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Surgery

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## Disability and uncertainty: How to proceed when we do not know

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### ARTICLE INFO

#### Article history:

Accepted 7 January 2022

Available online xxx

What is it to restore health? Can one be healthy while experiencing what one would typically view as a disability? Advocates of disability rights have certainly made an emphatic case that disability and health are not mutually exclusive. Scholars such as Anita Silver have argued that disabilities, akin to race, only negatively affect one's quality of life when society fails to treat individuals with disabilities as equal and to provide services and opportunities that are suitable for their different needs. Silver lauds the Americans With Disability Act's pivot away from understanding disability as a physical condition inherent in an individual; instead, "it is the way society is organized rather than personal deficits which disadvantages [the disabled] minority."<sup>1</sup> The World Health Organization's International Classification of Functioning, Disability, and Health (ICF) echoes a similar shift away from a purely biological model of disability. Although ICF construes "impairment" as a "a deviation from certain generally accepted population standards in the biomedical status of the body and its functions [defined] primarily by those qualified to judge physical and mental functioning according to these standards," having an impairment is neither necessary nor sufficient for being disabled. Contextual factors such as legal, professional, and governmental structures can render some impairments disabilities and some not. In that respect, whether a physical condition amounts to a disability depends on contextual factors that might affect an individual's functioning and their quality of life.

The migration from a purely medical model of disability (eg, disability defined entirely in terms of physiological or functional terms) to a social model such as that of Silver and the ICF has certainly garnered a great deal of support among scholars and policymakers. Indeed, one is hard pressed to identify any scholar

who maintains that disability can be defined in *only* medical terms. Even some of those who have advocated a biological analysis of health and illness, such as Christopher Boorse, have conceded that our commonsense, legal, and clinical usage of "disability" is too heterogenous and inconsistent to map cleanly onto any medical or theoretical concepts. As Boorse concludes, "Of two medically identical people, one can be disabled, the other not," which, by definition, entails that disability is not a purely medical concept.<sup>2</sup> The conceptual span between hybrid theories of disability (defining disability as a combination of physiological and social factors) and a pure social model is remarkably broad. These positions can make radically different determinations as to whether an individual with physiological condition X has a disability. More than of mere philosophical interest, understanding the nature of disability can significantly affect public policies and clinical practices. For the remainder of this essay, we will focus on the latter and offer a route to move forward when there is so much uncertainty about disability.

Consider body integrity identity disorder (BIID), also known as apotemnophilia—a poorly understood condition characterized by a person's deep desire to have one or more healthy limbs surgically removed.<sup>3</sup> The anxiety experienced by a BIID individual is often overwhelming and ubiquitous, akin to that felt by those suffering from gender identity disorder. Some BIID patients engage in self-mutilations in an attempt to ease the distress. In isolated cases, they have sought the help of trained surgeons to amputate the unwanted limbs. In 1997 and again in 1999, Scottish surgeon David Smith performed leg amputations on 2 adult males with BIID, one from England and one from Germany.<sup>4</sup> Both patients thought of themselves as incomplete until they had lost a limb. The individuals were not delusional, in any psychiatric sense. After the amputation, the patients reported that "their lives had been transformed by losing a limb and they were delighted with their new state." What makes BIID challenging is that amputation-as-a-treatment requires that surgeons inflict an apparent disability. But notice that if one does not consider having fewer than 4 functional limbs a disability,

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then much of the moral distress attached to amputation-as-a-treatment disappears. Just as we do not think of those who have undergone gender reassignment surgeries as disabled, recovered BLID patients with amputations are analogously “whole.” In this respect, how surgeons think about the nature of disability affects what they consider a reasonable treatment.

If one moves forward only when critical philosophical questions have been answered, then it is unlikely that we can ever get anything done. In the absence of a clear concept of disability, it is both pragmatically and morally necessary that we proceed in a thoughtful manner. The lack of firm answers obviously does not mean that anything goes. It also does not automatically entail that we proceed conservatively; after all, as much harm can be done moving too fast or too slow. Here the work of the philosopher of science Helen Longino can offer guidance. Longino has long argued for a sort of methodological objectivity (she calls it “contextual empiricism”) in response to the recognition that science is hopelessly subjective. Rather than embracing a kind of radical relativism that places all views on the same par, she urges that we mold our scientific practice in accordance with the values that we cherish. In our liberal democracy, stakeholders’ opinions matter in determining the direction of an institution (eg, educational policies, tax reforms, or social programs). We advocate for transparent deliberative systems that are sensitive to preferences of stakeholders not because it ensures that we arrive at the correct answers but that the results will be fair, and fairness is the best thing we can strive for when confronting recalcitrant uncertainties.

For most surgeries, the identities of the relevant stakeholders are obvious. The patient, first and foremost, can be significantly affected by the therapeutic direction. Their quality of life can be drastically altered by the choice of intervention and the decision to intervene. Surgeons and other clinicians involved are also affected by the clinical choices. From moral distress that they can experience if forced to undertake disagreeing procedures to professional liability of undertaking what they see as dubious, clinicians are clearly impacted by their participation in the care of a patient. Yet, among all the stakeholders, the patient is the one with the greatest to gain and to lose. As such, their preferences and values are likely weightier in a discussion of therapeutic direction. The upshot is

that when there is doubt about the reasonableness of a surgical intervention, we might be able to plot out the appropriate path by adopting Longino’s procedural objectivity. The inclusion of the stakeholders’ values in the deliberative process stems not from some vague progressive commitment to inclusiveness per se; rather, it originates from a realization that when confronting clinical uncertainties, doctors do not have a privileged access to the “correct” values. Moreover, given the disproportionate stakes patients have in the direction of their care, their values demand a higher degree of deference.

In the face of clinical challenges that are ultimately grounded in the lack of clarity for concepts of health, disease, disability, and so on, clinicians ought to be mindful of the implicit philosophical assumptions that they make. The fact is that there is no widely accepted definition of disability. Clinical interactions and decisions that depend on it should proceed with this critical acknowledgment. One path charted out by Longino is to embrace transparency in a clinician’s deliberative process and to ensure that it is sensitive to the greater weight of patients’ preferences. Operating with uncertainties is common in medicine. It is important to keep in mind that uncertainties exist in philosophy as they do in the empirical sciences.

#### Funding/Support

There is no relevant funding disclosure.

#### Conflict of interest/Disclosure

I do not have any conflict of interests.

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