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Empiricism and Rights Justify the Allocation of Health Care Resources to Persons with Disorders of Consciousness

Joseph T. Giacino^{a,b}, Yelena G. Bodien^{a,b,c}, David Zuckerman^a, Jaimie Henderson^d, Nicholas D. Schiff^{e,f}, and Joseph J. Fins^{e,f,g}

^aHarvard Medical School; ^bSpaulding Rehabilitation Hospital; ^cMassachusetts General Hospital; ^dStanford School of Medicine; ^eWeill Cornell Medical College; ^fThe Rockefeller University; ^gYale Law School

The unprecedented challenges to accessing health care in the face of the COVID-19 pandemic have illuminated the longstanding debate around allocation of resources to persons with disorders of consciousness (DoC) caused by acquired brain injury. Proponents argue that rights of persons with DoC should be retained unless these rights erode those of others who are equally deserving. Opponents contend that because it is not possible to clearly discern whether persons with DoC can enjoy an acceptable quality of life, it is unjust to offer high-acuity care to *all* persons with DoC as many cannot perceive benefit, and others who can benefit will be deprived. The crux of the argument is that the loss of sentience leads to uncertain moral status and less claim to limited high-cost resources. Current practice appears to align most closely with the opponents' view. Epidemiologic studies of persons who survive moderate to severe traumatic brain injury (TBI) suggest that approximately one in five receive any inpatient rehabilitation (Corrigan et al. 2012). Moreover, despite the complexity and dynamics of the long-term sequelae, authorization requests for reevaluation and supportive treatments often result in payor denials.

Peterson and colleagues (2021) appeal to the concept of *expected prospective benefit* to help reconcile the problems of uncertain moral status and cost-effectiveness. This concept derives from prospect theory, which is employed when assessing the utility of a decision that aims to represent the best interests of a group, but must be made under conditions of risk and uncertainty (Peterson, Aas, and Wasserman). As

proposed by Peterson et al., the outcome of interest is the net benefit attained by the DoC *population* when available health care resources are provided rather than withheld. The determination of prospective benefit is based on the anticipated proportion of favorable to unfavorable outcomes among *all* persons with DoC—not on the outcome of a single individual. The decision to commit scarce resources is morally-justified if the population demonstrates benefit.

We endorse Peterson et al.'s prospective benefit proposal and provide corroborative empirical evidence in support of this approach by juxtaposing data on early withdrawal of life-sustaining treatment (WLST), the most pronounced form of resource constraint, against recent findings from long-term natural history studies of persons with prolonged DoC (i.e. ≥ 1 month). We also supplement the prospective benefit framework by applying a complementary normative and legal-rights-based appeal that offers this vulnerable population enhanced protection against nihilism, marginalization and neglect.

HOW OFTEN IS LIFE-SUSTAINING TREATMENT WITHDRAWN IN PERSONS WITH SEVERE BRAIN INJURY AND WHEN IS THIS DECISION MADE?

Brain injury is broadly dichotomized into TBI and non-traumatic (non-TBI) etiologies. Persons with non-TBI generally demonstrate worse outcome as compared to those with TBI, reflecting differences in cause (e.g. cardiopulmonary arrest v. motor vehicle accidents), age (older v. younger) and pathophysiology

(diffuse v. focal injury). We focus our discussion on the incidence of WLST in TBI because outcome is known to be *more* favorable in this cohort. We recognize that as more effective treatments emerge for non-TBI the rationale to support the DoC population only strengthens.

We begin by describing two large-scale studies investigating WLST in persons with severe TBI completed over the last ten years. In 2011, a retrospective review of 720 persons with severe TBI admitted to six Level I trauma centers in Canada observed that 70% of the deaths in the ICU were associated with WLST (Turgeon et al. 2011). WLST cases were identified when mechanical ventilation, inotropes, vasopressors or renal replacement therapy was withdrawn without expectation of survival. Among in-hospital deaths (31.7%), 64% of those occurring within the first 72 hours of admission were due to WLST. Notably, the average age of this cohort was 42 years. There was significant variability in the incidence of WLST between centers after accounting for baseline risk factors, suggesting that physician *perception* of long-term prognosis was a major driver in decision-making. In fact, two of the three most common reasons cited by the medical team as the basis for recommending WLST were the belief that the chance of survival was poor and that prognosis for long-term outcome was unfavorable.

