



# Disorders of Consciousness, Disability Rights and Triage During the COVID-19 Pandemic: Even the Best of Intentions Can Lead to Bias<sup>1</sup>

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**ABSTRACT:** As a member of the New York State Task Force on Life and the Law and the author of *Rights Come to Mind: Brain Injury, Ethics and the Struggle for Consciousness*, the author draws upon his work as a clinical ethicist during the COVID-19 Spring surge in New York to analyze the impact of ventilator allocation guidelines proposed by the Task Force on people with disorders of consciousness. While a non-discriminatory methodology was intended by the Task Force, the author concludes that the guidelines would have discriminated against people with disorders of consciousness had they been promulgated. This was due to errors in exclusion criteria, the utilization of the Sequential Organ Failure Assessment (SOFA) score, and the Glasgow Coma Scale which assesses motor output and not consciousness. While allocation and triage decisions may be necessary during a pandemic, the ethical integrity of these determinations depend upon proper metrics.

**KEY WORDS:** COVID-19, triage, ventilator allocation guidelines, disorders of consciousness, Sequential Organ Failure Assessment score (SOFA), medical ethics

## Consultations and Commitments: Disorders of Consciousness Meets COVID-19

**D**uring the Spring surge of COVID-19, I directed an ethics consult service at an academic medical center in Manhattan (Fins and Prager 2020; Prager and Fins 2020). While consulting with my team on individual patients, I was also tasked with the equally challenging duty of trying to write institutional policies to allocate

ventilators (Huberman et al. 2020). This was no easy task for two reasons. One was political and the other was personal (Fins 2020d).

At the policy level, each hospital had to independently determine how to proceed because the State of New York never issued guidance for crisis standards of care, instead, hoping that the expansion of hospital and ICU capacity could outrun the pandemic, making rationing unnecessary (Fins 2020e).

At a personal level, the need to respond to this crisis placed me in the uncomfortable position of having to make an ethical choice between the utilitarian needs posed by the pandemic and my long-standing scholarly commitment to the needs of people with disabilities (Guidry-Grimes et al. 2020), particularly those with disorders of consciousness and severe brain injuries. These two goals were seemingly in opposition to each other and unreconcilable, and yet, both were already part of my academic workspace, having their origins in two publications I authored, or co-authored, five years earlier: *Rights Come to Mind: Brain Injury Ethics and the Struggle for Consciousness* (2015) and the *Ventilator Allocation Guidelines* (2015) drafted by the New York State Task Force on Life and the Law, of which I am a member.

In retrospect, it was ironic that these two documents were published in the same year. When they were written, these two domains seemed nicely separated in my life and work. Although we wrote to prepare for the pandemic, most of us were in a state of denial, much like Kubler-Ross had described when discussing stages of loss and grief (Fins 2009b). Even as we planned for the future, our hearts had not caught up with our minds. We were acting prudentially, but it was still improbable and more an academic exercise than something we would have to operationalize in real time, with real consequences. My work on brain injury and disability rights stood safely apart from these efforts, and was also protected by a hefty dose of discounting. Though public health officials warned of a pandemic, one would not come, and if it did the same sort of advances in medicine that were catalyzing a revolution in neuroscience and brain injury would protect us from the coming plague. But I was naïve. We all were.

I never truly imagined the confluence of intellectual and normative challenges that would arise as the pandemic hit New York City and I sought to reconcile my work on the ventilator guidelines, brain injury, and disability rights. This essay tells that story, one that continues to evolve as the nation grapples with the pandemic and as I reflect on my role in responding to the brutal surge of COVID-19 that struck New York City in the Spring of 2020.

### **Understanding Disorders of Consciousness**

To place my COVID-19 response into context, we need to step back and consider the origins and purpose of *Rights Come to Mind: Brain Injury Ethics and the Struggle*

for *Consciousness* (Fins 2015). This volume sought to recount the progress that has been made in diagnosing, categorizing, and treating disorders of consciousness over the past twenty years, drawing upon family narratives and my own work collaborating with neuroscientists. I told this remarkable scientific story through the prism of disability rights, asserting that the needs of patients with disorders of consciousness have been unmet, in large part because of the nihilism that dates to the origins of the “right-to-die” in America (Fins 2003).

