

# Shannan Keen - Brain Foundation Grant – Essay

## Disorders of Consciousness; A brief discussion of the practice, science and compassion of effective assessment

Can you imagine the horror of being misdiagnosed, trapped inside your own body, unable to communicate due to complete paralysis yet fully aware of everything that is going on around you? This can be, and for many people is, the outcome following traumatic brain injury (TBI) or coma leading to a disorder of consciousness (DoC). Approximately 43% of coma patients are being misdiagnosed and treated as being in Vegetative State while they are in fact in Minimally Conscious State.

This essay examines the methods available for evaluating TBI and DoC patients and looks at ways in which we, as clinicians, can be more effective and compassionate whilst maintaining rigorous, scientific standards using validated, appropriate tools.

In diagnosing DoC patients, the neuropsychologist must select appropriate neuropsychological assessment batteries (NAs) in order to sample a wide range of functional domains suitable for each individual. Performance on each test yields implications for different neurofunctional domains. The combination of a person's test performance, objective scores, behavioural observations, family/carer's reports (daily functioning, memory, changes in behaviour and cognitive abilities) together form the basis of each patient's diagnosis and hence treatment.

A carefully considered and constructed NA, through behavioural evaluation, helps us to understand *whether* cognitive dysfunction exists and *where* cognitive dysfunctions lie. For example, what may appear to be inability or unwillingness to read following TBI may be due to problems in specific brain regions of language perception or processing, or in visuoperceptual abilities, or in the patient's ability to attend to stimuli.

In cases of DoC, neuropsychologists might be guided by imaging reports depicting the region of damage and its putative correlations with cognition and behaviour. In regards to evaluation and diagnoses using neuroimaging techniques, the brain appears embedded; inputs and outputs overlap, interact and cooperate, neurons representing the same location may excite or inhibit each other, layers may be involved rather than single neurons, connections are strengthened through use etc. We are only beginning to understand these brain systems. It is clear that the site of brain lesion at best provides a guide to the type of impairments a patient may have. Clinicians and neuropsychologists must therefore avoid making assumptive correlations between site of brain damage, observed behaviour and expected cognitive deficits.

Neuropsychologists must understand the frustration, fatigue, helplessness and anger that patients feel. We must ensure we give patients sufficient time to rest between tests, show understanding and patience and adjust our testing techniques to allow for the patients' reactions and emotions. Although a patient's ability to perform on psychometric tests may be poor, the way they approach clinical tasks – their productive abilities – may reveal hidden, coherent abilities. Therefore, understanding and collaboration are important in effecting treatment and aiding rehabilitation.

Being evaluated in clinical settings can manifest itself as the flip side of personal control - helplessness. This has been found to be particularly detrimental in TBI and DoC. Self-efficacy expectations play an instrumental role in determining how long and how hard an individual will continue trying when faced with negative outcomes. Indeed, Bandura stresses that "...cognitive events are induced and altered most readily by experiences of mastery arising from successful performance." In an effort to reduce helplessness and

anxiety, it is beneficial to get the patient's family or carer to explain where the patient's strengths lie and intersperse testing with those they do well at.

Finally and importantly, because every patient is an individual, there is unlikely ever to be *the* answer to assessing TBI and DoC. There must be an holistic, existential approach, a sensitive understanding that life and behaviour is in essence healthy and free, not necessarily amenable to rigid, neuropsychometric analysis, nor simply a result of crude drives and impulses - what Oliver Sacks calls the 'blind force of the subcortex'.