Abstract

There has been no report on detailed temporal mapping of traumatic brain injury (TBI), especially diffuse axonal injury (DAI), rehabilitation process. A case study is presented here on four-year tracking of a 24-year old male adolescent with severe DAI. The study aimed to develop a theoretical visual model of TBI (DAI) cognitive rehabilitation, and to validate this model by mapping out the sequence of significant behaviour events. The ensuing spiral cone model concurs with two well-known TBI rehabilitation sequels. The sequence of cognitive rehabilitation should aid in planning interventions in other similar or comparable TBI (DAI) patients.

Introduction

Brain injury is a major societal and health concern worldwide. Traumatic brain injury (TBI), also called intracranial injury or head injury, results from a sudden trauma which causes brain damage. The injury can be focused or diffuse i.e. involving more than one area of the brain, hence the term diffuse axonal injury (DAI). At least half of all TBI is known to be caused by transportation accidents. It is widely held as a significant health epidemic (Levine, 2006). In the USA, each year, up to 2 million new cases of TBI, incurring a total cost of US $56 billion, have been reported (National Institutes of Neurological Disorders and Stroke, 2002; Tiersky, 2001). In Malaysia, in 2006, there were 341, 252 motor vehicle accidents (MVA), with 5719 fatalities, 7373 seriously injured, and 15, 596 slightly injured (Royal Malaysian Police, 2008). There are no data available on numbers of consequent brain injury-rehabilitating patients. Moreover, in Malaysia, to date, except for Hassan et al. (2006), no report is available on rehabilitation of TBI patient. This is in great contrast to the proliferating research and reports on brain injury rehabilitation, and on the concomitant cognitive functions deficits and impairments, in developed countries (e.g. Anderson et al., 2003; Anonymous, 2007; Burtscher & Szczyrba, 2007; Crothers et al., 2007; de Guise et al., 2005; Donahue, 2004; Donnelly et al., 2005; Glasino & Zasler, 1995; John-Steiner, 1997; Klonoff et al., 2006; Lundin et al., 2006; Petrella et al., 2005; Ponsford, 2004; Osborn, 1999; Rees & Storry, 1996; Sherer et al., 2006; Snodgrass & Knott, 2006; Sohlberg & Mateer, 2001; Spanos et al., 2007; and Wongvatunyu & Porter, 2005). Even single case studies of TBI home-based rehabilitation have been reported (e.g. Wilson & Robertson, 1992). Most reported researches on brain injury rehabilitation used quantitative approaches. Nevertheless some studies and reviews using the qualitative approach have been published (e.g. Carson, 1993; Chamberlain, 2006; Dye, 2000; Figueiredo, 1998; Jumisco et al., 2007; Karpman et al., 1985; Man, 2002; Orto & Power, 2000; Smith & Smith, 2000; Willer et al., 1990; and Wongvatunyu & Porter, 2005). These studies articulated mostly on experiences and practices on caring, coping and living with TBI, on available and expected health service and infrastructure provision, as well as on different meanings it had for persons suffering from TBI. Analysis of their data revealed differential perception and acceptance, in terms of personal and family traits and commitments, and personal and family well-being of the respondents involved. Problems, disabilities and deficits of TBI survivors comprise physical, physiological, psychological, emotional, behaviourial, social, cognitive, and motor functions and processes (Donahue, 2004; Mayfield & Homack, 2005; Orto & Power, 2000; Osborn, 1999; Sohlberg & Mateer, 2001; and Wongvatunyu & Porter, 2005). Carers and family members are challenged traumatically in caring for TBI patients (Jumisco et al., 2007; Katz et al., 2005). The outcome of TBI rehabilitation is always confounded by many latent factors (Corrigan & Bogner, 2004; Greiner, 2006). The traumatic experience has been best articulated by the survivors themselves (Meyers, 2003; Osborne, 1999). The majority continues to bear multiple long functional disorders and deficits (Kreber, 2005).
Mapping of generic system components to identify, assess, evaluate, and link important elements in a particular event or state has been reported. An example is the concept mapping of problem elements associated with TBI (Donnelly et al., 2005). In that study the systems approach was applied to partition determinants involved, in a simplified diagrammatic illustration. However there has been no detailed temporal mapping of the rehabilitation process. No visual graphic model was presented. In contrast, this paper provides both mapping and the conceptual visual model.