This is a complex story, worthy of a longer exegesis (Fins 2020f), but simply put, the right-to-die was established in the context of severe brain injury, namely the vegetative state. The presumption of futility became the moral warrant to allow for the withdrawal of life-sustaining therapy in landmark legal cases (Fins 2006a), beginning with *Quinlan* (In Re Quinlan 1976), and continuing on through *Cruzan* (Fins 2020a) and *Schiavo* (Schiavo ex Rel. Schindler v. Schiavo 2005; Fins 2006b). Yet, there was more complexity to the story: not only might some patients get better, but some thought to be vegetative had covert consciousness and were sensate. To make sense of this, it is critical to first define our terms and categories (Fins 2019a).

Let us begin with coma, which is an eyes-closed state of unconsciousness. A coma after traumatic brain injury (TBI) can last a week or two and can be a precursor to either brain death or recovery. Comas can also be induced and prolonged with sedative medication, which is a therapeutic strategy sometimes used to promote recovery after brain trauma.

When a coma does not resolve to consciousness, patients progress to the vegetative state, which represents the isolated recovery of the brain stem without higher cortical function. Patients in the vegetative state are clinically paradoxical to the untrained eye, as theirs is an eyes opened state of unawareness. Because we often ascribe awareness to the opening of the eyes, this brain state can be very difficult for families who expect that the opening of a loved one’s eyes coming out of a coma heralds recovery and the person that they knew. However, when a coma evolves into the vegetative state, the eyes are open, but there is neither awareness nor responsiveness.

The vegetative state was first described—as the persistent vegetative state—in a 1972 *Lancet* publication by Bryan Jennett, the Scottish neurosurgeon (also responsible for the *Glasgow Coma and Outcome Scale*), and Fred Plum (the American neurologist who first described the Locked-in-State). Jennett and Plum described the vegetative state as one that “seems wakeful without awareness” (1972). Since they did not have functional neuroimaging to peer inside the injured brain, they were unable to definitely exclude the possibility of awareness (Fins 2019b).

In 1994, the Multi-Society Task Force published two articles in *The New England Journal of Medicine*, which further classified the vegetative state into two distinct categories: persistent and permanent (Multi-Society Task Force on PVS 1994a; 1994b). According to this framework, a vegetative state became persistent if it persisted for a

month. The vegetative state was designated as permanent three months after anoxic brain injury, such as the brain injury that would occur after a cardiac arrest or twelve months after traumatic brain injury. This variable time course from persistence to permanence also reflects the more favorable prognosis of patients with traumatic versus anoxic brain injury.

A consensus definition of the minimally conscious state (MCS) entered the medical literature in 2002 under what was called the *Aspen Criteria* (Giacino et al. 2002). MCS patients demonstrate an awareness of self, others, and their environment. They may turn when they hear their name, look up when someone enters the room, or grasp an object presented to them, all of which are signs indicative of consciousness, according to the *Aspen Criteria*. MCS is further subdivided into MCS- and MCS+, which reflects whether patients can respond verbally or not (Thibaut et al. 2019).

The challenge with all behavioral manifestations in MCS is that these behaviors do not occur consistently or reliably, making diagnosis difficult. Because of this, MCS can be easily confused with the vegetative state. When the behaviors are not manifest, these patients appear to be in the wakeful unresponsive state of the vegetative state. In one study, over 40% of patients with traumatic brain injury in chronic care facilities that were thought to be in the vegetative state were in actuality in MCS (Schnakers et al. 2009). Patients who can reliably respond to commands are said to have emerged and are designated as MCS-E (Bodien et al. 2020).

Patients with a disorder of consciousness are best assessed by the validated Coma Recovery Scale-Revised (Giacino, Kalmar, and Whyte 2004), a neuropsychological bedside examination that assesses different domains reflective of consciousness, not simply motor function, as evaluated by the older Glasgow Scales (Fischer and Mathieson 2001). This is an important distinction for patients who lack motor output, but who have normal cognitive function. This would be the case of a patient in the Locked-in-State who is paralyzed from the neck down. Such patients have low scores on the Glasgow scales because it assesses motor function, not consciousness. According to evidence-based review, it is also recommended that patients receive five CRS-R exams, during different times of the day and over the course of two weeks, so as to capture the waxing and waning of behaviors characteristic of MCS (Wannez et al. 2017). A single exam is not dispositive of a patient's brain state because of this fluctuation in responsiveness and behavioral output.

