

Tragic Choices: Disability, Triage, and Equity Amidst a Global Pandemic

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ABSTRACT: In this paper, I make three arguments regarding Crisis Standards of Care developed during the COVID-19 pandemic. First, I argue against the consideration of third person quality of life judgments that deprioritize disabled or chronically ill people on a basis other than their survival, even if protocols use the language of health to justify maintaining the supposedly higher well-being of non-disabled people. Second, while it may be unavoidable that some disabled people are deprioritized by triage protocols that must consider the likelihood that someone will survive intensive treatment, Crisis Standards of Care should *not* consider the amount or duration of treatment someone may need to survive. Finally, I argue that, rather than parsing who should be denied treatment to maximize lives saved, professional bioethicists should have put our energy into reducing the need for such choices at all by resisting the systemic injustices that drive the need for triage.

KEYWORDS: Bioethics, Triage, COVID-19, Crisis Standards of Care, Resource Allocation, Pandemic Ethics, Public Health Ethics, Quality of Life, Systemic Ableism

In the Spring of 2020, bioethicists and physicians scrambling to develop triage protocols for the COVID-19 crisis might have been surprised that counsel from Self Advocates in Leadership (SAIL), Disability Rights Washington (DRW), and The Arc of the United States (The Arc) filed a complaint with the U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) over their concerns regarding disability discrimination in some of these protocols (Carlson et al. 2020). Perhaps it would have been easy to dismiss such concerns as mere “naïveté” that failed to recognize the inevitability of the hard choices coming down the pike in the United States. After all, “none of the above” is not one of the choices available for the

Trolley Problem. Such a dismissal would have been a serious mistake. More specifically, those who developed these protocols would have done well to pay attention to the critiques of bioethical reasoning that were made both by disability activists at the beginning of the pandemic (Kukla 2020) and by disability studies scholars who have consistently and substantively engaged with these issues for decades (Cureton and Wasserman 2020).

Several clinical bioethicists asked me what sorts of triage criteria *would* satisfy the disability critiques of these protocols (Disability Rights Education and Defense Fund 2020). As with most questions in bioethics, there is no easy answer. Of course, just because there may not be a perfect, non-discriminatory set of rationing criteria, that does not mean there are not better or worse ways of doing triage. Let me review some of the triage criteria that I will argue are on the “worse” side of ledger.

First, consider any criterion that deprioritizes people with specific disabilities as a group. A *New York Times* op-ed by Ari Ne’eman (2020) brought our attention to these kinds of protocols in the context of the COVID-19 pandemic, including Alabama’s protocol denying ventilators to folks with “severe or profound” intellectual disabilities under the state’s initial Emergency Operations Plan (Alabama Public Health 2010) and Tennessee’s original protocol denying treatment to those with spinal muscular atrophy who require help with activities of daily living (Tennessee Altered Standards of Care Workgroup 2016).

I would argue that this sort of criterion is clearly grounded in a deeply biased quality-of-life judgment. Unlike supporting a patient’s right to request the withdrawal of life-sustaining care, or even request assistance in dying, denying patients care on the basis of a non-terminal disability is not justified via the principle of respect for a patient’s autonomy and self-assessment regarding their own quality of life. Rather, the reason why such a person would be denied lifesaving care via triage is because a third-party judge, like a physician or policy maker, does not believe that their life has enough quality to be worth saving in comparison with that of non-disabled others. A person’s self-assessment of their own well-being is deemed irrelevant in the context of triage, and thus, I would argue, any third-party assessment of a person’s well-being is always deemed irrelevant.

Of course, there is a significant body of empirical evidence showing that there is a substantial gap between how a disabled person’s quality of life is assessed by the disabled person themselves rather than by people that have never experienced their disability. Some prominent bioethicists even refer to this as the “disability paradox.” I would maintain that it is not paradoxical for disabled people to value their own lives more than non-disabled people do, making judgments based on stereotype and stigma (Amundson 2010). To conceptualize this gap in assessment and valuation as paradoxical is to wrongly assume that disability inevitably diminishes well-being. This assumption is a central tenet of what Amundson calls the “ideology” of ableism because it grounds the notion that the disadvantages of disability are intrinsic and inevitable, rather than socially constructed, and thus, ameliorable via social interventions, like civil rights laws (Amundson 2005).

