectively to tackle the problem of institutionally entrenched values, i.e., detect and correct bias in such values. While this ability gained through standpoint is usually expressed in terms of knowledge, it can translate to the ability to see deficiencies in the dominant group's evaluation of phenomena, and to offer alternative values. For example, when intersex patients realize that genital ambiguity is not a bad thing to have but can be compatible with living a good life.

Moreover, I propose that the contribution to TIC that patients give via standpoint should be thought of as having a critical skill — a trained eye — to detect and correct deficiencies in the dominant biomedical framework. This counters skeptics who worry that, unlike scientists, patients are subjective. So, the skeptic might acknowledge the relevance of the patient perspective but favor qualitative studies on their viewpoint for "more objective" input to medical taxonomy. However, if the patients' epistemic advantage lies not just in knowing, but is an ability to do something, then such studies fall short. Therefore, if researchers fear bias due to institutionally entrenched values, and if patients have developed hermeneutical resources to counteract these biases and to contribute to accurate disease definitions, patients should be included in decisions about medical taxonomy in a way that allows them to use their critical skills. In practice, this could mean including them in work groups that write the expert review which makes recommendations on medical taxonomy based on accrued evidence. This suggests that the tempered equality of intellectual authority should include patients with the skills gained from a standpoint. This skill qualifies their perspective as epistemically relevant.

Before I conclude this part of the thesis, three comments about patient participation and feminist standpoint theory.

Firstly, not all patient groups develop a standpoint and are epistemically advantaged in this way. After all, a standpoint arises when similarly situated knowers, first, recognize their epistemic disadvantage in understanding their social experience. Some patient groups may lack cognitive abilities to perceive their shared epistemic disadvantage, while others may realize their marginalization but fail to collaborate on new hermeneutic resources due to illness or disability constraints.

Overall, the extent to which any patient group has developed a standpoint is a matter of degree and is case specific. It is clearer that autism and breast cancer patient communities have a standpoint, but it is less clear for conditions like high blood pressure. Ultimately, if a standpoint exists, it warrants inclusion in critical discourse for its potential to destabilize established assumptions.

Secondly, my explanation about how patients acquire a standpoint is preliminary and will require future clarification. However, using feminist standpoint theory has been a successful strategy in philosophy of science for advocating outsider inclusion in scientific practice. A notable example is Wylie (2015) who utilized feminist standpoint theory to extend Longino's criterion of tempered equality of intellectual authority to indigenous people in archeology. Echoing the concern over institutionally entrenched values, Wylie notes that the inclusion of marginalized groups can combat insularity in a scientific field, which shields foundational assumptions from critical examination (2015, 207).

Thirdly, employing feminist standpoint theory is preferable to Şerife Tekin's (2020, 2022) defense of patient participation in diagnostic revisions which also proceeds from Longino's value management ideal. Tekin argues for including patients in psychiatric classification decisions, based on their experiential knowledge which is epistemically valuable and complementary to third-person perspectives on mental disorders. By adopting Longino's account of scientific knowledge, she claims that patient inclusion diversifies the scientific community and thus promotes a more comprehensive understanding of mental disorders (Tekin 2022, 1171-1173).

There are several problems with Tekin's approach (see more Dings & Tekin 2022). However, in the context of the section, the key flaw in Tekin's approach is that she fails to recognize the critical and transformative potential of patient perspectives against the dominant biomedical framework. Instead, she primarily views patients' experiential knowledge as means to diversify the existing pool of knowledge about mental disorders. Therefore, if we are worried about institutionally entrenched values, standpoint feminist theory offers a better explanation of how patient perspectives can be epistemically relevant in this regard.

