How do you know when your patient is “waking up”: Coma recovery assessment in a complex continuing care setting

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Abstract
Coma, vegetative state (VS) and minimally conscious state (MCS) are disastrous outcomes following severe traumatic brain injury. Due to the extent of the resultant neurological deficits including hemisphere damage, loss of cellular integrity, altered and abnormal movements such as flexor and extensor patterns, and alterations in cranial nerve function, it can become difficult for the interprofessional team to identify when a patient is emerging from their coma. The Glasgow Coma Scale (GCS), commonly used to assess patients with traumatic brain injury (TBI) is not comprehensive or sensitive enough to provide concrete evidence that a patient is emerging from VS to an MCS.

The purpose of this paper is to present a case study of a patient who has emerged from a persistent VS to promote a deeper understanding of what is involved when working with this clientele. Challenges in assessment of cognitive functioning, the development of successful communication through the use of technology and the goals of therapy amongst the various health team members will be provided. Collaborative support with the family will also be discussed. Members of the interprofessional team explored the literature to determine coma recovery assessment tools and best evidence guidelines to direct their interventions with this patient.

Introduction
Severe traumatic brain injuries resulting in coma, VS and MCS most often present in adolescents and young adults due to their high-risk recreational and occupational activities, including but not limited to sports related injuries, motor vehicle collisions and/or battle field injuries (Adamides, Winter, Lewis, Cooper, Kossmann, & Rosenfeld, 2006; Arciniegas, Adler, Topkoff, Cawthra, Filley, & Reite, 1999; Chu, Beckwith, Leonard, Paye, & Greenwald, 2012; Dun-can, Summers, Perla, Coburn, & Mirsky, 2011; Karathanou et al., 2011; Selassie, Fakhry, & Ford, 2011; Shukla, Devi, & Agrawal, 2011). Brain injury is one of the major health care issues and a leading cause of death around the world (Karathanou et al., 2011; Selassie et al., 2011; Wagner, Hammond, Sasser, Wiercisiewski, & Norton, 2000; Watson, 2007). The sequel of this type of injury not only impacts individuals and their families, but also represents a significant public health concern in relation to immediate and ongoing costs of care.

In reviewing the literature to guide our interventions, the team was not able to find any articles that addressed our specific needs. Given this gap in the current literature, we felt that this under-represented topic was of particular pertinence in today’s health care system and ethical approval was granted to present this case study. Our patient’s journey will be compared to others documented in the literature from the perspective that “one size does not fit all” in relation to how these patients present and emerge from a persistent VS. The dynamism of this journey requires health care provider expertise in attending to vague signs of arousal, as well as flexibility in addressing patient and family needs.
Literature review

Human consciousness requires brainstem, basal forebrain, and diencephalic functions to support generalized arousal, and operating thalamo-cortical networks to respond to environmental and internal stimuli. Disorders of consciousness result when disconnection of these systems occurs (Goldfine & Schiff, 2011). Consciousness has two states—wakefulness (arousal) and awareness (content of thought) (Laureys, 2007). Consistent terminology and definition of terms is required in any exploration of this topic. For the purposes of this paper, some of the common and contradictory terminology will be identified to facilitate a shared understanding of the material presented.

Coma is a state of unconsciousness, lasting more than six hours in which a person cannot be awakened, fails to respond normally to painful stimuli, light, sound, lacks a normal sleep-wake cycle and does not initiate voluntary actions (Wehenmyer & Gallman, 2007). The distinguishing feature of coma is the continuous absence of eye-opening (spontaneously or following stimulation). In coma there is no evidence of visual fixation or pursuit, even after manual eye-opening; no voluntary motor behaviour is observed and behavioural responses are limited to reflex activity only; electrical activity is observed on EEG, albeit characterized by slow frequency bands, i.e., mostly delta and theta activity (Brenner, 2005).

VS is a state of wakefulness without detectable awareness. These patients are in an altered state of consciousness. Patients presenting in this state are unable to demonstrate an ability to follow commands, will open their eyes spontaneously and have reflexive motor activity only. Most physicians diagnose persistent VS after the patient has been in a vegetative state (VS) for four weeks and as a permanent VS after one year (The Multi-Society Task Force on PVS, 1994). The literature presents a confusing picture of the definition and nomenclature of the term PVS. The acronym PVS can refer to persistent, permanent, prolonged or continuous vegetative state depending upon the author(s) and practice locale. Thus, we will consistently define which type of vegetative state we are referring to throughout this document.

