

2nd Place: Humpty Dumpty without the King's Men

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*Humpty Dumpty sat on a wall.
Humpty Dumpty had a great fall.
And all the king's horses and all
the king's men
Couldn't put Humpty together
again.
~Mother Goose*

Equating the human brain to an anthropomorphic egg from a children's nursery rhyme may seem odd, but the comparison is apt for victims of traumatic brain injury (TBI). Like Humpty Dumpty, who fell and shattered into millions of pieces, these patients often suffer widespread damage across the brain; like Humpty Dumpty, who could never be put back together again, those who have suffered trauma to the head sustain lifelong physical, cognitive, and psychosocial impairments. There remains, however, one fundamental distinction between the two: all of the king's horses and all of the king's men tried to save the one and only Humpty Dumpty. It was a valiant and commendable effort. The same cannot be said about the treatment of 1.7 million annual TBI patients in the United States (1). People are five times more likely to incur a traumatic brain injury than multiple sclerosis, spinal cord injury, HIV/AIDS, and breast cancer combined, and yet no army fights for them or attempts to piece them back together (2). These patients are often forced to patch their lives on their own. The treatment of traumatic brain injuries is a profound public health concern, and a mounting one at that. From 2002 to 2006, TBI-related ER visits increased by 46%, hospitalizations increased by 34%, and deaths increased by 27% (3). The characteristics uniquely attributed to traumatic brain injuries that research, funding, and social acceptance for these patients is limited.

TBI patients share only one similarity—their status as TBI patients; barring that, they vary across the board in cause, severity, diagnosis, and treatment,

making it a grueling task to research their heterogeneous condition. Traumatic brain injuries stem from motor vehicle accidents, falls, assaults, and impact-related events such as sports and war injuries, each of which generate a range of mild to severe behavioral and mental alterations, depending on the areas of the brain that are injured. Since the phrase “traumatic brain injury” functions as an overarching label for a diverse patient population, grouping together all types of brain damage that occur in this manner, symptoms exhibited by TBI patients are often times extensive yet undetectable. They face many impairments, including those in memory, decision making, planning, sequencing, judgment, attention, communication, literary skills, thought processing speed, problem solving skills, organization, self-perception, thought flexibility, safety awareness, and/or new learning (2). However, neuroimaging and neuropsychological evaluations possess considerable limitations in the diagnostic sensitivity and specificity necessary for such distinct and expansive incapacities. Executive function (e.g., planning, decision-making) deficits are difficult to identify with standardized tests alone; in addition, patients often perform with pronounced inconsistency due to neurologic, emotional, and contextual factors, ensuring the difficulty of interpreting test results at face value. Raising the already trying challenge of treating and researching these patients, the recovery process prolonged but unpredictable, with patients making neurological improvements during the initial weeks, months, and even years following the injury. Thus, assessments completed early on in recovery many not be accurate of the individual's strengths and weaknesses. Take two hypothetical teenage boys who were in car accidents, and whose injuries look identical on paper—their brain scans show the same site of injury—but one might recover well enough to go to college and have meaningful relationships, while the other won't (4). It's hard to explain why, except that each case is different—each injury is different and each brain is different. In this way, the expression “traumatic brain

injury” serves not as an identifier of a condition, but as a generalization of injuries too nonspecific for neurologists and other clinicians to successfully treat and research.

Effective treatment—short-term and long-term—is restricted by the lack of financial support from the government and private insurance agencies. For the 5.3 million Americans, around 2% of the nation's population, currently suffering from TBI, the government has meagerly spent roughly three dollars for the treatment and services of each brain injury survivor (2, 5). In their eyes, “cognitive deficits are not really considered medical problems,” as exposed by Cathy Crimmins in *Where is the Mango Princess?*, a book that details the course of her husband's TBI and some of the ubiquitous struggles that TBI survivors and their family must face (6). TBI patients have invisible wounds, Crimmins says, and that is perhaps their greatest stumbling block. No one can see their injury; they appear normal from the exterior, therefore people assume that they must be so internally as well. Crimmins recounts her ongoing battle with her health maintenance organization (HMO) just to obtain minimal benefits for her husband Alan, who was run over by a speedboat in a boating accident at a lake. Not only did the insurance company deny her an air ambulance to transport her husband from Canada to the United States after his injury, claiming “[they] were not so sure [her] husband's condition warrant[ed] an air ambulance,” but they also refused him more than three weeks in rehabilitation when his injury required at least three months of treatment (6). The HMO's sole concern was that Alan could now walk around independently, not realizing that he was still inept at behaving appropriately, making sense in conversations, and handling stress or excitement without becoming agitated. Crimmins often times found herself wishing that there was a visual aspect to her husband's injury like a cast or crutches so that people could see his impairment, and not voice statements such as “gee, he doesn't look that bad” (6). Many might argue that her experience was an exception, but it is clear that an absolute

