

WHICH CONSEQUENCES MATTER MOST? AN ANALYSIS OF UTILITARIANISM AS A
GUIDE FOR THE TREATMENT OF DISABLED PERSONS IN A PANDEMIC

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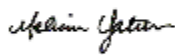
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CAPSTONE ABSTRACT

Which Consequences Matter Most? An Analysis of Utilitarianism as a Guide for the Treatment of Disabled Persons in a Pandemic

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This capstone explores the moral implications of the treatment of disabled persons during pandemics. Within the capstone, I will introduce my concept of *pandemic cognitive dissonance* which represents the moral conflicts that can arise due to differences between typical bioethical moral guidance and crisis standards of care moral guidance during COVID-19. Part 1 lays out the historical and empirical context of the mistreatment of disabled persons by healthcare practitioners and begins to analyze the justifications that might be used to authorize such treatment, especially during times of resource scarcity. In Part 2, I investigate the extent to which utilitarianism provides an ethical foundation for the discrimination and bias observed in Part 1, while also considering several ways utilitarianism itself is an equivocal perspective with more nuance than might at first be expected. Part 3 draws important contrasts between a collection of utilitarian views and Kantian approaches to pandemic care in order to crystallize the boundaries of consequentialist thinking and the extent to which egalitarian considerations are or are not compatible with utilitarianism. In Part 4, I conclude with a defense of hybrid utilitarianism as a theory that meets the challenge set out at the beginning of the project in terms of balancing an

actionable and concrete set of ethical principles while simultaneously incorporating egalitarian policies that more equitably support marginalized groups, inclusive of the disabled community.

Introduction

“There are no egalitarians in a pandemic.” (Savulescu et al., 2020) It was this kind of mentality that helped to justify the unfair treatment of the disabled population through both public health and clinical guidelines during the COVID-19 pandemic. From the refusal to provide care to disabled persons for the benefit of able-bodied persons via resource allocation guidelines to the development of legislation that would allow for resources to be removed from a patient due to their disability status to the coercion of disabled patients into signing do not resuscitate (DNR) orders, the treatment of the disabled population led to scathing criticisms of these sanctioned practices. But can we consider Savulescu et al.’s claim to be simply reflective of social psychology or is it a justification of employing antiegalitarian public policy during times of pandemic resource scarcity? Many practitioners and bioethicists used utilitarian ethical reasoning to defend just that. For example, medical ethics guidance set forth by both the American Medical Association (AMA) and the American Nurses Association (ANA) during COVID-19 pandemic addresses the multitude of challenges faced by front-line providers ranging from resource allocation to the clinician’s responsibilities to their patients, teams, and community overall. However, even though these organizations are committed to advancing the wellbeing of patients and providers, their guidance on managing the shift to crisis standards of care from typical operating practices/professional standards of care speaks both implicitly and explicitly to

the adoption of utilitarian principles to guide decision making¹². Additionally, the shift in the type of moral caregiving guidance that these key associations set forth in response to the pandemic created an opportunity for the development of *pandemic cognitive dissonance* for practitioners.

In this project, I will examine two core values seemingly at odds under pandemic conditions: the need for concrete and actionable clinical guidelines informed by stable and fair ethical values, and the need to respect and protect the dignity of all persons equally. In the following sections, I will explore the costs and benefits of adopting utilitarian ethical thinking in pandemic times in the context of the treatment of members of the disabled population. This will include an examination of the intersection between quantifiable outcomes and their relationship to the value of life as measured through quality of life determinations.

Ultimately, I will argue that utilitarianism can and must be adapted in promising ways to address its serious ethical shortcomings. The development of these adaptations should take into consideration the ways in which different theories may be able to provide a more seamless transition from typical moral guidance to pandemic moral guidance. This may help to mitigate the dangers of relying too heavily on a theory that society may not be convinced of in non-pandemic environments, but gravitates towards in pandemic conditions. It may also help minimize the development of pandemic cognitive dissonance by providing practitioners with more continuity in care guidance. Thus, a successful theory must be operationalizable across the

¹ See, for example: “In a pandemic, nurses can find themselves operating in crisis standards of care environments. In such situations, a utilitarian framework usually guides practice decisions and actions with special emphasis on transparency, protection of the public, proportional restriction of individual liberty, and fair stewardship of resources.” (American Nurses Association, n.d.)

² The obligation of stewardship requires physicians to strike an ethically justifiable balance between the specific needs of their individual patients and the global needs of the community of patients overall. Under conditions of a public health crisis, the obligation of stewardship may require physicians to consider alternative, less-preferred therapies for some individuals when there may be new critical public need for the same therapies. The goal is to minimize harm both to one’s own population of patients and to the community of patients. (American Medical Association, 2020)

full spectrum of healthcare, inclusive of everything from a single facility's procedural standards at the micro level to an overarching public health policy at the macro level.

Part 1

Contextualizing Healthcare Discrimination Against the Disability Community

“The feeling of being disposable is not new to me. It is knitted into my bones and sinews.”

(Kukla, 2020)

The defining and treatment of the disabled community throughout our society’s history is fraught with bias, stigmatization, and dehumanization. Thus, in order to truly understand how the disabled population was positioned to experience a disparately negative COVID-19 impact than their non-disabled counterparts, we must consider the significant healthcare discrimination against this population prior to the start of the pandemic. At the macro level, we find a plethora of examples of abhorrent treatment of people with mental illness, from visitors paying a fee to view mentally ill patients chained to the basement walls of the Pennsylvania Hospital in Philadelphia (Ouellette, 2013, p. 17) to compulsory sterilization laws across 27 states by 1931 (Powers, 2018 p. 98), to the 2016 development of virtual reality experiences allowing participants to explore psychiatric facilities filled with bloody bodies, “maniacal inmates,” and the sounds of people in pain (Solomon, 2016). We find similarities in the treatment of those with visible disabilities or differences as well.³

At the micro level, the human impact of disability discrimination is illustrated through stories such as those of polio survivor and iron lung user Edward Roberts, who in 1962 sued UC Berkeley to allow him to attend the institution (Nielsen, 2021 p. 162) and Dr. Lisa Iezzoni whose multiple sclerosis diagnosis in medical school led to the school deliberately blocking her from

³ These differences range from the 1881 Chicago ordinance banning “any person who is diseased, maimed, mutilated, or in any way deformed...from public places” (Coco, 2010 p. 1) to the Act of 1882 that sought to block disabled immigrants from entering the United States. (Baynton, 2021 p. 45)

entering a residency program (Catapano & Garland-Thomson, 2019 p. 83-84). Those perceived and labeled as *other* were ostracized through intentional exclusion and deplorable mockery. Though these examples represent only a fraction of the challenges faced by disabled persons historically, they also reflect the systematic, pervasive, and intentional disenfranchisement of this marginalized group.

The role of definitions of “disability” as a precursor for quality of life determinations

Those on the margins of society are all too easily victimized through their minority status, a perpetual moral conundrum that has plagued the U.S. healthcare system since its inception. This has been especially complex when considering the impact of mental health-related disabilities on social acceptance. A major reason for this is that society’s definition of what constitutes disability is amorphous and, to some extent, in a state of ongoing flux based on social perceptions of disability or the *other*. One manifestation of this occurred in the Salem witch trials when seizures and hysteria were viewed as the embodiment of witchcraft, which ultimately led to the killing of those deemed to be witches. (Quintanilla, 2010) In a more recent example, homosexuality was considered to be a mental health disorder in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM) until 1973. In fact, even when the vote to determine whether or not to continue viewing homosexuality as a mental illness took place, nearly 6,000 psychiatrists voted to remove homosexuality from the DSM while nearly 4,000 voted to keep it. (Burton, 2015) Shifting towards more contemporary examples, the American College of Chest Physicians (Park & Kluger, 2020) released resource allocation guidelines in 2008 that explicitly deprioritized those with conditions such as dementia and severe cognitive impairment. Though these examples do

not occur in the present day, they are representative of long-standing bias within our society, as well as the dangers of assuming that differing physical and/or mental characteristics correlate to another person or group being intrinsically flawed. And together, they help to lay a foundation for exploring the present-day impact of these types of biases on caregiving during the pandemic. Furthermore, these biases exemplify the theory of ableism, defined by Jun as the, “systemic oppression of individuals with disabilities/impairments on the basis of their disabilities.” (Jun, 2018 p. 246) In this way, ableism amounts to more than incidental discrimination; it reflects, in Jun’s words, “a system granting advantages for individuals without disabilities over individuals with disabilities or impairment.” (Ibid)

Within healthcare, ableism is a dangerous and potentially lethal lens through which to approach patient care. As noted by Doucette, “[i]n the social justice space, ableism would be classified as a macroaggression.” (Catapano & Garland-Thomson, 2019 p. 24) But some go further and suggest that ableism reflects a societal assumption that disability equates to a less valuable life, a view used to justify deeper unethical care and unnecessarily disproportionate outcomes for the disabled community.

This speaks to the underlying bioethical question of which life is more worthy of saving. If a certain set of criteria deems a given group to have less valuable lives, say, on the basis of being severely cognitively impaired, then the implications for personal and public healthcare affordances are quite significant. For one, less effort could be (and has been, as I will show) made to maintain and/or improve their healthcare outcomes because they are considered to be less worthy of saving. It also becomes easier to rationalize knowingly and willingly directing resources away from these groups for *the greater good* and in the interest of saving the most *valuable* lives and life years within the framework of utilitarianism. Such an approach certainly

runs counter to moral egalitarianism, or the idea that people are owed equal moral consideration – which I will argue later is a critical aspect of an ethical resource allocation framework – as defining some groups as having more valuable lives than others stands in strong opposition to equitable treatment.⁴

Today, current estimates are that 26% of the U.S. adult population is considered to be disabled. (CDC, 2020) And, ironically, the potential to become a part of the disability community is arguably humanity's true *great equalizer* – there is no one who is immune to the potential of becoming disabled. Whether this comes in the form of transient disability due to a broken limb or permanent disability in the form of worsening dementia or paralysis due to an accident, inclusion within the disability community is both unpredictable and conceivable. This makes defining disability quite problematic. Specifically, for those who are being impacted by a transient disability, it seems reasonable to question whether we should define them as disabled or whether they would even consider themselves to be disabled. For the purposes of social security, then yes, fitting into the framework of disability is a necessity. However, outside of that context, disability status and disability identity is fluid and cannot – and perhaps should not – be entirely mapped into a set definition.

And so, another important facet to effectively explore the moral implications of disability treatment during the pandemic is the consideration of *how* our society currently defines disability. Per the CDC, “[a] disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).” (CDC, 2019) Though this provides an overarching foundation to define disability, it does not speak to the

⁴ As we will see, morally equal treatment doesn't require that patients are given the *same* treatment, as we are deeply unequal in our needs and our abilities. Instead, it requires that we are treated as a whole person instead of the sum of our medical conditions.

nuances and intricacies that shape the disability community because it fails to recognize the ways identity itself is shaped by the medicalization of certain conditions as components of living a life as a disabled person. With this in mind, we must further consider how an individual's identity, or personhood, is a key facet of understanding the disability framework. Rosemarie Garland-Thomson argues in *About Us*,

Disability often presents a tough situation semantically as well as materially. Many of the writers here wrestle with the very words of "disability," whether we count ourselves or our particular embodiment as part of what the world considers "disabled" to mean and encompass. Some of us don't actually think of ourselves as disabled. We wonder whether stuttering, depression, anxiety, chronic pain or disfigurement are legitimate disabilities, alternately claiming and denying the category...For all of us, the assumption that ours is a deficit mode of existence is an insult. (Catapano & Garland-Thomson, 2019 p. xxv-xxvi)

Thus, though non-disabled persons, or even others who consider themselves to be members of the disabled community, may view someone as disabled, their viewpoint does not necessarily take into account how that person views themselves. Jonathan Mooney exemplifies this point when he explains his self-conception: "I've come to believe that I did not *have* a disability, as it is common to say, but *experienced* disability in environments that could not accommodate and embrace my differences. Ability/disability is not a fact in the world but a social construct..." (Catapano & Garland-Thomson, 2019 p.33) No doubt, society's desire to place its members into categories can lead to both marginalization and disenfranchisement. With this in mind, a particularly critical word in Mooney's quote is "accommodate." We hear that so often in the framework of education, but the same terminology aligns closely with the correlation between

disability and health equity. This word speaks to the negative connotation that can arise when an able-bodied society perceives that it must take added steps to provide something extra for those of differing needs, as opposed to recognizing that *all* persons should have the opportunity – and right – to experience life in an inclusive environment.⁵ Furthermore, this helps to demonstrate why the CDC’s definition of disability is inadequate as it places the onus too heavily on a person’s ability to interact with society rather than on the society’s need to create the inclusive environment.

Cognitivism and ableism

A glaring example of the present-day impact of defining whose lives are worth saving can be found in researching the intersection between cognitive impairment and COVID-19 outcomes. In fact, the impact of COVID-19’s spread was especially pronounced for those with cognitive impairments – both in terms of receiving a COVID-19 diagnosis and having a strong likelihood of mortality due to infection. As noted by Gleason et al. in the *New England Journal of Medicine*,

[a] cross-sectional study of 64,858,460 patients across 547 health care organizations reveals that having an intellectual disability was the strongest independent risk factor for

⁵ Though social and healthcare bias against disabled persons– or disability labeled persons– has gone on for centuries, disability has only recently emerged as a mainstream topic in public health. It wasn’t until April 2015 that Krahn et al. recognized that “[d]isability is an emerging field within public health.” (Krahn et al., 2015 p. S198) The sense that the lived experience of disabled persons had not been closely considered within public health serves as its own form of remarginalization. For a field that is dedicated to the promotion of health equity to view the inclusion of disability in its industry as emerging less than 10 years ago shows how little emphasis was placed on this social group. As such, Krahn et al.’s statement is crucial to reflect upon within the framework of disability ethics as it is indicative of the opportunity for a shift from stigmatization of disabled persons to their inclusion in public health’s pursuit of health equity. However, the long-standing history and perpetuation of present-day bias towards the disabled both socially and within the healthcare sector is not easily overcome – especially within the context of a global pandemic that led to resource scarcity and the implementation of crisis standards of care (CSC) guidelines that incorporated assumptions about the value and quality of lives into their criterion.

presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality. (Gleason et al., 2021)

This may be, at least in part, explained by the many resource allocation guidelines that deprioritize disabled persons, but there are also concerns surrounding the unethical coercion of disabled patients into signing do not resuscitate (DNR) orders.

In fact, the convergence of cognitive impairment and healthcare bias made headlines when doctors unlawfully decided to assign DNR orders to individuals with learning disabilities without discussing their decisions with the individuals' family or caregivers. (Alexiou, 2020) These DNR orders were not only unlawful, but morally unjust as well. Even if one considers that these patients were not cognitively capable of patient autonomy – i.e. in a position to be involved in their care decisions – inclusion of their legal guardians in the decision making process is morally required. Informed consent is a core tenet of our healthcare system and to deny these patients – albeit through their designated medical proxies – the opportunity to participate in decisions regarding their care shows callous disregard for their rights as patients, specifically for equitable and informed treatment, and their moral right to personhood. Thus, to remove these patients from their advocates is to deny them their patient rights and their rights as human beings. Though this practice appears to have been more widespread in the United Kingdom (Inclusion London, 2020; Care Management Matters, 2020; Tapper, 2021) than the United States, it speaks to the overarching concern from disabled persons that their lives are less valued than those of their non-disabled counterparts. There are also reports of disabled patients being told that they would not receive life saving treatment should they be taken ill (Tapper, 2021) and letters being sent to all care home residents – regardless of their diagnosis – stating that their “frailty” would preclude them from care. (Thomas, 2020) Clinicians should not be allowed to use

disability as a basis for denying care to patients – regardless of whether the care is required in the immediate term or whether there is a potential for the care to be required in the future.

Congregate living facilities and ableism

Another example of our healthcare system's failing of the disability community is illustrated by the disparate infection rates of those living in congregate facilities. Their day-to-day experience of living in close proximity to many others, coupled with the higher likelihood of having preexisting conditions such as advanced age, physical and/or cognitive disability, etc., put them at an enormous disadvantage when the COVID-19 pandemic began. As noted by Andrew Pulrang in a *Forbes* opinion piece, disability leads to higher vulnerability and a lowered ability to protect oneself or isolate – whether due to group living situations or the need for caregivers regardless of one's living situation. (Pulrang, 2021) This sobering reality had an enormous impact on anywhere from 2.6 to 4 million people designated as individuals with intellectual and developmental disabilities – a population that faced especially high rates of co-occurring conditions associated with more severe COVID-19 outcomes. (Landes et al., 2020)

While the health problems posed by aggregate care preceded pandemic conditions, it is extremely telling to consider just how little protection we, as a society, provided to these vulnerable communities – especially when we examine the practice of sending COVID-19 positive patients back to nursing homes. (Condon & Peltz, 2021; Sloan, 2021; The United States Department of Justice, 2020) By actively exposing nursing home residents to COVID-19, they were trapped in a situation that placed them at a heightened risk of contracting the virus in addition to experiencing negative outcomes overall.