Distinguishing the vegetative state from MCS is more than merely a diagnostic curiosity, it is scientifically, clinically, and normatively significant. At a scientific level, the neurocircuitry of the MCS patient is distinct from that of vegetative patients (Laureys et al. 2002). In neuroimaging studies, MCS patients have intact and distributed neural networks, which is the substrate for consciousness, unlike vegetative patients whose brains are functionally unable to achieve integrative

function (Schiff et al. 2005). These networks, when they are activated, allow for the demonstration of behaviors indicative of awareness and consciousness, which make the MCS patient clinically distinct from the vegetative patient. At a normative level, the presence of these distributed neural networks allow the patient to hear what is being said and to perceive pain (Chatelle et al. 2014). To quote a line from the musical *Hamilton*, the MCS patient “is in the room where it happens” (Miranda 2015; Fins 2016c). Unlike patients who are properly diagnosed as vegetative, MCS patients are aware and sensate, obliging us to be aware of their presence and to attend to their neuro-palliative care needs (Fins 2009a; Fins and Pohl 2015).

Assessment is further complicated by what my colleague and I have previously described as non-behavioral MCS (Fins and Schiff 2006), a state in which patients respond to commands on neuroimaging scans without demonstrating associated behaviors. For example, a patient might be asked to imagine walking through their house, playing tennis, or disaggregating similar sounding words with different meanings to activate the areas in the brain responsible for spatial navigation, motor activities or language processing (Owen et al. 2006; Bardin et al. 2011). These volitional tasks are manifest on the brain scans, but not in overt behaviors, hence the notion of patients being in a non-behavioral MCS (Fins and Schiff 2006). They appear to be in the vegetative state at the bedside, yet they have covert consciousness.

More recently, Schiff has described individuals with such discordances as having *cognitive motor dissociation* or CMD (Schiff 2015). CMD patients span a broader range of functional capacity than the non-behavioral MCS patient, including patients in MCS as well as those in the Locked-in-State who have normal cognition, but no motor output other than the cranial nerves.

In a milestone series of publications, the classification, diagnosis, and treatment changed in August 2018 when the American Academy of Neurology (AAN), the American Congress of Rehabilitation Medicine (ACRM), and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) came together to publish a systematic, evidence-based review of this space (Giacino et al. 2018b; 2018c) and to promulgate a practice guideline following upon this systematic review of the available data (Giacino et al. 2018a; 2018c). These were historic publications, and as such, were published in both *Neurology* and in *the Archives of Physical Medicine and Rehabilitation*, an unusual offering reserved for landmark publications. In addition to the evidence-based review and practice guideline, an extended commentary on the ethical, palliative, and legal implications of the practice guideline for the care of these marginalized patients was also published, for which I was privileged to be the lead author. This commentary also received dual-publication status (Fins and Bernat 2018a; 2018b).

The 2018 AAN/ACRM/NIDILRR guideline revised the 1994 *New England Journal of Medicine* Multi-Society Task Force statements on the vegetative state (1994a;

1994b), and further endorsed the 2002 definition of the minimally conscious state (Giacino et al. 2002). Cognizant of the marginalization of this population and how they are often neglected in chronic care, the practice guideline called for definitive standards of care for this vulnerable population (Fins and Bernat 2018a; 2018b).

They also offered a notable revision in nosology, or diagnostic classification, replacing the old 1994 category of a “permanent” vegetative state with the category of a “chronic” vegetative state. This was prompted by a review of data, which suggested that some 20% of patients characterized as being in the permanent vegetative state might actually progress into a state of higher cognitive function, such as the minimally conscious state. While 80% of the patients formerly described as being permanently vegetative would remain so, based on the data, others would not. This empirical observation was testimony to the fact that some brain states—thought to be fixed and permanent—can and do evolve (Fins and Schiff 2017), and perhaps more critically, that some patients thought to be permanently unconscious had unidentified or covert consciousness. The greatest proportion of these patients would be the roughly 40% who had been misdiagnosed and had been minimally conscious all along (Schnakers et al. 2009).