To conclude the chapter, I have argued that Longino offers a promising value management ideal for medicalization to manage the risk of pernicious influence from values. Namely, it describes how an epistemic community governed by four

criteria — recognized avenues for criticism, tempered equality of intellectual authority, shared public standards, uptake of criticism — can facilitate TIC, i.e., criticism that is effective against bias in research. In medicalization, TIC could be used against values that are employed to balance risks to enhance the epistemic and ethical acceptability of disease definitions. This means that the possibility that the values are not warranted by evidence and that they contradict medicine's ethical goals is pursued from multiple angles. However, because criticism must appeal to shared public standards to be relevant, criticism from outside the scientific community is restricted. This raises the risk that values prevalent in a scientific community are immune to criticism. This may perniciously influence how risks in disease definitions are balanced. To enhance TIC against institutionally entrenched values I proposed that sometimes patients should be included in decisions about medical taxonomy. Specifically, I argued that, unlike other perspectives, patient perspective is both ethically relevant (they can say whether medicine's fundamental values are respected) and epistemically relevant (they can detect and correct bias in institutionally entrenched values). I ended the chapter by explaining that patient perspective is qualified to detect and correct bias when it has had opportunity to develop a standpoint which enables patients to contribute to TIC with a critical skill. In this way we improve the chances that disease definitions are epistemically and ethically acceptable.

In the next chapter, I answer three concerns about TIC and patient participation. First, some may argue that the shared public standard criterion prohibits the participation of non-scientists who likely share few or none of the standards that define the epistemic community. Against this I suggest Jaana Eigi's (2019) reformulation of shared public standard criterion which encourages participation of non-scientists in science. Secondly, I answer the worry over the participation of controversial patient groups like pro-ana communities. I show that my account does not permit participation of such groups. Thirdly, I consider how the value management ideal I have proposed here manages commercial values in medicine.

3. Answering concerns about TIC and patient participation

3.1. Patient participation and the shared public standards criterion

Some readers of Longino may argue that non-scientists do not share the shared public standards held by scientists and, in as much as TIC is premised on them, patients as non-scientists cannot participate in the critical discourse over disease definitions. Although I have indicated that Longino is more open to the possibility of an epistemic practice between experts and non-experts, I agree that the shared public standards criterion discourages participation of non-scientists. Therefore, to answer the concern, it is worthwhile to consider whether the criterion can be reformulated in a way that supports, rather than discourages effective critical discourse between medical experts and patients. In this section, I suggest following Eigi's proposal to use Isabelle Peschard's (2007) interpretation of a scientific practice to do this. Patients and medical experts can share a practice without holding the same substantive norms if they recognize the relevancy of each other's claims to a problem and have an attitude of mutual responsiveness and accountability. Ultimately, this shows that merely formally including patients is insufficient to facilitate TIC between experts and non-experts. I begin with Eigi's reformulation of the shared public standards criterion.

To support the involvement of knowledgeable laypersons Eigi draws on Peschard's analysis of shared practice. Peschard rejects the understanding of practice which requires from its participants the commitment to the same norms. Such an understanding fails to account for the degree of discord and novelty in science. Instead, Peschard argues that to share a practice means to acknowledge the relevance of each other's claims to a common problem and to hold each other accountable in the process. Conversely, being consistently ignored by others indicates that the individuals do not share a practice. (Eigi 2019, 53) Based on this, Eigi reformulates shared public standards as a recognition among participants that in relation to a common problem "certain claims and perspectives make a difference, offer something of relevance, and demand accountability" (*Ibid.*). Therefore, rather than substantive principles, TIC is premised on how members of a scientific community interact with one another. In this way, non-scientists can

participate in research, but only those perspectives that are recognized as capable of contributing meaningfully to the critical discourse (*Ibid.*).

I support reformulating the shared public standards criterion in this way. It avoids the concern that patients cannot participate in the critical because they might not share the norms of a scientific practice. It also encourages the participation of non-scientists, such as patients, while still restricting the participation in the discourse to only relevant perspectives, thus avoiding cacophony. Therefore, to establish a productive scientific practice between medical experts and patients requires a willingness on both sides to respond to and be held accountable by the other. This complements Anderson's view that the correct attitude towards values is openness to consider that they are not warranted. To combine the two, TIC is premised on the attitude of mutual responsiveness and accountability, which includes the openness to consider that one's values are not warranted. Without such an attitude TIC does not occur.