Healthcare provider perspectives and biases

With this background in mind, it is clear that we cannot interpret contemporary healthcare policy with respect to disabled persons in a vacuum. Rather, we need to contextualize the ongoing challenges faced by this community to truly understand why the disparate impacts of COVID-19 were not exclusively the result of a few isolated flawed policies. Instead, such healthcare decisions may be rooted in the healthcare system's overarching inability to adapt to meet the needs of disabled patients – both due to provider bias and systemic failures. This can be especially complex within the context of determining what constitutes harm and how to avoid harm. A recent study highlights the alarming nature of the inequitable care provided to disabled persons:

[in a] survey of 714 practicing US physicians nationwide...[o]nly 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with disability, just 56.5 percent strongly agreed that they welcomed patients with disability into their practices, and 18.1 percent strongly agreed that the health care system often treats these patients unfairly. (Iezzoni et al., 2021)

Though this is only a small sampling of physicians from 2021, they are admittedly less welcoming to these patients even though there is a general awareness of the correlation between disability and an inequitable healthcare experience. In fact, the sentiments they express appear to be an indicative microcosm of our medical community. Similar trends were seen in a 2012 study of the implicit biases of 132 nurse educators from across the U.S.: “[The results showed that they] are strongly biased toward individuals without disabilities (N = 132, D = 0.76, SD = 0.46) and demonstrated a stronger preference than the general population (N = 38,544, D = 0.45, SD =

0.43)” (Aaberg, 2012 p. 505), as well as in a 2022 study of occupational therapy assistants (OTAs) and physical therapy assistants (PTAs):

A majority (42.1%) of OTA/PTA implicit attitudes strongly preferred nondisabled people. Nearly a quarter of participants (24.7%) moderately preferred nondisabled people, while 13.3% had a slight preference for nondisabled people and 12.3% had no preference. Just over 8% of participants preferred people with disabilities, with 1.0% having a strong preference, 2.8% having a moderate preference, and 4.1% having a slight preference. (Feldner et al., 2022 p. 5)

This data underscores the fact that many different types of healthcare providers feel, at best, ill prepared or, at worst, averse to treating patients deemed to be disabled. Iezonni et al.’s research is reinforced through the work of VanPuymbrouck et al. whose 2020 study of 25,006 health care providers sought to glean a better understanding about their attitudes toward disability through an exploration of the juxtaposition of their attitudes and their implicit and explicit biases. The conclusion of this research is perhaps even more indicative of the breadth of bias within healthcare as it showed that even though self-reporting denied bias against those with disabilities, the data found that the majority showed implicit bias against those with disabilities. (VanPuymbrouck et al., 2020)

Based on the data reviewed above, we can infer that a significant number of providers may feel ill equipped, reluctant, or even loath to care for disabled patients. Whether this is occurring due to a lack of experience, a lack of training, or even implicit and/or explicit beliefs, the impacts of provider viewpoints can result in a range of outcomes. Specifically, this discomfort may be minimal enough to be overcome by self-aware providers and therefore result in equitable care among the entire patient population, or extreme enough that the feeling of

otherness results in biased treatment decisions. If the bias is significant, certain patients may be deemed as less valuable than their non-disabled counterparts. This, in turn, may lead to these patients receiving substandard care. For example, if the provider does not believe that the patient has a good quality of life, they may be less inclined to suggest life-prolonging, life-enhancing, and/or potentially life-saving treatment options and interventions for them. This was seen in the case of Lex Frieden, a quadriplegic whose doctor decided it was not necessary to repair his broken hip because he couldn't walk. (Shapiro, 2020b)

When is unequal treatment discriminatory in a morally objectionable way?

But does this evidence support a broad claim that such practitioners are *discriminatory* toward their disabled patients? To address this question, we need to unpack what is morally significant and objectionable about discrimination. In *Treating People as Individuals* (Eidelson, 2013), Benjamin Eidelson argues that discriminatory behaviors often result from a failure to recognize people as autonomous agents who help to shape their lives. Furthermore, he provides insights into the morality implications of such failures

Central among the various moral problems with much discrimination is a distinctive failure to engage with the person who is discriminated against in the right way—including by failing to treat him as in part a product of his own past efforts at self-creation, and as an autonomous agent whose future choices are his own to make. (Eidelson, 2013, 30)⁶

Applying Eidelson's account, we fail to treat members of the disabled community as morally equal and as individuals when we fail to recognize them as having the same rights as their

⁶ This aligns well with a Kantian moral framework in thinking about the significance of being treated with respect by enabling autonomous decision-making.

able-bodied counterparts. We cannot simply reduce the moral worth of these individuals exclusively along the lines of diagnoses or a single characteristic. Instead, we must make moral decisions based on a holistic view of the person and not an arbitrary subset of their lived experience. Furthermore, as Eidelson puts it, “we must not make predictions about [an autonomous individual’s] choices in ways that demean the role of her autonomous agency in making up her own mind.” (Ibid p. 3) This aligns with the notion of how our biases about what constitutes a good quality of life can lead to morally discriminatory behavior. It is not for us to undermine autonomy by assuming that our viewpoints – especially when viewed within the framework of ableism – are accurate. And, even if they *are* accurate, it is not for us to make the determination and decision for someone else.

As we saw above in examples such as forced DNR orders and deprioritization of care based on disability status, practitioners are in fact failing to treat members disabled persons as individuals in that way. The failure to provide equitable care based on a morally arbitrary characteristic is tantamount to discrimination against a member of this group because it reflects a practitioner’s unwillingness to see each member as an individual apart from their social group. Though an individual may have a developmental disability, their experience may be vastly different than another individual with the same high-level diagnosis. This aligns with Eidelson’s argument that humans are differentiated from objects because we have distinct differences from one another and objects can be replicated. (Ibid p. 9-10) We are *all* individuals and must be treated as such.

But perhaps practitioners can justify failures to provide potentially life-saving or life-sustaining treatment in cases of triage and in times of scarce resources. Specifically, the utilitarian ethical focus on aggregate approaches to moral decision making based on improving

outcomes for the greater good might support overriding individual rights in some contexts.

Within the framework of disability ethics and the pandemic, this manifests as the undermining of the personhood of disabled persons due to cognitive and/or physical differences. And so, could utilitarian ethics justify the devaluation *en masse* of the disabled community in the interest of *the greater good*? In the next section, we will consider the ethical theoretical underpinnings of the treatment of disabled persons during the COVID-19 pandemic.

Part 2

Crisis Standards of Care: Ableist Concepts of Quality of Life and Personhood

“Concepts of triage and medical rationing are a barometer of how those in power in a society value human life.” (Fink, 2013, p. 129)

When COVID-19 was beginning to rapidly reshape lives in the United States in March 2020, the Department of Health and Human Services (HHS) flagged an immediate concern about equitable treatment for patients. Within this bulletin, entitled *Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)*, HHS addressed the need for care to be provided to patients fairly and in accordance with our nation’s civil rights protections. The bulletin specifically noted the importance of addressing the needs of disabled persons fairly:

In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else. (HHS, 2020)

Unfortunately, this guidance was not ultimately reflective of the treatment that disabled persons received during the pandemic. Instead, as I will demonstrate within this section, disabled persons were subject to multi-faceted and deeply unfair discrimination through a wide range of COVID-19 healthcare policies and protocols. For one thing, high-level, widespread bias and misinformation surrounding the correlation between disability and adverse health outcomes led to the discriminatory practices that corrupted our nation’s COVID-19 response. These practices

included everything from deprioritizing the disabled in resource allocation plans; encouraging cognitively disabled patients to refuse care and sign do not resuscitate (DNR) orders; denying care to disabled patients; and more. Given the context of discrimination we examined in Part 1, we can see that these glaringly discriminatory practices are part of a broader ableist discrimination that exists within our society both during and before pandemic conditions.

But were these examples of mistreatment episodic, reflective of the incredibly unusual stress conditions and material shortages during the pandemic? No doubt some were. But perhaps surprisingly, I'll demonstrate below that many of the unfair policies and protocols directed against disabled persons during the pandemic were bolstered by careful and reflective applications of core biomedical ethical principles, largely derived from utilitarianism, to the detriment of both disabled people and the wider U.S. healthcare system. As such, these examples of mistreatment point to deeper problems with the ongoing reliance on utilitarianism in healthcare.

There are some good reasons to think that this ethical system fits the context of a pandemic particularly well. A multitude of factors seem to have contributed to the dominance of utilitarian thinking in medical research and practices during the peak of the pandemic. From the individual clinician to the overarching institution of healthcare, medicine is rooted in healing the sick. Unlike other prominent bioethical theories such as care ethics and virtue ethics that require individual interpretation of virtuous characters and good intentions, in emergency conditions public health practice seemed to gravitate to an ethical framework designed to be concrete and consequence-oriented. And so, it stands to reason that the utilitarian framework might be used as a method to promote the most good – or healing – for the most people – or patients.

Utilitarianism also supports the shift from focusing on patient autonomy to focusing on public health that took place in our healthcare system during the pandemic. Since our care model is typically focused on patient autonomy during non-crisis times, the shift to public health created a palpable change from the usual approach of patient-and-family-centered care. This is a key facet of how ethically problematic it can become during a pandemic when “[i]ndividual liberty and autonomy give way to relational autonomy and the interdependence of people.” (Demetriades, 2021 p. 599) We see this at its most extreme when it comes to scarcity of resources and how to best allocate them. Because the utilitarian framework stresses the importance of promoting the overall good and utility of the community, the ability for clinicians to remain steadfast in the importance of patient autonomy became deeply contested and most likely unfeasible. I refer to this clash between typical bioethical moral guidance and crisis standards of care moral guidance during COVID-19 as *pandemic cognitive dissonance*. This term represents the ethical complexities that accompany providers essentially being forced into making decisions that are counter to one’s typical moral framework and beliefs.

Furthermore, the juxtaposition of group versus individual approaches to ethical healthcare is intrinsically linked to the notion of medical agency. Though commonly considered within the context of a patient’s healthcare proxy, medical agency can be expanded to address how pandemic decision making led politicians, hospitals, practitioners, state and local governments to supersede the standard approach of advancing patient autonomy. This is representative of a shift from the typical bioethical approach of prioritizing the patient’s wishes and the relationship between the patient and clinician to a much more complex approach. This is not to say that patient and clinician relationships do not come with their own complexities, but rather that pandemic, group-focused ethics lead to the development of guidelines that can

undermine the personal relationship and a patient's medical agency. For example, a hospital ethics committee may be tasked with making resource allocation decisions rather than the attending physician or the state government may dictate how resources will be distributed among its healthcare facilities. It is possible that a practitioner's autonomy is also undermined here which, in turn, worsens the impact of pandemic cognitive dissonance. Additionally, the distinct shift from individual and/or proxy-oriented agency to public health oriented agency during a pandemic aligns with the adoption of utilitarian principles.

In what follows, I will analyze two crucial examples of ableist assumptions about the moral status and value of disabled patients as indicated by the prioritization of critical care resources toward those deemed to be more physically and cognitively deserving and the potential reallocation of personal ventilators (PVs) away from those with preexisting conditions that rely on PVs to live. These ableist assumptions are closely correlated with utilitarianism and its goal of promoting *the greatest good* as the needs of able-bodied majority superseded the needs of the disabled minority.

Examples of ableist devaluing of disabled persons under pandemic conditions

Within this analysis, I will explore the question of whether we should deprioritize disabled persons when it comes to resources on the grounds that their quality of life expectations – especially in terms of longevity – is worse than non-disabled persons. As noted above, one of the ways that disabled persons were impacted by discrimination at the start of COVID-19 was through resource allocation. Thus, another major challenge faced by disabled persons as COVID-19 spread was healthcare facilities' use of utilitarian principles to ration limited resources. The disparate impact of these rationing procedures on the disabled community

occurred both in terms of providing access to care and coercing patients into refusing care. In addition to the distribution of scarce resources – albeit ventilators, vaccination, etc. – being arguably the most widely debated ethical question within the pandemic, decisions surrounding distribution frameworks were also one of the most egregious examples of healthcare bias permeating our nation’s pandemic response. Therefore, one of the most grievous ways in which healthcare bias towards disabled persons manifested during the pandemic was in the form of resource allocation.

Specifically, based on an analysis performed by the Center for Public Integrity, “policies in 25 states would ration care in ways disability advocates have denounced.” (Essley Whyte, 2019) They argue that

[t]hese policies take into account – in ways that disability advocates say are inappropriate – patients’ expected lifespan; need for resources, such as home oxygen; or specific diagnoses, such as dementia. Some even permit hospitals to take ventilators away from patients who use them as breathing aids in everyday life and give them to other patients.

(Ibid)

Before reviewing several examples of these discriminatory practices below, it is important to consider how closely they align with utilitarian principles surrounding promoting the wellbeing of the majority (able-bodied patients) over the wellbeing of the minority (disabled patients). The conscious decision to devalue patients due to morally arbitrary characteristics and ableist perceptions surrounding quality of life also align with utilitarianism. If we are to assume that the ultimate goal is to promote the most good, then we can easily rationalize deprioritizing disabled populations based on the assumption that their quality of life, and therefore experience of

pleasure, is diminished. With this in mind, let us consider the following examples of healthcare discrimination and disability bias within COVID-19 protocols:

- “Louisiana's and Utah’s lists include[d] severe dementia and advanced neuromuscular diseases, such as multiple sclerosis and Lou Gehrig’s disease...[and] Alabama’s protocol [gave] those with severe mental disabilities lower priority.” (Nielsen, 2020 p. 233-234)
- Tennessee’s guidelines stated that “people with spinal muscular atrophy who need assistance with activities of daily living [are] among those excluded from critical care.” (Ne’eman, 2020)
- Texas, in conjunction with the North Texas Mass Critical Care Guidelines for Adults and Children, also faced legal action due to the failure of the guidelines to expressly prohibit discrimination based on protected class; the lack of triage accommodations for patients requiring them; and “penaliz[ing] patients with certain medical conditions, excluding some altogether from hospital admission, intensive care unit (ICU) admission, and ventilator access...based on predictions of long-term prognosis without regard to short-term survival or survival from COVID-19.” (Disability Rights Texas, 2020 p. 1)
- New York State’s approach to the fair allocation of limited resources was also flagged as discriminatory against the disabled community due to the potential for those who used ventilators for long-term care to lose their ventilators if they were admitted to the hospital. (Fink, 2020 p. 3)
- In an NPR investigation, Oregon was thrust into the spotlight when it was uncovered that patients with developmental disabilities in the state were facing care rationing – even when resources were readily available. One woman’s physician actually attempted to have her sign a legal document that enabled the hospital to deny her care. (Shapiro,

2020c) Another intellectually disabled patient in Oregon, 55-year-old Timothy Roessel, was denied both access to a COVID-19 test and treatment due to his disability deprioritizing him for treatment. (Shapiro, 2020b)

- There were further issues identified with regard to disabled patients being able to access test sites. For example, Nebraska’s testing program required internet access, the capacity to complete the prescreening process, and the ability to drive to the site and wait in a line of vehicles for some time. (Frohboese, 2021)

In response to these types of practices, The Arc⁷, “the largest national community-based organization advocating for and with people with intellectual and developmental disabilities” (The Arc, 2021a), served on the forefront of the fight for disability rights during the pandemic advocating on behalf of individual patients and the community at large. Their robust efforts, often pursued in conjunction with local and/or state-wide disability advocacy organizations, challenged a long list of state governments regarding both the development and revisions of their crisis standards of care (CSC) frameworks, inclusive of legal filings regarding illegal discrimination on the basis of protected classes. These Arc filings occurred in some of the aforementioned states, as well as in a series of other states such as Arizona, Kansas, North Carolina, Oklahoma, Pennsylvania, and Utah.

- In their complaint against the state of Arizona, they flag several examples of discrimination including long-term life expectancy, a failure to prohibit criteria such as the existence of pre-existing conditions in allocation decisions, consideration of intensity of resources, and a lack of required communication and/or visitation policies to accommodate the needs of disabled patients. (Arizona Center for Disability Law, 2020)

⁷ The Arc’s mission is to “[promote] and [protect] the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.” (The Arc, 2021)

- Regarding Kansas, the Arc notes that the state’s guidelines not only discriminate against the disabled by excluding them from critical care such as ventilators and allowing for PVs to be taken away from the disabled for redistribution, but also excluding people with “advanced untreatable neuromuscular disease” from receiving treatment for COVID-19. They further excluded people with disabilities such as “advanced and irreversible immunocompromise’ and some people with metastatic cancer, from receiving necessary care.” (Disability Rights Center of Kansas, 2020)
- The North Carolina filing notes that the state’s CSC framework’s focus on numerical scoring will result in the deprioritization of those with disabilities and comorbidities being denied care and put in a position of increased mortality as a result. (Disability Rights North Carolina, 2020)
- Their Oklahoma brief notes bias against patients with “life-limiting and major comorbidities,” as well as the deprioritization of access to life-saving treatments due to age and disability, assumptions about expected long-term prognosis, and a focus on life stages. Additionally, Oklahoma’s CSC fails to include reasonable modifications to triage, communication, and visitation policies which unfairly disadvantages disabled patients requiring accommodations. (Oklahoma Disability Law Center, Inc., 2020)
- Unfair visitation policies also led to legal filings in Washington DC, Texas, Nebraska, Rhode Island, Virginia, Maryland, Alabama, and Connecticut. (COVID-19 CSOC 50 State Overview, 2020)

A key takeaway from this breadth of examples is that a wide range of policies placed disabled patients at an unacceptable medical and ethical disadvantage to their able-bodied counterparts. Furthermore, whether the crisis standards of care and their corresponding

disenfranchising of disabled patients were drafted prior to or after the start of the pandemic, they all provided a collective determination that these lives had less value in relation to the greater good. This, in turn, allowed for the allocation and reallocation of resources to be directed away from the disabled population through ableism and utilitarian guidance. This is because, as determinations about what constitutes the *best* outcome are developed, two major components of this calculation are the assumptions that disability correlates to a lower projected length of life and assumptions about what makes a life valuable. If we are looking to determine how to decide which lives are saved, then the guidance must reflect which lives are deemed as having the most value. This is closely aligned with assumptions about the quality of life of the disabled population, as reflected by the policies above that overarchingly deprioritize specific groups based on morally arbitrary characteristics. Thus, we can see how determining which outcome is best for the patient may already be viewed as less important than the outcome deemed fit by institutional guidelines. For example, a patient may wish to receive lifesaving care, but that desire is overridden by policies that automatically exclude them from care. This, in turn, precludes these patients from receiving equitable access to care from the perspective of patient autonomy. The same challenge is created through visitation policies that prevent disabled patients from having their advocates at their bedsides to ensure that their interests were heard. Here, we also see how the calculation of risk to the institution via COVID-19 exposure from a visitor can be seen as outweighing the risk to a patient who does not have access to their advocate. Therefore, it is clear that not only does utilitarian guidance allow for such practices, but the CSC guidance referenced above also exemplifies unfair disability discrimination and ableism.

