A Systematic and Evidence-Based Approach to Clinical Management of Patients with Disorders of Consciousness

Joseph T. Giacino, Christopher G. Carter, Carrie Charney, Denise Ambrosi, Matthew J. Doiron, Seth Herman, and Timothy Young

Abstract

Disorders of consciousness include coma, the vegetative state, the minimally conscious state and the post-traumatic confusional state. These conditions exist along a two-dimensional continuum comprised of arousal (i.e., wakefulness) and awareness (i.e., recognition of self and environment). Accurately characterizing and distinguishing these disorders early after onset is critically important as diagnosis is closely linked to prognosis and drives clinical decision-making. Unfortunately, published rates of misdiagnosed consistently approach 40 % with most of the error accounted for by failure to detect consciousness when it is preserved. Misdiagnosis may limit access to medical and rehabilitation services and lead to premature withdrawal of life-sustaining care. In this chapter, we describe a systematic, evidence-based framework for clinical management of patients with DoC. The primary aim is to demonstrate how a standardized, multi-tiered approach to assessment organized around a structured "care map" can be instituted in

J.T. Giacino, Ph.D. (✉)
Spaulding Rehabilitation Hospital,
300 First Avenue, Charlestown, MA 02129, USA

Department of Physical Medicine and Rehabilitation,
Harvard Medical School, Boston, MA 02115, USA

Department of Physical Medicine and Rehabilitation,
Massachusetts General Hospital, Boston, MA, USA

MGH Institute for Healthcare Professionals,
Boston, MA, USA
e-mail: jgiacino@partners.org

C.G. Carter, Psy.D.
Spaulding Rehabilitation Hospital,
300 First Avenue, Charlestown, MA 02129, USA

Harvard Medical School, Boston, MA 02115, USA

MGH Institute for Healthcare Professionals,
Boston, MA, USA

C. Charney, M.S., CCC-SLP
D. Ambrosi, M.S., CCC-SLP • M.J. Doiron, B.A.
Spaulding Rehabilitation Hospital,
300 First Avenue, Charlestown, MA 02129, USA

S. Herman, M.D. • T. Young, M.D.
Spaulding Rehabilitation Hospital,
300 First Avenue, Charlestown, MA 02129, USA

Harvard Medical School, Boston, MA 02115, USA

M. Sherer and A.M. Sander (eds.), *Handbook on the Neuropsychology of Traumatic Brain Injury*,
Clinical Handbooks in Neuropsychology, DOI 10.1007/978-1-4939-0784-7_7,

the rehabilitation setting to inform diagnostic, prognostic and treatment decisions, ultimately improving the consistency and effectiveness of care.

Keywords

Vegetative state • Minimally conscious state • Rehabilitation • Neuropsychology • Assessment • Outcome measure

There are approximately 18,000 new cases of severe traumatic brain injury (TBI) annually in the civilian population of the United States [1] and 200–300 more cases per year in active-duty military personnel. Many of those who survive severe TBI experience prolonged disorders of consciousness (DoC). In *coma*, the eyes remain continuously closed even when vigorous stimulation is applied, indicating that the arousal system is "offline" [2]. The failure to achieve a wakeful state eliminates any possibility of self or environmental awareness. This condition is self-limited and resolves when spontaneous eye-opening reemerges, almost always within 4 weeks of injury. The *vegetative state* (VS) is distinguished from coma by the reemergence of sleep-wake cycles (signaled clinically by spontaneous or elicited eye-opening); however, there are still no behavioral signs of self and environmental awareness [3]. VS is considered permanent after 12 months following TBI and after 3 months following non-traumatic causes [4]. In most cases, VS evolves into the *minimally conscious state* (MCS). MCS is characterized by the presence of at least one clearly recognizable behavioral sign of consciousness [5]. The diagnosis of MCS requires reproducible evidence of command-following, discernible yes–no responses, intelligible verbalization, or movements and affective behaviors provoked by relevant environmental stimuli that cannot be accounted for by reflexive activity. Some examples include manual object manipulation, visual tracking, and situation-specific emotional responses (e.g., smiling or crying in the presence of a family member). To meet existing diagnostic criteria for MCS, supportive behavioral evidence must be clearly discernible and reproducible on bedside examination. Emergence from MCS is established when there is clear evidence of reliable communication through verbal or gestural yes–no responses, or recovery of functional object use [5]. Following emergence from MCS, the next point along the continuum of recovery of consciousness is the *posttraumatic confusional state* (PTCS). PTCS is marked by temporal and spatial disorientation, distractibility, anterograde amnesia, impaired judgment, perceptual disturbance, restlessness, sleep disorder, and emotional lability [6]. During PTCS, 24-h supervision and assistance are required to ensure safety and com-

