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SPECIAL COMMUNICATION

Disorders of Consciousness: Outcomes, Comorbidities, and Care Needs

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Abstract

Over the last decade, research on patients with disorders of consciousness (DOC) has suggested that their prognosis for functional recovery early after injury is surprisingly positive, particularly for those with traumatic etiologies; that meaningful recovery proceeds for longer intervals than previously appreciated; and that such individuals are often medically complex and challenging to manage. However, access to intensive specialty rehabilitation is limited for most individuals with DOC in the United States. The evolving understanding of DOC calls for a reconsideration of appropriate models of care. This collection of articles provides insight into the functional recovery of individuals with DOC, new tools for assessing prognosis, and the patterns of comorbidity that complicate the recovery process. In addition, models of care from the United States and Europe that attempt to address the needs of patients as well as their caregivers are presented.

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Rehabilitative care in the United States for individuals with disorders of consciousness (DOC) has had a chaotic history. In general, a systematic approach to the rehabilitation of individuals with severe brain injury was uncommon until the 1970s because high levels of cognition were assumed to be central to the adaptations and compensatory strategies required in rehabilitation. As organized brain injury rehabilitation programs developed and evolved in the fee-for-service health care environment of the 1980s, some were specifically designed to deliver intensive rehabilitation and "coma stimulation" to patients with DOC and were reimbursed by insurers as long as rehabilitation goals remained. It was not uncommon to find patients in a vegetative state undergoing several hours of daily therapy for many months after injury regardless of the neurologic progress achieved. Faced with the growing costs of such programs and without evidence that they altered the trajectory of recovery, the pendulum swung in the opposite direction. Highly restrictive coverage policies were adopted by many public and private insurance plans. At present in the United States, many health care payers require that a patient with brain injury be at least in a minimally conscious state and undergoing identifiable functional improvement to gain admission to acute inpatient rehabilitation programs.[1] This is a particularly challenging standard to meet, in view of a number of studies demonstrating that misdiagnosis of a patient's level of consciousness is very frequent in the hands of nonspecialists.[2-4]

For those not directed to inpatient rehabilitation, varying levels of medical support are commonly delivered in skilled nursing facilities or in their caregivers' homes, depending on insurance funding and family support. Although this is the predominant payment policy in the United States, it is not universal here, nor globally. In the Veterans Affairs system, patients with DOC receive a 90-day trial of acute inpatient rehabilitation to receive intensive neurobehavioral assessment, address medical comorbidities affecting recovery of consciousness and promotion of general health, and family intervention to prepare for discharge to community living, if desired.[5] Many patients who are covered by Workers' Compensation also receive acute inpatient rehabilitation. In addition, several European countries provide initial intensive

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rehabilitation for all patients with DOC or with traumatic DOC. Interestingly, these systems of care that provide early intensive rehabilitation to individuals with DOC are systems that are responsible for the long-term costs of such patients' care.

Such early intensive rehabilitation care is thought to provide benefits for both patients who make functional progress and those who do not. Identification and management of medical complications may reduce later acute care hospital readmissions, as well as provide a more stable physiologic milieu for neurologic recovery. Simplification of care needs and family training and support may make it possible for such patients to be cared for in their family homes. Ongoing refinement of prognosis may support more rational care decisions in the long term. Importantly, an ongoing connection to a specialized rehabilitation program may allow for the detection of late functional change that can be capitalized on.

Against this policy backdrop, there have been enormous strides in research on DOC. The vegetative state and minimally conscious states have been defined and operationally distinguished, which alone has led to an enormous growth in diagnostic and prognostic research.[6] New assessment tools, which can play a role in accurate diagnosis, have been developed and psychometrically evaluated.[7] Longitudinal outcome studies have proliferated, providing evidence of substantial late recovery.[8-12] Advances in electrophysiology and functional imaging have provided an insight into brain activity, as distinct from motor behavior, suggesting that some individuals who appear unconscious on behavioral grounds may have occult evidence of conscious mental activity.[13-18] And several treatments have now been shown to affect function in at least some individuals with DOC.[19-21]

Research on DOC takes place in a clinical context, and health care coverage policies for individuals with DOC have an enormous secondary impact on the progress of research. The infrastructure to conduct mechanistic and clinical research generally resides in universities and large rehabilitation treatment programs. Yet in the United States, patients with DOC are divorced from such systems within weeks of their injuries and placed in widely distributed homes and nursing homes in which they are generally cared for by primary care clinicians with no specialized training in DOC diagnosis and comorbidities. Thus, they are underrepresented in rich longitudinal databases such as the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems and difficult to recruit into well-designed treatment studies in which large sample sizes are needed. Indeed, much of the recent innovative research on DOC comes from Europe where there is generally greater access to rehabilitation.