disregard for cognitive impairments in the TBI patient population as a whole is an ongoing trend in today's society. Those who cannot afford state-of-the-art rehabilitation centers cannot count on support from Medicare, Medicaid, or insurers. While these programs may cover brain surgeries and intensive care necessary to save the lives of such patients, they consistently skimp on benefits for rehabilitation programs that would allow patients to relearn abilities destroyed by brain trauma. In fact, research shows that as the demand for medical care decreases post injury, the demand for nonmedical services and support spikes immediately after the patient's discharge, pending through the time in their lives when insurance coverage expires and they attempt to integrate into the community, up until the time of death.

Besides being "invisible" to observers, TBI is a difficult condition to garner support for in the community; rather than invoking sympathy, it frequently repels societal acceptance. TBI patients have been known to "indulg[e] in the grossest profanity (which was not previously [their] custom)." Upon the onset of her husband's disease, Crimmins describes her husband as "mean and all nasty like," referring to him as "another Alan." For this same reason, TBI survivors and their spouses have a high divorce rate: 75% (6). The TBI patients' inappropriate behavior and unremitting tempers, which people often forget are not voluntary actions but rather a construction of their injury, expel them as outcasts in society as well as in their homes. Few care to fund or research or foster what they perceive as a vulgar population of patients; few care to spread social awareness about them either. Instead, the majority of TBI survivors, especially war veterans, are cast aside, and they often struggle to assimilate back into society (4). As particularly high-functioning individuals with TBI attempt to resume their usual daily activities, the environment places increasing demands upon them. Occasionally, a TBI survivor returns to the workplace. At first, coworkers celebrate the return of their colleague who has overcome a terrible accident and survived in what Crimmins dubs the "halo effect." They may even cover for him by helping him out with his extra workload so as to ease him back into the routine. "Then, after a few months, the changes in his short term memory and ability to juggle projects or his weird penchant for cornering them at the coffee machine and telling them long,

tedious stories begins to wear on them" (6). Essentially, coworkers get tired of mopping up after their colleague's mistakes and doing extra work because he is not up to speed. They have assumed, mistakenly, that he is all put back together again. After then, after a year or so, the once triumphant TBI patient will quit either in frustration or fatigue, or perhaps he'll be fired because of unfavorable evaluations. "Case studies of brain-injured people who try to return to work without help chronicle how those workers often lose their jobs years down the road, and by that time no one really attributes it to the brain injury because they think all that was over a long time ago" (6). What people don't realize, though, is that the TBI patient is a patient for life.

The characteristics inherent to traumatic brain injury condemned those suffering from the condition to a lifetime of difficulties. Not only is TBI complicated to diagnose and treat, but rehabilitation is not adequately funded. Even if patients independently salvage enough of their old selves to consider rejoining the community, their TBI has socially ostracized them to the point of limited recovery. Society's approach toward and misunderstanding of TBI victims have condemned them to suffer alone. The leading cause of death and disability in the United States, affecting people of all ages, races, ethnicities, and incomes, has but a minority of healthcare professionals championing for their cause. TBI patients are lost to all but a tiny, yet growing cluster of beacons for hope and change. Dr. Melissa Duff, one of such beacons, is a researcher at the University of Iowa Hospitals and Clinics. She founded the first national TBI patient registry in 2011 (4). In an interview, Dr. Duff says that the TBI registry is a mechanism to "know more about who's going to get better, how can we help them get better, and what we can do to put all brain-injury survivors on a better life trajectory" (4, 7). Her registry indicates the beginnings of interest in clinical research that translates into treatment and hope, beyond saving of lives of such patients. She is one of the king's men endeavoring to save the Humpty Dumpties of today. It is a valiant and commendable effort, but one that requires an entire army— more researchers, more funding, more awareness— to succeed.

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4. M. Duff. Personal communication. July 15-27 2012. "Shreya, I'm writing to grant you permission to use any portion of our personal communications this summer in your essay for the DUJS International Science Essay Competition. Good luck, and let me know if I can provide any additional information."
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