The researchers mapped out qualitatively significant components in the process of rehabilitation of a severe diffuse axonal injury (traumatic brain injury) patient, commencing 31 January 2003 through 31 January 2007. It is a case study, which employed a mapping technique using the MindManager® software. The report presented here is part of a continuous ongoing study. The detailed sequence of cognitive advancement provides rich information, which offers good understanding of brain injury rehabilitation. Consequently, such information can contribute towards planning and actualizing interventions for recovery of other similar TBI or DAI patients. This case study is of special significance too since it is a successful survivor of severe DAI. It is well established that DAI accounts for nearly half of all severe cases of TBI, which is due to extensive shearing lesions in the grey and white matter particularly in the frontal and temporal regions (Sohlb erg & Mateer, 2001). High morbidity and mortality is common in DAI (Adams et al., 1989; Gennarelli, 1994; and Heath & Vink, 1999).

**Methodology**

Based on the interpretive phenomenological approach (IPA), a four-year (31 January 2003 to 31 January 2007) observational-tracking of a 24-year old male adolescent with severe DAI was done by meticulously recording and capturing data of daily events and behaviour elements. Subsequently we continually converted the information into annotated rehabilitation map, commencing from the unconscious period through the major discernible phases of achieving some memory recalls, sensing the environment, orienting, thinking and evaluating. Triangulation of observations, throughout the study, maintained research rigour (Pope and Mays, 2000).

Except for a 3-months (February through April 2003) stay at Hospital Kuala Lumpur, rehabilitation was mainly home-based. In the hospital, the intervention was mainly to ensure his survival. Details of treatments including a continuous battery of antibiotics and a series of physical intubations and exercises (physiotherapy) are not accessible. At home, data capture was done by the entire family (3 persons) and helpers (2 persons) in the household. This ensures obtaining data from multi-sources, hence conforming to the polyvocal (Thody, 2006) protocol. A visual model (Illustration 1) was subsequently constructed using the sequence of events, and aligned and compared with two well known TBI recovery sequels. Although the visual model differentiates affective, social, psychomotor, and cognitive components, the actual rehabilitation event and outcome (Illustration 2) comprise a composite blend (Sohlb erg & Mateer, 2001). Hence in the rehabilitation map (Illustration 3), produced by using MindManager®, no separation of components is made.

Everyday, commencing 31 January 2003, notes on observable significant behaviour, activities, events, happenings, and sayings (of the patient through his spelling by pointing to the alphabets, commencing 2004), were recorded in a diary of the two investigators. A house-helper also recorded daily observable behaviour of the patient. All information was subsequently transcribed into digital format by the senior author/researcher. Using SuperNote® software, daily recordings were transcribed into the diary section of the application. Ending the daily record was a brief interpretation of essential elements of the rehabilitation process. This was termed as “Coding”. Apart from textual data, digital images and audio-video recordings were also captured by the senior author (technical expertise was required) and imbedded in the text files.

An expanding spiral-layered cone (Illustration 1) was constructed to represent the progress in rehabilitation of affective, social, psychomotor, and cognitive components. The contiguous layers and expanding cone connote the inter-connectedness of affective, social, psychomotor, and cognitive components and their increasing progress with time, respectively (Hassan et al., 2006). The two measuring scales for comparison are the Rancho Los Amigos Levels Cognition and the Recovery Stages Diffuse Axonal Injury. The significant data components (Illustration 2) in the rehabilitation process were extracted from “Codings” in the daily Diary. The identified events or
topics, subtopics, and their detail components were subsequently linked chronologically in the map (Illustration 3). The methodology used is innovative since it was based on intensive daily data (textual, auditory, visual, video) and it invoked a mapping technique to capture, interpret, and explore the possible meaning of events and behavioural elements.

Illustration 1. A visual model of cognitive rehabilitation progress. The expanding cone connotes progress and inter-connectedness of affective, social, psychomotor, and cognitive components (Hassan et al., 2006). The two measuring scales are the Rancho Los Amigos Levels Cognition and the Recovery Stages Diffuse Axonal Injury.

Illustration 2. A list of some themes (bold) which represents the sequence of events and outcome in the rehabilitation process. The hierarchy of themes and sub-themes, which emerged from captured data (coding), frames the chronological map (Illustration 3).