MCS is defined as a condition of severely altered consciousness in which minimal but definite behavioural evidence of self- or environmental awareness is demonstrated (Giacino et al., 2002). This definition is based on external manifestation of responses and behaviours, detectable by the observer. Examples of this type of observable responses are the patients’ voluntary use and manipulation of objects and their attempt to reach for items (Giacino, Kalmar, & Whyte, 2004). For instance, patients may be observed reaching for a cloth to wipe their face.

Research now focuses on more sensitive behavioural measures and advanced technological procedures to assess brain function as a predictor of positive patient outcomes. The need for clinicians to be able to determine the difference between VS and MCS is extremely important since the latter has a significantly better prognosis for recovery in the initial phase of the injury (Fischer & Luauté, 2005; Giacino & Kalmar, 2005; Goldfine & Schiff, 2011; Kobylarz & Schiff, 2005).

As Avesani and colleagues suggested in 2006, “sometimes patients declared to be in prolonged VS have the possibility to recover, especially when initial clinical conditions are particularly severe and do not allow the emergence of the state of consciousness. It is important to conduct regular follow-ups to better evaluate changes and, if it is necessary, to re-adjust the rehabilitation accordingly” (Avesani, Gambini, & Albertini, 2006). The differentiation between the VS and MCS is extremely difficult to quantify since current assessment tools rely on observed behaviour and demonstrate inconsistent inter-rater reliability (Gosseries, Vanhaudenhuyse, Bruno, Demertzi, Schnakers, & Boly, 2011; Sara, Pistoia, Pasqualetti, Sebastiano, Onarati, & Rosini, 2011; Thompson, Hurtado, Liao, Byyny, Gravitz, & Haukoos, 2011; Wilson, Graham, & Watson, 2005).

An inter-professional approach is vital in assessment of these patients and, ideally, should include neurophysiologic and imaging techniques (Baguley et al., 2012; Pistoia, Sacco, Palmirotta, Onorati, Carolei, & Sari, 2008). It has been suggested that diagnosis of MCS results from repeated specific neurological assessments and cannot be diagnosed only from electrophysiological evaluations (Thompson et al., 2011; Pistoia et al., 2008).

In the complex continuing care setting (CCC), access to advanced technological assessment tools such as positron emission tomography (PET) is limited. Health care providers in these settings must ensure in-depth knowledge of, and ability to consistently utilize behavioural coma recovery scales such as the expanded GCS (McNett, 2007), Ranchos Los Amigos Levels of Cognitive Functioning Scale (Gouvier et al., 1987), and/or JFK Coma Recovery Scale-Revised (CRS-R) (Giacino et al., 2004).

The purpose of the JFK CRS-R is to assist with differential diagnosis, prognostic assessment and treatment planning in patients with disorders of consciousness. The scale consists of 23 items that comprise six subscales addressing auditory, visual, motor, oral-motor, communication, and arousal functions. CRS-R subscales are composed of hierarchically-arranged items associated with brain stem, subcortical and cortical processes (Giacino & Kalmar, 2006). At the time of our patient’s admission, we were not familiar with the JFK CRS-R. If we had access to such a scale, we could potentially have utilized it to assess Jane Doe for early signs of awareness.

As with the assessment of consciousness, there is lack of consensus in relation to the effectiveness of pharmaceutical interventions. Several pharmaceutical studies have focused on patients in the first few days post TBI. However, as our case study explored the patient’s journey 60 days post trauma, these interventions were not applicable.
TBI can often cause upper motor neuron (UMN) syndrome, resulting in changes to motor control, such as skeletal muscle weakness, spasticity, and decreased coordination. One current hypothesis stipulates that the disabling consequences can be avoided and improvement in function obtained with early intervention (Wissel et al., 2009). Conventional therapies, such as physiotherapy/occupational therapy treatments combined with pharmaceutical and/or surgical interventions, are an important approach to alleviate the symptoms of spasticity (Wissel et al., 2009). The European Consensus Table paper 2009 identifies Botulinum toxin type A (Botox) as a valuable treatment option in regards to the management of spasticity following an acquired brain injury (Wissel et al., 2009). Botox is a neurotoxin that works at the neuromuscular junction of the injected muscle by blocking the release of acetylcholine, thus essentially weakening the muscles and decreasing or eliminating the increase in tone (Allergan, 2012). The use of Botox is well studied in regards to focal spasticity in the adult post-stroke population, as well as with pediatric cerebral palsy (Bergfeldt, Borg, Kullander, Julin, 2006; Borg et al., 2011; Calderon-Gonzalez, Calderon-Sepulveda, Rincon-Reyes, Garcia-Ramirez, & Mino-Arango, 1994; Koman, Mooney, Smith, Goodman, & Mulvane, 1994; Wissel et al., 2009). The effects of Botox on the patient population seen in a CCC setting, however, have received little study.

