

Self awareness in persons with brain injury



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Acquired brain injury (ABI) is a major medical issue which can affect anyone regardless of class, race, ethnicity, gender, or age. It can be defined as “ damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent and cause partial functional disability or psychosocial maladjustment” (Brain Injury Association, 2009). People who have sustained an acquired brain injury are not easily pinpointed in society due to the lack of external symptomology, and therefore ABI is usually referred to as “ the hidden disability”. This title, named accordingly, is due to the extensive damage to their cognitive and social functioning and less to do with their physical appearance, which in many cases remained unchanged.

So what causes ABI, and who can be affected by it? This type of injury can occur due to a series of incidents, and anyone can be affected by it. Some possible incidents include a road traffic accident, a fall, an assault, a stroke which causes damage to the brain, complications during brain surgery, tumours, viral infections, or lack of oxygen to the brain (a possible result of a heart attack, hypoxia, or anoxia). ABI can be split into two types – traumatic and non-traumatic. A traumatic brain injury can occur due to a closed or open injury. The more common type, closed injury, occurs when “ the brain is bounced around in the skull due to a blow to the head”, such as the impact from a road traffic accident. What this impact results in is damage to the brain tissue. An open injury, on the other hand, occurs when “ an object such as a bullet, fractures the skull and enters the brain” (Headway, 2009). This type of injury is less common and usually damages a specific part of the brain, therefore resulting in specific problems. The other type, non-traumatic

injury, is simply one that does not occur as a result of a trauma, such as a stroke or a tumour.

Prevalence of ABI is unknown within Ireland, however Headway (2009), an Irish organisation specialising in brain injury rehabilitation, accumulated ABI data from various countries and applied this to an Irish population in order to estimate the prevalence. With this information they suggested that between 9, 000 and 11, 000 people sustain a traumatic brain injury each year in Ireland. They estimated that there are approximately 30, 000 people in Ireland between the ages of 16-65 with long term problems following trauma to the brain, and that the 15-29 year old group are three times more likely to sustain a brain injury than any other group. Another Irish study, O'Brien & Phillips (1994), recorded individual patient details for all head injury admissions to the Neurosurgical Unit at Beaumont Hospital, Dublin. They estimated a prevalence of head injury among patients in Ireland to be approximately 13, 441 per year, which is just slightly higher than Headway's (2009) estimation. Results from the 225 patients they studied portrayed that road traffic accidents accounted for 48% of injuries sustained (the largest proportion), and falls accounted for 36%. The researchers also found that between 1987 and 1993 there were 3, 154 people killed and 64, 971 injured on Irish roads. Alcohol consumption prior to the injury was also found in 31% of cases. In a larger study, Tagliaferri et al. (2006) attempted to locate the prevalence rate of brain injury, this time in Europe. They claimed that " the absence of prevalence data hampers the full assessment of medical treatment and rehabilitation needs" (p. 265) and that prevalence studies in Europe are essential, and should be undertaken extensively. With this in

mind they suggest that “ brain injury patients will increase by 775, 500 each year in the EU, and that 6, 246, 400 people are alive with some degree of TBI [traumatic brain injury]” (p. 260). Thus we can conclude from these studies that Ireland has a prevalence rate of ABI from about 9, 000 to 13, 5000, a slight impingement upon Europe’s figures, but a worryingly high statistic for Ireland alone.