Table 1 Behavioral features associated with specific disorders of consciousness

Behavior	PTCS	MCS	VS
Eye opening	Spontaneous	Spontaneous	Spontaneous
Attention	Impaired selective/sustained attention	Inability to focus/sustain attention	None
Response to pain	Defensive/anticipatory	Localization	Posturing/withdrawal
Movement	Goal-directed/appropriate object use	Automatic/object manipulation	Reflexive/patterned
Visual response	Object recognition	Object recognition/pursuit	Startle
Commands	Consistent	Inconsistent	None
Verbalization	Intelligible sentences	Intelligible words	Random vocalizations
Communication	Reliable yes–no	Unreliable yes–no	None
Affective response	Contingent	Contingent	Random

pletion of routine self-care activities. Sherer and colleagues found that severity of confusion contributed significantly to ratings of employability at discharge from inpatient rehabilitation and productivity at 1 year post-injury [7]. Table 1 compares behavioral features of the four major DoCs.

Because there is no established objective test for conscious awareness, the determination of level of consciousness and corresponding diagnosis is based on a clinicians' subjective appraisal of elicited behavior. There is growing evidence, however, that clinicians frequently misjudge level of consciousness. Investigations consistently report that 30–40 % of patients believed to be unconscious on bedside examination actually retain conscious awareness [8–10]. This error rate is largely due to an obligatory over-reliance on behavior as a proxy for consciousness. Although behavioral observations are considered the "gold standard" in the evaluation of level of consciousness, behavioral signs can be misleading [11]. Reflexive behaviors may appear to be volitional while volitional responses may be masked by underlying sensory and motor impairments. In addition, behavioral output often fluctuates and a single observational period may be insufficient to capture evidence of conscious awareness. Nonetheless, diagnostic accuracy is critical to assure appropriate clinical management, establish an accurate prognosis, and provide appropriate information to caregivers. Misdiagnosis may limit access to medical and rehabilitation services and inappropriately influence end-of-life decision-making, including premature withdrawal of life-sustaining care.

The primary goals of rehabilitation for persons in the early phases of recovery from severe brain injury are to maintain medical stability, restore communication, and promote independence in self-care. An array of treatment interventions, including pharmacotherapy, physical management strategies, and structured sensory stimulation, are routinely administered in the inpatient rehabilitation setting to promote recovery of cognitive and motor functions. However, the absence of well-controlled treatment studies has slowed the development of standards of care to guide clinical decision-making regarding treatment selection. This has led some observers to describe the current approach to rehabilitation as a "black box" [12]. As a result, treatment interventions are often selected and applied in a "trial and error" manner, and the evaluation of treatment effectiveness is subject to observer bias. In the absence of objective data, treatment may be withdrawn prematurely or prolonged unnecessarily, hindering the recovery process and wasting limited resources.

Against this backdrop of diagnostic uncertainty and the prevailing "trial and error" approach to treatment, we describe a systematic, evidence-based framework for clinical management of patients with DoC. The primary objective is to demonstrate how a standardized approach to assessment can be instituted in the rehabilitation setting to inform diagnostic, prognostic, and treatment decisions. The importance of adopting an empirical approach to clinical care is underscored by recent published evidence indicating that individuals with DoC recover over a longer period of time than previously thought, and many regain the capacity to function independently [13–16].

Disorders of Consciousness Program Framework

The Spaulding Rehabilitation Network (SRN) Disorders of Consciousness Program was developed to provide a continuum of care specifically designed for individuals who have experienced severe acquired brain injury and have not yet regained the ability to follow instructions, communicate reliably, or perform basic self-care activities. The marked variability in the physical, cognitive, behavioral, and emotional sequelae of severe brain injury suggests that a one-size-fits-all model of rehabilitation is likely to be ineffective. In the remainder of this chapter, we describe a specialized 8-week program in which assessment and treatment procedures are standardized and administered systematically by a multidisciplinary neurorehabilitation team.

The 8-week SRN DoC Program is organized into three levels of care, each intended to address the clinical needs of patients functioning at different levels of consciousness. Program services are initiated and modified based on level-specific criteria. *Level I* focuses on individuals who have