However, it is also important to note before we delve deeper into this topic that although an overarching discriminatory framework is morally unfair, there could be cases in which it is morally appropriate to deprioritize extremely disabled patients based on healthcare conditions and a scarcity of resources. For example, if someone has been clinically diagnosed and validated as experiencing brain death and is being kept alive by a ventilator, there is a strong argument to be made that their ventilator will better serve the greater good and public health needs via reallocation to a patient with at least some degree of brain function. A similar argument can be made for patients who have been in medically induced comas for extended periods of time with limited to no chance of recovery.⁸ Though it is emotionally charged to make such decisions, many bioethicists would argue that the moral responsibility to direct resources to those whose illness may be overcome must supersede the rights of those with significantly and *objectively* poor clinical prognoses. This can certainly be supported through the utilitarian principle of promoting the greatest good through sound predictions surrounding what will result in the best outcomes for the most people. If certain patients are expected to have worse outcomes, then directing resources towards those who are anticipated to have better outcomes is not just morally acceptable, but morally dictated.

Fairness (and unfairness) in resource allocation

Now, to better understand how these practices were unfair from a discriminatory and moral standpoint, it is crucial to consider what conditions would constitute a fair determination of resource allocation. First and foremost, the development of fair resource allocation guidelines must be fundamentally concerned with recognizing and valuing a patient's

⁸ Both of these examples are, of course, fraught with their own ethical debate.

ethical rights to personhood and treatment regardless of disability status. A fair framework will grant equal rights to all patients and will not allow for patients to be grouped into categories that undermine patient autonomy. It must include objective criteria that is intentionally evaluated and re-evaluated to ensure that it reflects inclusivity and does not rely on ableist assumptions and/or morally arbitrary characteristics such as a person's ability to converse at a high level, a physically disabling or differently abling comorbidity, dependency on a PV to survive, or the presence of a developmental disability. These are just a few examples of the situations in which healthcare decision-making priorities are less clinically transparent, based on assumptions about a patient's *perceived* quality of life, and/or are inappropriately substantiated by weak empirical evidence.

In terms of empirical evidence, it would be reasonable to compare the potential outcomes of two clinically similar patients from a physical perspective (i.e., congestive heart failure), but not to include cognitive disabilities as a deciding factor when determining who should receive a resource. If two patients are otherwise similar, then allocation should be based on equitable access to care rather than valuing the non-disabled patient's life more due to morally arbitrary characteristics alone. Though ableism and utilitarianism may lend themselves to choosing a non-cognitively disabled patient over one with cognitive disabilities, that does not constitute fair and equitable resource allocation. Furthermore, considerations such as reliance on a personal ventilator (PV) or feeding tube to survive should not automatically preclude or deprioritize a patient from care. We will explore the ethical implications of relying too heavily on these types of clinical traits within the framework of Sequential Organ Failure Assessment (SOFA) scoring in the following section.

It is also important that care decisions take into consideration a patient's and/or their caregiver's sentiments surrounding their quality of life rather than relying on the provider's viewpoints on how a disability impacts quality of life. Though quality of life is highly subjective due to it being an individual reflection, a patient's lived experience is certainly better understood by them/their caregiver than a provider, especially in times of resource scarcity when the provider likely has little to no background understanding of who the patient is and what their baseline is. Providers cannot just deem a certain patient to be less deserving of care based on limited information and a focus on disability as a benchmark for decreased quality of life.

Next, to truly delve into the human impact and ethical challenges arising from these discriminatory practices, let us consider the stories of three disabled people who joined the CSC lawsuits against their respective states. Washington State's lawsuit included the stories of "Rose" and Ivanova Smith. In Rose's case, clinical teams could have denied her care based on her Cystic Fibrosis (CF) diagnosis alone even though she had actually never been hospitalized or received IV antibiotics, and comes in above the 70th percentile in breathing capacity tests as compared to the *entire* population. (Disability Rights Washington, 2020 p. 13-14) Here, CSC would have made the nuances of her actual health status, such as the fact that her CF is well managed, irrelevant as her right to care could have been removed based on a single and morally arbitrary clinical diagnosis. Additionally, clinical teams would be relying on predicted CF outcomes overall rather than providing Rose with individualized care that reflects her actual lived experience and quality of life. A co-plaintiff in the Washington case, Ivanova Smith, has an intellectual disability that places her at an automatic disadvantage for care and resources because the CSC has reduced her personhood due to a morally arbitrary characteristic. The guidelines do not take into account the fact that Ms. Smith owns a home, has a young child, and is an

accomplished disability rights advocate. (Ibid p.3) Once more, a potential patient's lived experience and quality of life is rendered meaningless in this approach.

The story of Blake Pyron, a complainant in a group who filed the aforementioned discrimination case in Texas due to the North Texas Mass Critical Care Guidelines for Adults and Children (Disability Rights Texas, 2020), is similar to that of Ms. Smith. Though their life stage and lived experiences are unique from one another, Mr. Pyron is an extremely accomplished 24-year-old with Down Syndrome, a heart condition, and sleep apnea. He also is a high school graduate, owns his own business, and is a disability advocate.⁹ (Ibid p.4) While there is clearly a strong argument to be made from this case that Mr. Pyron is a contributing and impactful member of society, his Down Syndrome diagnosis, coupled with preexisting medical conditions, placed him in a position of vulnerability due to discrimination within the CSC. While his heart condition may allow for a medically validatable - and therefore morally acceptable - comparison between his survival and that of another patient with the same heart condition, basing resource decisions on his Down Syndrome diagnosis is a strong example of how morally arbitrary characteristics can undermine a patient's perceived quality of life, patient autonomy, right to personhood, and even right to life.

Specifically, a major challenge faced by these individuals and disabled persons overall is rooted in the pervasive macro-level "assumptions" that those with disabilities have a lower

⁹ Blake Pyron, 24, lives with Down Syndrome, a heart condition, and sleep apnea. He resides at home with his parents in Denton County. After graduating from high school, Blake started his own business, Blake's Snow Shack, in Sanger, Texas. Blake is a Texas Ranger's fan and loves country music. As a self-advocate, Blake lobbied the Texas Legislature for fair wages for persons with disabilities, which culminated in the passage of a minimum wage bill for persons with disabilities. As a National Down Syndrome Society Ambassador, Blake spoke at a United Nations conference on the employment of persons with disabilities and rang the opening bell at the New York Stock Exchange. Recently, on behalf of Blake and other persons with disabilities, his mother participated in a public service announcement called "Coronavirus: Loved Ones of Those at Risk." Blake is worried about what will happen to him if he is admitted to the hospital during the COVID-19 pandemic especially given the North Texas Guidelines. He wants to be treated the same as everyone else and wants to make sure that other people with disabilities are also treated the same. Blake and his family have a reasonable fear that he will be denied life-saving medical care under the Guidelines for Adults due to his disabilities. (Disability Rights Texas, 2020 p. 4)

quality of life. In fact, there is abundant empirical evidence of the wide discrepancy between non-disabled people's ideas about the quality of life with disability and disabled people's own evaluations. (Albrecht and Devliger, 1999; Ubel, Loewenstein and Jepson, 2003). One reason for this "disability paradox" is the cognitive barrier that makes it hard to project oneself imaginatively into an unfamiliar kind of life without experiencing it as lesser instead of just different. (Mackenzie and Scully, 2007 p. 603) This sentiment is furthered by Adams (2022) who notes that "judgments based on quality of life often pit the opinions of health professionals against the self-reporting of people with disabilities and their supporters." (Adams, 2022 p. 430) For example, the case in which clinicians assisted a man with ALS in ending his life and their "assumption – some would say presumption – that life quality can be measured against a physical norm ignores the social, familial, and interpersonal contexts that together permit a person to evaluate his or her life." (Kaufert & Koch, 2003 p. 463)

To disregard who a patient is as a person because they are disabled should be morally unacceptable, but utilitarian and Kantian ethical frameworks lend validation to the devaluing of disabled patients. By ascribing to a belief that one community – especially a minority community – is experiencing a lower quality of life than another majority community, this theory will lead to a very slippery slope when it comes to care decisions relating to the disability community. Thus, the question remains as to whether these frameworks truly work in that they are operationalizable and validatable. To effectively address this question, we must first consider how we determine, or measure, quality of life.

Contemporary measurements of quality of life are inextricably linked to ableist assumptions about the connectivity between quality and duration of life; patient autonomy; and the moral status of personhood. Unfortunately, the concept of what constitutes a good, valuable,

and/or worthwhile “quality of life” is, for practitioners, heavily slanted in favor of cognitivism – the view that strong cognitive capacity and the ability to reason are directly correlated with a greater quality of life and, therefore, a stronger claim to personhood and its corresponding moral rights. Those with low cognitive capacity are deemed to have a poor quality of life and a lesser – or even no – claim to personhood and its corresponding moral rights. This aligns closely with utilitarianism which would allow for considerations such as quality of life to factor into moral decision making.

There might be good reasons to employ cognitivist preference when engaged in the difficult task of weighing the values of different lives, all of whom cannot be cared for equally given external conditions of scarcity. The belief that those of differing abilities have a lower quality of life is pervasive in our society and within the theory itself. It is all too easy to see someone and think “I could never live like that.” These thoughts cause us to lose our ability to understand that the person we are referring to may actually feel even more fulfilled than we do. Indeed, perhaps a key facet of determining one’s quality of life is the arguably subjective interpretation of one’s sense of fulfillment and happiness. This subjectivity leads to one of the most problematic ways in which bias against disabled persons occurs in healthcare – both within and outside of pandemic conditions – and that is through misconceptions about their quality of life. As noted in Iezzoni et al.’s pre-pandemic survey of 714 practicing U.S. physicians nationwide, 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people. (Iezzoni et al., 2021) This judgment can easily lead to healthcare bias and deprioritization of disabled persons due to an assumption that their lives are inherently more challenging and less pleasurable. To that end, utilitarian beliefs surrounding the notion of

pleasure and utility¹⁰ serve the healthcare system well – if disabled patients are determined to be experiencing less pleasure than their able-bodied counterparts, then it stands to reason that care should be directed to those who will ultimately experience more pleasure and fulfillment in their lives.

Paths paved by utilitarians in crisis standards of care

In response to the COVID-19 pandemic, Julian Savulescu, a prominent contemporary utilitarian, and his colleagues strongly advocate for the adoption of utilitarian principles as the most ethically viable response to the crisis. At a high level, their stance is rooted in a strong belief that utilitarianism provides the tools required for optimal moral decision making surrounding everything from allocating resources to determining the appropriateness of lockdowns. In laying the foundation for their argument, Savulescu et al. provide insight into the theories of classic rule utilitarianism – act and rule¹¹ – and also incorporate modern utilitarian concepts from Richard Hare. Specifically, they speak to Hare’s beliefs “that moral thinking

¹⁰ Here, we must consider Bentham’s principle of utility and its connectivity to the overarching value that Bentham’s utilitarianism places on pleasure as an indicator of morality. To Bentham, all pleasure is weighed equally when one is contemplating a moral decision: [P]leasure is in itself a good: nay, even setting aside motive is in itself a bad immunity from pain, the only good: pain is in itself an evil; and, indeed, without exception, the only evil; or else the words good and evil have no meaning. And this is alike true of every sort of pain, and of every sort of pleasure. (Bentham, 1879 p. 102) Applying the principle of utility in a medical context, especially in conjunction with the principle of utility, can be a powerful tool for decision making. Specifically, pleasure in a healthcare setting can be viewed through the lens of absence of pain. On a basic level, many institutions use a one to 10 scale to ask patients about their degree of pain with one representing no pain and 10 representing the worst pain one has ever experienced. Though subjective based on a patient’s tolerance for pain and comparative medical history, this is one opportunity for clinicians to quantify a patient’s baseline pain level. From there, treatment plans and goals can be personalized to meet a pain target. In a more complex way, treatment plans and goals can consider a temporary increase in pain to be valuable if it ultimately leads to a long-term increase in pleasure. For example, resetting a dislocated shoulder will theoretically intensify the pain in the short term, but ultimately lead to a decrease in pain and increase in pleasure and mobility.

¹¹When exploring utilitarianism and its implications for bioethics overall, it is important to reflect on its other founding school of thought: rule utilitarianism. Mill’s rule utilitarianism states that moral decision making is guided by a set of predetermined social rules. Within this framework, individual decisions are weighed against the utility, or morality, of the rule. As such, it views the correct implementation of utilitarian principles to be more pre-determined by social norms than individually driven through personal values. These social norms are commonly manifested in society through the development of laws. This not only legitimizes the norms, but theoretically helps to ensure that more people will abide by the rules set forth by their society’s governing bodies.

occurs at two levels: intuitive and critical, and that we should move between these depending on the circumstances” and his concept of the *utilitarian archangel* who is “a decision-maker [with] perfect knowledge of the outcomes of all available options.” (Savulescu et al., 2020 p. 622) By incorporating both classic and moral principles into their discussion, Savulescu et al. lay a multidimensional framework on which to explore a utilitarian pandemic response that spans utilitarian schools of thought.

A key facet of Savulescu et al.’s framework is fundamentally connected to what they refer to as Quality Adjusted Life Year (QALYs). Here, their juxtaposition of length of life and quality of life underscores the idea that “[t]he important issue for utilitarians is not the number of deaths, but the QALYs lost.” (Savulescu et al., 2020 p. 627) To such utilitarians, QALYs are considered to have the utmost value in assessing the morally appropriate response to a given situation. This is closely connected to the desire to achieve the best outcomes for the greatest number via a quantifiable approach that takes into account how the value of a life is measured. Specifically, ensuring the wellbeing and length of life for certain patients is more important than preventing the loss of life for other patients. As such, it is within this context that Savulescu et al. discuss considerations such as cognitive impairment as a potential benchmark to de-prioritize patients for care. Due to his Down Syndrome diagnosis, Mr. Pyron will be viewed as having some degree of cognitive impairment and, through ableist biases, be viewed as having a lower quality of life than a cognitively normative patient. However, these factors are potentially harder to quantify as even the language Savulescu et al. use to describe the impairments leaves room for ambiguity and debate. They say, for example, “the threshold might be set at the ability to recognize and respond meaningfully with other people.” (Savulescu et al., 2020 p. 624) If this threshold is adopted, it should ensure that Mr. Pyron is viewed as having minimal impairment

due to his education, career, and disability advocacy, and yet CSC does not seem to appreciate this nuance.

On the opposite end of the spectrum, this threshold may prove to be problematic for those with cognitive disabilities who are non-verbal or non-communicative as a baseline, such as in the case of 22-year-old Matthew, one of Mr. Pyron's co-plaintiffs, who has muscular dystrophy, requires a wheelchair, compromised respiratory status, and is nonverbal. Though Matthew's respiratory condition can be used from a medical level, his inability to verbally communicate is morally arbitrary and should not be used as a means to deny him care. (Disability Rights Texas, 2020 p. 4) An inability to communicate through typical means does not necessarily equate to a lower quality of life for the patients in question, but is seen as such because it does not align with the mainstream sentiments as to what indicates a good quality of life – i.e., relationships, social connectivity, the capacity for language, etc.

However, though utilitarianism may lend itself to this type of thinking overall, the theory runs into difficulty when it comes to operationalizing determinations about how to measure a patient's quality of life outside of the COVID-19 infection. For one, as critics of utilitarianism have long pointed out, it is challenging to quantify anything that is rooted in subjective assumptions. Let us consider this through the example of visitor restrictions, which became commonplace across the healthcare spectrum at the height of the pandemic. In fact, they became so strict that loved ones were often banned from the bedside even at the end of life. This separation between critically ill patients and the world outside, coupled with a lack of resources, can quickly make it hard, if not impossible, for clinicians to even attempt to accurately measure quality of life for their patients – especially for those who, like Matthew, are nonverbal. And,

without the ability to do this in any sort of standardized way, the utilitarian approach is proving to be neither efficient nor operationalizable at the micro level.