As clinicians become better at differentiating between VS and MCS, they must also become familiar with managing the consequences of prolonged hospitalization/altered functional realities of patients by utilizing new treatments/methods/options and innovative technologies. Not only does the health care team need to manage the physical aspects of care required by TBI patients, as their level of consciousness changes, but psychosocial, spiritual, and emotional needs of the patient and their family must also be addressed. Social workers assist the family, as they deal with the stress of this significant change in their family dynamic, and assist them to enhance or develop new resiliency strategies to cope with these changes (Coco, Tossavainen, Jääskeläinen, & Turunen, 2011; Tomberg, Toomela, Pulver, & Tikk, 2005).

Case report
This case study relates to a 19-year-old female, Jane Doe, and her nuclear family. Prior to Jane's transfer to a complex continuing care (CCC) facility, she was involved in a serious motor vehicle collision. Her resulting injuries included a right vertebral artery dissection, a left scalp hematoma, a small subarachnoid hemorrhage, a ruptured diaphragm, a left pleural effusion, a vaginal laceration and a fractured inferior acetabulum. Although EMS was on scene within minutes, it took almost one hour to extricate Jane from her vehicle. Her Glasgow Coma Scale at that time was 3/15, indicating a very severe brain injury.

The observation of brain stem reflexes on arrival to the trauma unit was considered a positive finding in relation to Jane's recovery potential, since lack of these reflexes suggests a negative long-term outcome in severe TBI (Wedekind & Lippert-Grüner, 2005). However, the extent and severity of this patient's injuries suggested to the acute care trauma team a very guarded prognosis for survival or recovery (Weninger & Hertz, 2007; Wong, Yeung, Graham, Zhu, Rainer, & Poon, 2011).

On Day 60 post trauma, Jane was transferred to a CCC facility with a diagnosis of persistent VS with decortication of the left arm and decerebration of the right arm. Her Glasgow Coma Scale score was 8. She was not able to follow commands. Her pupils were unequal with the right non-reactive to light. Jane wore a neck collar during transfers and when up in chair due to lack of active neck control. She had decreased passive range of motion and contractures to all four extremities. Jane had pins in both hips connected by a bar to support her hip fracture. She also had a tracheostomy tube with the cuff inflated and demonstrated good air entry bilaterally with no adventitious sounds auscultated, despite a history of pre-morbid asthma.

Jane presented with irregular fluctuations in temperature with extreme diaphoresis that was suspected to result from injury to her hypothalamus. She was prescribed regularly scheduled acetaminophen to address this symptom. Ensuring that a true infection was not overlooked was a nursing challenge for this patient.

Jane continued to receive prophylactic anticoagulation therapy, despite negative leg ultrasounds and ongoing physiotherapy. Since no definite guidelines for stopping low molecular weight heparin are available, this treatment modality was maintained upon admission to CCC.

Early after admission, it was evident that one of our roles, as a health care team, was to explore what the patient's new reality would be given her lack of recovery to date, and to help guide the family towards a more realistic hope for her future. The interprofessional team consisted of, among others, registered nurses, physiotherapists (PT), occupational therapists (OT), speech-language pathologists (SLP), a registered dietitian (RD), a social worker (SW), a pharmacist, respiratory therapists (RT), and a recreational therapist, all collaborating with each other and with the physician who directed the patient’s overall care. The nurses working directly with Jane on a day-to-day basis observed a young woman who did not demonstrate any response to their touch or to their attempts to communicate with her. Despite this lack of observable response, nurses continued to provide stimulation by explaining what they were doing with her, and talking about current events and other various topics of interest. Nurses interacted with Jane's family to determine her likes and areas of interest to inform their conversations with her, as they provided care.