1. Recovery
2. Unconscious
   Apraxia (disability to execute learnt purposeful movement)
   Aphasia (loss of the ability to produce and/or comprehend language)
   Adynamia (loss of strength or vigour)
3. Forced nutrition
   DHA; salmon, "Efalex®
   VITAMINS; B complex, "Neurobion®
   "Colloidal Minerals"
   ANTI-OXIDANTS
   Vegetables & fruits
   WATER
   CHOLINE
   LECITHINE
4. Forced stimulation
   Physical, Sensual, Mental
   Smart drug; "Nootrophil®; increased oxygen to brain
   Sight, sound, smell
   Repetitive persistent stimulation
   Increased response to stimulation with time
Used basic innovative tools & techniques
Massages; muscles & nerves
Increased gradual movement of limbs

5. Gain consciousness
   **Eyes Open**
   Head always turn to left
   **EARLY COGNITION**
   **Eyes SLOW Movement**
   Limbs Slight Movement
   **LEFT LEG CONTINUOUS JERKS**
   **SHAPES, DESIGNS, MEANINGS**: spelling, counting
   **Recognize Alphabets, Numbers, colours, odours**

6. Memory
   **OLD:** Flashes
   Disjointed
   Out-of-context
   Back to teenager period
   **NEW:** Weak/non-existence

7. Better awareness and recognition
   Faster response
   Turning of eyes & head

Illustration 3. Map of stages of rehabilitation, commencing from stage 1 (affliction of brain injury/commencing recovery) to stage 15 (more recovery). The dates (circle and oval) are from 31 January 2003 to 31 January 2007. The yellowed words or phrases are the states of capability of the patient. The green and white numbered boxes represent the most apparent observable stages (emerged from data coding of themes). A hierarchy of sub-themes comprises the main theme (numbered stages).
Results

Observation/Outcome

The cognitive rehabilitation process was gradual. Noticeable progress was detected only after a year in a state of coma. Varying degrees of confusion, especially with respect to spatial-temporal dimensions, persisted. Initially, a three-month period of total unconsciousness, with eyes closed, was followed by eight-month duration of minimal awareness. The latter phase was marked by total immobility except for open eyes with movable eyeballs. These two periods, extending from stages (2) Unconscious to (5) Gain Consciousness (Illustration 3), were visibly without any detectable cognitive advancement. Stages (2) through (4) were marked by forced feeding (3) and forced stimulation (4).

During January 2004, the patient entered the “gain consciousness” stage (stage 5 of Illustration 3). He became aware of his environment, and began to recognize objects. Thus “recognition” and “memory re-emergence” capability phases began. Spatial and temporal awareness began to increase. Memory, awareness, and recognition continued to progress (Stages 6, 7, 8). At stage (9), the patient began to respond to commands. By June 2005 i.e. 2.5 years of brain injury, recognizing of objects, people, places, media, and surrounding artifacts gained momentum. Speech and mobility were not possible yet then. Thus the patient was largely confined to bed. By August 2005, respond-to-command ability greatly improved. This was noted as enhanced-awareness (stage 10), in-command (stage 11), and improved-thinking (stage 12) phases. A notable feature on reaching stage (11) was the patient’s ability to concentrate watching television shows for at least one hour without turning his head to the left. This contrasted with earlier phases when he was not able to focus more than 5 minutes without turning his head to the left.

Enhanced awareness led to the patient actively seeking attention (stage 11) of the carers. He expressed his desires such as wanting to sleep in his own bedroom upstairs, and not at the setup provided i.e. on a bed in the lounge room facing the television set. He expressed these requests continually for about two months. As time progressed, the patient’s improved thinking (stage 12) enabled him to watch longer, television shows, especially those which were interesting to him. During 2005, rehabilitation was gradual but significant. Thus rehabilitation progressed from memory re-emergence through increasing response, improved obeying of commands, analyzing and interpreting of surrounding events, increasing cognition, and increasing memory (especially pre-accident memory) (stage 13). A persistent functional deficit was the inability to form short term and present memory. The pre-accident memory emerged randomly, disjointed, and as out-of-context “memory flashes”. Surprisingly, recalls of intricate matters e.g. correct telephone numbers of residence of 15 years ago, were accurately enunciated.

The year 2006 witnessed significant refinement of memory and cognition. Increasing overall response indicated better brain functions (stage 14) and more functional recovery. Gradually motor and kinetic ability began to improve. The impact of brain injury affliction left the patient with a paralysed right side of the body, notably the right hand and right leg. Three years after the affliction, significant recovery of limb movement such as lifting of right hand and right leg began to gradually occur. Brain injury rehabilitation does not necessarily progress in a linear predictable manner. In terms of magnitude of observable new and/or improved behavior performance, the year 2005 comparatively recorded high achievement. In contrast, throughout 2006 the cognitive functions became more refined. Thus more thinking, learning, and communicating occurred. This trend seems to concur with recent understanding of how the brain works (Dubin, 2002).