Challenges to utilitarian approaches to healthcare ethics

Because quality of life serves as a major component of the utilitarian framework and can be rooted in subjectivity, determining what constitutes a good quality of life is fraught with complexities. A major component of this is the consideration of who can, or even should, be able to make these determinations. Thus, we must now consider one of the most sacrosanct principles in our healthcare system: patient autonomy. This critical principle lays the foundation for empowering patients to be involved in decisions impacting their care. As explained by Beauchamp and Childress, “[w]e analyze autonomous action in terms of normal choosers who act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action.” (Beauchamp & Childress, 2001/2019 p. 102) Though patient autonomy is at the forefront of patient care, this approach can prove to be problematic in the context of disability. On a basic level, this is due to the fact that one of the overarching criticisms of the theory is that it undermines individual rights for the sake of the happiness of many. This, in turn, can lead to the exploitation of a minority group for the benefit of the majority. Specifically, patients who have conditions that impact their cognitive capabilities are intrinsically at a disadvantage from an autonomy standpoint. These include patients such as those with severe dementia, significant cognitive disabilities, limited language and/or communication capacity, and traumatic brain injuries. Though they may have guardians and medical proxies to help guide, or even make, decisions on their behalf, there is ambiguity surrounding whether or not these decisions actually align with the patient’s needs and goals. An example of this bioethical

conundrum comes to the forefront in the context of euthanasia as the disability community voices strong concerns that this practice will inherently lead to disability discrimination. (Ouellette, 2013 p. 26) Euthanasia and its connectivity to the concepts of killing vs. letting die within the context of the COVID-19 pandemic will be discussed in the next section.

Additionally, within the patient care setting in the United States,

“[i]n standard, non-crisis clinical care, the physician’s *prima facie* obligation is to the individual patient...[and] the physician-patient relationship is a deontological construct.

Morality is determined by the nature of the action and the duty is to the patient. In

deontology, harmful actions are unacceptable, even if the end result is a net benefit.”

(Vearrier and Henderson, 2021 p. 48)

This deontological framework stands in support of patient autonomy and individual rights and is therefore in opposition to the utilitarian framework. On a day-to-day basis, clinicians are focused on providing the best possible care for each of their patients rather than on providing large-scale care. This is true even in the case of institutions such as vaccine clinics. Though the clinician may be seeing a large quantity of patients during a given shift, their focus is on each patient for the few minutes in which that patient is in their care. And though the clinic is ultimately designed to improve health at the population level through herd immunity, the patient-provider relationship is the focal point of these interactions.

This leads to another subset of the patient autonomy and quality of life challenge and that is utilitarianism’s inability to incorporate patients’ viewpoints into their own quality of life into its implementation. Though its proponents claim that utilitarianism offers a strong ethical approach to decision making, the application of utilitarian principles proves to be problematic within the framework of the measurement of quality of life. Superficially, the utilitarian focus on

promoting good should align well with a desire to enhance a patient's quality of life. However, one challenge is immediately posed by the fact that quality of life is often considered on an individual basis. As such, it becomes complicated to try to calculate the greater good in relation to a single patient. The need to make care decisions in a given healthcare setting will arguably often be between a pair of patients or a small number of patients. If these patients all have similar backgrounds and comorbidities, the decision-making process will be extremely challenging based on a lack of differentiating factors. And, if there are patients who have specific disabilities and characteristics that push them to the back of the line per utilitarianism, this is also ethically unfair.

Another challenge with the devaluing, if not disregarding, of patient autonomy in utilitarianism is that it may lead to what I deem as societal paternalism. This is because of the way in which the framework actively devalues the lives of certain groups of people. Though Savulescu et al. argue that “[u]tilitarianism seeks to avoid biases, emotions, intuitions or heuristics that prevent the most good being realized,” (Savulescu et al., 2020 p. 626), it is constantly being used to justify the marginalization of the disabled community. By failing to respect a person's autonomy and personhood and undermining their value to society, the implementation of utilitarianism equates to society saying that the lives of certain groups have less utility. Coupling this with the quality of life bias that is often associated with disability, the dominant (able-bodied) social group is reinforcing the sentiment that those in a minority/subordinate (disabled) social group may be better off dead than living with a given disability.

Therefore, though Savulescu et al. (2020) purport that utilitarianism provides society with operationalizable and scientifically driven decision making tools, the actual implementation of

the theory is morally inefficient. For one, the theory places far too much emphasis on subjective measurements such as quality of life and quality of life years saved. It is not possible to accurately benchmark one life against another life on a widespread scale without inherently depending on biases. Because the theory is rooted in a desire to promote the most good for the most people, utilitarianism is fundamentally lacking when it comes to micro-level decisions such as who receives a scarce resource. If decisions are being made on a patient by patient basis, then it is much harder to determine what will truly result in the greater good.

How is the concept of personhood morally relevant for care within the context of identifying what contributes to quality of life? The Kantian theory of personhood claims that one's personhood, or moral worth, is linked to their ability for *rational* thought

The beings whose existence rests not on our will but on nature nevertheless have, if they are beings without reason, only a relative worth as means, and are called things; rational beings, by contrast, are called persons, because their nature already marks them out as ends in themselves. (Kant, 2017 p. 46)

Those without the capacity for *reason* are dehumanized and devalued through this theory, which undercuts the moral foundation for preserving the rights of those with cognitive disabilities. To Kant, a lack of capacity for rational thought leads to one being characterized as a *means* rather than as a *human* – regardless of biology. Therefore, from a Kantian perspective, it is entirely reasonable and ethically sound to deprioritize the care of someone who is not deemed to be of a rational mind. This same viewpoint aligns with the utilitarian guidance that pervaded many states' crisis of care standards which allowed for those with severe dementia and other cognitive disabilities to be deprioritized for care. It is clear that both of these frameworks support the deprioritization of the disabled for care. However, what makes them even more interesting is

their definition of what constitutes a rational being and what constitutes personhood should theoretically be considered on a case-by-case basis. As such, there is an inherent focus on an individual patient's cognitive capacity for moral decision making, and yet their frameworks are supporting the group-approach to care decisions. This is problematic because the group approach allows for mass generalizations about whether certain groups of people have the rationality and personhood to deserve care. These same challenges apply to the concepts of utility and quality of life, which stand at the core of utilitarianism¹².

The Kantian theory of personhood aligns surprisingly well with a different contemporary utilitarian, Peter Singer's, viewpoint on speciesism. Because Singer has such strong beliefs about what defines a person in comparison to a sentient being, he raises questions about the moral veracity of considering human rights as more important than the rights of other animals. Part of his concern here is that the power we have to place ourselves at the forefront of moral importance.

Some say that it is anthropocentric, even speciesist, to order the value of different lives in a hierarchical manner. If we do so we shall, inevitably, be placing ourselves at the top and other beings closer to us in proportion to the resemblance between them and ourselves.

Instead we should recognise that from the points of view of the different beings

themselves, each life is of equal value. (Singer, 1993 p. 105)

¹² A major reason that certain groups are deemed to be less deserving of care is that they are deemed to have less social utility and a lower quality of life. Though these two concepts are theoretically quite difficult to quantify, there are certainly guidelines that can be put in place to help make these determinations. For example, utilitarians may consider whether an individual has the capacity to make decisions for themselves or whether they are able to take care of themselves. If an individual is unable to do one or both of these things, then questions arise about their quality of life and social utility. This closely aligns with utilitarian concerns about how the greater needs of certain groups of patients could inhibit the ethical distribution of scarce resources and lead to worse outcomes overall. As such, if a disabled patient's baseline needs are higher than those of an able-bodied person, then resources may be better served supporting the able-bodied person. Though this comparison is being discussed at the individual level, its application in crisis standards of care spanned the breadth of individual to group-level decision making as specific qualifiers automatically deprioritized patients for care.

By taking the stance that human lives are more valuable than the lives of others, we create a situation in which the consideration of other beings is not factored into our moral decision making.¹³ Within this framework, it is clear that Singer is questioning how we determine not only what creates personhood, but also our approach to assuming equality and superiority for humans over other living beings. While Bentham sought to view all human interests as equal, Singer is advocating for not only viewing human interests as inequitable, but some animal interests as holding greater moral importance. For example, “the fact that someone is an innocent human infant does not automatically grant them privileges over the innocent life of another being such as a lab rat.” ((Singer, 1993 p. 170-171) Thus, Singer believes that being biologically human does not necessarily mean that one has moral primacy, nor does it mean that one is automatically granted personhood.¹⁴

Here, it is important to note that there is connectivity between consequentialism and bioethics from the perspective of treatment plans. The morally correct approach to patient care, from a

¹³ As he notes in *Practical Ethics*,

I have argued that the life of a fetus (and even more plainly, of an embryo) is of no greater value than the life of a nonhuman animal at a similar level of rationality, self-consciousness, awareness, capacity to feel, etc., and that since no fetus is a person no fetus has the same claim to life as a person. Now it must be admitted that these arguments apply to the newborn baby as much as to the fetus. A week-old baby is not a rational and self-conscious being, and there are many nonhuman animals whose rationality, self-consciousness, awareness, capacity to feel, and so on, exceed that of a human baby a week or a month old. If the fetus does not have the same claim to life as a person, it appears that the newborn baby does not either, and the life of a newborn baby is of less value to it than the life of a pig, a dog, or a chimpanzee is to the nonhuman animal. (Singer, 1993 p. 169)

¹⁴ The intersection of social utility and personhood is connected to another problematic utilitarian moral viewpoint. Specifically, at its inception, Bentham argued that moral choices should be dictated by the behaviors that will lead to the most pleasure. At the crux of Bentham’s utilitarian framework is his nuanced definition of the principle of utility. “By the principle of utility is meant that principle which approves or disapproves of every action whatsoever, according to the tendency which it appears to have to augment or diminish the happiness of the party whose interest is in question: or, what is the same thing in other words, to promote or to oppose that happiness.” (Bentham, 1879 p. 1) This statement embodies the concept of act utilitarianism which is focused on the notion that moral decision making is dependent on the outcome of a decision. It also takes a more individualistic approach to utilitarian principles. An interesting nuance within this framework is that one’s motives are not considered when determining the morality of a choice; rather, the morality of the choice is determined by the results of the action taken. As such, act utilitarianism is closely aligned with consequentialism due to the latter’s moral framework being rooted in the consequences of an action rather than the rationale behind a decision.

utilitarian perspective, is to promote the most good for said patient, and that measurement is based upon patient outcomes. Outcomes are all-important, but impossible to predict. As Stone explains,

[i]n order to base decisions on their likely outcomes, practitioners, as moral agents must have sufficiently strong reasons to think that certain consequences will follow ...

Practitioners who base decisions on the likely outcome are drawing on their practical experience and professional wisdom to help them make calculated choices. This is not the same as a decision based on gut instinct; rather, it involves reflecting on past experiences to be able to weigh up the likely positive and negative outcomes. (Stone, 2005 p. 46)

As is clear from Stone's explanation, consequentialism serves as an effective and easily utilized moral framework in healthcare. However, as is the case with the application of many ethical theories to healthcare, it is not entirely foolproof. The theory's implementation falls in between an art and a science, which is akin to the practice of medicine overall.

The notion of falling between an art and a science also aligns with another way in which practitioners attempted to effectively and ethically ration care – the implementation of SOFA scoring¹⁵ as a method for triaging patients. This type of strategy will work well for rule utilitarians as there is a clear set of rules to follow within SOFA scoring in order to make the right choices¹⁶. It will also work well within the context of consequentialism because, in theory,

¹⁵ As defined by HHS, the Sequential Organ Failure Assessment (SOFA) score is a scoring system that assesses the performance of several organ systems in the body (neurologic, blood, liver, kidney, and blood pressure/hemodynamics) and assigns a score based on the data obtained in each category. The higher the SOFA score, the higher the likely mortality. (HHS, 2020)

¹⁶ The utilitarian rule of maximizing the number of lives saved is widely accepted during a public health emergency. The Ontario and New York working groups both propose modifying a relatively simple mortality prediction model - the Sequential Organ Failure Assessment score - to determine an individual's priority. There is no compelling evidence that one mortality prediction model will be more accurate than another, but the Sequential Organ Failure Assessment score is the easiest to implement and requires the fewest laboratory tests. Although existing models are imperfect, they are as accurate as physicians' prognostic estimates and have the added appeal of being objective and transparent. Prioritizing individuals according to their chances for short term survival also avoids ethically irrelevant considerations - such as race or socioeconomic status. Finally, it is appealing because it balances utilitarian claims

following this clinical guidance will lead to more positive – and therefore ethical – patient outcomes. Further support for this type of approach comes from Savulescu et al.’s *utilitarian rules of thumb* which can be used to guide rapid decision making inclusive of number; length of life; quality of life; equivalence of acts and omissions, withdrawing and withholding; social benefit; responsibility; and the avoidance of psychological biases, intuitions and heuristics. (Savulescu et al., 2020) Their first rule of thumb – number – is one of the most critical differentiators between utilitarianism and other moral theories as it can offer specific, quantifiable guidance to practitioners. Through its focus on and inclusion of measurability, utilitarianism seeks to remove some of the ambiguity and moral complexities surrounding difficult decisions. Specifically, Savulescu et al. argue that utilitarianism’s connectivity to numbers can be translated into use cases such as probability of recovery, expected duration of treatment, and the allocation of resources. (Savulescu et al., 2020 p. 623) This echoes the numeric predictions of a patient’s anticipated length of life based on treatment, lack of treatment, and any relevant comorbidities. But this does not make our decision morally sufficient due to the fact that the implementation of SOFA and other scoring systems is intrinsically flawed from the perspective of disability ethics and reliable results.¹⁷

The nuances that occur in triage settings can prove to be problematic when attempting to apply utilitarian principles. First of all, patients are prioritized for care based on the acuity of their complaint(s) in triage settings. In a non-crisis situation, those patients who are deemed to be

for efficiency with egalitarian claims that because all lives have equal value, the goal should be to save the most lives. (White et al., 2010 p. 3)

¹⁷ “The SOFA is intended to assess short term impairments arising out of an acute care episode and their impact on survivability to discharge. Instruments like the SOFA may inappropriately penalize individuals with stable, chronic disabilities even when based on individualized medical evidence. For example, the Glasgow Coma Scale, a tool used for measuring acute brain injury severity in the SOFA, adds points to a patient’s score when the patient cannot articulate intelligible words even if this condition is due to a pre-existing speech disability. The Glasgow Coma scale also disadvantages patients with pre-existing motor impairments because it requires moving in response to verbal commands.” (Disability Rights North Carolina, 2020 p. 4-5)

the most critically ill will be treated first. This approach actually operates in contrast to utilitarianism because, in theory, the patients who are treated first will not only require the most resources, but also prolong the wait time for other patients¹⁸. Furthermore, during emergent care situations, whether within crisis standards of care or otherwise, clinicians are focused on identifying the cause of the patient's symptoms and/or stabilizing them. Language barriers, cognitive impairments, minimal consciousness, intoxication, etc., not only prove to be problematic when attempting to treat these patients, but also result in a lack of connectivity to the patient. Additionally, emergency care is not built upon ongoing patient-provider relationships. It is predicated on saving lives through prioritizing care. Compounding these challenges is the fact that in situations such as a pandemic, a care team may not be able to easily determine whether someone's disorientation is a result of a preexisting condition or due to the virus. They do not have a baseline understanding of who the patient was before arrival and that makes determining a patient's potential – especially within the framework of quality of life and quality of life years saved – to be fraught with ambiguity.

Whether a patient arrives with a cognitive impairment or arrives so ill that they are disoriented or unable to speak, many decisions about treatment may end up being rooted in assumptions rather than certainties. This is not to say that clinical teams are inefficient or providing substandard care to patients, but rather to say that making these determinations from a

¹⁸ For example, imagine that there are three people in the emergency department's waiting room – one with a dislocated kneecap, one with a superficial laceration that requires stitches, and one with persistent vomiting over 12 hours. The department is staffed by a triage registered nurse, a registered nurse, a nurse practitioner, and a doctor. As the triage nurse is inputting patient information about the patient with the dislocation into the system for bed assignment, an ambulance arrives with a patient in active cardiac arrest. The newest patient requires all members of the on-site team to participate in their care – from rotating through CPR cycles to administering medications to contacting the patient's family to determine if the patient is willing to be intubated. Whereas a utilitarian approach would dictate that the emergency department resources were shared among the three patients in the waiting room to minimize harm and promote happiness for a larger group of people, this fictitious vignette illustrates how the non-crisis approach to care elevates the needs of one patient over the needs of many patients. In the time it took the team to treat and stabilize the patient in cardiac arrest, they could have resolved, or at least improved, the complaints of the other patients.

medical or moral standpoint en masse is inherently not operationalizable. Each case must be evaluated on an individual basis to determine whether or not a patient ultimately falls into a category of deprioritization.

If pandemic triage guidance does not explicitly state that quality-of-life considerations should be limited to extreme tie-breaker decisions, and in any case be based on evidence rather than assumption, it risks reinforcing the prejudice that a life with disability can never be as good—however a “good life” is defined—as a life without. (Scully, 2020 p. 603)

The greater good becomes an amorphous entity due to the virus and its unpredictable and disparate impact on patients. Without a clear understanding of what needs to be done and how to best do it, the treatment is predicated on guesswork and the outcomes cannot be accurately quantified – at least early on. Thus, the pandemic cannot be used as a means to rationalize and essentially promote ableism as a healthcare solution.

Another challenge is determining how to define a good outcome, which as noted above is quite amorphous within the context of the pandemic. In fact, even utilitarian proponents Savulescu et al. note that our framing of the best outcome is linked to everything from COVID-19 deaths to collateral deaths due to the deprioritizing of non-COVID-19 care to stress-related deaths resulting from economic stressors. (Savulescu et al., 2020) Though the breadth of impact is certainly of the utmost concern, there was still a notable shift away from focusing on other non-emergent and not-contagious diseases and focusing nearly exclusively on the pandemic. As such and due to the immense fear caused by the pervasive and virile virus, a great deal of the conversation surrounding how to ethically manage patient care during the peak of COVID-19 was focused on prioritizing pandemic-related care. This was inclusive of

everything from developing the most effective treatment plans to the race to develop a vaccine. Additionally, the global and disparate impact of the virus between communities and between nations makes quantifying good to be immensely difficult, if not impossible. For example, the fact that wealthy nations prioritized vaccinations for their own citizens over those of disadvantaged nations arguably stands in opposition to the utilitarian guidance that framed much of the decision making in these nations. This may pose issues with the implementation of utilitarianism as it is intrinsically outcome oriented.