In the weeks following admission to CCC Jane was regularly mobilized to a manual tilt wheelchair. Early in the recovery process, it is important for the patient to get up in a wheelchair to promote increased arousal levels and allow the patient to interact with and gain a more normal view of their environment (Munday, 2005). Nurses
and physiotherapists began to observe subtle inconsistent signs of arousal and they requested that she be assessed by the Neurology Advanced Practice Nurse. The assessment determined that she did have some minimal responses, specifically slight movement of her right thumb and right quadriceps muscle tightening. It was felt that she was inconsistently responding to command and, therefore, demonstrating some early signs of arousal and of awareness. These findings suggest that Jane was arousing from a VS to a MCS, unable to communicate her thoughts and feelings, but able to demonstrate inconsistent but reproducible behavioural evidence of awareness of self or environment.

She was assessed to be at RANCHO level II (generalized response) and over the following month progressed to level III (localized response). However, at about 90 days post trauma, this scale was not found to be a useful tool to track changes with this patient. She did not exhibit any of the confusion or agitation of levels IV, V and VI. We could not observe her ability to complete activities of daily living (ADL) because of her significant physical impairment. Social functioning and insight were also difficult to observe due to her inability to communicate verbally.

As with many patients with TBI, Jane demonstrated spastic hypertonia and began to develop muscle contractures. She was observed to have spontaneous movements of the right hand, although these were difficult to distinguish as reflex or purposeful movements due to general increased tone of the arm. The use of botulinum toxin type A was proposed by the physiotherapist (PT) to improve range of motion, prevent further soft tissue contractures, facilitate personal care and improve comfort (Wissel et al., 2009). During the Botox injections signs of responsiveness were not readily observable. This demonstrated the fluctuation in Jane’s level of arousal.

In the three to five months post-trauma, Jane was observed by the nursing staff to inconsistently blink on command with reproducibility limited by fatigue. Fatigue following TBI is the body’s defence mechanism to allow for healing and must be taken into consideration by all disciplines, as they work with this type of patient. Jane was also beginning to demonstrate facial reactions to noxious stimuli, such as grimacing secondary to a loud noise or attempting to turn her head away from an unpleasant physical sensation. Reproducibility and consistency were still an issue, however, it was clear to the family and the entire care team that Jane was beginning to show the early signs of “waking up”.

At approximately 140 days (20 weeks) post trauma, Jane was considered to have emerged from an MCS to a state of arousal and awareness. She was now able to respond to her name being called by turning her head towards the voice and visually tracking people in her room. The patient’s mother noted that she seemed to be attempting to communicate by moving her right thumb or by blinking. Jane was also seen to smile at family members. At this point, the involvement of the speech-language pathologist (SLP) and the occupational therapist (OT) was pivotal. With her tracheostomy requiring cuff inflation to prevent aspiration, verbal speech was not an option. An alternative method of communication had to be established in order to provide her with an outlet for communicating her needs, as well as to allow further assessment by the health care team. Jane was assessed by the physiotherapist (PT) as able to follow one-step commands within her available movement range, such as commands to touch her right thumb to her right index or clicking the pen a specified number of times. She was able to demonstrate all of these requests on command, in a consistent and timely fashion.

It was evident that Jane was aware and had some preserved cognitive functions. It was important to conduct further assessments in order to establish realistic expectations in relation to her potential for recovery. Although the patient’s performance in evaluations was encouraging, it was prudent to ensure expectations for her performance were set neither too high nor too soon, resulting in frustration for her, her family and the team.

With patients who have significant motor involvement, such as Jane, it may be very challenging to administer standardized tests to evaluate the patient’s cognitive status. Initially, informal assessments were performed by adapting portions of different tasks and screenings, as well as utilizing functional activities in order to translate Jane’s competence into practice.

Formal testing to explore higher functions of language and cognition were conducted by the OT and SLP through the use of pictures, alphabet boards and high-tech communication devices. By use of an augmentative and alternative communication device with switch scanning, they were further able to assess Jane’s language and cognitive function. This device looks like a rugged tablet; Jane operated it by pressing a switch with her right thumb when the letter or item she wanted was highlighted. As well, by providing alternative communication methods, Jane was able to communicate care needs and re-establish social relations with her family.