While the publication of the AAN/ACRM/NIDDLR practice guideline represented a critical advancement for patients with disorders of consciousness and their families, it neither received broad attention within the bioethics community nor fully captured the full scope of the scientific advancement that has occurred in the years since the publication of the *Aspen Criteria* in 2002 (Giacino et al. 2002). Elsewhere, I have sought to explain the neglect of the bioethics community (Fins 2019c), but suffice it to say that this was a function of both a crowded news cycle and a lingering residue of presumptions about futility linked to the relationship between patients with severe brain injuries and the evolution of the right to die.

This prevailing notion of futility was mitigated by the practice guideline, but only partly so. While the guideline included an evidence-based endorsement of Amantadine as a treatment, which can accelerate the recovery of consciousness (Giacino et al. 2012), the methodology employed by AAN/ACRM/NIDDLR only included data from studies which had at least twenty subjects (Fins and Bernat 2018a; 2018b; Armstrong 2019). This threshold left out smaller studies of emerging diagnostic and therapeutic interventions that will hopefully shape the clinical landscape in the decades ahead. For example, on the diagnostic side, it is highly probable that neuroimaging will, in due course, be employed to identify covert consciousness in patients who, behaviorally, appear vegetative (Bardin et al. 2011; Monti et al. 2010; Owen et al. 2006).

With respect to therapeutics, beyond Amantadine, Zolpidem has been reported to restore consciousness in case reports (Brefel-Courbon et al. 2007). Additionally, there are a suite of experimental proof-of-principle studies of neuromodulation in-

terventions, including thalamic deep brain stimulation (Schiff et al. 2007), non-invasive ultrasound (Monti et al. 2016), transcranial magnetic stimulation, and vagal nerve stimulation (Corazzol et al. 2017). All of these interventions target the thalamus, which has the potential to activate what has been called the meso-circuit and to promote integrative cognitive function. In aggregation with comprehensive neurorehabilitation, assistive technologies, and available pharmaceuticals, 22% of patients with the most severe forms of brain injury can regain functional independence (Nakase-Richardson et al. 2012). These data give lie to the presumption of futility too often attendant to this population, a true cause for reflection and celebration.

## Disability Rights and Disorders of Consciousness

A large part of my academic work has been to advocate for the better and more humane care for this patient population, by advancing the ethical framing of our obligations informed by emerging scientific knowledge and novel applications of disability law (Fins and Wright 2018; Fins, Wright, and Bagenstos 2020). This is sadly necessary because patients with disorders of consciousness are among the most vulnerable and neglected of our citizenry. Saved by heroic measures from certain death only decades earlier, most are destined to receive what has been euphemistically called custodial care in chronic care facilities ill-equipped and ill-disposed to track their evolving brain states or attend to their pain and suffering. It is not an assertion of hyperbole that these patients suffer in isolation segregated from mainstream medical care undiagnosed (Fins 2015) and often with their pain unrecognized and untreated (Berube et al. 2006; Chatelle et al. 2014).

I believe that this is a human rights violation under international law (Convention on the Rights of Persons with Disabilities 2006; Fins 2016a; 2016b; Wright et al. 2019). Domestically, as I have maintained in *Rights Come to Mind* (Fins 2015) and more recently in a *New York Times* Op-ed, the neglect of this population is a pressing civil and disability rights issue that demands our attention (Fins 2017). The segregation question is particularly apt because this constitutes a stark violation of the *Americans with Disabilities Act* (ADA) (1990), which includes the social integration of people with disabilities as one of its mandates. As explained by a contemporaneous advisory memo from the George H. W. Bush era Department of Justice, the ADA was a “mandate for the elimination of discrimination against individuals with disabilities,” in large part because, “historically, society has tended to isolate and segregate individuals with disabilities” (Albrecht 2006). When Justice Ruth Bader Ginsburg later wrote the majority opinion upholding the ADA in *Olmstead v. L. C.*—a case involving the deinstitutionalization of two women in a Georgia psychiatric hospital—she explicitly pointed to Congressional intent in the drafting of the ADA. Justice Ginsburg noted that, “Congress explicitly identified unjustified ‘segregation’

of persons with disability as a form of discrimination” (*Olmstead v. L. C.* 1999). In opposition to segregation, the *Olmstead* court called for societal re-integration for individuals who have been placed outside of the mainstream because of their disability.

In the context of brain injury, the issues are similar to what was contested in *Olmstead v. L. C.* For some, it is the possibility of deinstitutionalization, but for patients with disorders of consciousness who may not be able to live with family or in the community, the question of reintegration is less about physical place and more about restoration of functional communication (Fins, Wright, and Bagenstos 2020). Let me explain this key difference.