not yet recovered consciousness and whose level of functioning is consistent with coma or the vegetative state. Patients admitted to *Level I* are either unarousable or demonstrate fluctuations in arousal and display no command-following, purposeful movement, or communication ability. The Coma Recovery Scale-R (CRS-R) [17] (see description under section "Core Metrics") is the primary assessment measure used at this level to track neurobehavioral recovery and monitor response to interventions. Behavioral and pharmacologic protocols are commonly employed to facilitate arousal at this level. *Level II* focuses on patients in the MCS who show clear but inconsistent evidence of conscious awareness, are unable to communicate reliably, and require maximum assistance for basic care. The transition from *Level I* to *Level II* requires demonstration of at least one feature of MCS on three consecutive CRS-R exams. The CRS-R and Individualized Quantitative Behavioral Assessment (IQBA) protocols [18], which rely on single-subject research methodology to investigate case-specific questions, are the key assessment procedures used at this level. Therapies designed to foster response consistency, augmentative communication, and environmental control strategies are typically initiated at this level. *Level III* focuses on individuals in the posttraumatic confusional state. Patients in PTCS are alert and have regained the ability to communicate reliably, but remain confused and highly distractible, often with sleep disturbance, impulsivity, and agitation. Progression to Level III is achieved once reliable yes–no responses are demonstrated across three consecutive CRS-R exams. The primary assessment measure used in Level III is the Confusion Assessment Protocol (CAP) [6], which monitors seven cardinal signs associated with acute confusion (see description in section "Core Metrics").

DoC Program Care Map

In order to institute a systematic approach to care and maintain adherence to the program timeline, a specialized DoC Care Map was developed. The Care Map is divided into two sections. The discipline-specific section details the clinical services for which each rehabilitation specialist on the team is responsible. In contrast, the interdisciplinary section displays the activities that are shared by all team members. The Care Map specifies the timing of all assessment, treatment planning, and educational activities that are administered over the course of the 8-week program. The primary aim of the Care Map is to ensure that all components of the program are administered systematically and in accord with the pre-arranged timeline. Table 2 shows the interdisciplinary section of the DoC Program Care Map.

Assessment and treatment interventions are provided by a multidisciplinary team comprised of specialists in neuropsychology, physiatry, nursing, physical therapy, occupational therapy, speech language pathology, social work, case managers, and other specialists as appropriate. On admission to the DoC Program, participants undergo a standardized assessment carried out jointly by all members of the team. A comprehensive battery of "core metrics," referred to as the "DOC COMPASS" (i.e., Disorders of Consciousness COMPrehensive ASSessment Battery), is administered to establish a functional baseline across multiple domains. Some of the core metrics are administered by all members of the team, while others are assigned to particular disciplines, based on expertise. A fixed assessment schedule has been established with the frequency of administration varying by measure. Table 3 provides a summary of the core metrics and corresponding assessment schedule.

DOC COMPASS

Core Metrics

All patients admitted to the DoC Program undergo comprehensive assessment using a battery of core metrics that have been vetted for use in patients with DoC. Performance criteria have been established that determine when a particular core metric should be discontinued (e.g., when valid assessment is not possible) or transitioned to a "higher-level" measure (e.g., when ceiling

Table 2 SRN disorders of consciousness program care map

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8
Assessment								
Initial team assessment	X							
Family interview to obtain history	X							
Neurobehavioral clinic		X						
Clinical team meeting		X			X			
COMPASS administered	X	X	X	X	X	X	X	X
Specialized metrics			X	X	X	X	X	X
Final review of data								X
Treatment								
Interdisciplinary team conference (ITC)	X	X	X	X	X	X	X	X
Implement initial treatment intervention(s)		X	X	X				
Implement revised treatment intervention(s)					X	X	X	X
Establish transition/discharge plan						X		
Implement transition/discharge plan							X	X
Neurobehavioral profile finalized for transition/discharge								X
Family education								
Family orientation w/case manager, nurse manager, and program director	X							
Meeting w/outreach coordinator	X							
Family team meeting w/clinical team		X				X		
Family education seminar	X	X	X	X	X	X	X	X

Table 3 SRN DoC program assessment schedule

Neurobehavioral measure	When to start administration	Frequency	When to discontinue
Agitated Behavior Scale (ABS)	Admission	1× per nurse shift 1× per therapy session	3 consecutive days of scores ≤21
Coma-Recovery Scale-Revised (CRS-R)	Admission unless EMCS	2× per week	3 consecutive subscale scores of 4 for Auditory, 2 for Communication, and 3 for Arousal
Confusion Assessment Protocol (CAP)	Admission if EMCS or upon discontinuation of CRS-R	1× per week	2 consecutive scores of not confused
Galvenston Orientation Attention Test	Completion of the CAP if disorientation remained a symptom	1× per week	2 consecutive administration with Total Error points <25
Disability Rating Scale (DRS)	Admission	1× per week	Never
Functional Communication Measures (FCM)	Admission	Bi-weekly	Never
Limb Movement Protocol (LMP)	Admission	1× per week	2 consecutive scores of 72
Verbal Fluency	Consistent intelligible speech is present	1× per week	Never
Medical Complication Checklist	Admission	1× per week	Never

effects are apparent). The section below provides a brief summary of the core metrics in the *DOC COMPASS* that were selected to represent particular domains of function.