Perspectives and Discussion

Qualitative approach is an information-enriching way of tracking progress of extended brain injury rehabilitation. The data captured are rich in content and diversity (textual, images, audio, and video), enabling detailed description and validation. Brain injury rehabilitation, especially that of diffuse axonal injury (DAI), is not an exact science, nor is it a fully understood or predictable phenomenon. Hence it is not easily quantified. This is especially so for recovery from a severe traumatic brain injury (TBI). Nevertheless, especially for the less severe TBI cases, some quantitative measurements of behavioural and psychological parameters to predict cognitive outcome of TBI rehabilitation have been attempted with varying degree of success (e.g. Himanen
et al., 2005; Sherer et al., 2006; Wechsler, 1997a, b; Williamson et al., 2000). In this study, the spiral cone model fittingly encapsulates the broad overview of major events and their components. Although this visual model conjures a perception of linear rate of rehabilitation, differential progress occurred at different periods of the recovery, with significant improvement during the years 2005 and 2006. Such differential rate has been recorded in other studies (e.g. Carriker, 1996). It is well established too that recovery, including that which includes some training regimen, can take years, or even throughout life after a TBI or DAI affliction (Carriker, 1996; Donahue, 2004; Novack et al., 1996; Osborn, 1999; Sohlberg & Mateer, 2001; Sohlberg et al., 2000; Sohlberg et al., 2001; Williamson et al., 2000). Nevertheless, continual rehabilitation, however small and gradual, persists due to plasticity of the brain (Tracey et al., 1998). The mapping frame details those major events and components chronologically, which approximately fits the rehabilitation scheme of two separate scales of brain injury recovery measurement. In essence, the visual cone model (Illustration 1) represents the proposition (the model) while the tracking map (Illustration 3) links the data (Illustration 2) to the proposition (Zucker, 2001).

It is widely articulated in the literature that if the coma period extends beyond six months, usually the patient enters the vegetative state, and a patient with a posttraumatic amnesia of at least 1-7 days is considered as having severe TBI (Kraus & McArthur, 2000). This case study (this paper) proves otherwise i.e. for a year the patient moves only the eyeballs and at present he is not in a vegetative state. Even for severe TBI, significant levels of cognitive functions, especially the intra-personal components (Donnelly et al., 2005); can be achieved after many years of rehabilitation (Donahue, 2004). Hence, although the patterns of recovery may be similar in TBI cases, the rate of rehabilitation varies with different individuals and with different kinds of injury afflicted. Compared to other highly-publicized diseases, brain injury is a silent epidemic. In the U.S.A. brain injury is the leading cause of death and disability of children and adolescents (Wongvatunyu & Porter, 2005). The effect and impact are in many ways devastating to the affected family’s life (Jumisco et al., 2007). Nevertheless, Orto & Power (2000) portrayed it positively and succinctly as “… a sensitive journey through loss, trauma, fulfillment, and attainment, and validates the premise that there can be life after a brain injury”.

The physical injury leaves a languishing impact on the patient for the rest of his or her life. It is known that following cerebral lesions, quality of life outcome can be predicted by severity of injury, but subjective well-being was less well predicted (Tomberg et al., 2005). Reduction in quality of life is in itself an indicator of relative importance of impairment impacting on a person’s daily life (Fayers & Machin, 2000). Hence this paper on mapping of TBI provides a clear visual roadmap towards recovery, and should sparkle hope of rehabilitation and spur active intervention planning. This is in spite of trauma and tribulation of caring for and living with TBI patients. Moreover, once a detailed rehabilitation map is clear, definitive management and costing strategies (Wood et al., 1999) can be plotted and actualized. This facilitates coping with challenges of behavioural change, cognitive deficits, depression and anxiety, impaired executive functions, memory dysfunction, and social and communication problems (Gillis, 1996; Richardson, 2000; and Sohlberg & Mateer, 2001). This study (this paper) indicates that motor function improvement is subsequent to those of cognitive components. Such dynamic shift in progress has not been emphasized adequately in the literature, except in description of personal experience by actual TBI survivors (e.g. Osborn, 1999). Hence to understand the dynamics of brain injury rehabilitation, it is imperative to maintain a continuous record of behavioural events.