For people with a mobility disability, the ADA has allowed for societal integration by providing for a more accommodating physical environment. While certainly not perfect, reforms made because of the ADA have helped make it possible for many to go to work, utilizing changes to the built environment, like kneeling buses or a cut in the sidewalk that allows wheelchair access. However, it is different for people with disorders of consciousness whose integration is often limited by their inability to communicate or to make their voice heard (Fins 2015). In this context, community is built (and indeed, restored) by fostering functional communication or community’s cognate (Fins 2017). This is the goal of all who work in disorders of consciousness and it is more than merely aspirational.

This was what my colleagues and I accomplished when we restored functional communication in a MCS patient with thalamic deep brain stimulation (Schiff et al. 2007). Before entering this phase I clinical trial, his highest level of function was inconsistent command-following with eye movements. With bilateral stimulation of the intralaminar nuclei of the thalamus, he was able to say six or seven word sentences, recite the first 16 words of the *Pledge of Allegiance*, and tell his mother he loved her. He could also express a clothing preference when his mother took him to Old Navy (Fins 2015). By returning voice to these patients through the restoration of functional communication, we helped to overcome his isolation and to restore the social and biological networks that had been disrupted by his injury. While this work was at the proof-of-principle level, it is a promissory note for others in this condition and step a forward in fulfilling the reintegration mandate to which the ADA aspires.

### **New York State Task Force Report on Ventilator Allocation**

It was against this backdrop that I entered the pandemic. I consider myself a disability rights advocate for patients made vulnerable by virtue of severe brain injury. They are deserving of the same respect and consideration as other individuals in the face of the pandemic, notwithstanding the utilitarian challenges posed by scar-

city and crisis. Nonetheless, these commitments were tested when the pandemic hit New York City in the Spring of 2020. How does a clinical ethicist responsible for his hospital's ethics committee respond to a crisis while maintaining fidelity with his intellectual and normative commitments to people with disability?

To answer this question, we need to again step back to 2015, and the Ventilator Allocation Guidelines developed by the New York State Task Force on Life and the Law, to appreciate how they came into being, what the intent of Task Force was, and which metrics we employed. The Task Force came up with an allocation scheme that we hoped we would never use, reflecting the comforting sense of denial that has been shattered by the COVID-19 pandemic (Fins 2009b). Despite this sense of improbability, we took our responsibilities seriously, and after nearly of decade of research, hearings, and internal deliberations, we came up with a plan that sought to be non-discriminatory using the Sequential Organ Failure Assessment (SOFA), a methodology score originally developed during the H1N1 influenza epidemic to assess a patient's need for ventilatory support and likelihood of survival should it be provided (Shahpori et al. 2011).

Triage decisions utilizing the SOFA framework were meant to be physiologically determined in a neutral fashion, without regard to race, ethnicity, gender, age, disability, or other social determinants, which might skew the triage process. Age did not explicitly play a role in the SOFA score. Instead, the omnibus score, which tracked the functionality of several organ systems, was used as a proxy for the patient's physiologic age.

The Task Force also sought to avoid discriminating against individuals with disabilities (2015). Disability discrimination occurs when a disability that is irrelevant to the acute triage decision is used to bias analysis and to deny or limit care. This can be the disability itself or a medical condition associated with a disability, even if neither has a bearing on whether or not the individual will survive the episode of respiratory failure that necessitates the provision of a ventilator. Previously, I have labeled the latter as crypto-discrimination associated medical conditions that are comorbidities of a disability, such as the heart conditions associated with Down Syndrome (Fins 2020b; 2020c).

After the authorities declared a public health emergency and invoked crisis standard of care (Institute of Medicine 2012), which would replace "usual" care with "sufficient" care (Fischkoff et al. 2020), this methodology would be put into place and patients would be triaged based on their SOFA scores. These scores would be an aggregation of an assessment of the patient's blood pressure, lung, liver, and kidney functions, as well as the integrity of the blood's clotting system. In addition, the patient's neurological status would be assessed using the Glasgow Coma Scale (GCS) (Jennett and Teasdale 1977). Each of these six metrics were divided into scores of 0

to 4, with progressive deterioration yielding a higher score, for a maximal score of 24 points.