Neurobehavioral Status

Coma Recovery Scale-Revised (*CRS-R*): The CRS-R is a standardized measure of neurobehavioral function that has been widely used in dif-

ferential diagnosis, prognostic assessment, and outcome measurement in persons with DOC [10, 17, 19, 20]. The scale consists of 23 behavioral items that are weighted to reflect progressively increasing neurologic function. There are six subscales designed to assess arousal level, audition and language comprehension, expressive speech, visuoperceptual abilities, motor functions, and communication ability. Scoring is based on the presence or absence of operationally defined behavioral responses elicited by standardized stimulus presentation. The lowest items on each subscale represent brain stem reflexes, while the highest items reflect cognitively mediated behaviors. The CRS-R has been shown to be reliable and valid when administered by licensed medical and rehabilitation personnel [17, 19, 20]. The scale is completed on admission to determine diagnosis (e.g., VS or MCS), establish a neurobehavioral baseline, and identify level of care. Following baseline assessment, the CRS-R is administered twice weekly to monitor rate of recovery. CRS-R administration is discontinued in favor of the CAP when the criteria for emergence from MCS (i.e., consistent functional object use and/or functional communication) are met on three consecutive examinations.

CAP: The CAP is a compilation of items extracted and/or modified from existing standardized measures used to assess delirium, posttraumatic amnesia, and agitation [6]. The CAP includes seven subscales that assess level of cognitive impairment, disorientation, agitation, symptom fluctuation, sleep disturbance, decreased daytime arousal, and psychotic symptoms. In the SRN DoC Program, the CAP is initiated when CRS-R performance stabilizes at ceiling. The CAP is discontinued when fewer than four symptoms of confusion are present and there is no further evidence of disorientation on two consecutive examinations.

Disability Rating Scale (DRS): The DRS is the most widely used functional outcome scale in TBI research and practice. The scale monitors degree of disability and tracks change over time in patients recovering from coma [21]. Areas of function assessed include arousal level (i.e., eye opening), motor responsiveness, communication ability, and cognitive ability for feeding, toileting, and grooming. General level of functioning and employability are also rated. DRS scores are obtained weekly by certified team members.

Cognitive-Linguistic Function

Functional Communication Measures (FCM): The FCMs were developed by the American Speech-Language Hearing Association to grade a variety of communication, swallowing, and cognitive abilities [22]. Performance is rated on a 7-point Likert scale. FCMs selected for use in the SRN DoC Program include Motor Speech, Spoken Language Comprehension, Spoken Language Expression, Swallowing, Augmentative-Alternative Communication, Fluency, Attention, and Memory. FCMs are completed by certified Speech Language Pathologists on admission, at week 4 and at week 8.

Controlled Oral Word Association Test (*COWAT*): After intelligible speech is recovered (i.e., CRS-R Oromotor/Verbal subscale score of 3), the COWAT is added [23]. The COWAT assesses verbal initiation and fluency by instructing the patient to name as many words as possible within 60 s that begin with a designated letter of the alphabet. Three trials are administered and a total score is obtained. The COWAT is completed weekly by the Speech-Language Pathologist.

Motor Function

Limb Movement Protocol (LMP): The LMP was developed to track motor recovery in patients with DoC [24]. This measure focuses on upper extremity function and is designed to investigate functional movement sequences that involve use of objects (4 items) and social gestures (4 items). Three trials of each item are administered and the score is based on the accuracy, completeness, and consistency of the movement sequence executed. This protocol is administered weekly by the Occupational Therapist from admission through discharge or until the maximum score (i.e., 72) is achieved on three consecutive examinations.

Medical Status

Medical Complications Checklist (*MCC*): The MCC is an inventory of medical complications that are commonly observed in patients with post-traumatic DoC. The complications included on the list represent those found to have the highest incidence in a large cohort of patients with DoC enrolled in a TBI Model Systems-sponsored study [25]. The intent of the checklist is to track the number and duration of complications to help determine the influence of medical instability on rate of recovery and functional outcome in patients undergoing inpatient rehabilitation. Complications represented in the MCC include, cardiac, pulmonary, fluid/electrolyte/nutrition, infectious, neurological, endocrine, hematological, gastrointestinal, urological, orthopedic, pain, neurobehavioral, skin, and head/eyes/ears/nose/throat. The MCC is completed weekly by the attending physician or resident.

