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The Complex Relationship Between Disability Discrimination and Frailty Scores

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Open Peer Commentary in response to Dominic JC Wilkinson's "Frailty triage: is rationing intensive medical treatment on the grounds of frailty ethical?"—forthcoming.

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Wilkinson (2021) argues that the use of frailty scores in ICU triage does not necessarily involve discrimination on the basis of disability. In support of this argument, he claims, "it is not the disability per se that the score is measuring – rather it is the underlying physiological and physical vulnerability" (x). While we appreciate the attention Wilkinson explicitly pays to disability in this piece, we find the distinction between disability and underlying vulnerability untenable both theoretically and practically. We begin with a brief overview of research in philosophy of disability concerning the meaning of the concept itself. We argue that this research demonstrates that many forms of disability do not involve underlying vulnerabilities, and, furthermore, that Wilkinson equivocates between "disability" understood as a medical category vs. "disability" understood as a feature of lived experience. We reject Wilkinson's distinction on these grounds and offer further considerations to avoid disability discrimination in emergency and crisis standards of care contexts.

I. Contemporary Research on the Concept of Disability

Over the last thirty years, our understanding of the philosophy of disability has grown exponentially (Cureton and Wasserman 2020). Elizabeth Barnes' 2016 book *The Minority Body* marked a watershed moment by placing a decisive nail in the coffin of *bad difference views* of disability. Bad difference views hold that disability is by itself (a) something that makes one worse off; and (b) would still be "bad" even if society was fully accommodating of disabled people (Barnes 2016, 50). She instead defends a mere difference view of disability on which "having a disability is something that makes you different, but not something that *by itself* makes you worse off *because of* that difference" (Idem, 78, our italics). This does not mean that certain disabilities cannot engender negative consequences; on the contrary, that is certainly true. Her claim is instead about the prudential effect of disability on a person taken *as a whole*. Since the book's release, the field has considered and deliberated upon Barnes' arguments. Tellingly, the bad difference view of disability has continued to be broadly rejected, but there remains significant disagreement about the mere difference view. Barnes purposely limits her account to physical disabilities, and, unsurprisingly, most find it far less fitting as an account of many psychological disabilities. Others argue that conditions such as chronic pain challenge the mere-difference view on its own terms and are exceptions that should instead be understood as bad difference forms of disability (Campbell and Stramondo 2017).

II. The Lived Experiences of Disability

We will not take a side in this debate here. We have instead cursorily summarized the last five-plus years of work in this area in order to make a very simple point: one cannot simply refer to "disability per se" as if that picks out some uncontroversial set of features of the world without engaging in scholarly debates over the concept of disability itself. What "disability per se" means on a bad difference view is different in theoretically and practically decisive ways than what "disability per se" means on a mere difference view and so on for other views, *mutatis mutandis*. Furthermore, even within a specific disability or impairment category, which view is most appropriate can be contested.

For example, consider deafness. Accommodations for hearing impairment comprise a large subset of expenses incurred through the Americans with Disabilities Act. Effective hearing rehabilitative technology and services are also available for many deaf/hard of hearing individuals. However, a subset of individuals with profound hearing loss instead embrace a Deaf

culture based upon sign language as a valued aspect of their lived experience and social identity (Bauman 2014). The fact that Wilkinson's model cannot distinguish between deafness and Deafness (capital D) is a considerable flaw (see Mauldin 2016).