SOFA scores would then be cohorted into four color-coded categories for triage: Blue, Green, Red, and Yellow. Patients in the Blue category (SOFA > 11) had the most dire prognosis and likely would not survive the acute infection despite maximal efforts. Those who were designated Green (No significant organ failure) were sick, but not sick enough to require a ventilator. Red patients (SOFA < 7 or single organ failure) were very sick, in need of a ventilator, and most likely to survive if they received one. Yellow (SOFA 8–11) was an intermediate category between Red and Blue. These patients were sicker than those in the Red category and would receive a ventilator after those designated as Red were allocated this scarce resource.

### **SOFA and Brain Injury: A Critical Analysis**

If we turn to the overall SOFA score, we can see what an outsized impact the GCS could have had on triage decisions if the guidelines were implemented. Patients with a GCS of 6–9 yield 3 points on the SOFA score, while those with a GCS < 6 generate 4 points on the SOFA score. If the goal is to end up in the Red Zone, SOFA < 7, patients with lower GCS scores are at great risk of having scores outside of the triage range.

Consider this scenario: a patient who opens their eyes to sound, who produces “inappropriate words” (the language used in the GCS), and who did not have motor output would have a GCS of 6 and generate 3 points on the SOFA score. If they also had a slight decrease in their platelet count (1 point), and some mild liver (1) and kidney (1) insufficiency, they would have a total of <7 points. This would be their SOFA score before their need for supplemental oxygen was considered. That need, depending upon their level of oxygenation, could yield an additional 2 to 4 points bringing their SOFA score to 9–11, placing them in the Yellow category, and on the cusp of ineligibility as they approached the Blue category.

This would be problematic and potentially discriminatory enough, even if the GCS were the correct metric to use for the assessment of patients with disorders of consciousness. While GCS is predictive of outcomes for patients who have had an acute traumatic brain injury (Royal College of Physicians and Surgeons of Glasgow; Jennett and Teasdale, 1977), it has no role in assessing the vast majority of patients who would enter a hospital during a pandemic with severe brain injury. Most would not be victims of acute trauma of the sort associated with a car accidents or a cardiac arrest, but rather residents of congregant living settings with chronic brain injuries. Those patients should not be evaluated by the GCS, but rather the Glasgow Outcome Scale-Extended (Jennett et al. 1981), if we sought to stay in the Glasgow family of assessment tools.

However, even this is insufficient for patients with disorders of consciousness, as all Glasgow assessment tools rely heavily on motor output as a marker of brain state. Thus, a patient who had inconsistent or scant motor output would yield low scores even when they might have higher levels of cognitive function. This would be the case of a patient in MCS or with CMD. These patients would have a low GOS-E score and would be potentially indistinguishable from a patient in the vegetative state devoid of consciousness. All of these patients should instead be evaluated by the Coma Recovery Scale-Revised, which evaluates levels of consciousness (Giancino et al. 2004). This instrument's inter-observer reliability and scientific utility was vetted in the aforementioned AAN/ACRM/NIDDLR evidence-based review and was recommended as the neuropsychological assessment tool to be utilized in assessing patients with disorders of consciousness by the associated practice guideline, instead of the Glasgow scales (Giancino et al. 2018a; 2018b; 2018c).

Beyond these methodological challenges, there are outright errors in the SOFA “exclusion criteria,” concerning those conditions that would automatically place a patient into the Blue category, thereby making them ineligible for a ventilator. Relevant to our discussions, one of these criteria is “traumatic brain injury with no motor response to painful stimuli (i.e., best motor response = 1)” (Royal College of Physicians and Surgeons of Glasgow). This criteria is flawed for the reasons already enumerated regarding the fact that motor output, as assessed by the Glasgow Coma Scale, may not be an accurate reflection of a patient's cognitive state. Yet, there is a second, and more telling, error as well: this exclusion criteria reflects poorly on the knowledge base of those who drafted it. The careful reader will note that the exclusion applies to patients with traumatic brain injury (TBI), but what of those with anoxic brain injury—as would occur following severe oxygen deprivation during a cardiac arrest? It is well appreciated that patients with anoxic brain injury fare far worse than those with TBI (Posner et al. 2019). While cardiac arrest is one of the other exclusion criteria, that alone is not the same thing. There will be those who survive a cardiac arrest who are subsequently in an anoxic coma. Under the exclusion criteria for brain injury, patients in an anoxic coma would not be excluded, while those in a coma secondary to TBI would be. This fails to acknowledge that 77% of patients with anoxic coma, versus 50% of those with a trauma, will remain in the vegetative state. Again, this is a limitation of the SOFA score, which was apparently written without an adequate appreciation of the scholarly literature informing the care of patients with disorders of consciousness.