A second study published in 2020 using the Trauma Quality Improvement Project database included 37,931 patients with severe TBI from 825 trauma centers (Williamson et al. 2020). Of these, 7,864 (20.7%) had documented WLST. As in the prior studies, the decision to initiate WLST occurred within a median of 3 days (IQR, 1–7 days) from hospital admission. Several non-injury-related factors—namely, age (older, more likely), race (white, more likely), payor source (self-pay and Medicare, more likely) and geographic region (Midwest and Northeast, more likely) were significantly associated with WLST. Taken together, the findings from these two studies indicate that WLST is common after TBI, typically occurs within 3 days of injury and is not limited to the elderly.

HOW OFTEN DO PERSONS WITH DOC RECOVER, WHEN DO SIGNS OF RECOVERY EMERGE AND HOW MUCH IMPROVEMENT IS POSSIBLE?

From 1995 to 2018, clinical reasoning about the prospects for recovery in persons with DoC was informed

by the American Academy of Neurology's practice guideline on prognosis in the persistent vegetative state (PVS) (American Academy of Neurology 1995) and its case definition on the minimally conscious state (MCS). The PVS guideline stated that, with a high degree of clinical certainty, this condition could be judged to be *permanent* 12 months after TBI and 3 months after non-TBI, in both adults and children. The MCS case definition advised that most patients who remain in this condition for 12 months remain severely disabled.

These influential guidelines likely contributed to present-day nihilism on the probability of recovery from prolonged DoC and have normative implications (Fins 2015). Unfortunately, the recommendations for permanence were based on sparse data and follow-up that did not extend past 12 months. Subsequent investigations have shown that many persons with prolonged DoC do not recover clearly-discernible behavioral signs of consciousness until after the typical ICU window for WLST has closed (Giacino et al. 2020). Longitudinal studies extending out to five years demonstrate that approximately 20% of patients admitted to inpatient rehabilitation unable to follow commands recover functional independence and are judged capable of returning to school or work (Giacino et al. 2018a). Based on these data, updated practice guidelines sponsored by the American Academy of Neurology, American Congress of Rehabilitation Medicine and the National Institute on Disability Independent Living and Rehabilitation Research were published in 2018 (Giacino et al. 2018b). The guidelines strongly recommended that clinicians avoid statements suggesting a universally poor prognosis before 28 days post-injury and called for replacing the term, "permanent vegetative state," with, "chronic vegetative state." The frequency of late recovery observed in recently-completed long-term outcome studies stands in stark contrast to the prevailing high rates of early WLST reported in this population and helps inform the normative obligations of providers.

We believe the protections against inequity afforded by the prospective benefit framework can be enhanced further by appealing to a normative and legal-rights-based approach (Fins 2015). While an economic argument is interesting, persons with DoC are also due legal protections centered around the application of the Americans with Disabilities Act (ADA) (Fins et al. 2020). The ADA calls for the maximal integration of individuals with disability into civil society, back into the nexus of their families, homes

and communities as is possible. For persons with DoC, this integration hinges access to clinical and rehabilitative services that can help restore autonomy and functional independence.

Our support for the prospective benefit approach is underpinned by evolving empirical knowledge summarized in the updated DoC practice guidelines demonstrating that a significant proportion of persons who remain unconscious during the ICU stay (i.e. the period during which goals of care are established), eventually achieve functional independence (Giacino et al. 2018a). The new guidelines, coupled with Peterson's invocation of prospect theory, reinforces the civil and disability rights of this population and their enfranchisement with respect to health care services. While we believe that allocation decisions should be predicated upon an affirmation of civil and disability rights and not an economic model, we are pleased that prospect theory aligns with these rights. We agree with Peterson and colleagues that it is not necessary to know precisely which persons will benefit to determine the net benefit of resource allocation *in toto*. Resource expenditure for persons with DoC is justified by virtue of prospective benefit, at least until sufficient evidence is garnered to reduce the high level of uncertainty attendant to early person-specific prognostication.

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