Specialized Protocols

In addition to the core metrics, the *DOC COMPASS* includes a wide variety of specialized assessment protocols that are employed to address case-specific clinical questions. These individually tailored protocols are designed to complement the core metrics and are typically used to address more granular assessment questions pertaining to diagnosis, prognosis, and treatment. The Neuropsychology service meets with the rehabilitation team to develop the protocols, analyzes the results, and discusses their implications for treatment and long-term care needs with the rehabilitation team and family. Examples of specialized protocols include arousal monitoring procedures to gauge the length of time the patient maintains wakefulness, command-following protocols to help differentiate volitional from involuntary behavioral responses, and response consistency protocols to determine the consistency and accuracy of specific target behaviors (e.g., yes–no responses). All specialized protocols include scripted instructions for administration and corresponding forms for data collection. Data collection is conducted jointly by all members of the treatment team, regardless of discipline. Protocols are conducted during therapy sessions and typically require no more than 10 min for administration. Protocol adjustments are initiated by the therapy team as needed. Results are discussed at rehabilitation team meetings, during family conferences and are incorporated into reports submitted to the payor. Figures 1 and 2 depict examples of Arousal Monitoring and Yes–No Response Consistency protocols.

Clinical data generated by all measures included in the *DOC COMPASS* are uploaded to an online database and progress is monitored weekly during Interdisciplinary Team Conferences coordinated by the Case Manager. A "Comprehensive Neurobehavioral eProfile" is automatically generated for each patient in the program and updated each week. The *eProfile* demonstrates current performance as well as the trajectory of recovery across domains of function. Clinical benchmarks derived from the core metrics are employed to guide decision-making regarding the need for treatment modifications, program transitions, and recommendations for discharge. A case illustration showing an example of a completed *eProfile* is presented at the end of this chapter.

Treatment interventions are carried out in the same manner as the comprehensive assessment battery. That is, after establishing the primary treatment goals, standardized treatment methods are scripted and implemented by all members of the team. The treatment plan is reviewed in week 5 and modified as indicated, based on the data collected by the rehabilitation team. Figure 3 shows an example of a standardized treatment protocol intended to facilitate arousal.

Family Education and Support

Recognizing that family involvement will be essential to the long-term success of the survivor, family support is viewed as a vital component of the DOC program. While there is no standard approach to family support [26], research into self-identified family needs following TBI has identified consistent themes in terms of the supports families need: (1) the need for general

AROUSAL MONITORING RECORD

Patient:_____ Therapist:_____
Date:_____ Therapy:_____
Time:_____ Medications:_____

Behavior	First 5 mins of tx session (0-5 mins) Duration of eyelid closure	Middle 5 mins of tx session (25-30 mins) Duration of eyelid closure	Last 5 mins of tx session (25-30 mins) Duration of eyelid closure	Total duration of eyelid closure
1-60 seconds				
61-120 seconds				
121-180 seconds				
181-240 seconds				
241-300 seconds				
Total duration of eyelid closure				

Procedure: This protocol is designed to gauge arousal maintenance using a time sampling procedure. Arousal level should be monitored during the first, middle and last five minutes of each therapy session.

Operational Definition of Underarousal: An episode of underarousal begins when contact between the upper and lower eyelids is maintained continuously for longer than 3 seconds and ends when contact is released for longer than 3 seconds.

Instructions: During the first, middle and last 5 minutes of the therapy session, observe the status of the eyelids. Any time the eyelids are observed to close for at least 3 seconds, begin timing the length of time they remain closed. Stop timing when the eyelids remain open for at least 3 seconds. Continue recording episodes of sustained eye closure in this manner during the first, middle and last 5 minutes of the session. At the end of each 5 minute interval, record the *total length of time* the eyelids were closed during that period and enter it in the appropriate time block. Next, record the *total length of time* the eyes remained closed within and across each 5 minute interval.

Fig. 1 Arousal Monitoring protocol. The Arousal Monitoring protocol includes scripted instructions for gauging the length of time arousal is maintained over a predefined time period. Arousal level is monitored using a time sampling procedure intended to sample the first, middle, and last 5 min of each therapy session. An episode of underarousal begins when contact between the upper and lower eyelids is maintained continuously for longer than 3 s and ends when contact is released for longer than 3 s

information about brain injury, as well as specific information concerning their family member's injury, (2) guidance on how family members can be involved in care, and (3) the need for assistance in making sense of their experience [27–29]. Based on these findings, several components have been built into the SRN DOC program to address these needs. The program helps prepare family and friends for the future by providing training in effective caregiving and advocacy strategies, while providing emotional support in adjusting to the new challenges in their lives.

Family support begins at the point of initial contact, prior to admission. Educational materials

Yes/No Comprehension

Directions: Administer runs of 6 paired yes/no questions, as outlined below, within the domains of personal information, orientation information and/or general knowledge. Please attempt administration of at least *one set* per tx session. Record pt's arousal as noted below, and record response (if any) occurring within 10 seconds of auditory stimulus.