Furthermore, even if we can agree to focus exclusively on COVID-19 patient outcomes as measured exclusively by survival, it is difficult to validate and predict outcomes through quantifiable, evidence-based measures. White et al. (2010) explain that

[t]here is no compelling evidence that one mortality prediction model will be more accurate than another, but the Sequential Organ Failure Assessment score is the easiest to implement and requires the fewest laboratory tests. Although existing models are imperfect, they are as accurate as physicians' prognostic estimates and have the added appeal of being objective and transparent.” (White et al. page 3 2010)

As noted previously, SOFA scoring played a role in COVID-19 crisis standards of care because of its operationalizability. However, because we cannot rely on tests or physicians to have 100% accuracy in predicting outcomes, then utilitarian consequentialism will only be morally sound in cases with positive outcomes. As explained by Ballantyne “[m]aximising the number of lives saved is a function of (1) prognosis (chance of survival) and (2) length of time benefit (how long each patient is likely to need ICU care). A key problem for utilitarianism has always been the accuracy of predictions.” (Ballantyne, 2020) In fact, “the ability to predict a given patient’s life expectancy or risk of mortality at 1 or 5 years is generally poor.” (Robert et al., 2020) If we

cannot be certain of any patient outcome, then choosing to prioritize one group over another is even more ethically problematic. Ironically, within White et al.'s article, they purport that using scoring systems leads to more fair and ethical outcomes:

Prioritizing individuals according to their chances for short term survival also avoids ethically irrelevant considerations - such as race or socioeconomic status. Finally, it is appealing because it balances utilitarian claims for efficiency with egalitarian claims that because all lives have equal value, the goal should be to save the most lives. (White et al., 2009 p. 3)

What they are not considering here is that some groups are deprioritized *before* the scoring system is implemented, thus undermining equity and falling short of a *balanced* egalitarian approach. Furthermore, outside of crisis standards of care, this prioritization is based on helping those who are the most ill and at the greatest risk first. As such, asking clinicians to remove a life-saving resource from one patient to provide it to another or to deprioritize a more vulnerable patient will lead to pandemic cognitive dissonance.

Another strong argument in favor of utilitarianism comes from Browning and Veit. Their open peer commentary is resolute and affirming of utilitarianism as the *only* viable pandemic framework: "What the COVID-19 pandemic has shown is that a utilitarian approach—far from creating injustices—is the only effective way of creating the most good in the world." (Browning and Veit, 2021 p. 41) They opine that the utilitarian approach provides explicit guidelines whereas other ethical approaches lead to too much ambiguity. Additionally, they argue that utilitarianism can have widespread benefits for addressing other diseases outside of COVID-19. (Ibid) This speaks to the potential benefit of leveraging utilitarianism in both crisis and non-crisis situations because it aims to offer some degree of specificity to guide decision making.

Interestingly, further support for the implementation of utilitarian principles in triage scenarios comes from studies and literature reviews of public and layperson sentiments. In Tutić et al.'s 2021 study of 2,646 subjects who participated “via respondi, a German online access panel provider where people can voluntarily register to participate in opinion polls,” the researchers found

that the hypothetical triage decisions of our nonexpert respondents agree with the official triage guidelines developed by experts on prioritizing utilitarian attributes. That is, the two most important utilitarian attributes (i.e., short-term survival chance and long-term life expectancy [measured by age]) have the greatest influence on hypothetical triage decisions among all attributes under consideration. (Tutić et al., 2022 p. 11)

This type of feedback was similar to what Biddison et al.'s Maryland 324 layperson study, conducted from 2012-2014, found – “the foundational principles embraced by study participants (ie, “save the most years” and “live longer”) parallel priorities that have surfaced in other parts of the country.” (Biddison et al., 2018 p. 193) Though, as noted earlier in this project, concerns about the disparate treatment of minority communities due to utilitarianism made headlines, there appears to be strong evidence of layperson support for considerations such as life years saved, quality of life, etc., within triage decisions.

This variation in public sentiment between theory and practice also showcases a degree of pandemic cognitive dissonance. For the layperson, what may seem to be a common sense application of resources outside of an actual need becomes ethically worrisome when it is actually implemented. It also illustrates the impact of ableism and one's sense of self-preservation on real-life decision making. Conversely, as articulated by Ne'eman, a visiting scholar at the Lurie Institute for Disability Policy at Brandeis University, “[o]ur civil rights laws

don't go away in the midst of a pandemic... We don't suddenly replace the ADA or other civil rights laws with generalized utilitarianism the moment things get difficult." (Shapiro, 2020a)

Within this quote, Ne'eman is alluding to a sacrosanct aspect of our nation's belief system – equality – while simultaneously not referring to the breadth of ableist policies and behaviors outside of the pandemic. And so, while he notes the shift towards utilitarianism in a crisis, his language does not reflect the fact that our society's overarching views about the value of disabled persons is an omnipresent affront to civil rights. The pandemic served to spotlight the breadth of inequality in our healthcare system. Thus, the utilitarian approach also serves as a reminder of one of the key aspects of a fair resource allocation system, equity via the inclusion of egalitarianism. And yet, while we as a society would like to believe that we are unbiased and welcoming to all, we are not willing to sacrifice ourselves for the sake of others that we ultimately deem to be less worthy than ourselves. We choose to save ourselves through the sacrifice of others. We choose utilitarianism.

In further exploration of utilitarianism, it is important to recognize that it does allow for the operationalizing of macro-level needs – i.e., creating a framework that can be used to determine if overarching *groups* of people should be deprioritized in the distribution of care – but the same operationalization is much more problematic on the micro level. This is because it is highly unlikely that decision making is happening en masse in the sense that large groups of prioritized patients are arriving for care at the same time as large groups of deprioritized patients. It is also reflective of an oversimplification in the assumption that cognitive impairment x or physical impairment y will have the same clinical outcomes across the board. In fact, as we experienced during the pandemic's trajectory, COVID-19 had a devastating impact on large numbers of able-bodied, healthy, and relatively young patients. And, conversely, patients who

may have been considered to have a lower likelihood of survival due to preexisting conditions were able to overcome the virus. This underscores the fact that, though medicine is a science, it is extremely difficult to predict pandemic outcomes with certainty – especially when the virus is still in its nascent and clinically complex stage. This was exemplified by the overarching and tragic irony caused by the frequent adoption of utilitarian principles that can be found in the case of ventilator allocation, which will be discussed in depth in the next section of this project.

Part 3

Case Study: Killing vs. Letting Die in the Reallocation of Personal Ventilators

“All persons are deemed to have a right to equality of treatment, except when some recognised social expediency requires the reverse.” (Mill, 2009 p.112-113)

Beyond the policies that were adopted to allocate new critical care resources away from disabled persons, some policies advised reallocating already assigned critical care resources, like ventilators, away from disabled persons who had been dependent on them separate from pandemic needs. This raises a further question about the bodily rights of disabled persons to personal ventilators as an extension of their personal identity. And, beyond the policies that were adopted to allocate new critical care resources away from disabled, there was concern that personal ventilators (PVs) could be reallocated to prioritized groups in a healthcare setting. As explained by Aas and Wasserman (2021), the question of whether these individuals have *bodily rights* to their ventilators was ethically complex. They note that, while there are arguments both for and against providing said rights, neither side provides an impenetrable case.

Critics of such reallocation policies argue that there is weak justification for such a move on the grounds of maximizing life years saved because there is not strong evidence to validate this assumption. (Aas & Wasserman 2021). Reynolds et al. (2020 p. 4-5) argue that, when seeking to determine the moral claim an individual has to personal ventilators, these tools should be considered as *integrated technology*. This is due to the fact that the ventilators are required for the individual to live, rather than serving as a life-enhancing adaptive technology. They ultimately argue that personal ventilators should not be reallocated irrespective of the need for

ventilators because of the moral claims connected to one's lived experience. (Ibid p. 11) If we attempt to judge someone's quality of life based on whether they rely on such technology to live, we are very likely to incorrectly assume that such an existence is less pleasurable and valuable than that of a non-disabled person.

The debates that emerged surrounding the reallocation of personal ventilators serve as a useful case study to help clarify the soundness of major ethical principles in practice, including utilitarian and Kantian values. Such practices raise questions about directing resources to one group over another by removing life-sustaining resources from one group for another, but they also point more fundamentally to how our society views disabled persons. I'd like to note at the outset that to my mind there should be no disagreement about whether one can consider a life-sustaining technology that an individual requires to breathe – which is the most critical need we have to survive – to be a part of them, albeit physically, emotionally, or morally. In fact, one can argue that removing a person's PV is actually akin to a form of forced and socially sanctioned euthanasia. However, from a utilitarian perspective, a belief that the removal of the PV from one patient to provide it to a patient in a prioritized group (based on physical and/or cognitive capabilities) is morally acceptable. Kantians would also approve of such a decision if the patient using the PV was severely cognitively disabled and therefore viewed as lacking personhood. These moral frameworks are illustrative of some of the nuances that arise between the concepts of killing and letting die.

How Crisis Standards of Care address reallocation of personal ventilators

To explore how these nuances can impact actual clinical decision making, let us consider New York State's crisis standards of care (CSC), which allowed for personal ventilators (PVs) to

be reallocated away from their users. First, it is important to note that New York State developed their CSC in 2015. Thus, the guidelines can be viewed as very much reflective of the state's viewpoints on the value of disabled lives vs. non-disabled lives overall due to the fact that they were created well in advance of pandemic conditions.¹⁹ One of the most critical examples of this is that the guidelines recommend that a patient's physician not make decisions about their patient's ventilator therapy, rather a triage committee that does not interact with the patient will make these determinations based on clinical attributes such as likelihood for survival and SOFA scoring to make these decisions. ((New York State Task Force on Life and the Law & New York State Department of Health, 2015 p. 37) Therefore, in addition to completely undermining the patient-provider relationship, these guidelines proved to be problematic in many moral and care-related ways such as disregarding patient autonomy, denying disabled patients the right to equitable treatment due to morally arbitrary characteristics, potentially allowing for the killing of PV users for the sake of the *greater good*, and more.

By developing guidelines that justify unfairly taking away a PV from one of these patients to serve a patient who is deemed more worthy, the state and the CSC authors were allowing the PV patients to be killed (euthanized) – if necessary – in the supposed interest of society at large. As a result, a group of chronic PV users and advocacy groups filed a class action lawsuit against New York Governor Andrew Cuomo and the Commission of the New York State Department of Health, Howard A. Zucker. (Wilson et al., 2020) For the four patients involved in this lawsuit and PV-users throughout the state, their need for a PV to live positioned them to essentially be sacrificed for the *greater good* due to morally arbitrary reasons. This sacrifice is morally notable as it is a more active form of killing than allowing someone to die by not treating

¹⁹ Here, we see that ableism and bias – even in typical public health operating circumstances – pervade our healthcare system and set the stage for potentially catastrophic impacts on the disability community during times of scarcity.

them. While still morally unjust, choosing to direct a resource away from a disabled patient for the sake of a non-disabled patient is a more passive action in that the disabled patient may or may not die. Though this is also not acceptable due to decisions being made based on arbitrary and discriminatory characteristics, the passive action(s) that may lead to a patient passing away may be viewed as more morally acceptable because there is no guarantee that the disabled patient will die as a result of the action(s). Conversely, actively choosing to take a life-sustaining resource such as a PV away from a disabled patient *does* guarantee that that the patient will die. Furthermore, while it is certain that the PV patient requires the PV to live, it is not certain that the other patient will live. Therefore, the ultimate result may be that two patients die in the interest of saving one and that seems to be misaligned with any notion of the best outcome or greater good.

In order to explore the moral implications of directing resources away from one group to give them to another group in the interest of the *greater good* on a more personal level, let us consider the story of one of the case's plaintiffs, Michelle Brose.²⁰ While one may argue that Ms.

²⁰ Michelle Brose is a 45-year-old chronic ventilator user and a resident of Staten Island, New York. Ms. Brose is studying biology at Columbia University. Although she usually lives on campus at Columbia, she currently attends classes remotely from her family home in Staten Island due to the ongoing COVID-19 pandemic. Ms. Brose is a member of organizational plaintiff NMD United. Ms. Brose is a qualified individual with a disability within the meaning of Title II of the ADA, Section 504, and Section 1557 of the ACA. She has Charcot Marie-Tooth disease, which causes motor and sensory neuropathy of the peripheral nervous system characterized by progressive loss of muscle tissue and touch sensation across various parts of the body, and which affects her ability to breathe on her own. Ms. Brose has used a ventilator since 1994. She is completely ventilator dependent and uses a ventilator 24 hours per day because she cannot breathe on her own. Ms. Brose uses one ventilator during the day and the other ventilator at night.

Ms. Brose knows of the provision in the New York Ventilator Allocation Guidelines that permits hospitals to reallocate personal ventilators during triage scenarios. Ms. Brose first learned of the Guidelines from her biology classmates who were joking about the pandemic and ventilator shortages in an online forum. Ms. Brose clicked on the link they shared and discovered with horror that the Guidelines specifically contemplated taking her personal ventilator from her. Ms. Brose understood the Guidelines to mean that she could not go to a hospital if she tested positive for the coronavirus for fear of losing access to her life-sustaining personal ventilator.

Prior to the COVID-19 pandemic, Ms. Brose had 24-hour personal care attendants. However, once the pandemic began, she no longer felt safe risking aides coming into her home due to her greater susceptibility to the virus. As a result, her mother and sister have been tending to her care since the beginning of the pandemic. Ms. Brose knows that during COVID-19, hospital policies have limited family members' ability to stay with patients, and she fears that in a triage scenario with nobody there to advocate for her, she could have her ventilator taken away from her pursuant to the Guidelines. As a New York State resident and chronic ventilator user to whom the

Brose is living an atypical life due to her need for assistance with personal care and reliance on a PV to breathe, those morally arbitrary characteristics cannot be used to deem her life less valuable or to deem her as having a poor quality of life. However, due to these misconceptions and biases, the legislation resulted in Ms. Brose being stripped of her personhood, humanity, and right to be treated as a moral equal. Specifically, and perhaps most critically, a major concern with utilitarianism – both for the disabled community and the patient community at large – is its disregard for patient autonomy. As noted in the previous section, a facet of healthcare that is strongly incompatible with utilitarianism both within and outside of a pandemic is respect for patient autonomy. For Ms. Brose, her reliance on a PV outweighs her right to advocate for her own care and treatment plan and it outweighs her right to keep her PV. Not only is this approach morally unjust, but it completely disregards the breadth of her quality of life and social utility. As a biology student at an Ivy League school – Columbia University – her cognitive capacity is not only sound, but arguably more advanced than many able-bodied patients. It is possible that her studies will advance the field of biology for generations to come, even as her own biology is leading to an unfair assumption that she has less right to care than someone else. Even worse, she is not only in a position to be denied care, but in a position to be left with even less care than her baseline. And so, in addition to Ms. Brose being in a position to be excluded from future care decisions, her prior care decisions are being overridden as well.

Ironically, as the pandemic spread and potential treatments were implemented, it was discovered that mechanical ventilation was actually leading to worse patient outcomes and that the preferred approach was proning of patients. Considering this through the lens of utilitarian

Guidelines would apply, Ms. Brose fears having to make the impossible choice between foregoing needed medical care or going to the hospital where, due to the lack of a nondiscriminatory emergency preparedness plan, her personal ventilator could be taken away, resulting in her inability to breathe and imminent death. (Wilson et al., 2020 p. 8-10)

consequentialism, there is an argument to be made that not only did the use of ventilators worsen patient outcomes, but it worsened the outcomes for the *prioritized* patients – the very same patients deemed to have the most social utility, the highest quality of life potential, etc. As such, the approach essentially failed at mitigating and ameliorating the adverse effects of COVID-19, which can be equated to an unethical outcome since consequentialism is focused on results and not intentions. In addition, reallocating a ventilator from someone who uses one to live essentially guarantees their death and we cannot offer the same guarantee that this sacrifice is ultimately worthwhile due to the fact that the other patient may also pass away. Consider if Ms. Brose was admitted to the hospital for a broken limb that required surgery. She arguably would have a much stronger chance of surviving this surgery than a patient suffering from an extreme case of COVID-19 has of surviving. And yet, CSC could have dictated that Ms. Brose's PV was reallocated. However, as noted in the previous section, utilitarianism does offer moral validation for allocating resources away from one group to pursue the utilitarian notion of *the greater good*.