An important insight from the reformulation offered by Eigi is that to increase the chances of epistemically and ethically acceptable disease definitions it is insufficient to include patients merely formally in taxonomic decision-making groups. It requires an appropriate attitude from both sides. Otherwise, as Eigi notes, a meaningful collaboration between scientists and non-scientists may fail due to imbalance of power which enables the former to effectively dictate the results of such a collaboration (2019, 54).

This is exemplified again by the controversy over clinical management guidelines for intersex individuals. In 2005, the International Consensus Conference on Intersex was held which concluded with the Consensus Statement of Management of Intersex Disorders (Merrick 2019, 4429). Two intersex advocates were included in the revision process: the founder of the ISNA (Intersex Society of North America) Bo Laurent and one of the organization's board members, Alice Dreger. Both were involved in writing and editing the clinical guidelines for the Consensus Statement. (*Ibid.*, 4440) One of the contentions between physicians and intersex advocates was the former's desire to replace the term 'intersex' in the medical nomenclature with 'disorders of sexual development'. Against this, the intersex advocates argued that the new name reinforces, rather than challenges the belief that intersex bodily features are abnormal, rather than a variation from the

typical anatomy. They worried that the new name may promote overtreatment of intersex bodies in medical care. (*Ibid.*, 4438-4441)

Ultimately, the advocates conceded to the label change, but not because of TIC between physicians and advocates. According to Alice Dreger the physicians' skepticism of ISNA was the main roadblock to being heard in the revision process. (Merrick 2019, 4440) More importantly, there was a clear power imbalance between the groups. Dreger writes that she conceded to the use of the new label to be taken seriously by the "powerful biomedical stakeholders suspicious of the socio-political aims of the ISNA and other self-identifying 'intersex' groups" (*Ibid.*). Abandoning the term 'intersex' was thus "a price to be paid" to get a seat at the table (*Ibid.*). This indicates that physicians failed to afford the attitude of mutual responsiveness and recognition to the advocates and, consequently, TIC could not take place, even though alternative perspectives were formally included. Advocates' input was largely ignored if it went against the dominant professional perspective, pointing to a dogmatic attitude towards institutionally entrenched values.

In conclusion, the shared public standard criterion should be reinterpreted be more open for the inclusion of patients, who are non-scientists. An appropriate reinterpretation is given by Eigi: an epistemic community is not bound by commitment to the same standards, but a recognition of the relevancy of each other's claims to a shared problem, mutual responsiveness, and accountability. Furthermore, merely formally including patients does not suffice for TIC to take place – it requires an appropriate attitude on both sides. How to achieve such an attitude between medical professionals and patients is outside the scope of the thesis, but it is likely that it entails changes in medical practice and its institutions, for instance how medical students are taught to perceive and interact with patients. All in all, it is a serious challenge, but one that is worth taking on to improve the epistemic and ethical quality of medical taxonomy (and medicine in general).

3.2. The inclusion of controversial patient groups

I have claimed that some patients can contribute positively to TIC through the ability to detect deficiencies in the expert point of view and justify alternative values through their marginalized standpoint in medicine. This ability is nurtured in collaboration with other patients, oftentimes in online spaces. However, some

such patient groups hold beliefs and values that are deeply controversial in medicine, for example chronic Lyme activists[7] and pro-anorexic, or 'pro-ana', communities. A critical question for my account follows from this. Do the duties of inclusion and cultivation of alternative, dissenting voices that Longino emphasizes also extend to such groups?

To begin with, as noted in the previous section, a scientific practice with someone is premised on a recognition that there is a shared problem which needs resolution and that the other can contribute meaningfully to solving it. With some controversial patient groups, shared practice may not emerge because their interests diverge too far from the ones of medicine. This may be the case with pro-ana communities whose primary aim is to encourage and support its members to achieve extreme thinness. While the communities have sometimes expressed the idea that anorexia is a lifestyle choice rather than a pathology, they do not actively seek the exclusion of anorexia from medical nosology. In other words, it is not just medical experts, but also pro-ana individuals who do not consider there to be a problem in need of resolving to which the other could make a difference.