III. The Mistake of Applying the "Frailty Phenotype" to Disabled People

Wilkinson might respond that this distinction is irrelevant because both fall under his stipulated exception of "stable, long-standing disability." But that qualification does not get us as far as Wilkinson supposes. Consider a patient with Trisomy 21. In a significant portion of cases, the "stable" nature of Down syndrome correlates to the presence of underlying, "non-stable" disabilities (as Wilkinson deploys the term), namely, cardiovascular pathophysiology. (Current statistics confirm a shorter-than-average median lifespan for people with Down syndrome related to complex physiologic and social factors (Kaposy 2018)). What frailty scores are meant to measure is where a patient falls on the continuum of progressive decline. Another way of looking at frailty scores is as an approach to determine "salvageability" or "recoverability." For a person with a physical or cognitive disability, their disability may be neither stable, nor immediately progressive. A frailty score would make an assessment at one point in time but would not accurately capture the individual's potential to recover, or disease state across a dynamic continuum. In that way it would be not only an inaccurate predictor but also unjust in attempting to apply a static system that unfairly discriminates (cf. United Nations 2020). We would take issue if one were to suggest that frailty scores as applied to one with Down syndrome are not discriminatory because they are not tracking the "disability per se" but instead an underlying cardiovascular vulnerability. To treat patients with Down syndrome differently than patients without Down syndrome by virtue of the fact they have Down syndrome is, in our view, patent discrimination on the basis of disability. In short, attempting to split out "physiological and physical vulnerability" from "disability" does not solve the problem.

Next, it is worth considering the distinction between "vulnerability" and "frailty." While Wilkinson uses the former as a way to explain the latter, we do not see how these concepts are in fact different. This raises a deeper issue. While Wilkinson concludes by arguing that "the concept of frailty is conceptually clear and measurable," we remain unconvinced. In practice, "frailty" has a *predictive* function; more specifically, it is thought to predict risks concerning various adverse outcomes and events, including morbidity and mortality. Yet, our current abilities to engage in prediction and risk assessment beyond a few months are notoriously deficient, and the definition of frailty itself relies on multivariate models that integrate heterogeneous and ever-changing covariates. Predictive ability is especially problematic when a progressive model is applied to a person whose physical or cognitive manifestation of disability may wax and wane. As Solomon et al. argued during the heat of debates concerning how to deal with COVID-19-related crisis standards of care, "the ability to predict long-term survival is poor and therefore susceptible to bias. Furthermore, many disadvantaged populations have reduced life expectancy, and triage protocols should not exacerbate health inequities. [Only n]ear-term survivability [1-12 months]…can be assessed independently from disability" (Solomon, Wynia, and Gostin 2020, e27[2]).

Despite attempts to achieve standardization, frailty scores are often observer-dependent and therefore subject to bias. Similar to clinician bias in assessing a similar comorbidity as more severe based on race, a given measure may be viewed differently in a person with a disability as opposed to one without. Although a patient using an assistive device may be able to travel the same distance as someone without an assistive device, it may take the person with the device longer and require more exertion and effort to travel the same distance. Based on this, an observer may (misguidedly) view the person with an assistive device as more fragile based on biased perceptions of physiological and physical vulnerability. Frailty measures are frequently applied as an adjunct to determining operative candidacy, and with modifications to current algorithms, they could well serve a valuable role in assisting surgical teams in particular. However, even with modifications, such scores do not exist in a vacuum, and are but one data point when making nuanced decisions regarding ones' ability to recover from a major surgery.

In addition to the aforementioned difficulties, applying frailty scores to persons with disability would perpetuate structures of inequity. A person with a disability may have the same or better overall probability of survival as a person without a disability, although treatments such as ventilatory support and physical rehabilitation may need to continue for a relatively longer period of time or in greater intensity in order for the outcome to be achieved. Equality would stipulate that everyone be given the same chance whereas equity would recognize that some classes of patients, such as those with disability, would need more treatment in terms of intensity or duration in order for the same outcome to be achieved. Invoking equality rather than equity in triage decisions based on frailty scores would disproportionately harm persons with a disability and thus be unjust.

IV. The Complicated Relationship of Frailty Scores and Disability Discrimination

Clearly, understanding the drivers and conditions of discrimination on the basis of disability is extremely complex. Researchers interested in doing so should look to and draw upon resources in philosophy of disability as well as disability studies, and engage with the lived experience of people with disability more broadly. A more nuanced and sophisticated conceptual architecture concerning disability is needed, especially in relationship to clinical practice. Because of the conceptual complexity of disability as well as the conceptual ambiguity at play in concepts such as "frailty" and "vulnerability," we remain unconvinced by Wilkinson's arguments that current algorithms for frailty scoring can be utilized in triage—and applied beyond triage—in a way that avoids disability discrimination.

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