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Leveraging the patient support network in traumatic brain injury

TRAUMATIC BRAIN INJURY AND ASSOCIATED DISORDERS CAN OBSTRUCT THE PATIENT-CARE PATHWAY

A recent single-topic issue of this journal (*JRRD*, 49(7)) gave forum to common—yet often overlooked—sequelae of traumatic brain injury (TBI): sensory and communication dysfunction. The issue gave excellent context not only for the diffuse and idiosyncratic nature of these deficits but also for their prevalence. Perhaps the most compelling aspect of sensory and communication disorders following TBI is that impairment of these compartments frequently affects perception and cognition as well. This phenomenology was addressed directly in some of the articles [1–3] and tacitly in others.

The high association of sensory and communication deficit with TBI presents a quandary for the care provider, who relies on oral communication in assessing, managing, and monitoring therapies. Particularly for specialists treating TBI—and especially so for those treating Veterans with service-connected injury—discourse with the patient is an integral aspect of history-taking, assessing tolerability and compliance, and counseling. More broadly, the Department of Veterans Affairs (VA) regularly incorporates patient feedback in its continual effort to provide cutting-edge care. The dilemma is how to give a voice to those who are challenged in speaking to their own needs.

Furthermore, what roles do these associated disorders play in the widely reported estrangement of brain-injured patients from proper therapy [4–5]? As with any condition, there are many reasons why treatment might elude persons with head trauma [6–7]. For our Veterans with brain injuries, obstructions to care may also involve, among other things, factors of a personal (e.g., fear of stigmatization [8]), circumstantial (e.g., lack of full appreciation for the severity of their injury or awareness that diagnosable and treatable conditions exist [9]), or operational nature (e.g., difficulty in managing complex activities associated with a multistaged rehabilitation and restoration [10]). These considerations compound the problems arising from the organic consequences of the original physical insult, viz. the impairments of higher cortical function, i.e., sensory perception, cognition, and emotional management.

Bridging this gap in care delivery would equate to greater success rates in rehabilitation of head trauma, and for our service personnel greater faculty for repatriation. We should ask ourselves whether we fully appreciate the barriers that constrain our ability to provide effective care for patients with TBI, and if not, we should ask whether the unique challenges posed by TBI and its associated disorders could be more facily identified by the patients themselves in cooperation with their support network. Could a crowd-sourced approach facilitate our stewardship of care?

A COMMUNITY ISSUE CALLS FOR A COMMUNITY SOLUTION

More so than most other clinical issues facing our Veterans, TBI presents a spectrum of consequences with a complex, diachronic evolution. Though TBI of itself often associates with impaired executive function, Veterans with brain injuries also have a high comorbidity with posttraumatic stress disorder (perhaps as many as 65% of TBI patients) [5,11], suggesting an even greater likelihood of stress on maintenance of employment, interpersonal relationships, and community integration [12]. These are matters central to the quality of life of TBI patients and rank highly among the primary objectives of our returning soldiers and separated Veterans [13]. Moreover, they are burdens borne not by the Veteran alone, but by the entire community.

Though perhaps unpredicted, it may be that the distributed effect of brain injury creates a unique opportunity for improved utilization of available healthcare opportunities. Family members often attend VA appointments and can articulate the patient's needs with great cogency; it is not unusual for loved ones to advocate vociferously when their Veteran demures [14]. This paradigm is not unique to TBI [15], but TBI may be among the circumstances where this facilitated communication is of the greatest potential effect: members of the family and the patient's support network may be the more effective agents in articulating the special needs of the Veteran with brain injury.

A TWIST ON LINCOLN'S MANDATE

VA operates in service to President Lincoln's advocacy for the wounded warrior, i.e., "To care for him who shall have borne the battle, and for his widow and his orphan" [16]. Ironically, it may be the empowerment of the "widow and orphan" that facilitates the connection of patient to care in cases of head trauma. That is, experience shows that the patient support network can have equally important voices in identifying opportunities to improve care. For patients with TBI, their support network may

well be critical in facilitating care [17]; they should be actualized in the clinic whenever possible.

Given the wide recognition of sensory and communication disorders associated with brain injury and the heavy implication for compromised perception, cognition, and executive function, the challenges facing both the patient and the clinician are steep. The recent single-topic issue speaking to this topic was replete with subtext invoking the widely felt burden of brain trauma within the family and throughout the community. In keeping with the tradition of VA clinicians engaging the patient's support system and sustaining the VA Mission Statement, we urge: let us continue to consider ways to leverage the support of the family and community in ushering the patient to care and care to the patient.

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