And yet, the moral validation it provides rests on quite an unsteady foundation when we consider the actual implementation of utilitarian theories – especially in the context of ableism. The pervasive presence of ableism across the healthcare spectrum lends itself to utilitarianism regardless of whether the institution or nation is in a crisis or non-crisis situation. This is because, at the highest level, the overarching utilitarian framework can be synopsisized as having the ultimate goal of promoting the most good, or happiness, for the most people while simultaneously minimizing harm. As discussed previously, within the context of quality of life, which is a key consideration in utilitarian and general clinical decision making as providers seek to minimize the suffering of their patients and promote their wellbeing, ableism can become extremely problematic for the disabled community. This is because the goal of minimizing

suffering may be unjustly and dangerously skewed towards ableist viewpoints as opposed to considering the value of disabled lives. As disability ethicist and adjunct professor at the University of Alberta's John Dossetor Health Ethics Centre Heidi Janz, PhD, puts it,

Within this milieu of “common sense” ableism, people with disabilities are routinely made vulnerable in medical settings. This is because “common sense” ableism in medicine very often results in the application of a utilitarian approach to defining “extraordinary,” “heroic” and “futile” measures that may be employed to preserve or prolong human life. The danger that this poses for people with disabilities entering the medical realm is that things that are considered routine parts of daily living within the disability community, such as the use of feeding-tubes and respirators, suddenly become indicators of an unacceptably low quality of life. (Janz, 2019 p. E479)

To examine this through the lens of a COVID-19 related example, let us return to the story of Ms. Brose. Because she is living with Charcot Marie-Tooth disease, which, as noted via a footnote previously, “causes motor and sensory neuropathy of the peripheral nervous system characterized by progressive loss of muscle tissue and touch sensation across various parts of the body, and which affects her ability to breathe on her own,” Ms. Brose’s diagnosis can easily correlate with a diagnosis of chronic pain. (Wilson et al., 2020 p. 8-10) Thus, if the utilitarian approach is to minimize pain and harm, Ms. Brose’s ongoing physical challenges will deem her as less valuable in relation to promoting the most good than someone who does not have chronic pain. And so, in determining how to allocate resources, directing them toward someone who has a stronger likelihood of living a life without chronic pain and without requiring the need for ongoing ventilation is morally correct. Additionally, decisions may be rooted in the false assumption that Ms. Brose’s clinical disability status correlates to both a lower quality of life and

less predicted Quality Adjusted Life Years (QALYs), as discussed in depth in section two of this project. Therefore, it is clear that Ms. Brose is at a significant disadvantage when compared to non-disabled patients for myriad reasons.

Ethical considerations of ventilator reallocation

In further consideration of the ethical implications of PV reallocation in relation to utilitarianism, it is clear that the theory provides strong bioethical support for euthanasia during both typical and pandemic times. This is because, even though the United States has access to some of the most renowned clinicians and advanced medical technologies and treatments, the system has finite resources. Patients who require high-level, long-term care may end up using vast amounts of resources without, at the risk of sounding callous, a return on the investment through a healthy, cognitively sound outcome. For example, let us imagine a patient who has been in a medically induced coma for several months due to a traumatic brain injury with no sign of improvement. In addition to requiring significant personnel and equipment resources to maintain their life, the expense of treatment can become cataclysmic for loved ones and/or the healthcare institution attempting to absorb the cost of treatment. Though this person may have had a fulfilling life prior to the accident, their current existence is prolonging the emotional suffering of loved ones through helplessness and financial distress. They are also using up vital financial and physical resources that the institution could direct to patients with a stronger likelihood of improvement. This leads to a correlation between the removal of treatment from the patient and improved happiness – or wellbeing – overall. Though the loved ones may experience pain at the loss, they were already experiencing the pain of loss through their loved one's lack of awareness and improvement. Furthermore, as explained by contemporary utilitarian Peter Singer:

If a human being is not capable of understanding the choice between life and death, euthanasia would be neither voluntary nor involuntary, but non-voluntary. Those unable to give consent would include incurably ill or severely disabled infants, and people who through accident, illness, or old age have permanently lost the capacity to understand the issue involved, without having previously requested or rejected euthanasia in these circumstances. (Singer, 1993 p. 179)

As such, Singer would not even view the removal of treatment to be morally problematic as the patient's condition had led to a loss of their personhood. The notion of non-voluntary euthanasia provides a strong foundation on which to argue for the withholding or withdrawing of limited resources from those in the disability community. Adding to the moral complexities of this school of thought is the implication for patients who, like Ms. Brose, are not just cognitively aware, but most likely cognitively advanced. Her use of a resource ensures her very existence, and yet her disability is stripping away her personhood and right to life in much the same manner as Singer describes above or Kantian belief within the context of cognition.

This same pattern is reflected by Savulescu et al., who use a survey pertaining to infant resource allocation to support a utilitarian approach to pandemic triage:

In one survey investigating the public's views on how to allocate intensive care beds amongst critically ill infants, we found the general public widely supported utilitarian allocations. They supported allocating the intensive care bed to save the infant with a greater chance of survival, who would have a longer life or less disability.

They also supported saving the greater number. This suggests that there may be public support for the algorithm that we have proposed for the triage question. When people understand that there is an unavoidable need to choose between patients, they appear to

recognize that securing the most benefit overall is both logical and ethical. (Savulescu et al., 2020 p. 630)

Here, we once more see a social, medical, *and* moral acceptance of allowing the infant predicted to have the greatest disability to be sacrificed for the sake of an infant predicted to have less disability. It is also important to note here that, once again, the notion of *longer life* appears to be correlated to *less disability*. These assumptions and inclinations towards non-disabled patients – even within groups as vulnerable as critically-ill infants – exemplify ableism. Here, the allocation of resources is an example of letting die as opposed to killing.

With the survey noted above in mind, we must consider what these beliefs mean within the framework of disabled community's right to life and the concept of personhood without discussing Singer in more depth. Specifically, the survey is representative of Singer's assertion that infants are not granted the right to personhood as they have no sense of self. Compounding this belief for the disabled community is his strong argument for the euthanasia of disabled infants, such as those with hemophilia or spina bifida, for the purpose of creating greater happiness overall: "When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second." (Singer, 1993 p.186) As one would expect, these viewpoints have proved to be extremely provocative from an academic debate perspective, as well as extremely distressing from the perspective of the disabled community.²¹ Crucially, part of Singer's rationale for the

²¹ Singer's viewpoint on the morality of killing disabled infants is perhaps one of the most contentious and widely debated approaches to disability within the field of bioethics today. However, it is critical to note here that Singer's approach to ethical debates is rhetorical and intentionally extreme. He chooses examples of questions that, arguably, many people would find to have obvious moral solutions and then leverages the examples to illuminate cognitive dissonance. This is a powerful tool that Singer uses to support and advance his arguments – both to those who share his beliefs surrounding utilitarianism and those who challenge his beliefs.

example of euthanasia of disabled infants is rooted in his beliefs surrounding personhood.

Singer's approach to what constitutes the presence of personhood is reminiscent of the Kantian approach in that it is based, in part, on rationality. As explained by Singer

There are many beings who are sentient and capable of experiencing pleasure and pain, but are not rational and self-conscious and so not persons. I shall refer to these beings as conscious being. Many non-human animals almost certainly fall into this category; so must newborn infants and some intellectually disabled humans. (Singer, 1993 p. 101)

As such, Singer views these individuals as *conscious beings* as opposed to people. This approach helps Singer to build a foundation for the consideration of prioritizing one group of living beings over another – i.e. speciesism or choosing to end the life of a disabled infant for the sake of the greater quality of life of a non-disabled infant and his parents. And yet, even if we were to agree that infants are merely things and not people due to their cognitive capacity, Savulescu et al.'s resource guidelines still devalue the lives of the disabled more than the non-disabled.

As explored throughout this project, by following a theory that considers some humans to be less valuable than others, or even less than human, it is far easier to justify the deprioritization of these groups in the healthcare setting. Ironically, this sentiment comes full circle with euthanasia when considered alongside Kant's view about suicide and killing:

[I]n accordance with the concept of the necessary duty toward oneself, the one who has suicide in mind will ask himself whether his action could subsist together with the idea of humanity as an end in itself. If he destroys himself in order to flee from a burdensome condition, then he makes use of a person merely as a means, for the preservation of a bearable condition up to the end of life. The human being, however, is not a thing, hence not something that can be used merely as a means, but must in all his actions always be

considered as an end in itself. Thus I cannot dispose of the human being in my own person, so as to maim, corrupt, or kill him. (Kant, 2017 p. 47)

The Kantian approach to personhood and suicide/killing can actually support the euthanasia of those with severe cognitive impairment. If these people are not deemed to have personhood due to their lack of capacity to reason, then they are essentially being categorized as *things* or *means* rather than as people. This also translates into there not being a need to consider patient autonomy within treatment decisions. Therefore, this group does not have the same rights afforded to those with personhood. This approach can clearly lead to discrimination and bias, as well as potentially leading clinicians toward a eugenic²² approach to practicing medicine. For example, providing pregnant women with the opportunity to selectively abort a fetus due to conditions such as trisomy 21 (Down syndrome) or withholding treatment from a patient with severe dementia. Interestingly, and perhaps ironically, Kantian beliefs surrounding personhood would actually preclude patients like Ms. Brose from being stripped of their personhood. Thus,

²² The impact of the historic eugenics movement is a fascinating tangent to consider in juxtaposition with bias and ableism. Though often considered within the context of Nazi Germany, eugenics actually began in the early twentieth century and arguably occurs to this day through practices such as embryonic selection. The term for the newfound genetic capability of selective reproduction, which “derive[s] from the Greek word *eugenes*, meaning ‘well-born’...was coined by Francis Galton, a cousin of Charles Darwin.” (Washington, 2010 p. 190) It was Galton who “first formulated the desirability of using selective procreation to refine the human race while conquering social dysfunction” (Ibid, 191), the concept of which became widely embraced after the publication of his first edition of *Hereditary Genius*. (Powers, 2018 p. 90) In addition to Adolf Hitler, philosopher Friedrich Nietzsche and former President Theodore Roosevelt were among those who found this theory to offer the potential for improving society. At a high level, embracing the theory of eugenics can enable leaders and clinicians to rationalize discriminatory treatment of those deemed to be less worthy. In perhaps the most grievous manifestation of such, the implementation and practice of the theory led to everything from forced sterilization to forced euthanasia.

It can be further argued that legitimizing the theory of eugenics paved the way for the acceptance and normalization of using discriminatory language and employing discriminatory practices against the disability community. Because scientific advances were, and are, making it possible to intentionally limit the development or potential perpetuation of certain characteristics, societal viewpoints about groups of people can now translate into the reduction or elimination of these groups. Though some of the characteristics being targeted could be argued to be in what is deemed as a person’s best interest such as eradicating a life-threatening genetic disease – and even this is open to debate as one’s lived experience with said disease may actually be quite fulfilled – the overarching manifestation of the theory led to targeting a variety of groups deemed as *other*. This included homosexuals, people of color, the poor, criminals, and more. As such, eugenics can be seen as more indicative of social norms and values than of virtuous scientific advancement – at least in many facets of its implementation. This may have helped to lay the groundwork for the bias and ableism that occurred against the disability community in the pandemic.

the CSC framework focusing on physical disability would also be morally problematic from a Kantian standpoint.

On the other hand, utilitarianism also provides moral grounds to direct any type of medical resources away from certain groups of people – such as the cognitively disabled or those requiring more intensive resources – for the purpose of improving survival for a community overall. By following this approach, there is a moral rationale for sacrificing some for the sake of others. In this way, the adverse impact of crisis standards of care on the disabled community can be viewed as a necessity and, therefore, facilitate decision making. Rather than having to compare all patients when considering who should receive a limited resource, certain patients can be immediately removed from consideration. If this approach frees up enough resources, then other morally challenging decisions about patients may not arise.

In the interest of promoting the most good and the greatest utility for the majority, individual healthcare goals can be overridden. However, as strong proponents of utilitarianism, Savulescu et al. purport that autonomy is less *universally* agreed upon than well-being:

The universal common ethical currency is well-being. What matters to each of us is how well our lives go. This is the very heart and basis of utilitarianism: it takes an impartial approach to everyone's well-being. While people may argue other things matter (autonomy, privacy, dignity), everyone can agree that well-being matters. (Savulescu et al., 2020 p. 630)

Though it is quite valid to speak to an overarching desire for wellbeing, it is certainly unreasonable to describe the utilitarian framework as *impartial*. It is predicated on advancing the needs of certain majority groups and cannot, therefore, be impartial. The only impartiality it may offer is broadly looking at groups of people rather than individuals, but that is still rooted in bias

toward a dominant group and against a smaller – and therefore inherently weaker (*in the eyes of utilitarianism*) – group. In fact, there can be no impartiality in situations where the lives of some are determined to be more worthy than others for arbitrary reasons. There can also be no equality in this framework.

All of this is not only unfair, but shows a callous disregard for equity of care. Ironically, Singer et al. argue that utilitarianism is in alignment with equality, even though their framing of such showcases the bias surrounding who *should or should not be supported*. The authors argue that though the theory of utilitarianism may not focus on equality overall, it does include the notion of equality within the context of utility. However, their argument is also inclusive of a key caveat which is that “[u]tilitarianism supports those forms of equality (or of priority for the worse off) that should be supported, and does not support those that should not be supported.” (Singer & Lazari-Radek, 2014, p. 349) Thus, while in principle Singer's passage supports moral equality for any being with the morally relevant features that he identifies such as sentience, in practice this lays the groundwork for the unequal treatment of people based on their respective group membership. Most problematically, because persons do not have a right to equal treatment in virtue of membership in the species, members of the disability community have to demonstrate that they live up to the moral qualities utilitarians deem most important. Thus, when the theory is put into practice, it is morally unsound to consider the rights to equality to be limited to only select groups within a population. Not only does this approach further undermine patient autonomy, but it also advocates for a deeply paternalistic view of human worth. Furthermore, because utilitarianism deems certain groups to be less valuable and therefore having less moral rights due to the framework's perception of utility, it is essentially deciding who has the opportunity to pursue life and who does not. And yet, by limiting or restricting their

access to treatment, the disability community was essentially placed in a position of potentially forced euthanasia. In the same way that that concerns arise about what euthanasia will mean for the disability community in non-pandemic conditions, the de-valuing of disabled lives during the pandemic ultimately left disabled patients at the back of the line for – or even excluded *and/or* removed from – life-saving treatment.

And so, what is critical to consider now is how other ethical frameworks may prove to be more morally sound than the juxtaposition of utilitarian and Kantian biases.

Part 4

Prioritizing Equality – Alternative Ethical Frameworks for Crisis Standards of Care

“Justice implies something which it is not only right to do, and wrong not to do, but which some individual person can claim from us as his moral right.” (Mill, 2009, p. 90)

First and foremost, an overarching concern for minority communities about the implementation of utilitarian principles in a pandemic is that they will *always* be disparately negatively impacted by the approach. This concern is connected to the fact that the utilitarian framework is intrinsically problematic for disabled people as members of a social minority. Because utilitarianism is focused on promoting the greatest happiness for the greatest number of people, then it stands to reason that the needs of a smaller group will be easily – if not always – overridden by the needs of the larger group. This aligns with the old adage *majority rules* and the reality that discrimination often is a direct result of a larger – more powerful group – disregarding, undermining, or even illigitimizing the needs of a smaller – and therefore weaker – group. As noted earlier, current estimates are that 26% of the U.S. adult population is considered to be disabled. (CDC, 2020) Though this may be a higher number than many would have imagined, it still puts them at a stark disadvantage to the 74% of U.S. adults who do not have mental and/or physical disabilities.

As explored throughout this project, the impact of the implementation of utilitarian principles on disabled persons during the pandemic spanned from theoretical scholarly debate to actual care guidelines. And, because utilitarian principles and the voices of its proponents were at the forefront of the conversation within the resource allocation debate, these recommendations

were no longer being made in an abstract form. They were impacting real lives, and these real lives were continually being viewed and discussed as, at best, less important and having less social utility than those around them. At worst, these lives were being stripped of their humanity, personhood, and moral claim to life.

Interestingly, within the context of the pandemic, Weismann and Holder assert that the notion of “ruthless utilitarianism” as articulated by Office for Civil Rights (OCR) Director Roger Severino in the March 28, 2020 HHS is innately linked to the fact

that Black and ethnic minorities, who develop more serious comorbidities and who are unfairly excluded from equal access to health care in the first instance, are then punished a second time under the triage protocol designs—they are pushed to the back of the line to receive limited medical resources as a result of poorer health outcomes based on subjective judgments about the patient’s ability to survive after treatment. (Weismann & Holder, 2021 p. 277)

Although this statement illustrates deep concern for a different subset of the minority community in the United States, it fails to include the fact that the disabled community faces these same challenges and that there is intersectionality between the two minority groups. As such, it underscores the fact that, even when we seek to promote equity and visibility for minority groups – in the midst of a global pandemic no less – the disabled community can be excluded from the conversation. This lack of reference to the disabled also fails to recognize the intersectionality between Black and ethnic minorities and disability and the reality that this same lack of equity and marginalization of the disability community is correlated to the notion of “ruthless utilitarianism.” There are members of the disability community found within every racial, social, and economic group and, therefore, we cannot consider certain minority groups without

including the disabled community; nor can we forget that no one is immune to disability and that they bring a minority status to *any* larger group. The deprioritization and active discrimination against disabled persons is indicative of the lower value that society is placing on their personhood and fails to recognize the immense importance of disability serving as our society's true *great equalizer*.

While it is clear that the widely accepted utilitarian approach results in both physical and moral inequities, it was still a key ethical framework employed to manage crisis strands of care in the pandemic. We have considered that there is a strong case to be made for using utilitarianism during times of resource scarcity, but it is clear from the research and practices that we have explored throughout this project that an exclusively utilitarian framework may not be morally or operationally sufficient for the development and implementation of crisis standards of care. Therefore, there is a much stronger case to be made for not using it – especially in terms of promoting health equity among *all* citizens. To do this successfully, we must transition away from strictly utilitarian models that are predicated on outcomes en masse and consider other approaches that will advance health and moral equity for *all* members of society. And so, let us now consider what more ethically sound alternatives might be.