Date: _____
Positioning during administration: _____
Did eyes remain open throughout administration (circle): YES / NO
Was deep pressure stimulation provided (circle): YES / NO
Did pt benefit from deep pressure (circle): YES / NO / NA

Personal Information Questions:

Stimulus:	**Response? (+/-)**	**Accurate? (+/-)**
Are you a man/male?		
Is your name _____*?		
Are you a _____**?		
Is your name _____***?		
Are you a woman/female?		
Are you a _____****?		
TOTAL:	/ 6	/ 6

*enter name of patient
**enter an occupation other than patient's occupation
***enter a name other than patient's name
****enter patient's occupation

Orientation Information Questions:

Stimulus:	**Response? (+/-)**	**Accurate? (+/-)**
Are we at a shopping mall?		
Is the year 2002?		
Are we in a hospital?		
Are you sitting in a bathtub?		
Is the year ___*?		
Are you sitting in a chair?		
TOTAL:	/ 6	/ 6

*enter current year

General Knowledge Questions:

Stimulus:	**Response? (+/-)**	**Accurate? (+/-)**
Is grass green?		
Is ice hot?		
Is a rock hard?		
Is grass red?		
Is ice cold?		
Is a rock soft?		
TOTAL:	/ 6	/ 6

Fig. 2 Yes–No Response Consistency and accuracy monitoring protocol. After presenting a question concerning personal orientation, situational orientation and semantic knowledge, the examiner records whether a discernible verbal or gestural "yes" or "no" response occurred, and whether or not it was accurate. Percent accuracy is determined for each type of question and for all questions collapsed

Sustained Attention Protocol

SRN Disorders of Consciousness Program

Patient:

Time: _____

Therapist: _____

Objective: Mr. A will independently sustain performance on a low cognitive load task for 10s continuously.

Protocol Description:

This protocol is designed to facilitate recovery of sustained attention. Three different tasks will be administered requiring uninterrupted performance. Three trials of a single task will be conducted per session. Tasks can be modified as needed but should be characterized by low cognitive demands and should be able to be completed within a 10s timeframe. Protocol steps are as follow:

1. Describe the task in simple terms.
2. Request verbal reinstatement of the task. Repeat until accurate or change task if 3 consecutive attempts are failed.
3. Initiate task.
4. Re-direct attention to task by calling out patient's name.
5. Request verbal reinstatement of task.
   a. If accurate, prompt to continue task.
   b. If inaccurate, re-state task and rehearse until task is accurately repeated or 3 consecutive attempts are failed.
   c. If accurately repeated, complete trial.
6. On completion of steps 1-5, re-administer task instructions (repeat instructions 1x) and conduct a new trial but provide no assistance.
7. In the table below, record whether the trial was completed without loss of set and without assistance, completed with verbal prompts to "Keep going" or failed (ie, set loss even with verbal prompting)..

Patient: **Date:** _____

Task Description	Persists on task for 10" w/o loss of set	Persists on task for 10" but requires prompts to "keep going"	Fails to persist on task for 10" even with verbal prompting

Fig. 3 Sustained Attention Training protocol. The protocol record shows detailed instructions for administration of an attention training protocol on the left flanked by a corresponding scoring grid on the right. The objective of this protocol is to improve the duration of time the patient remains on-task. A combination of verbal cuing, verbal reinstatement, and in vivo rehearsal strategies is utilized and performance is monitored using a standardized record sheet that tracks the frequency of occurrence of operationally defined target behaviors

describing the program and staff are provided during a tour of the facility. Once admitted, a notebook containing a description of the program, the disciplines involved, basic information about brain injury, and information about support and educational resources is provided. The Case Manager and Social Worker meet with the family within the first 72 h of admission. The Case Manager helps orient the family to the facility, identifies immediate family issues or concerns, and begins to explore discharge options and family resources. It is important that this discussion begins at the point of admission so that realistic expectations for treatment goals and length of stay are established at the outset of treatment. The Social Worker evaluates the family's psychosocial status and needs and provides education about the DOC program and facility resources available to the family. Ongoing support is provided to the family, assisting with housing, obtaining outside counseling, encouraging healthy self-care habits, and coping strategies for family members, such as how to be an effective member of the treatment team. The Social Worker offers a family support group to facilitate meetings among family members for various patients and to address emotional stress experienced by family members. A mentor, often an experienced family member of a brain injury survivor, is available to meet with family members to provide further emotional support and practical advice. Both the Case Manager and the Social Worker help the family prepare for the next level of care which may involve identifying further treatment options, transitioning to a lower level of care, exploring funding options, and accompanying family members in visits to other facilities.