There are three levels of brain injury, which indicate the severity of the neurological injury - mild, moderate, and severe brain injury. To qualify for a mild brain injury, one must score between 13 - 15 on the Glasgow Coma Scale, which records the conscious state of a person. This type of brain injury can occur due to a brief loss of consciousness, and the patient may present himself or herself as confused, and suffering from a concussion. Symptoms that occur within this severity of brain injury are predominantly headaches, fatigue, irritability, sensitivity to noise or light, balance and memory problems, nausea, decreased speed of thinking, depression, and mood swings. A moderate traumatic brain injury can be diagnosed when the patient scores a 9 - 12 on the Glasgow Coma Scale. This injury occurs when there is a loss of consciousness that lasts from a few minutes to a few hours, and confusion lasts from days to weeks. Patients in this category usually make a good recovery with treatment. The last level of brain injury is severe brain injury, and this occurs when there is a prolonged unconscious state or coma that lasts days, weeks, or months. This category can be categorized into subgroups of coma, vegetative state, persistent vegetative state, minimally responsive state, akinetic mutism, and locked-in syndrome. (Brain Injury Association, 2009).

There are many changes and consequences that affect a person after they have suffered from an acquired brain injury, whether mild, moderate, or severe. These changes may be temporary, improving in time, or permanent, dictating the way they live the rest of their lives. Not only do the changes affect the victim, but they also affect the victim's support system (i. e. their surrounding family and community). Each brain injury is unique and subject to change, and depending on the severity of the injury, a patient will witness cognitive changes – shifts in the ability to think and learn, affecting memory, concentration, flexibility, communication, insight, and responses. Physical changes will also be apparent in the form of fatigue, headaches, chronic pain, visual and hearing problems, and sexual function. Behavioural changes may include impulsivity, irritability, inappropriate behaviour, self-centredness, depression, lack of initiative, and sexual behaviour.

Challenging Behaviour

As stated earlier, most people who have a head injury are left with a change in the form of their emotional or behavioural pattern. “ This is inevitable as the brain is the seat and control centre of all our emotions and behaviour” (Powell, 1994, p. 96). With this in mind, challenging behaviour alone has become synonymous with ABI as one of the main behavioural deficits that occur following injury. The literature of ABI has accentuated that challenging behaviour presents the most significant behavioural disturbance within this diagnosis, and can pose serious problems for their recovery, their family, and also their community. Kelly et al. (2008) provided evidence that challenging behaviours have often been associated with “ risks such as family disintegration, loss of accommodation, reduced access to rehabilitation or

community facilities and legal charges” (p. 457). Results of their study indicated that 94% of the patients they studied showed broad behavioural disturbance, with 60% engaging in four or more behaviour problems (p. 463). However, due to convergent opinions on what constitutes a challenging behaviour, defining such behaviour has become difficult. However, Headway Ireland (2009) have made one such attempt to define challenging behaviour:

“ any behaviour, or lack of behaviour of such intensity, frequency and/or duration that has the potential to cause distress or harm to clients/carers/staff or one which creates feelings of discomfort, powerlessness, frustration, fear or anxiety. It is also behaviour, which delays or limits access to ordinary community facilities and is outside socially acceptable norms.”

As mentioned earlier, types of behavioural problems that may occur following an acquired brain injury include agitation, depression, anxiety, self-centredness, withdrawal, physical aggression, increased/decreased libido, impulsivity, self harm, restlessness, paranoia, and many others. As each brain injury is unique, some patients may suffer with some symptoms, whereas others may not. Each person is entirely unique, with severities and symptoms being completely individual.

So why exactly do patients suffering from an ABI present with challenging behaviours? Powell (1994) suggests that there seems to be four main reasons why these challenging behaviours exist: “(a) direct neurological damage; (b) exaggeration of previous personality; (c) the stresses of adjustment; and (d) the environment the person lives in” (p. 97). With