Conditions of a morally adequate alternative to contemporary utilitarianism

To begin the process of identifying a potentially more ethically viable solution, let us review some of the key facets of a more equitable framework that have emerged implicitly in my criticism of both utilitarian and Kantian approaches. First, it is not morally adequate to focus on numbers alone when managing pandemic triage – whether this is viewed in terms of hospital operations or occurs under the guise of efficiency. This is because that type of approach is too

removed from the human impact of the disease – albeit directly for the patients, their loved ones, and/or their caregivers. We cannot justify utilizing an approach to crisis standards of care that in effect amplifies the crisis from a moral and societal standpoint. This means we must shift from crisis standards of care being focused on group outcomes and instead remain true to our healthcare system’s strong commitment to patient autonomy. Specifically, we must thoughtfully review the criteria for scarce resource allocation and its implications for minority – and for the purpose of this argument, disabled – communities.

Second, we must consider the unique moral needs of the disabled population which includes several key components. The protection of patient autonomy is critical. This is especially important for those patients who have cognitive impairments such as developmental disabilities and dementia. In the same way that neuro-typical patients are given the opportunity to provide informed consent, these patients must be provided with the same opportunity. In practice, this means that cognitively impaired patients should always have an advocate with them in the healthcare setting – but especially when it comes to crisis standards of care and emergency situations. If care decisions are a matter of life and death, such as choosing to sign a DNR order or agreeing to mechanical ventilation, it is incumbent on providers to ensure that these patients have access to someone who can advise them or make decisions on their behalf through a true medical proxy. This cannot be a physician pressuring a patient to make such decisions on his own.

A third key moral consideration for this population has been discussed at length throughout this project – we need durable safeguards against ableism. Because our society has a strong preconceived notion that disabled patients are inherently experiencing a lower quality of life than their able-bodied counterparts, these patients have their access to care and resources

reduced. This occurs even in non-crisis situations, as noted earlier with regard to the patient with ALS, but is far more significant numbers wise in a pandemic situation. Providers have a moral responsibility to treat all patients as worthy of treatment and care – at least to the extent that the patient and/or their advocate wish for such care. In crisis care, there cannot be a focus on the unfair belief that these patients bring less utility to society. Just like able-bodied patients, these patients all have lives and a right to life.

It is clear that this population has distinct moral requirements in the healthcare setting due to having differing health needs overall, but this is not to say that disability necessarily equates to having more needs. In fact, as noted previously, there is a pervasive misconception that disability has a strong correlation with adverse patient outcomes, lower quality of life, and/or a shorter predicted lifespan. Rather, it is to say that our healthcare environment must operate in a way that is inclusive of the many different facets that make each of us uniquely ourselves – of what makes us *all* human. We cannot take an approach that deems certain people and groups to lack personhood or equitable moral rights to care based on arbitrary differences. We cannot reduce individuals to an inferior status simply because we deem them as *other* or deem this status as a viable means to rationalize intolerable ableist biases. Instead, we must recognize that we have a moral responsibility to meet the needs of *all* patients in a manner that is moral and equitable.

As such, it is critical to consider what other ethical frameworks we can consider using to handle future crises in a potentially more ethical and just manner. There are several different options to review as possible alternatives to utilitarianism as ethically preferred to that model. To make this determination, they must be analyzed in terms of their operationalizability and capacity to consistently provide ethical guidance across social groups. Within this discussion, it is also important to address whether a given framework will help to minimize or even eliminate

pandemic cognitive dissonance for clinicians in the distribution of treatment. Potential alternatives to the utilitarian framework are care ethics, virtue ethics, and hybrid utilitarianism – inclusive of utilitarian principlism and multiprinciple allocation framework – but none are wholly satisfactory.

Care ethics as an alternative

First, let us consider care ethics, also “known as ‘the ethics of care, [which] implies that there is moral significance in the fundamental elements of relationships and dependencies in human life.’” (Gallagher, 2017) Crucially, care ethics takes for granted unequal starting points in the needs and abilities of humans, and rejects the ideal of autonomy as an out-of-reach myth that is damaging. Because relationships, and not autonomous individuals, are the key moral agents in care ethics, interconnectivity between a patient and a provider is key. This is not to say that this is the goal of care ethics, rather that a focus on relationships between one another places patients in a position of self-advocacy and collective advocacy via their provider.²³

In another approach, the notion of how justice relates to care ethics and the pandemic is explored by Wirth et al. (2020). With regard to justice in medical context, they note that it

²³ Within care ethics, “[w]hat is particularly valuable... is the recognition that care is crucially important and that any analysis of care requires both ethical and political insights.” (Gallagher, 2017 p. 60) This inclusion of both ethics and politics does map very closely, at least at a high level, with the copious number of challenges created by the pandemic. What is interesting here though is that it would be quite difficult to consider our nation’s politics without simultaneously considering our ethical beliefs. This is not to say that everyone feels the same way, but certainly our response to the pandemic on a macro scale seemed to have a direct correlation to our political beliefs. Furthermore, the development of CSC guidelines was reflective of the value we place on different groups of people and which consequences we were willing to accept – albeit as clinicians, individual citizens, or politicians. However, in consideration of the earlier review of CSC guidance from a number of states, the ableist bias was found in states that spanned both sides of the aisle. Here, perhaps we may find that care ethics can not just become biased due to politics, but politics can lead to a biased result when the care ethics framework is applied. If we are to consider that utilitarianism focuses on the greater good and then consider that care ethics leans heavily on politics, we may ultimately end up with the same result – the desires of the majority (those in power with ableist viewpoints) will override the rights of the minority (the disabled population).

provides an incomplete ethical lens on the situation; what needs to be addressed is its claim to completeness, especially in relation to triage's claims to meet or solve all justice problems. [ethicist] Tronto wants to focus on the persistence of suffering. She calls the unconditional recognition of the needs of others the main focus of care ethics. (Wirth et al., 2020 p. W18)

What is interesting about this excerpt is the reference to suffering. This aligns not just with the suffering of patients, but also with the suffering of providers, an ethical consideration often overlooked by predecessors to care ethics. In times of resource scarcity, the inability to treat all patients equally (in the sense of providing every patient with the same level of and access to care) is immensely problematic for providers and for patients. This makes a care ethical approach particularly relevant here: during a pandemic, under crisis standards of care everyone involved suffers. To resolve some of this suffering, Wirth et al. suggest that we should seek to send patients elsewhere, even to other countries, before relying on triage systems. Though they do note that there has not been much global collaboration in terms of our COVID-19 response, that may not actually be the biggest barrier to care access. Even if we take into account *the unconditional recognition of the needs of others* and assume that collaboration will work, that does not solve the issue of variations in quality of care between nations. Even within our country, access to care and the quality of said care can be immensely disparate. If the needs of patients must be kept at the forefront, then even a triage system that provides equitable access to care at a given medical facility may be more morally sound than sending patients outside of the country. Additionally, by not providing equitable triage systems to rely upon within a medical facility and instead trying to distribute patients externally, this approach will be very hard to operationalize. And, if providers are entirely focused on the needs of their patients, this may prove to be very

detrimental to their physical and mental health – which could lead to an even greater lack of human resources.

In further exploration of care ethics, Gallagher (2020) suggests that there is an opportunity to learn from the teachings of Florence Nightingale and leverage Gallagher’s concept of slow ethics²⁴ in conjunction with care ethics. She explains that

[t]he pandemic urges a bolstering of care ethical values and processes for these extraordinary times. [This is inclusive of] a renewed focus on solidarity and social justice; less preoccupation with moral distress and more focus on moral resilience; [continuing] to increase the visibility of creative compassionate care and prioritisation of non-abandonment; and learn[ing] and avoid[ing] post-pandemic forgetfulness.

(Gallagher, 2020 p. 2-3)

Though these are all important facets of a just and ethical healthcare system, none of these suggestions offers truly actionable guidance for providing care. We see a strong focus on an improved provider experience and connectivity to patients, but that may only serve to intensify experiences of pandemic cognitive dissonance. For example, Gallagher’s discussion about the importance of providers facilitating connections between critically ill patients and their families. This is, of course, immensely important in terms of human connectivity and the need to provide both patients and families with some sense of peace during a horrific time. However, focusing on these types of actions does not help to guide the decisions between directing resources among or between critically-ill patients. In fact, placing such a strong focus on one of the most emotionally charged aspects of caregiving – death – may result in even more pressure on providers to try to

²⁴ “The six elements of slow ethics—stories, solidarity, sustainability, space, scholarship and sensitivity—are elements that connect past and present and remind us of the fundamentals of care. These elements of nursing care are brought to the fore during this pandemic...Politicians and the public need to demonstrate that they are genuine in their praise and honour promises to support, reward and respect nurses and other care-givers. The future of this most critical work, that operationalises humanitarianism, depends on it.” (Gallagher, 2020 p. 3)

determine whether their time is best served prioritizing those who are actively dying or those who require human resources to survive. This is, of course, a crucial moral question, but it cannot be resolved through care ethics as such. I would caution that what is ethically required in an equitable CSC framework is actionable guidance for providers to follow during times of resource scarcity, and this (by design) is something care ethics would be ill-equipped to provide.²⁵

Virtue ethics as an alternative

Next, let us consider virtue ethics. Defined by bioethicist David Sellman as “an approach that focuses on character with the assumption that a person of good character will tend to behave in ways that are consistent with their character” (Sellman, 2017), at a high level virtue ethics might align well with caregiving roles due to its focus on the intrinsic goodness of a person. As patients, we most likely desire that those treating us are *good* people and that they will behave in *good* (moral) ways. Conversely, the ambiguity surrounding how one defines what good is – either as the patient or the provider – could make utilizing this ethical theory quite difficult within conditions of resource scarcity.

Virtue ethics also empower providers to behave and treat patients in a manner that is meaningful to them and is in sync with their individual moral frameworks. The theory acknowledges and celebrates provider autonomy, which may help with avoiding pandemic

²⁵ Another interesting aspect of patient - provider connection is the idea that “[f]rom a care ethics perspective, trust cannot be built through an action, but is an ongoing, mutual process of relationship.” (Robinson, 2021 p. 347) When this is viewed through the lens of a pandemic and resource scarcity, it seems quite improbable that providers will be able to dedicate nearly enough time to build trust with their patient(s). This will be especially difficult in cases where patients have decreased cognitive capacity and may require additional time and/or resources to develop a baseline connection with a provider. Therefore, though there is truth in the idea that trust is not typically created via one action, the reality of pandemic triage complexities may render this facet of care ethics to be entirely unattainable.

cognitive dissonance *if* the moral questions a provider is faced with can be answered effectively within their moral code. For example, Daly explains that,

virtue provides agent-specific action guidance. A virtue approach accounts for both relative and absolute moral excellence. Although an agent ought to strive for absolute excellence, at a given moment, she may need to strive for moral excellence relative to her stage of moral development. (Daly, 2021 p. 579)

What is interesting to note here is that although Daly views this as a positive aspect of the theory, the ambiguity that surrounds moral decision making for a practitioner who is less experienced – either due to age or tenure – or is less morally evolved for any reason is quite concerning. Thus, what may be viewed as morally justified by someone inexperienced may be completely unjustified through the eyes of a more established practitioner.²⁶

However, there is a potentially problematic aspect to this component of the theory and that is its connection to reason. As we have seen throughout this project, a major moral failing of both utilitarian and Kantian viewpoints on personhood are often linked to cognitive capacity. In his book entitled *Happiness for Humans*, Daniel Russell (2012) dedicates an entire chapter to the junction of happiness, eudaimonia, and practical reasoning with an ultimate goal of “show[ing] that there is a very strong case to be made for the idea that eudaimonia is the final end for practical reasoning.” (Russell, 2012 p. 35) Even if we consider that the providers themselves are all capable of high level reasoning such as this, it is possible to use this framework to once again de-prioritize disabled patients based on morally arbitrary characteristics. If a key desired outcome within virtue ethics is eudaimonia

²⁶ Within virtue ethics, the concept of eudaimonia, “a key term in ancient Greek moral philosophy, [that] is standardly translated as ‘happiness’ or ‘flourishing’ and occasionally as well-being,” (Hursthouse & Pettigrove, 2003) is at the forefront. Each of these translations can be viewed in terms of positive patient outcomes and a positive provider experience. By acting virtuously, the providers and their patients areshould, in turn, improving their own flourishing. experience eudaimonia.

and this is reached through reason, then one can take the leap to assume that patients with diminished cognitive capacity are not capable of reaching it. Therefore, it could be morally acceptable to exclude these patients from access to scarce resources.

With this background in mind, let us consider some of the arguments that were made in support of the use of virtue ethics during the pandemic. Bellazzi & v. Boyneburgk (2020) argue that “[f]or an action to be virtuous, the agent has to voluntarily decide on it, to rationally choose it. We are able to decide on what we can achieve through our agency, on what is up to us.” (Bellazzi & v. Boyneburgk, 2020 p. 6) Here, we are faced once more with concerns about what it means to make rational choices and how we can ensure patient agency for those with cognitive impairment. Though their article is focused on the context of mask wearing and its relationship to utilitarianism and personal freedoms, its core message is that we must rely on the tenets of virtue ethics to guide our pandemic moral decision making. Though mask mandates may seem to be outside of the scope of this conversation, we must remember that the impact of crisis standards of care (CSC) guidelines are another form of mandate. Thus, the mask mandate can serve as a metaphor for the experience of providers who are tasked with implementing the CSC. However, the tenets that the authors focus on – generosity, courage, and prudence – will create pandemic cognitive dissonance in the case of CSC because they should “prevent us from forgetting the most vulnerable, the old and the weak, because a virtuous person regards everyone.” (Bellazzi & v. Boyneburgk, 2020 p. 8) This is because, in following the CSC, the providers are actively required to deprioritize – perhaps even forget – the moral worth and personhood of disabled patients for the sake of *the greater good*. The CSC, therefore, places providers in a position in which the guidelines are forcing them to disregard the needs of the exact types of patients that virtue ethics is seeking

to support within this aspect of the theory. Thus, not only will the providers be prevented from adhering to the aforementioned tenets within the context of virtuous and equitable care, but they will also be acting in a manner that stands in direct opposition to patient-centered care and their typical moral framework.

In our pursuit of the greater good, del Castillo (2021) notes that “[a] close examination of some of the responses to the COVID-19 pandemic shows apathy and indifference” (del Castillo, 2021) and that incorporating virtue ethics into the responses will reintroduce compassion. The need for compassion is entirely accurate, but compassion alone cannot offset the implications of CSC. Providers may have the utmost compassion for all of their critically ill patients, but the addition of compassion into utilitarian guidelines will only serve to worsen pandemic cognitive dissonance. The compassion will not save the patients who have been deprioritized unless it is used to override the discriminatory resource allocation system. Nor can compassion serve as a means to expand resources or provide a means through which to quantifiably save more lives. Furthermore, even if it is somehow incorporated into the CSC, it would need to be done in a way that is actionable to be impactful and its subjectivity does not lend itself to action.

Interestingly, a common thread in the articles advocating for the adoption of virtue ethics within our pandemic response is the desire to find an alternative to utilitarianism. This is due to both the impact on patients and the impact on providers. However, virtue ethics does lend itself more intensely to ensuring a positive experience of the providers within the context of the pandemic. Because the desire, even pressure, to behave a certain way and achieve certain outcomes within virtue ethics is so focused on the providers themselves, they are at a high risk for being psychologically impacted by the approach. The same argument can be made for the impact of utilitarian principles on the providers, as found within the “viewpoint is offered that

many morally injurious events happen when healthcare workers, traditionally practicing Kantian and virtue ethics, are forced to follow utilitarian policies of [the] healthcare system.” (Akram, 2021 p. 1) This once more aligns with pandemic cognitive dissonance. However, what is perhaps a bit ironic is the call out to the practice of Kantian ethics due to the theory’s views on personhood. Therefore, the overlap between Kantian personhood and utilitarian personhood, or utility, may serve to undermine the connection between Kantian and virtue ethics. Additionally, another facet of Akram’s article notes “that cognitive approaches to understand outcome-based utilitarian judgments may help clinicians in balancing their empathy driven deontological judgments” and that “there is a need for utility-driven healthcare systems to keep in mind the deontological nature of physician-patient relationship and the role it plays in affective processing of morally difficult situations during the utility-based decision making.” (Akram, 2021 p. 4) While this may be true if our healthcare operations remain closely connected to utility during pandemic conditions, it does not answer for the challenges faced by the disabled population as a deprioritized group. Of course, we should seek to support the providers, but to focus too closely on their moral experience may allow for the continued disenfranchisement of the disabled population.

Though care ethics and virtue ethics are prominent schools of thought within bioethics, the guidance they offer will only serve to heighten pandemic cognitive dissonance. Within both of these theories, the added pressure on the clinical teams to perform to the most exemplary degree – for patients and for themselves – could become untenable. This is not to say that clinical codes of ethics are not designed to promote providing the highest level of care, rather that following one of these theories during a crisis situation does not allow for fault. The clinical teams would need to focus all of their attention on what the virtuous action would be or how to

best serve the relationship between them and their patients. When all resources – time, staff, treatment options, etc. – are limited, these amorphous and subjective theories are not only less useful, but not operationalizable either. In fact, the time it might take to try to answer ethical questions within these frameworks could easily lead to so much focus on one patient’s situation that the rest of the patient population would be left with little to no attention. There is also a challenge posed by the notion of how to manage one’s responsibility to do the right thing, as explored by González-Melado & Di Pietro, 2021.²⁷ Though their article focuses on vaccination, it illustrates issues surrounding equity and the ethics of forced decision making. Therefore, while utilitarianism is unable to appreciate the nuances of individuals, these theories are so focused on nuances that limited resources would likely preclude even a semblance of efficiency.