No large randomized trial has compared 2 or more systems of care for individuals with DOC in terms of the functional outcomes that result or the costs generated. Unfortunately, such a trial is unlikely to be done unless it is underwritten by the payer community, because no research grant can support the costs of an inpatient treatment program that is not covered by insurance. Moreover, access to intensive inpatient rehabilitation for higher level patients with brain injury is similarly unsupported by randomized trials for similar reasons. However, evidence-based medicine is defined not as determining whether or not optimal evidence exists, but as making a decision with the *current best available evidence*.[22]

List of abbreviations:

DOC **disorders of consciousness**

This collection of articles represents an international collaboration initiated by the Disorders of Consciousness Special Interest Group of the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems and the Disorders of Consciousness Task Force of the Brain Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine. This collection of articles was solicited and initially edited in an attempt to advance the best available evidence relevant to systems of care for individuals with DOC. The articles address 3 subtopics relevant to this population: prognosis, care needs, and models of care. In line with the research infrastructure issue discussed above, these studies were conducted primarily in systems of care in which rehabilitation is provided to patients with DOC. Thus, generalization to the many patients cared for in other systems must be done with caution.

Prognosis: Prognosis for functional recovery is critical to the planning of rehabilitation services. Indeed prognostication commonly begins in neurologic intensive care units. At the extremes, if a patient has no potential to improve, rehabilitation is futile, and if recovery is guaranteed to be swift and complete, rehabilitation is unnecessary. Implicitly, the provision of intensive rehabilitation to higher level patients with brain injury assumes that they can improve functionally but that they will need considerable help and support in optimally doing so. Conversely, the early referral of patients with DOC to less intensive models of care seems to assume a negative prognosis, or at least a prognosis that cannot be positively impacted by intensive rehabilitation. Several articles in this collection provide an insight into prognosis and long-term outcome for individuals with DOC. Collectively, these studies suggest that a large proportion of patients with DOC who are admitted to inpatient rehabilitation regain consciousness and even orientation, and that their further recovery can go on for more than 2 years (Whyte J, Nakase-Richardson R, Hammon FM: Functional outcomes in traumatic disorders of consciousness: 5-year outcomes from the NIDRR Traumatic Brain Injury Model Systems, this issue; Nakase-Richardson R, McNamee S, Howe L, et al: Rehabilitation of active duty military personnel and veterans with disorders of consciousness, this issue), and that structured programs that care for patients with the worst prognosis may result in surprisingly positive outcomes (Grill E, Klein AM, Howell K: Rationale, design and preliminary results of the prospective German registry of outcome in patients with severe disorders of consciousness following acute brain injury, this issue). They also suggest that medical comorbidities (Ganesh S, Guernon A, Chalcraft L, et al: Medical comorbidities in disorders of consciousness patients and their association with functional outcomes, this issue) and the mechanism of injury (Nakase-Richardson R, McNamee S, Howe L, et al: Rehabilitation of active duty military personnel and veterans with disorders of consciousness, this issue) may affect prognosis and that advanced imaging techniques may hold promise for refining prognostic predictions (Vogel D, Markl A, Yu T: Can a mental imagery fMRI predict recovery in patients with disorders of consciousness? this issue). Together, these articles add to the growing body of literature demonstrating that patients with profound brain injury can continue to recover meaningful function for considerable periods, suggesting that systems of care must be able to identify and respond to functional improvement with updated rehabilitation plans in the acute and chronic phases of recovery.

Care needs: Besides monitoring for and being attentive to functional change, what do individuals with DOC and their families need from a system of care? Several articles in this