regards to direct neurological damage, the challenging behaviour results directly from the damage done to the certain area of the brain. Many of the challenging behaviours stem from damage done to the frontal lobes, which are important for the regulation of emotions, motivation, sexual libido, self-control and self-awareness. Following a brain injury, the patients existing personality traits, tendencies, and problems may be exaggerated, “ it is as if the controls or ‘ brakes’ which modify and regulate the personality have been loosened, and traits and mannerisms become distorted and exaggerated” (p. 97). It is highly important for the professionals working along side the patient to be aware of the patient’s previous personality when attempting to understand their challenging behaviour. Thirdly, stress of adjustment can also be a major contributor to the challenging behaviour that persists in patients with ABI. Finding out that one can no longer do the simple things in life anymore, such as play their favourite sport or instrument, can be extremely frustrating and stressful for the patient. It is more likely that under these extreme conditions of stress that one would become more angry and irritable, and become more preoccupied with their problems than before. Finally, the social and physical environment can also contribute to the onset of behavioural problems. The social environment relates to the natural supports surrounding the patient such as family, friends, neighbours, and professional staff, whereas the physical environment depicts the patients setting, whether it’s an institutional setting or a family home. Taking into consideration both the social and physical environment, if the person suffering from ABI is not understood, and communication and support is poor, then their behaviour is likely to

deteriorate as a result. It is crucial for the patient to be in the correct environment to reap the best opportunities possible.

How others respond to the challenging behaviour of a person with an ABI plays a crucial role in the rehabilitation process, as well as the quality of life of family and friends surrounding the patient. Of concern is the setting in which the patient is located - " these behaviours can endure and worsen over time, particularly in unstructured settings where there is often little control over the environmental contingencies that govern behaviour" (Kelly et al., 2006). Alderman (2001) has stated how behaviour modification programmes can create profound changes within the neurorehabilitation setting. There exists an amalgamation of research conducted in this area with some very mentionable results.

Watson et al. (2000) conducted a case study on patient, JH, who had sustained a brain injury as a result of a gunshot wound, and developed severe behavioural problems. A differential reinforcement of low rates of responding (DRL) intervention was devised for 85 weeks, which allowed JH the opportunity to gain stars at the end of the day if he had absolved from aggressive behaviour to a created limit. This treatment resulted in JH's level of Clopixol being reduced from three times a day, down to two without any side effects on his challenging behaviour. DRL has demonstrated the effectiveness in reducing both " the frequency and severity of aggressive behaviour 10 years after a very severe TBI had been sustained" (p. 1011).

Other studies stress different approaches to treatment of challenging behaviours, such as remedial behaviour therapy approaches, or Rothwell et

al. (1999) who suggest the main emphasis in treating challenging behaviours should be upon behavioural assessment as it “ engenders an empathic understanding of what is often offensive behaviour, which helps reduce the stress experienced by the people affected by the behaviour and leads to respectful, individualized and holistic interventions” (p. 530).

Self-Awareness

As mentioned earlier, challenging behaviour is synonymous with ABI, however deficits in self-awareness have also been well established in the literature to be evident in patients with brain injury. Impaired self-awareness poses great challenges for rehabilitation, and also for the safety of the patient suffering from the ABI. Self-awareness can be defined as “ the capacity to perceive the ‘ self’ in relatively ‘ objective’ terms while maintaining a sense of subjectivity” (Prigtano & Schacter, 1991, p. 13). The ability to think subjectively and objectively of ourselves, and to adjust our behaviours accordingly, are abilities that are often overlooked, but are none-the-less crucial for daily living, and integration into society. These skills are commonly impaired following a brain injury, “ as both are constructs associated with executive functions and related to frontal-executive systems dysfunction” (Goverover et al. 2007, p. 913).

Oddy et al. (1985) undertook a study in a bid to portray the implications of a decreased level of self-awareness (specifically behavioural limitations) after traumatic brain injury. The researchers asked patients and their surrounding families to describe the behavioural problems that prevailed seven years following the brain injuries’ occurrence. The results noted that patients

tended to underestimate their problems in comparison to their families reports. For example, 53% of patients noted that memory problems were the most common long term difficulty, whereas 79% of the families noted memory problems as significant sequelae. Also, patients failed to report two problems that the families reported. 40% of the families noted that the patient behaved in a much more childlike manner, and also that the patients refused to admit to their difficulties. This study brought to light the issue of self-awareness impairment.

