

COMMENTARY

Consciousness, Conflations, and Disability Rights: Denials of Care for Children in the “Minimally Conscious State”

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Abstract: This essay critiques the fiercely utilitarian allocation scheme of Cameron et al. Children have no hope of recovery if their lives are cut short based on administrative protocols that misrepresent the nature of their conditions. Unilateral futility judgements - especially those based on a false predicate - are discriminatory. When considering the best interests of children, we should see possibility in disability and not advance ill-informed utilitarianism.

In their essay, “Raqeeb, Haastrup and Evans: Seeking Consistency Through a Distributive-Justice Based, Approach to Limitation of Treatment in the Context of Dispute,”¹ Cameron et al. advance a fiercely utilitarian framework to deny care to children described as being in the minimally conscious state (MCS). Their argument is made within Britain’s National Health Service, a universal coverage system

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which Norman Daniels describes as a closed system of justice where saved resources accrue back to beneficiaries.² Beyond the questionable generalizability of their argument beyond Britain’s NHS, their appeal to distributive justice is flawed by its mischaracterization of MCS in children. This error undermines the factual basis for their appeal to distributive justice as they seek to deny care to children with serious brain injury.

MCS is state of liminal consciousness in which patients demonstrate an awareness of self, others, or the environment.³ In contrast to patients in the vegetative state,⁴ those in MCS may respond to their name, look up when someone enters the room, reach for a cup, and even speak. At a physiologic level, they are also distinct from patients who are vegetative⁵ because they have intact distributed neural networks.⁶ On neuroimaging they can perceive language⁷ and experience pain.⁸ Fundamentally, unlike those in the vegetative state MCS patients are conscious.

Despite the protestations of the authors about the high costs of ventilator support, MCS patients do *not*, by definition, need to be on a ventilator. While they may need respiratory hygiene to prevent aspiration, they have intact brain stems and so breathe on their own. This is a salient factual error given that the authors’ rationing scheme is predicated upon the cost of mechanical ventilation, asserting that its benefit should be subject to the same scrutiny as other treatments.

Speaking of definitions, it is curious that despite the predicate of the expense of MCS and the alleged need for ventilator support, the authors never once proffer a definition of MCS. This is even more troubling because the authors make the claim that their appeals constitute “... ‘Precision Justice,’ mirroring the advance of precision medicine.” It is difficult to weigh

utilities when one gets the particulars wrong at an evidentiary level. Indeed, as I have asserted in a forthcoming anthology on precision medicine,⁹ there is an emerging science related to disorders of consciousness where precision of diagnosis is tied to emerging treatments such as the use of amantadine¹⁰ and neuromodulation.¹¹

The lack of an evidence base advanced by Cameron et al. is even more scientifically and normatively problematic given that the American Academy of Neurology, the American College of Rehabilitation Medicine and the National Institute on Disability, Independent

to limit the care of these children. For many of them, MCS is a conceptual conflation that may not even exist as a legitimate diagnostic category.

The authors' epistemic certainty of what constitutes the "best interest" of the child becomes ever more disquieting because a child's nervous system is in flux. Early in life there is the potential for developmental workarounds.¹⁹ This hopeful biological process, however, can be derailed absent human engagement, focused rehabilitation, and access to assistive technologies. If children are neglected and relegated to what is euphemistically described as "custodial care,"²⁰

Instead of therapeutic nihilism, why not view our collective obligations to children with severe brain injury through the prism of disability law? Why not invoke new insights from translational neuroscience to frame our collective obligations? When consciousness is present, it should be identified, celebrated, and given voice. When considering the best interests of children, we should see possibility in disability.

Living and Rehabilitation Research have issued a practice guideline setting standards for the diagnosis and treatment of patients with disorders of consciousness based on a ten-year evidence-based review.¹²

Despite this progress, diagnosis, and prognostication in MCS patients remains challenging. The behaviors that distinguish MCS from VS are episodic and intermittent so when MCS patients do not exhibit signs of awareness they can appear vegetative, leading to a failure to identify consciousness in 41% of cases.¹³ Prognosis is equally perplexing as the temporal dynamics of MCS are *not* time dependent. As Lammi has shown, the length of time one is in MCS is *not* predictive of emergence from MCS.¹⁴ Finally, there is the challenge of covert consciousness, or cognitive motor dissociation, where patients evidence volitional responsiveness on neuroimaging but not do so behaviorally.¹⁵

Pediatric diagnostic and prognostic challenges are even more challenging as children start off with a primitive nervous system that is developing. Early on, it may be difficult to classify children as minimally conscious as the requisite visual, motor, and language-based skills necessary for assessment have yet to develop.¹⁶ Moreover, assessment tools used to evaluate MCS in adults¹⁷ are only now being modified and calibrated for a pediatric population.¹⁸ Given this evolving nosology, it is remarkable that the authors use MCS as a stalking horse for their rather draconian approach

they will miss critical developmental milestones compounding the impact of their initial injury.

Of course, children have no hope of recovery if their lives are cut short based on administrative protocols that mischaracterize the nature of their conditions. These unilateral futility judgements marginalize parents, the child's natural surrogates, and operate in willful violation of disability law, including the UN Convention on the Rights of Persons with Disabilities and the Americans with Disabilities Act, each of which call for the integration of people with disabilities into civil society.²¹ It is self-evident that children who are prematurely withdrawn from life-sustaining therapy before they can manifest their potential will be irreversibly marginalized. While decisions to withhold or withdraw care can be ethically proportionate,²² the factual predicate asserted by Cameron et al. makes any judgement of proportionality impossible. In this context, it is discriminatory to assert that continued treatment is harmful because of cost.

Instead of therapeutic nihilism, why not view our collective obligations to children with severe brain injury through the prism of disability law?²³ Why not invoke new insights from translational neuroscience to frame our collective obligations?²⁴ When consciousness is present, it should be identified, celebrated, and given voice.²⁵ When considering the best interests of children, we should see possibility in disability.²⁶

Note

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