Team members participate in the educational process on an on-going basis by explaining their role in treatment and providing information about brain injury, DoC, assessment tools, and treatment approaches. Families are encouraged to attend therapy sessions and participate in the care of the patient where appropriate. Therapy staff and nursing staff provide formal training in how to care for and support individuals with brain injury. This may involve how to provide supervision while walking, feeding, or bathing instructions, encouraging use of a consistent communication system, or how to maintain a gastrostomy tube. This "hands-on" approach is the best way for family members to learn about brain injury in general, and their family member's needs, specifically. It is also the best way for them to acquire the skills they will need to care for their family member at home or to advocate for services for their family member if continued residential care is needed.

In Week 2 of the Program, the family meets formally with the interdisciplinary team. At this meeting, detailed information is provided about the results of the initial assessment, treatment objectives, procedures to be implemented, and expectations for the rehabilitation course. The 8-week timeline is strongly emphasized, as is the use of clinical benchmarks to guide decision-making regarding the selection of assessment and treatment procedures. Because of the time-limited nature of the DOC program, preparation for discharge and transition to the next stage of care and treatment starts at this meeting. The Case Manager meets with the family on a regular basis to keep the family informed about care and progress and when the time comes, assists with preparation for discharge to the next stage of care. The frequency of these meetings is determined on an individual basis, based on the support needs of the family. Families are made aware of treatment resources within the community (e.g., state chapter of the Brain Injury Association of America), in addition to resources available within the hospital (e.g., educational sessions, outpatient support groups). The team meets again formally with the family at the end of Week 5 to review progress and discuss plans for discharge from the program.

Case Illustration

To exemplify the application of a systematic, evidence-based approach to clinical management of patients with DoC, we provide a case illustration below.

Medical History: AB is a 24-year-old female who sustained a severe TBI with loss of consciousness

when she was struck by a car as a pedestrian. She had a Glasgow Coma Scale [30] score of 4 at the scene, indicating deep coma. Initial neuroimaging studies showed a subarachnoid hemorrhage which did not require neurosurgical intervention. An ICP bolt placed for pressure monitoring was discontinued on day 4. Follow-up MRI on day 8 revealed punctate hemorrhages in the posterior corpus callosum, right cerebellar region along the posterior falx and over the left posterior parietal lobe, consistent with grade II diffuse axonal injury. She also sustained significant polytrauma requiring multiple orthopedic surgeries. She regained spontaneous eye-opening on day 15 but remained poorly responsive. Active movement was noted in the left upper extremity, but there was no evidence of command-following or purposeful movement. The acute course was complicated by ventilator-dependent pneumonia and recurring cardiorespiratory problems which eventually stabilized. She remained in a vegetative state for approximately 6 weeks after which she began to display automatic movements (e.g., nose-scratching, grasping the bedrail) followed by inconsistent movement of the right hand and toes to command. She was started on amantadine but this was discontinued as there was a concomitant increase in restlessness and stereotypical movements of the left arm.

On day 45, AB was transferred to the SRN Disorders of Consciousness Program for comprehensive inpatient neurorehabilitation. Repeat MRI of the brain revealed an extra-axial fluid collection, thought to be a subdural hygroma, overlying the left frontal lobe and a small focus of hyperattenuation in the left medial temporal lobe. The ensuing neurorehabilitation program was guided by the 8-week Care Map described below.

Week 1: The core measures of the *DOC COMPASS* were initiated by the rehabilitation team in week 1 to establish a baseline across functional domains. The opening score on the Coma Recovery Scale-Revised was 14, reflecting poorly sustained eye-opening, inconsistent command-following, visual pursuit, automatic motor behavior, unintelligible vocalizations, and no discernible yes–no responses (see CRS-R Profile in Table 4). Performance on the CRS-R confirmed her transition from VS to MCS and triggered implementation of the remaining core measures. Administration of the LMP by the occupational therapist resulted in an initial score of 38/72. Item analysis showed a high rate of partially executed movement sequences. AB's lack of verbal or gestural communication produced a Level 1 rating on the Spoken Language Expression subscale of the FCM. Global functional status as assessed by the DRS yielded a score of 26, which falls in the most severely disabled range of function. The results of the core metrics were presented at the biweekly Interdisciplinary Team Conference (ITC) to maintain communication across therapeutic disciplines and provide clinical status updates to the in-house case manager. To address the daytime fluctuations in arousal level, the Arousal Facilitation Protocol was administered by all team members at least once during each therapy session. In addition, simple cuing strategies were used to redirect attention and improve time-on-task during therapy sessions.