We have so far spoken of self awareness deficits and its prevalence within people who have ABI, but what exactly are the implications of such a deficit? It is widely suggested that an increased impairment of self-awareness is associated with increased problems in most other areas of the patient's life. For example, Larn et al. (1998) studied that ABI patients with poor self-awareness show less compliance and participation during treatment in rehabilitation. Malec & Degiorgio (2002) found that ABI patients with decreased level of self-awareness are considerably more at risk of being referred for more intensive rehabilitation. Malec et al. (2000) found that such patients require longer lengths of stay in rehabilitation; Sherer et al. (2003) found that patients are more likely to be associated with a poorer functional status at time of discharge from rehabilitation. Ezrachi et al. (1991) found that deficits in a patients level of self-awareness is foretelling of a low rate of return to employment following a brain injury. And finally, Ergh et al. (2002) found that a high level of impairment of self-awareness with the ABI patient is reflective of higher distress among caregivers (as cited in High, 2005).

With regards to treatment of impaired self-awareness in individuals with ABI, there is a vast range of methods which have been studied. Crosson et al. (1989) have shown that group therapy programmes can be beneficial in increasing intellectual awareness. Zhou et al. (1996) studied three adult males who “ were trained in knowledge of ABI residuals using a game format to present training information” (p. 1). Results suggested that all participants increased their knowledge relating to areas of behaviour, emotion, cognition, communication, physical, and sensory residuals. Many studies have exemplified the role of observation and feedback to improve individual’s level of self-awareness. For example, Schlund (1999) undertook a case study of a 21-year-old male who was a TBI survivor and was 5 years post-injury. Results of this study showed that report-performance measurement, feedback and review, positively altered the patients awareness deficit. However, observation and feedback are not without its faults as Bieman-Copland & Dywan (2000) point out. Their study suggested that direct feedback becomes confrontational and can lead to agitation among patients with severe brain injury. This study highlights the need for each treatment to be individualised to ensure the best possible outcomes of treatment. Fleming et al. (2006) evaluated the usefulness of an individualised occupation-based approach for participants dealing with ABI, specifically with regards to the level of self-awareness and emotional status. “ The unique focus of the program was the use of meaningful occupations to provide the individuals with experiential feedback of their current level of ability through the use of self-monitoring and supportive therapist feedback” (p. 51). The results supported the use of this type of therapy in increasing self-awareness, and that occupational performance may be highly important in increasing the

self-awareness of people with ABI. Finally, Goverover et al. (2007) conducted a randomised controlled study on the self-awareness treatment model, stipulated upon Togliola and Kirk's model (2000). Their study provided evidence for experiencing different tasks and everyday activities for enhancing self-awareness and self-regulation.

Although treatment of impaired self-awareness is crucial for the patient's full recovery, it has been studied that increasing the level of self-awareness in ABI patients can also have some negative consequences. Fleming & Strong (1995) suggested that the belief that increased self-awareness is essential for positive outcomes in rehabilitation and needs to undergo further investigation, as " a literature review suggests that the development of self-awareness can be associated with emotional distress in the individual" (p. 55). This study further exemplifies the necessity to create individual treatment plans when in rehabilitation.

Interventions

With technology constantly advancing in the medical sector, it is evident that sustaining a brain injury no longer suggests a death sentence. With this in consideration, the emphasis has shifted towards rehabilitation of those who have sustained such an injury in order to help them attain the best quality of life possible. Many interventions have been conducted and researched for improving self-awareness, and also for managing challenging behaviours, which directly improve the life of the patient.