However, while this answer explains how a scientific practice between different groups may not materialize, it does not address the question whether it *would be better* if such a practice *did* form. For example, let's imagine that pro-ana communities were actively seeking depathologization of anorexia. Were the medical professionals to revise the diagnostic category of anorexia, should they seek out and cultivate pro-ana perspectives? Would a perspective that views anorexia more like a lifestyle than a pathology contribute positively to the revision process?

An affirmative answer would hinge on the idea that such groups could recognize the medical experts as capable of making a difference in the question, take responsibility for the claims that they make and respond to the criticisms of others in an open-minded fashion. For example, if medical experts present evidence that participation in pro-ana groups negatively impacts self-esteem, self-efficacy and mood, and that anorexia has the highest mortality of any psychological disorder, a pro-ana advocate would have to take this evidence into account and revise her statements accordingly (Bardone-Cone & Cass 2006; Edakubo & Fushimi 2020). This seems improbable considering that researchers have noted similarities

[7] Chronic Lyme activists advocate for acceptance, research and improved treatment of chronic Lyme disease, a condition not recognized in the medical community.

between pro-ana communities and cults meaning that individuals from such spaces are likely to resist criticism or opposing viewpoints (Boniel-Nissim & Latzer 2016, 161-162).

Simply put, the answer is that the duties of inclusion and cultivation do not extend to perspectives that display resistance to evidence. A pro-ana standpoint which values anorexia as a good thing to have, regardless of facts, should not be sought out and cultivated. Similarly, we should not seek out and cultivate the views of chronic Lyme activists who claim that long-term antibiotic therapy is safe and effective, despite proof to the contrary. Thus, the answer harkens back to Anderson's view that it is the dogmatically held values that are problematic in science. It is also the answer given by Longino herself who writes that criticism that has become repetitive or ceases to have a connection with empirical research — both characteristics of dogmaticism — can be disregarded (1990, 79).

Overall, as already emphasized, the question which groups to involve depends on many factors and requires case-by-case consideration. In this section, I discussed an extreme example — pro-ana communities. In other instances, it may be more difficult to discern the degree of and the extent of dogmaticism within a perspective (i.e., the number of beliefs held dogmatically and how much they matter for the question at hand). Moreover, the pro-ana case — a minority view among those who have an eating disorder — is also an example of how there can be more than one perspective among the patient population. Therefore, it is crucial to carefully evaluate the diverse range of perspectives and the possibility of including them.

3.3. Commercial values

The final point of discussion revolves around commercial values in medicine. Undoubtedly, profit-driven interests have had the most pernicious influence over medicine in recent decades. Therefore, it is important to ask what does the value management ideal I have offered here tell us about the inclusion of such values. In my analysis, I describe how commercial values can be detrimental to medicine, even if research that is produced in the pursuit of them is empirically accurate. In doing so, I focus on both the dominance and the presence of commercial values in

medicine. I conclude that my approach either fares as well as or better than Longino's against commercial values.

One problem with commercial values, even if they do not harm the empirical accuracy of research, is that due to their financial power they may distort the critical discourse to their advantage. Financial stakeholders can steer criticism to pre-determined conclusions by limiting the effect of input of those without profit-driven interests. In that case, the discourse would fail to be transformative.

For example, a pharmaceutical company may lobby for lowering the diagnostic criteria of a disease to expand their markets and sell more drugs (although they will claim it will be for the benefit of the patient). This is called disease mongering. As previously noted, many diseases do not have a natural boundary. Slightly lower diagnostic criteria in these cases are not empirically inaccurate. Moreover, a pharmaceutical company may point to rigorous research which indicates that their drug has a modest effect on some markers of the disease. In this way, it would seem as if there were empirical evidence to lower the diagnostic criteria. Even so, it may still not be justified. This is a classic example of risk in medicalization: when weighing the risks of lowering or not lowering the threshold, we may conclude that the slight benefit of a drug may not outweigh the harms of over-medicalization. If financial stakeholders have power to determine the risk calculus, genuine critical discussion over values from multiple perspectives will not occur. Thus, even when commercial values do not harm the epistemic quality of diagnostic categories, their dominance drastically undercuts effective criticism.