Mapping facilitates and expedites exploratory or interim analysis (Pope et al., 2000) of field notes or diary notes on the patient’s behaviour and actions. Moreover, mapping enables linking and connecting of various components and elements. Hence mapping of a process enables framing of main events, identification of trends, and portraying an insight of the recovery journey. Mapping also allows for quick valuation of components of the study (Leong et al., 2006). Essentially, mapping too validates a measuring process in health behaviour research and evaluation (Di Iorio, 2005). Most studies referred to TBI, and only a few focuses on DAI cases. Hence the case study described in this paper is one of the few DAI reports (example see Fork et al., 2005). Debilitating neurobehavioural sequel exists after TBI affliction (Lippert-Grünner et al., 2006), especially for DAI cases. Examples are the short term and posttraumatic (PTA) memory deficits. Moreover DAI patients are known to suffer considerable persistent neuropsychological impairment (Spree & Strauss, 1998), especially the executive and memory dysfunction (Fork et al., 2005). Thus the higher cognitive function e.g. higher thinking and higher multitasking skill takes longer to recover
A rehabilitation map indicates temporal points where interventions can be initiated. Stage 13 shows capability for analyzing and interpreting. The patient began to ask for his computer games and wanted to surf the internet. Osborn (1999) had shown that cognitively-impaired TBI survivors could learn Internet skills using specialized training materials. Moreover readiness of the TBI/DAI patient for certain type of intervention activity is important in the recovery success. At stages 6 and 15 of Illustration 3, recalls of pre-injury memory were "patchy"; some events and entities were remembered and recalled more frequent than others. Perhaps those that formed "strong memories" were captured and stored over a wider “network nodes” of neurons relative to others that were not (Goldblum, 2001). No two brain injuries are exactly alike; hence rehabilitation programmes (Engberg et al., 2006) need to be individualised, catering to each person’s unique, changed and differential needs (Kang, 2004). In this study (this paper), the patient’s high IQ coupled with the middle class and academic background of the carer family evidently assisted and expedited rehabilitation. Hence, a patient and his/her family’s characteristics, their cultural, religious, social and economic backgrounds should be considered when planning a person’s rehabilitation programme.

Understanding TBI rehabilitation process is important for the patient, carer, family members, and the health professionals (Anderson et al., 2003; Lefebvre et al., 2005), and the community and society (Carriker, 1996; Osborn, 1998). Severity of the patient’s injury directly determines carers’ stress symptom, especially the Post-traumatic Stress Disorder (PTSD) (Courtney, 1997). Once knowledge-based understanding is established, resolve, resilience, and strength of the carers can be enhanced; hence empathy and compassion will develop and prevail towards and among the carers, family members and others in the community. As shown by Man (2002) not all carers were able to cope satisfactorily with the stress and burden of caring for their TBI-afflicted loved ones. Such conviction is further corroborated by Knight et al.’s (1998) and Tomberg et al.’s (2005) studies which indicated that adequate social support network is essential to ensure effective rehabilitation and enhanced patients’ well-being. This conclusion is rational despite well-being being considered as a subjective construct or concept with varied interpretation and measurement protocols (Hird, 2003; Huppert et al., 2005; Veenhoven, 2000, 2004). The visual model and the tracking map presented in this paper indicate the need for multi-domains intervention approach in rehabilitation of TBI (and DAI). A cohesive team approach, involving carers and health professionals, experts, and practitioners, is imperative (Lefebvre et al., 2005; Man, 1998; Thornton et al., 2005). Experimental (quantitative) and social (qualitative) studies corroborated the need for team-approach rehabilitation (Klonoff et al., 2006; Orto & Power, 2000). Optimal intervention strategies and actions are needed to justify the total cost of rehabilitation (Robinson, 2001). In Malaysia and probably in many other developing and poor countries, more research and community based actions and intervention are necessary to care for the increasing yet unknown numbers of brain injured members of society.

Authors of this paper have placed annotated interpretations through innovative visual model and map. These meanings are a form of contextualization, based on accepted definitions and notions of brain injury rehabilitation. Creative alternative ways of researching and presenting case studies are laudable because they allow focusing on, and interpreting from the patient’s perspective (Zucker, 2001) and his life-world (Spichiger et al., 2005; Yoshida, 1992) or his life-ecosystem (Mirani, 2003). Consequently, rehabilitation practitioners can minimize the patients’ and carers’ feelings of devaluation, and initiate appropriate intervention strategies (Chamberlain, 2006). Perception, definition, and well publicized allusion, do affect public opinion and policy and even strategies and directions for research in a nation (Bourdelaïs, 1999). It is widely held that if the coma period extends beyond six months, usually the patient enters the vegetative state. This case study proves otherwise; hence implicating the overriding importance of an intensive long-term research. Such research should lead to designing and formulating of strategic models of long term support and care to alleviate suffering and pains of brain injury victims and their carers (Verhaeghe et al., 2005).
References