### **Good Facts make for Good Ethics: Disability Advocacy in Context**

As I complete a final draft of this article, I write in mourning as I remember the life and work of Albert R. Jonsen, one of the founders of bioethics (Rubenstein 2020).

Jonsen was a personal mentor of mine (Fins and Guillén 2016) and a towering figure in bioethics. He was a member of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research as well as the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, and chronicled his experiences as a member of these commissions in his classic volume, *The Birth of Bioethics* (1998). Jonsen was fond of saying—and I paraphrase—that good facts make for good ethics, and that long before we get to normative considerations in a case, we need to be secure in the facts that are the basis for deliberation.

Discussing why he wrote *Clinical Ethics* (2015), a practical guide to bring ethical theory into clinical practice, written with Mark Siegler and William J. Winslade, Jonsen explained the importance of clarifying the facts before engaging in ethical decision-making. In a 2007 interview at the University of Washington, Jonsen explained why he used a four-quadrant approach to flesh out medical indications, patient preferences, quality of life considerations, and contextual features, which would need to be understood before ethical reflection. Jonsen observed, “I developed this so health care professionals can get the facts of the case clear and argue about the priorities of one quadrant over another” (Rule 2007).

Good facts do make for good ethics. This is especially true when a legacy of discrimination clouds judgment and leads to the acceptance of metrics, which seem to be precise, but which actually affirm a flawed analysis. Such is the application of the SOFA score to patients with disorders of consciousness.

Despite the best intentions of the New York State Task Force, namely to not engage in discriminatory practices with respect to ventilator allocation, there were errors in our methodology that lingered beneath the surface (Fins 2020b; 2020d; New York State Task Force on Life and the Law 2015). While SOFA's reliance on the Glasgow Coma Scale appears to be objective, it was misused when applied to patients with chronic disorders of consciousness. As such, it was ill-suited to the task of predicting survival from COVID-19 associated respiratory failure. These limitations could lead to the denial of services to this population, and thus, the compounding of vulnerability during times of crisis. While there might be an ethical rationale to limit access to ventilator support to patients with disorders of consciousness, those deliberations must first be predicated on a solid set of data. Neither the SOFA score nor Glasgow Coma Scale can provide that evidentiary base.

It has recently been asserted that society has been subject to a “tyranny of metrics,” which can simplify complex situations and promote reductionistic thinking, leading to erroneous conclusions dressed up in a façade of objectivity (Muller 2019). Such is doubly the case when we consider ventilator allocation and patients with disorders of consciousness. The seemingly-objective conclusions drawn from SOFA

scores applied to patients with disorders of consciousness can be especially insidious. They seem so logical and supported by the data, but in reality, they reinforce a priori assumptions about the futility caring for these patients (Fins 2015). This makes these patients especially vulnerable during a pandemic.

It is highly unlikely that a busy ER or ICU doctor will drill down into the methodological weeds of the SOFA score and appreciate the methodological peril that lurks beneath its veneer of objectivity. That is probably too much to expect of busy clinicians trying to do their earnest best during a pandemic, but is not too much to expect of disability advocates who must be vigilant when reviewing allocation schema for methodological errors and implicit bias.

While the tale of this advocate is but one of many narratives, which speak to the ways that the disabled community has been further disadvantaged by the COVID-19 pandemic (Fins and Bagenstos 2021), it is emblematic of a pervasive set of challenges that must be addressed by the disability community and its allies. Advocacy resulting from this pandemic needs to be more than sloganeering. It needs to be both granular and informed, ever cognizant that bias can find its way into even the best of intentions.

Note: The views expressed are those of the author and do not represent the New York State Task Force on Life and the Law or any other organization with which he is affiliated.

## ENDNOTE

- 1 For context on this piece as part of a special cluster on Covid-19, please see the editor's introduction to this issue of the *Journal of Philosophy of Disability*.

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