Around the nine-month period post-trauma, Jane progressed from having the tracheostomy cuff deflated to having it corked. She did, however, continue to require regular tracheal suctioning. She continued to improve with her communication, was able to address her needs by activating a modified call bell, and she was beginning to phonate. The OT and SLP encouraged the regular use of both methods of communication, as the use of assistive technology, as well as verbal output are perfectly compatible and one does not exclude or interfere with the other (Fager, Beukelman, Fried-Oken, Jakobs, & Baker, 2011).

Three hundred and ninety-eight days following her injury, Jane had a normal wake/sleep cycle, was aware of her environment and was able to make decisions regarding her goals of therapy and specific aspects of her care. Based upon her recovery she was transferred to a slow-to-recover TBI rehabilitation program.
Discussion

A diagnosis of persistent VS is often made at four weeks following trauma (The Multi-Society Task Force on PVS, 1994) and critical decisions are made as a consequence of that diagnosis. Some researchers suggest that a significant percentage of patients thought to be in a persistent or permanent VS are, in fact, incorrectly diagnosed. Schnakers et al. (2009), suggest that up to 43% of these patients exhibit unambiguous signs of awareness. Currently, the standard method of determining if a patient is exhibiting signs of consciousness remains the behavioural assessment (Schnakers, Giacino & Laureys, 2013). It is suggested in a recent study by Bekinschtein, Manes, Villarreal, Owen, and Della-Maggiore (2011) that the precision of the diagnosis may be enhanced by the use of functional imaging as an adjunct to clinical assessment. However, such tools to evaluate patients who are potentially exhibiting early signs of emergence from VS remain controversial and are not readily available for patients in CCC settings.

A meta-analysis of behavioural assessment scales for disorders of consciousness was completed by the American Congress of Rehabilitation Medicine (ACRM) in 2010. That analysis recommended promoting the use of the JFK Coma Recovery Scale-Revised. This outcome measure evaluates a patient’s emergence from an MCS and has been found to be valid, reliable and easy to use. Adoption of such tools is critical to health care providers considering the growing number of TBI adults throughout the world who are considered to be in persistent VS. Other areas of research focus on the recommendations of the ACRM that the diagnosis of persistent VS be made by experienced interprofessional teams over a period of time. This emphasizes the importance of assessing the persistent VS patients from a multisystem perspective. We urge caution in relying only on neurological and technological assessments as, in Jane’s case, they did fail to predict her emergence from coma. In the acute care facility, Jane had undergone CT scans and EEG testing, all of which were unable to detect any awareness of her environment at that time. When she was admitted to the CCC facility at 60 days post TBI, she was diagnosed as being in a persistent VS, with a poor potential for further improvement. In CCC, a consistent interprofessional care team became familiar with her and her family. This approach enabled the team to identify changes over time to her level of arousal and awareness. Motor response, primarily visual tracking or blink to threat response (Andrews et al., 1996) is often essential to the manifestation of awareness and these signs are often missed in patients such as Jane who have severe physical impairments. The coordinated efforts of an interprofessional team, including the clinical nursing staff and the family, were needed to continually reassess awareness despite limited motor responses. This allowed the team not only to detect these early signs of arousal, but also to create an environment that ensured this patient received the stimulation and interventions required to optimize her recovery. Observation made at the bedside, either by the family or by the care team, proved critical in discerning the first potential signs of awareness and, thus, ensuring timely referrals to appropriate health professionals. Under the physician’s leadership, the team met regularly in team rounds to discuss observations, progress and intervention planning. Communication between all health professionals was vital in order to ensure consistency with the evolving care plan. Various methods were utilized, both formal (team rounds, family conferences) and informal (face-to-face discussion between specific team members, etc.) and this helped foster a sharing of knowledge and expertise in order to better care for our patient. With this collaborative approach, we were able to observe Jane emerge from a persistent VS to MCS to one of full awareness.

Conclusion

The popular press frequently publicizes “miracles” of patients awakening after many years in coma. This phenomenon highlights the challenges health care providers face in the accurate diagnosis and treatment of persistent VS and MCS. The case study presented demonstrates how the interprofessional team utilized their knowledge and skills to optimize one patient’s care based upon her evolving level of consciousness. The team used this opportunity to increase their assessment knowledge and intervention skills based upon current scientific evidence while maintaining a holistic approach to patient and family care.

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