Approaching a hybrid utilitarian alternative

In continuing to explore ethical alternatives and due to the fact that utilitarian principles have remained at the forefront of our society’s approach to crisis standards of care, it is prudent to now consider hybrid approaches to scarce resource allocation that include utilitarianism and/or its principles. First, by not overhauling the entire ethical framework, the adaptation of any existing clinical guidelines may be easier. This will theoretically allow for a more seamless transition between sets of guidelines rather than via a complete overhaul. Additionally, adopting a hybrid approach may best position bioethicists and practitioners to reach a consensus for a

²⁷ Obscured by this question on mandatory vs. voluntary vaccination is a much broader debate about the ethical model that is applied when making political decisions on public and community health issues. The first model is the normative ethical model (third person ethics), which defends the legality of mandatory vaccination. The second model is a virtue ethics model (first person ethics), which defends the individual’s right to make decisions about their own health, based on the premise that the common good of society is achieved through the personal good. When making public health policy decisions in times of COVID-19, we propose a shift from a normative ethical model to a virtue ethics model via an ethic of responsibility. (González-Melado & Di Pietro, 2021 p. 511)

non-utilitarian approach among the dominant, purely utilitarian voices and the dissenting ethical voices.

To begin this stage of the review process, I will survey some of the commonalities and benefits among these hybrid approaches. One common thread between these approaches is that they are all flagging the challenges that can arise in choosing a single ethical framework to direct moral decision making – in this case, patient care. These challenges include precluding the opportunity to properly and consistently address nuances in decision making due to the rigidity of specific frameworks; the inevitable gaps and/or problematic aspects found within a specific framework; and, conversely but equally as problematic, the lack of rigidity within a specific framework as this can leave too much gray area in decision making. By advocating for a hybrid approach, there is an immediate opportunity to address anticipated difficulties before they arise. It also may provide the adaptability to manage unexpected nuances effectively in real time. Furthermore, by finding a way in which to identify more of a middle ground between theories, there is arguably a higher likelihood that a larger group of stakeholders will be able to agree on a given approach.

The first hybrid theory we will explore is utilitarian principlism. This approach was put forth by Vearrier and Henderson (2021) in their article entitled *Utilitarian Principlism as a Framework for Crisis Healthcare Ethics*. Within the article, the authors explore the idea that clinicians are typically approaching care through the lens of principlism as defined by Beauchamp and Childress. Within Beauchamp and Childress' theory of principlism (Beauchamp & Childress, 2001/2019), the four key facets of ethical care include autonomy, beneficence, non-maleficence, and justice. Therefore, while examining the challenges arising from the pandemic, Vearrier and Henderson consider the idea that, though the four principles remain

present in care decisions, they need to be weighted differently to address resource scarcity. With this in mind, they suggest that

[i]n Utilitarian Principlism, autonomy transitions from individualistic to relational, nonmaleficence tolerates a “learn as we go mentality”, beneficence seeks population health, and justice takes on a more important role as healthcare adjusts to the needs of many over the needs of an individual. (Vearrier & Henderson, 2021 p.46)

While it is clear that the volume of patients calls into question the ability to maintain a focus on patient autonomy, the long-term implications of disregarding such a critical part of our healthcare approach make this shift ill-advisable. At the simplest level, the shift from individually focused care to public health focused care represents a change from typical operating procedures. This statement about the shift from typical operating procedures may seem obvious due to the widespread attention given to the pandemic and fears of resource scarcity, but the significance of such change within our healthcare system is massive. In some ways, it even seems that the need to shift moral frameworks and adapt atypical medical practices – at least for the present-day United States healthcare system – led to a resurgence of paternalism. As explored in detail previously, considerations about a patient’s best interest were far less individualized and generalizations about things such as the definition of personhood and quality of life led to ethical failings across the nation. This hybrid utilitarian principlism approach is not satisfactory because it will also allow for decision makers to identify delineations between groups that would allow them to deprioritize those deemed less worthy for the sake of saving – or at least prioritize – those seen as having more social utility.

Another integrative approach comes from White and Lo (2020), who advocate for the use of a multiprinciple allocation framework in managing the distribution of resources in a crisis

situation. They argue that current guidelines for managing scarce resources are ethically flawed due to their exclusion of certain groups of people. What is fascinating about their approach is that they argue that “categorical exclusions are too rigid to be used in a dynamic crisis, when ventilator shortages will likely surge and decline episodically during the pandemic.” (Ibid E1) This moral argument is built upon White et al.’s 2010 article which claims that the most ethically sound approach to scarce resource allocation during a crisis will comprise three key facets: “Principles guiding allocation decisions should include maximizing survival to hospital discharge, maximizing the number of life-years saved, and maximizing individuals' chances to live through each of life's stages.” (White et al. page 14 2010) Within their framework, they argue that considerations such as “social value” and “instrumental value” should not be included in decision-making criteria. This certainly aligns with the goal of ensuring that there is equity and respect for all persons when allocating resources.

Overall, the multiprinciple allocation framework is a strong option as it comprises the utilitarian strength of maximizing life years saved without focusing on quality of life biases; aligns with the egalitarian approach of advocating for the moral equity for all; meets the virtue ethics goal of leading a moral life through practice as the practitioners will not be faced with pandemic cognitive dissonance; the care ethics approach of promoting wellbeing and benevolence; and three of the four facets of principlism – non-maleficence, beneficence, and justice. Though it does not necessarily support patient autonomy in that the distribution of resources is based on a framework outside of the patient’s control, the multiprinciple approach certainly seeks to provide more equitable treatment for patients than utilitarianism. Conversely, a challenge to this approach is that it does include age as a factor in its predictive modeling – which can result in ageism. The authors respond to this critique within the work and note that the

focus is more on comorbidities and not on *penalizing the healthy*, but this still leaves us with an age-based disadvantage to contend with and concerns about how preexisting conditions may result in precluding patients from care.

With the above discussion in mind and due to the fact that utilitarian principles were found within many CSC and resource allocation frameworks, there are good reasons to think that our healthcare system should adopt a hybrid utilitarian triage system for future pandemics. First, taking a hybrid approach will allow for some of the widely-utilized and validated utilitarian principles to be leveraged during times of resource scarcity. Secondly, merging key facets of an additional ethical framework can create the opportunity to treat all patients with the dignity and respect they deserve as autonomous individuals. As we have already determined that care ethics, virtue ethics, and the hybrid frameworks discussed so far will not solve the concerns surrounding equality and actionability, the hybrid framework I suggest we consider is egalitarian utilitarianism.

To better understand why this approach offers promise, let us briefly consider egalitarianism and, specifically, non-instrumental egalitarianism. This facet of egalitarianism is defined as “[the belief] that equality of some sort is a component of justice, and morally required as such.” (Arneson, 2013) When this concept is juxtaposed with the impact of a global pandemic, the notion of justice is extremely complex. As we have explored throughout this project, the impact of COVID-19 was imbalanced due to a variety of factors. However, a common thread among many of these factors was the bias against disabled persons. Our healthcare system cannot be just if it undermines the worth of particular persons for the purpose of advancing *the greater good* for non-disabled patients. Therefore, incorporating an egalitarian approach to the ethical management of scarce resources is also a potential solution.

As noted by Tate, there is an opportunity to reframe our approach to managing scarce resources by considering the concepts of being harmed and being wronged. To explain the difference between the two, Tate describes a situation in which a piece of slate falls off a roof and onto his head. Though this may cause him harm, he will not have been wronged unless the roof had been built negligently. (Tate, 2022 p. 249) He carries this into the treatment of patients in the pandemic by considering how the prioritization of some groups of people over others or some groups of patients over others leads to harm *and* wrong. (Tate 2022) It also implies that no one person has a stronger claim to life than another. This runs counter to the utilitarian framework as its intense focus on personhood, utility, and maximizing wellbeing for all inherently allow for making the claim that some lives are more valuable than others. We see the same approach in Kantianism in terms of the focus on rationality as a critical indicator of human value. As discussed earlier in this project, to a Kantian, it is morally acceptable to prioritize someone with *meaningful* cognitive capacity over someone with limited cognitive capacity.

Tate, conversely, states that from an egalitarian perspective it is unethical to remove the resources from one person to serve another because “[n]obody has a claim on resources that cannot be provided without violating somebody else’s rights...This will change only if beds become available, or if an individual occupying one of those beds ceases to have any interest in continued treatment, say because they decline to the point that continued efforts are futile.” (Tate, 2022 p. 251) In a related example, the disabled persons who use personal ventilators could not have them removed within this framework as it would be a clear violation of their rights. This is extremely compelling as it ensures that our healthcare system’s focus on patient autonomy remains at the forefront of care decisions and that the pandemic does not undermine the values that define us.

Another key facet of the conversation surrounding our values found within Tate's egalitarian approach to the ethical allocation of resources during the pandemic is the impact of these decisions on the clinical teams. Within his argument, Tate speaks to the notion of the potential emotional challenges and *moral injury* faced by those who are forced to make decisions that are morally wrong within their jobs. Specifically, he notes that this is especially problematic in instances where providers are not only witnessing the deaths of many people that they are unable to save, but also being placed in a position where they are choosing whether they live or die based on policy. (Tate, 2022 p. 252) This aligns very closely with the concept of pandemic cognitive dissonance and how challenging it is for caregivers to repeatedly be placed in horrific situations in which they cannot lean on their typical moral practices. It is highly concerning to consider the potential for front-line clinicians to experience long-term, if not permanent, psychological trauma due to not just the pandemic, but the moral unease that arises from uncertainty and inequity. While utilitarianism is considering impacts overall, the egalitarian approach and its corresponding commentary are much more attuned to widespread implications of being forced to behave in a manner that is counter to one's training.

In considering all of these approaches, there is one crucial irony that must be addressed – and that is the strong likelihood of bias and ableism among these providers even on the hybrid model. However, though this can be empirically supported, the true crux of our patient-centered healthcare system is respect for the patient. Thus, the sacrifice of one patient to save another will arguably always be intrinsically linked to cognitive dissonance – pandemic or otherwise. As noted by Tate,

[w]e risk abandoning our principles just when we need them the most, and inadvertently licensing the infliction of a huge number of wrongs in the name of avoiding harm. Where

one cannot avoid doing harm, we should be open to the possibility that the next best action-guiding principle is to “do no wrong.” (Tate, 2022 p. 252)

His words, though advocating for an egalitarian approach to care, align with just how deeply problematic our society’s approach to the allocation of resources was. This same concern about the impact of shifting our care dynamics was articulated by Wagner & Dahnke (2015) with regard to the moral challenges that arise for providers when care choices – specifically utilitarian triage choices – run counter to medical codes of ethics. (Wagner & Dahnke, 2015 p. 303)

As counterintuitive as it may seem to consider approaches that may result in *less* lives saved, the pursuit of approaches that align with values such as patient autonomy and equity should be omnipresent and omnipotent. We cannot relegate groups of our citizens to inhumane and unjust treatment in the name of the *greater good*. As a nation built on *freedom and justice for all*, patient autonomy must be held sacrosanct and we cannot knowingly and actively demolish individual rights under the guise of utilitarian medical ethics. As a healthcare system, we cannot allow crises of any magnitude to shift our approach to care from patient-centered to paternalistic. Taking this approach *will* guarantee that we are behaving in a way that is counter to our overarching moral and social beliefs, but it *cannot* guarantee that this sacrifice will even be worthwhile in terms of quantitative or qualitative outcomes.

Within the hybrid egalitarian utilitarianism framework, the key manifestation of the inclusion of an equality-focused theory would be the need for some sort of lottery system to be included during times of resource scarcity. While this is not a perfect solution in terms of ensuring the best clinical outcomes, neither was a strictly utilitarian framework. The main difference here is that the hybrid solution will help to adjust our thinking and our practices to be focused on equitable justice rather than discriminatory justice.

There are certainly counterarguments to be made in relation to egalitarian utilitarianism. At the start of the pandemic, Savulescu et al. (2020) authored an article that sought to answer the question of *equality or utility*. The article, which comes in response to the National Institute for Health and Care Excellence (NICE)'s CSC and resource allocation guidelines, seeks to challenge the notion of adopting a more egalitarian approach to care – inclusive of discussion surrounding the lotteries that may take place in the interest of fairness and equality. To the authors,

[t]he current NICE guidance provides an unstable compromise between egalitarianism and utilitarianism. Instead, a precautionary utilitarian approach should be adopted. This would recognise the importance of striving towards the greatest good for the greatest number, but it would also recognise that, in circumstances in which there is little net gain in discriminating based on a relevant factor, people should be treated equally. We should consider, to some degree, not only the probability of achieving a beneficial outcome, but also the value of that outcome. It is ethically justifiable to give lower priority to patients who will have a significantly lower chance of survival, and also those who will have a significantly reduced length or quality of life. This strikes a balance between equality and utility. (Savulescu, Cameron, et al., 2020)

Though they make a strong case for why utilitarian guidance should be considered as the preferred decision-making framework, once more they are relying on morally arbitrary factors such as quality of life to guide care determinations. Perhaps they are giving a nod to egalitarianism when they discuss equal treatment as it connects to the “little net gain in discriminating based on a relevant factor,” but the relevant factors they adhere to diminish the personhood of disabled patients. To consider the notion that one can not only quantify quality of life based on morally arbitrary characteristics, but place a *value* on that outcome is highly

subjective and fraught with the potential for ableist bias – albeit implicit or explicit. Furthermore, the link between value and utility, as addressed throughout this project, is one of the most significant shortcomings of utilitarianism. Additionally, as evidenced throughout this project, measuring utility based on attributes such as cognitive capacity is detrimental to our healthcare system.

Savulescu et al. are correct in that egalitarian utilitarianism will not entirely resolve ethical dilemmas. However, taking this approach should provide for a more equitable distribution of resources that reframes *the greater good* as potentially applicable to all as opposed to only the majority. Determinations surrounding care will be made either based on clinically sound guidance – i.e. comparing two clinically similar patients to one another – or via a lottery system when such comparison is too difficult. And yes, this hybrid approach may lead to the prioritization of groups that have traditionally been deemed as having less value. However, I do believe that it is incumbent upon us as a society to maintain an egalitarian approach to care to ensure that we do not succumb to ableism and bias. Rather than assuming that those who differ from us are experiencing a lower quality of life or even going so far as to morally strip them of their personhood and human rights, we must remember that – especially in the case of disability – no one is immune to becoming *other*. Thus, we should operate under the assumption that we must *all* be egalitarians in a pandemic and we must reevaluate our policies to reflect this.

Conclusion: Limitations and Additional Considerations

No matter which approach we take, there will be loss and grief and suffering. However, we should not amplify the trauma by doubling-down on a system that embraces discrimination and inequity and runs counter to our nation's founding principles. And, regardless of the ethical framework employed to help make care determinations during pandemics and times of resource scarcity, the pervasive presence of ableism may lead to bias in treatment decisions. Therefore, there is a strong likelihood that a provider will have a skewed and biased viewpoint about a disabled patient's quality of life. Since quality of life is a key consideration within healthcare decision making, the impact of said bias – albeit explicit or implicit – may undermine patient autonomy and lead to disparate outcomes. In order to help mitigate these biases, it is imperative that the issue of disability bias is comprehensively addressed in the healthcare system.

Additionally, as was referenced earlier, Agaronnik et al.'s research showed that physicians actively chose to communicate with caregivers rather than with cognitively impaired patients. (Agaronnik et al., 2019) Though this poses a clear challenge in ensuring patient confidentiality and autonomy (Ibid), it also underscores a key facet of ethical care for this population during a pandemic: allowing for access to an advocate for those patients who rely on others to help them communicate. When we consider this in the context of patient care during the height of the pandemic, it is clear that visitation rules are something that must be kept in consideration in ensuring equitable care for these patients.

Furthermore, I have argued in support of identifying a moral framework that will not only serve as sufficient moral guidance both within and outside of pandemic operations, but one that will also serve as a means to limit *pandemic cognitive dissonance*. It is crucial that we consider how devastating the impact of moral inconsistencies can become for our front-line providers. The ethical framework we decide to follow – especially if it is one that, like utilitarianism, is something our society is less comfortable with outside of pandemic times – can lead to lasting damage to our caregivers and our collective social psyche. We must maintain a balance in how we approach equitable care regardless of whether the care is taking place in emergent or non-emergent situations. This means that the approach that we endorse in typical times cannot be overridden by allowing ableist discrimination to seep into the very ethical theoretical foundations we are relying upon for guidance.

The hybrid ethical framework we ultimately utilize must, like utilitarianism, be actionable and it should still comprise some adapted forms of key utilitarian facets such as operationalizability and quantifiability. We must include these important aspects of a functional moral framework, but also recognize that it is not acceptable to allow morally arbitrary characteristics and ableism to dehumanize and deprioritize patients in the name of *the greater good*. Thus, unlike utilitarianism, the hybrid theory must place a much stronger emphasis on equality and respect for personhood, while also taking a more holistic and patient-centered approach to considerations surrounding quality of life.

Lastly, at the macro level, we are still not clear about the breadth of impact that COVID will have on our society. This is inclusive of both the physical and mental health ramifications of the virus. For patients experiencing long-COVID, they may be in a position where they are never able to return to their pre-virus health status. For providers who witnessed the devastating impact

of the virus firsthand and may also have experienced pandemic cognitive dissonance, there is a potential that they either are, or will, experience mental health related symptoms due to trauma. Additionally, the mental health impact of the isolation, anxiety, loss, etc., caused by the pandemic may result in significant mental health symptoms across generations, socioeconomic status, health status, and more. We were *all* impacted by this pandemic and the true magnitude of the impact, and its correlation to the prevalence – or even growing prevalence – of disability now, remains to be seen.

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