Some of the triage protocols developed early in the COVID-19 pandemic avoided singling out particular disabilities that are presumed to make life barely worth living, but were still problematic. For example, the University of Washington Medical Center's "Material Resource Allocation Principles and Guidelines," which formed the basis of the HHS OCR complaint, avoided this rationale. However, it used the concept of "health," instead, as a proxy for quality of life (University of Washington Medical Center 2020). This might be even more morally troubling because it was not as obviously prejudicial to the average observer.

In my view, this reliance on an allegedly objective and unbiased concept of health was the biggest flaw in the University of Washington's original guidelines. This protocol explicitly committed itself to utilitarian principles as the basis of triage, and then stated that the "greatest good, in a protracted clinical situation such as the COVID-19 outbreak, is generally considered maximizing survival of patients with COVID-19. . . . Overall survival may be further qualified as healthy, long-term survival, recognizing that this represents weighting the survival of young otherwise healthy patients more heavily than that of older, chronically debilitated patients." This should be read as an attempt to smuggle in a quality-of-life criterion for triage because health is meant to equate to well-being in this context.

One might think that this reading is mistaken and that health was not actually a proxy for quality of life in this protocol. Perhaps there are legitimate reasons why health should be considered during triage, such as the intuition that a "healthy" person is more likely to survive than someone who is "chronically debilitated." Indeed, we don't want to waste scarce resources on people who will not survive, even with treatment. However, this clearly is not what this original University of Washington protocol called for. Likelihood of survival and general health come apart conceptually, and in fact, they were parsed in this protocol. Upon a close reading it was adding health as a criterion on top of the criterion concerning likelihood of survival. In other words, the way this protocol was worded did not aim to maximize the survival of everyone, but rather, to maximize the survival of people who will be "healthy" (i.e., non-disabled) after receiving treatment.

It may just be the case that this initial University of Washington protocol was recommending that people with a bad prognosis for overall survival, separate from their experience with COVID-19, be deprioritized. Maybe all that was being recommended was that folks with, say, pancreatic cancer should not receive aggressive treatment because, even if they have as good a likelihood as anyone else of surviving the virus, they are not likely to survive much longer after that. However, health and disease are notoriously broad, vague concepts in medicine (Kukla 2014). Thus, we must ask if these guidelines from University of Washington would have recommended withholding critical care from someone who is "chronically debilitated" because, for instance, they are blind or deaf or they have achondroplasia or a spinal cord injury. Without further specification (i.e., language about having a near-term terminal diagnosis), it seems that many things could disqualify someone from treatment because they will not be "healthy," even after they recover. To be sure, this was the aim of the protocol in that it assumed health equates to quality of life. Such an assumption would not just ignore the self-assessment of many

disabled people, but would also dismiss a rapidly growing scholarly literature arguing that it is simply false to believe that disabled people tend to be worse off (Barnes 2016; Campbell and Stramondo 2017).

In sum, I would argue that any triage protocol is unjustly discriminatory against disabled people insofar as it deprioritizes them due to a belief that their lives are of less value because they are of less quality. However, what about the triage strategy of assessing the likelihood that a patient will survive COVID-19, even with aggressive treatment? As already conceded, on the face of it, this seems safer from ableist bias than the previously examined quality-of-life criterion. After all, even someone who rejects utilitarian ethics out of hand would likely not advocate for patients to be provided with futile care that will not actually help them survive the virus and save their life.

Yet, judging the futility of treatment is a rather inexact science under the best of circumstances, and in the context of pandemic triage, what we are really talking about is not futility, but a scale of likelihood of survival. That is, especially given the lack of detailed, accurate knowledge about the variable effects of a new virus in the time of a pandemic, there will not be a bright, clearly-discernable line between those for whom treatment is absolutely futile and those who are merely unlikely to survive. Further, there will be significant overlap between the population of patients that are unlikely to survive even with treatment and those that have disabilities, some of which will entail comorbid risk factors. However, this isn't itself an argument that such a likelihood-of-survival criterion is necessarily unfairly biased in the same way that a quality-of-life criterion seems to have ableist bias baked right into it.

If and when tragic choices need to be made, it seems that some disabilities are relevant insofar as they are associated with comorbidities that we are reasonably sure will reduce the likelihood that a patient will respond to treatment and survive. There is still a risk of ableist bias finding its way into the application of this sort of likelihood-of-survival criterion, but there are ways to reduce this risk. A deeper concern is whether we ought to also deprioritize, on the same grounds, disabled folks that may have as good a likelihood of surviving as anyone else, but may require more treatment to get there. We can call this the level-of-resource-intensity criterion. Ultimately, the question is: Can we consistently justify excluding patients that are less likely to survive in order to conserve resources, and thus, save more lives, without also excluding patients who will use more than an average amount of resources to survive? I think we can.