To avoid this, Longino relies on the criterion of tempered equality of intellectual authority which states that consensus in a scientific practice should not be reached due to socio-economic power (1990, 78). This principle was incorporated into the reformulation of the shared public standards offered by Eigi who also expressed concern over power imbalances in science. Accordingly, a practice that involves financial stakeholders *and* generates transformative criticism entails that those who seek profit see others as capable of making a difference and respond to criticism. This requires an equal playing field, so that the financial stakeholder has no choice but to adhere to normative standards of TIC to participate in the scientific practice. As with addressing the power imbalance between medical experts and patients, institutional arrangements and, in this case, regulations are needed to achieve this. For example, substantially changing or even eliminating the patent

system would go a long way to curtail power pharmaceutical companies currently possess in medicine (see for instance Brown 2008, 2017).

For some (Biddle 2007; Pinto 2014) the overly general character of Longino's account, particularly in the context of privatization of science, is a serious limitation. It fails to offer specific solutions to actual controversies in science. While I agree that the approach needs to be supplemented with additional analyses that focus on problems in current research, by defining broad norms against which to measure existent practices, TIC still helps identify areas for regulatory improvement, thus serving as a useful guide.

Secondly, some authors point out that it is not just the dominance, but the mere presence of commercial values that is undesirable in science and that Longino fails to recognize this. In her liberal view, if research is empirically accurate, there is no difference between socially beneficial values and commercial values, regardless of their social worth. What's more, the duties of inclusion and cultivation of alternative perspectives means that — assuming there is an equal playing field — we should seek out and cultivate the perspectives of those with financial interests, even if they promote socially irresponsible science. For Intemann and de Melo-Martin (2014) this is counterintuitive in medical research: why in the name of eliminating bias should we give equal weight to voices who advocate for, say, cure for baldness and those who want to address important public health needs? According to the authors, an impartial stance to values is unsuitable for medicine which has important moral obligations and limited resources to realize them (2014, 9-10).

I generally agree with the criticism and I have two comments about how my approach fares better in answering it. First, I stated that in the context of the thesis I place myself somewhere in between those philosophers of science who are only concerned with eliminating bias and those who also want research to promote robust ethical values. Consequently, my approach is partial towards such medicine's ethical aims as to reduce harm and to respect patient autonomy. Certainly, these goals are easy to satisfy and can be used for industry's interests (e.g., you could argue for researching treatment for baldness based on these values). However, I am open to the possibility that medicine could have stronger ethical aims, such as fighting against ableism, and perspectives that support these aims should be privileged. While I do not argue for this here, I think it is compatible with my overall

claim that to have more epistemically and ethically acceptable disease definitions we need to deliberate values from multiple angles.

Secondly, by following Anderson's idea that values are sensitive to evidence and thus, can be measured against facts, my account already entails that some values — those that depend on how the world really is — are better than others and that we should exclude values that ignore the actual state of affairs. This opens the possibility to critique commercial values in medicine. For instance, given what we know about profit-driven medical research — that it systematically and sometimes knowingly introduces bias in research, often at the expense of patients' health[8] — how warranted commercial values (e.g., 'profit-seeking motives are good for medicine') really are in medicine? How one answers this question, likely depends on the specific area of medical research. In any case, the duties to include and cultivate values do not extend to commercial values if after scrutiny they are found to be unwarranted. In this way, Intemann and de Melo-Martin's concern can be avoided.

In sum, commercial values can be undesirable in medicine even if they produce empirically accurate research. What sets my account apart from Longino's is that the value management ideal which I have offered can be critical of commercial of both the dominance *and* the presence of commercial values in medicine. However, to truly counteract commercial values, additional institutional and regulatory measures are required.

[8] Of course, there are also evidence that support commercial values in medicine. For example, Intemann and de Melo-Martin point out that financial interests led to the development of drugs against high blood pressure — statins — that have had significant benefit to population health (2014, 8). However, Stegenga (2018) undermines the accuracy of this and similar claims arguing that we should have low confidence in the effectiveness of most pharmaceuticals, especially those developed by the pharmaceutical industry.