There are limited studies focusing on the effectiveness of interventions in reducing self-awareness deficits, and whether these interventions contribute

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to positive outcomes in rehabilitation. However, in a literature review, Lucas & Fleming (2005) suggest that interventions in self-awareness can be broken into two categories – restorative/facilitatory, or compensatory. Within the restorative/facilitatory category, “ education, direct feedback, and experiential feedback [are] the most frequently recommended” (p. 163), with others such as behavioural therapy, psychotherapy and rating of task performance also being recommended. Education relates to ensuring the patient understands his or her injury and the impairments that this injury brings. This can be delivered through a variety of ways such as group therapy, visual aids, and support groups. Direct feedback following a task performance can be used to “ facilitate intellectual, emergency, and anticipatory awareness” (p. 164), whereas experiential feedback allows the patient to go through difficulty in a real-life situation and is useful in emergent and anticipatory awareness (p. 164).

Compensatory strategies then

As noted earlier, challenging behaviours and problematic social interaction have been linked to individuals with brain injury, which result in an amelioration of difficulties in areas such as family life, integration into the community and employment, to name but a few. Applied Behaviour Analysis (ABA) works with environmental stimuli that impede on the challenging behaviour, and it is “ behavioral [sic] research in the field of brain injury rehabilitation [that] is an effective means of identifying techniques for reducing challenging behaviours and improving adaptive skills” (Selznick Gurdin, Huber & Cochran, 2005, p. 15). This research is extensive and

incorporates many different behavioural interventions, all of which have been proven to be successful.

Within schools and residential programs, intervention procedures have been undertaken to reduce challenging behaviours that disrupt academic behaviour. Feeney & Ylvisaker (1995) incorporated antecedent treatment using “ graphic organizers, cuing, plan-do-review routines, and inclusion of the participant in decision-making.” This treatment reduced the intensity and frequency of aggressive behaviour evident in three males with TBI. Gardner, Bird, Maguire, Carrario, & Abenaim (2003) also reduced challenging behaviours using antecedent control procedures, however their success was due to interspersal and fading techniques. Selznick & Savage (2000) examined self-monitoring methods for individuals who had sustained a brain injury. These methods proved to be effective for “ increasing attending, academic responding, and task accuracy as well as for improving social skills with individuals with behaviour disorders, mental retardation, and learning disabilities” (p. 243). This study found that on-task behaviour increased to 89 - 100% for three boys with brain injury when these self monitoring procedures were undertaken. Consequence-based interventions have also been studied extensively in this area and prove to have significant positive results. Peck, Potoczny-Gray, and Luiselli (1999) used instructional motor activities when a 15 year old boy with ABI showed signs of stereotypy in the classroom. This intervention reduced stereotypy and maintained its reduction when treatment was faded.

Within the rehabilitation area, there has been extensive research depicting behavioural procedures that reduce challenging behaviour. Hegel (1988)

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implemented a token economy system to an 18 year old boy with a brain injury during therapy session in order to reduce his disruptive vocalizations and his noncompliance. As a result of the token economy system, his vocalizations decreased and his achieved goals increased. On a similar note, Silver et al. (1994) used a monetary reward system on a 12 year old girl with an anoxic brain injury. This was incorporated in a bid to improve her performance of morning tasks. She was reinforced with one penny for each step that she correctly completed. Reinforcement was gradually faded, and by the end of the intervention her verbal cues and physical assistance had decreased by 70 - 92%. Differential reinforcement of alternative behaviour (DRA) has also been proven to be successful in reducing challenging behaviour. Slifer et al. (1993) used this technique with extinction, response cost, and a token economy, to reduce disruptive behaviour. In most cases, DRA reduced disruptive behaviour and also increased compliance. From examining these studies, it suggests that " various reinforcement procedures may facilitate more efficient therapeutic goal attainment and subsequent home and community reintegration" (Gurdin et al. 2005, p. 12).

Purpose of current study

The purpose of the current study was to investigate the prevalence of self-awareness and challenging behaviours in persons with acquired brain injury, intervention types, and success ratings. This study will incorporate a sample of Irish patients who have ABI, which is presently absent in the research conducted to date. It will also provide information on what intervention types are most regularly used among persons with ABI, and the success ratings of such intervention types.