Given that there is still so much to learn about COVID-19 and its variants, there are going to be as many questions as certainties when making judgments about how various comorbidities effect prognosis. Data have become more reliable over the course of the crisis, but these data seem to have significant limits due to the enormous variation between patients, even those sharing the same diagnosis. Consider the case highlighted in the press release announcing the legal action against the state of Washington:

I am concerned that a doctor will see my diagnosis of cystic fibrosis in my chart and make lots of erroneous assumptions about me. Cystic fibrosis often comes with significant breathing difficulties and a life expectancy of 30

years. . . . However, tests show that I have better breathing capacity than most people without cystic fibrosis. . . . (Katz 2020)

I think the worry being expressed here is that, in its application, the likelihood-of-survival criterion will sometimes slip into ableist bias by relying on disability as a heuristic. As Jackie Leach Scully puts it in her discussion of using likelihood of survival as a triage criterion, since disabled people are stereotypically assumed to be ill, “individual differences mean global rules (of the “no one with cystic fibrosis to be placed on ventilation” kind) could easily be unjust” (Scully 2020). So, even if people with disability X that typically occurs with comorbidity Y are less likely to survive in general, we ought to do our best to ensure that actual person P with disability X truly has comorbidity Y before denying treatment. Otherwise, there is a good chance that the denial is being motivated by stereotype rather than evidence. This is the sort of scenario the HHS Office of Civil Rights’ recent bulletin is trying to account for when it states that “whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence” (2020).

Feminist bioethicist Alison Reiheld has argued that some kind of feedback loop would be the best way to account for these biases.¹ One procedural safeguard would be for hospitals to conduct reviews of triage decisions against treating someone who would have been a candidate for treatment under ordinary circumstances. This is not to say that such decisions are inherently discriminatory. After all, these are not ordinary circumstances. However, this could serve as a trigger for closer examination of certain cases. Additionally, watching for ableist bias in the misapplication of the likelihood-of-survival criterion may deter assessment errors in which a person is unfairly assumed, contrary to evidence, to have a lower likelihood of survival because of a disability.

The motivation behind denying resources to people that are less likely to survive is to reserve those resources, which can then be used to save others who are more likely to survive, in an attempt to maximize the number of lives saved. If we endorse this kind of thinking, are we then committed to also withholding resources from those who have a good chance of survival, but only by using more resources? After all, this too would increase the number of people who survive. I actually think we can consistently accept the likelihood-of-survival criterion while rejecting the level-of-resource-intensity criterion, even if both aim at maximizing the number of lives saved.

According to the first criterion, patients that fall below a certain threshold of likelihood that they will survive may be turned away because these scarce resources may be *wasted*. This is the scenario in which the ICU bed is filled, the ventilator is in use, and yet the patient dies. According to the second criterion, even though it may take more resources to get the job done, those resources aren’t wasted because they save someone’s life. This may be *inefficient*, but is surely not *wasteful*. Inefficiency implies that a resource was not used to achieve its maximum benefit. Waste implies that a resource was not used to achieve any benefit.

It would be a serious moral error to conflate these two scenarios. Harking back all the way to the American eugenics movement, there is a long, grim history of con-

fusing inefficiency with wastefulness when it comes to the fair treatment of disabled people. One could even conceptualize the entire disability rights movement as an attempt to draw this distinction. It may reduce efficiency to bring disabled people into the mainstream of education, employment, and so on, but that does not mean that the resources used to do this are wasted.

I see no reason why we can't draw this same distinction when it comes to triage. By ignoring the level-of-resource-intensity criterion, it is true that fewer lives may be saved, but perhaps it would guarantee greater fairness when it comes to individuals' chances to access care that they would benefit from (Ballantyne 2020). Ensuring this sort of fairness would not be a waste.

Thankfully, at the time at which I am drafting this essay in the summer of 2021, most regions and hospitals have been able to avoid activating crisis standards of care. What's better is that many of the most discriminatory of these protocols have been revised over the course of the crisis, including the most problematic of those referenced above (Neëman et al. 2021).