Conclusion

In this thesis I argued that medicalization is inevitably value-laden and if we want epistemically and ethically acceptable disease definitions, we need to be critical of them. I proposed that to manage values in medicalization, they should be deliberated from diverse perspectives, including sometimes from the perspective of patients. This requires an attitude of mutual responsiveness and accountability on all sides, including an openness to consider that one's values are not warranted. However, this does not guarantee epistemically and ethically acceptable disease definitions. It only means that they are likelier. Other, especially institutional and regulatory measures are required to further guarantee the epistemic and ethical integrity of medical taxonomy.

The thesis consisted of three chapters. In the first chapter, I established against the value-free ideal of science that medicalization is inevitably value-laden. However, this does not mean that anything goes in terms of value influence. We should be weary of pernicious influence of values over disease definitions. Hence, I also clarified when do values interfere with medicine's epistemic and ethical goals. Following Anderson, I claimed that this occurs when values are held dogmatically and/or they contradict medicine's ethical goals. Overall, I emphasized that values always pose an epistemic and ethical risk to medical taxonomy. Therefore, we need an approach to mitigate these risks.

In the second chapter, I proposed Longino's transformative intersubjective criticism as a promising method to mitigate the risk of pernicious influence of values in medicalization. Furthermore, to reduce the risk of pernicious influence from institutionally entrenched values I argued that sometimes we should include patients in decisions about medical taxonomy. Their perspective is both relevant to the issue and qualified when they have had the opportunity to develop a standpoint.

In the third chapter, I answered three concerns regarding transformative intersubjective criticism and patient participation as means to minimize the risk of harmful value influence in disease definitions. Firstly, I proposed a reformulation of the shared public standards to answer the concern that because patients do not share the standards of the epistemic community, they cannot participate in the critical discourse over medical taxonomy. Secondly, I argued that the duties of inclusion and cultivation of alternative voices does not extend to controversial

patient groups per my account. Thirdly, I claimed that my account fares as well as or better than Longino's against pernicious influence from commercial values.

Abstract

The question whether and how to define something as a disease has been contentious in practice. In the thesis, I argue that when deciding whether and how to define something as a disease, values must be relied upon. Against the value-free ideal of science, I use the argument from inductive risk to show that medicalization is inevitably value-laden. Instead of worrying about any value influence in medicalization, I propose that values interfere with medicine's epistemic and ethical goals only when they are held dogmatically and/or contradict medicine's ethical goals. To mitigate such pernicious influence of values, values should be managed through a negotiation between diverse actors. This includes sometimes patients who as outsiders are particularly well positioned to challenge values within medicine. In this way we improve the chances that disease definitions are epistemically and ethically acceptable. These are disease definitions that support medicine's epistemic and ethical goals.

Kokkuvõte

Küsimus, kas ja kuidas määratleda midagi haiguseks, on praktikas olnud keeruline. Magistritöös vaidlen vastu teaduse väärtusvabale ideaalile, mille järgi ei tohiks haigusi määratleda väärtuste abil, kuna need võivad õõnestada meditsiini episteemilisi ja eetilisi eesmärke. Ma kasutan induktiivse riski argumenti, et näidata, et haiguste definitsioonid on paratamatult väärtustega seotud. Selmet muretseda igasuguse väärtuste mõju pärast meditsiini episteemilistele ja eetilistele eesmärkidele, väidan, et väärtused kahjustavad neid eesmärke ainult siis, kui neisse suhtutakse dogmaatiliselt ja/või need on vastuolus meditsiini eetiliste eesmärkidega vähendada kahju patsiendi tervisele ja austada patsiendi autonoomiat. Et leevendada niisuguste väärtuste kahjulikku mõju meditsiinile, tuleks neid kritiseerida paljude osapoolte vaheliste läbirääkimiste kaudu. Läbirääkimised peaksid mõnikord kaasama ka patsiente, kellel on mitteekspertidena on eriti hea vaatenurk, et vaidlustada meditsiinisiseseid väärtushinnanguid. See tõstab tõenäosust, et haiguste definitsioon on episteemiliselt ja eetiliselt vastuvõetavad.

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