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 facilely identified by the patients themselves in cooperation with their support network. Could a crowd-sourced approach facilitate our stewardship of care?