Maybe most communities avoided having to make these tragic choices by not focusing their attention and effort on preparing for them. Indeed, by narrowly focusing on triage protocols and by deeming them the most morally salient problem that we faced during this unprecedented era, perhaps bioethics as a field has not been advancing the most important conversation. Towards the beginning of the pandemic, Shelley Tremain, a feminist philosopher of disability, argued that bioethicists should shift the focus of the conversation because targeting these protocols as the primary object of our analysis, at least indirectly, sanctioned the idea that these hard choices were inevitabilities. Rather than carefully parsing how to fairly deny treatment to some patients in order to maximize the number of lives saved, Tremain maintained that we, as professional bioethicists, should have been putting our energy behind efforts to reduce the need to make such choices at all (Tremain 2020). Arguably, Tremain was correct that *these* were ultimately the efforts that minimized the number of lives lost.

As we made great efforts to slow the spread of the virus by eliminating or radically altering all sorts of features of our daily lives, it became more and more obvious that the presumed need for triage was actually driven by economic, political, and personal choices, not an inevitable march of events (Porter and Tankersly 2020). Without a vaccine or effective treatment, the only means available for reducing the death toll were masking, social distancing, sheltering in place, and so on. These practices were quickly politicized, largely because of how they would impact people financially. Adherence to these practices and eventually vaccination, or lack thereof, have been the most significant variables determining the extent of the crisis. Tremain suggested that bioethicists, as a field, ought to have been putting our work into prompting individual and structural efforts to keep infection rates down and triage protocols locked away.

What Tremain was suggesting was a powerful paradigm shift. If maximizing the number of people saved was the top priority of professional bioethics, we should have put ourselves and our considerable social capital to work in the service of slowing down the spread of the virus and building the capacity of the medical response.

While we may not be engineers, nurses, physicians, or manufacturers who can work directly to make up for the shortfall in material and human resources available to those with the greatest need, there are some very specific ways that bioethicists could have worked to reduce the need for triage, which likely would have saved many more lives than perfecting a triage protocol.

First, we should have responded forcefully and persistently against politicians' constant flirtation with the idea that we should prematurely return to life as usual in the name of economics (Liptak and Collins 2020). Flattening the curve of the infection rate was our only effective means of reducing the unmet need for resources. As the virus has continued to spread via emerging variants and people have continued to die, arguments that prioritize the financial well-being of the politically powerful over the very lives of the politically vulnerable are nothing short of eugenic and bioethicists are positioned to point that out. It is clear that those impacted most by the virus, both in terms of health and finances, are poor, non-white, and disabled people, and thus, the U.S. is in a position where the most effective response would be a significant expansion of the social safety net, but this is often seen as a non-starter within basic liberal, capitalist social structures. That is, the kind of robust social support that would allow people to shelter in place rather than exposing themselves to the virus in order to meet their basic economic needs has been forcefully resisted by corporate interests because of the implications for redistributing wealth. Thus, neither of the two major political parties sees this as a viable political move. Fundamentally, though, this is a moral issue. Specifically, it is a question of public health ethics that bioethicists should have been willing to address. Put most starkly, it is deeply immoral to trade the lives of the most vulnerable for shareholder dividends and professional bioethicists need to say so.

Ultimately, professional bioethicists concerned with matters of justice are well positioned to make the case that there is a moral imperative to "flatten the curve" in order to save lives and to prioritize the public good over the limited interests of the economically and politically powerful. Zeke Emanuel's very good article in *The New York Times*, "Fourteen Days. That's the Most Time We Have to Defeat Coronavirus" (2020), is an example of how a bioethicist can show leadership on this issue. Of course, not all of us have the megaphone of an Emanuel brother. Even still, in my view, it is important that the public facing work bioethicists have been producing during the pandemic balances a discussion of triage protocol with a discussion of how the U.S. can take steps to avoid the nightmare scenario of triage by creating the public infrastructure to support the most vulnerable. Part of this argument should be an explicit acknowledgement that a failure to do so is driven by a eugenic ideology.

While I don't fault clinical ethicists for making a good faith effort to work on thoughtful triage protocols that try to take account of ableist bias, even if it is impossible to eliminate it altogether, it would be a serious mistake for professional bioethics as a whole to exclusively focus on triage protocols in their public work, rather than calling for an end to the kinds of large scale, systemic injustices that have hindered the country's ability to minimize the amount that triage has even been necessary.

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ENDNOTES

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