Table 4 AB's CRS-R Profile on admission to the SRN Disorders of Consciousness Program

	Coma Recovery Scale-Revised	
Subscale	Best response	Score
Auditory	Reproducible command-following	3
Visual	Pursuit	3
Motor	Automatic motor response	5
Oromotor/verbal	Vocalization/oral movement	2
Communication	None	0
Arousal	Eye opening w/stimulation	1
Total score		14
CRS-R diagnosis		MCS

Week 2: In week 2, AB was evaluated by the Neuropsychology service in the Neurobehavioral Clinic. The purpose of the Clinic visit was to further investigate AB's current level of cognitive function, confirm the working diagnosis, establish the prognosis for further recovery, and help determine the primary treatment objectives. Examination findings replicated the behavioral signs of conscious awareness reported by the rehabilitation team, which included inconsistent command-following, visual pursuit, and auto-

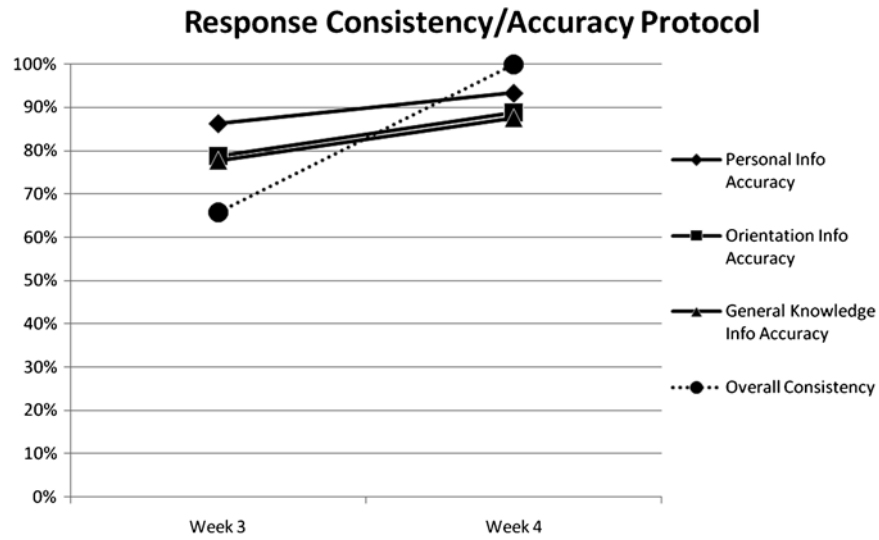

Fig. 4 AB's performance on the Yes–No Response Consistency and Accuracy Monitoring protocol. The graph shows the percentage of trials in which any discernible yes–no response was detected following presentation of a question (*circles* on *dotted line*) over a 1-week interval. The solid lines indicate the percentage of accurate responses to personal orientation (*diamonds*), situational orientation (*squares*), and semantic knowledge (*triangles*) questions. Results indicate that general response consistency improved from 65 to 100 %, while accuracy improved by approximately 10 % during the same interval across all three types of questions administered

matic motor responses. Episodes of intelligible verbalization were also elicited during this assessment. There was some evidence of left-sided sensory inattention and repetitive stereotypical movements of the right arm were again noted. Additional assessment of the right arm movements suggested these movements represented "frontal release behavior," likely reflecting loss of inhibitory control caused by the left frontal lesion noted on prior neuroimaging studies. It was recommended that the initial objectives of the rehabilitation program focus on establishing a reliable communication system and managing the right upper extremity motor disinhibition. At the end of week 2, the neurorehabilitation team met to discuss the program objectives, select the assessment and treatment procedures, and establish performance benchmarks. By the end of week 2, AB had begun to verbalize "yes" and "no." The emergence of yes–no responses triggered the use of a specialized protocol for determining the consistency and accuracy of these responses to different types of questions (see Fig. 4). These data were used to help determine readiness for communication training. Treatment continued to focus on improving arousal, attention, and response consistency. The initial family meeting was also completed in week 2 to familiarize the family with the 8-week DoC Program and to review the preliminary findings, treatment objectives, and treatment methods. The family was enlisted in the communication training protocol to maximize exposure to this intervention and promote generalization.

Weeks 3–5: During week 3, AB continued to progress. She achieved three consecutive scores of 23 (max = 23) on the CRS-R, indicating emergence from MCS and that she was performing at the ceiling of the CRS-R. Consequently, the CRS-R was discontinued and the CAP initiated. AB also achieved the maximum score of 72 on two consecutive assessments with the LMP, triggering discontinuation of this measure not shown in Fig. 5. The DRS score decreased by 14 points between weeks 2 and 4, reflecting significant improvements in arousal level, motor functions, and performance in self-care activities. The initial CAP score showed five symptoms of confusion, including cognitive impairment, disorientation,

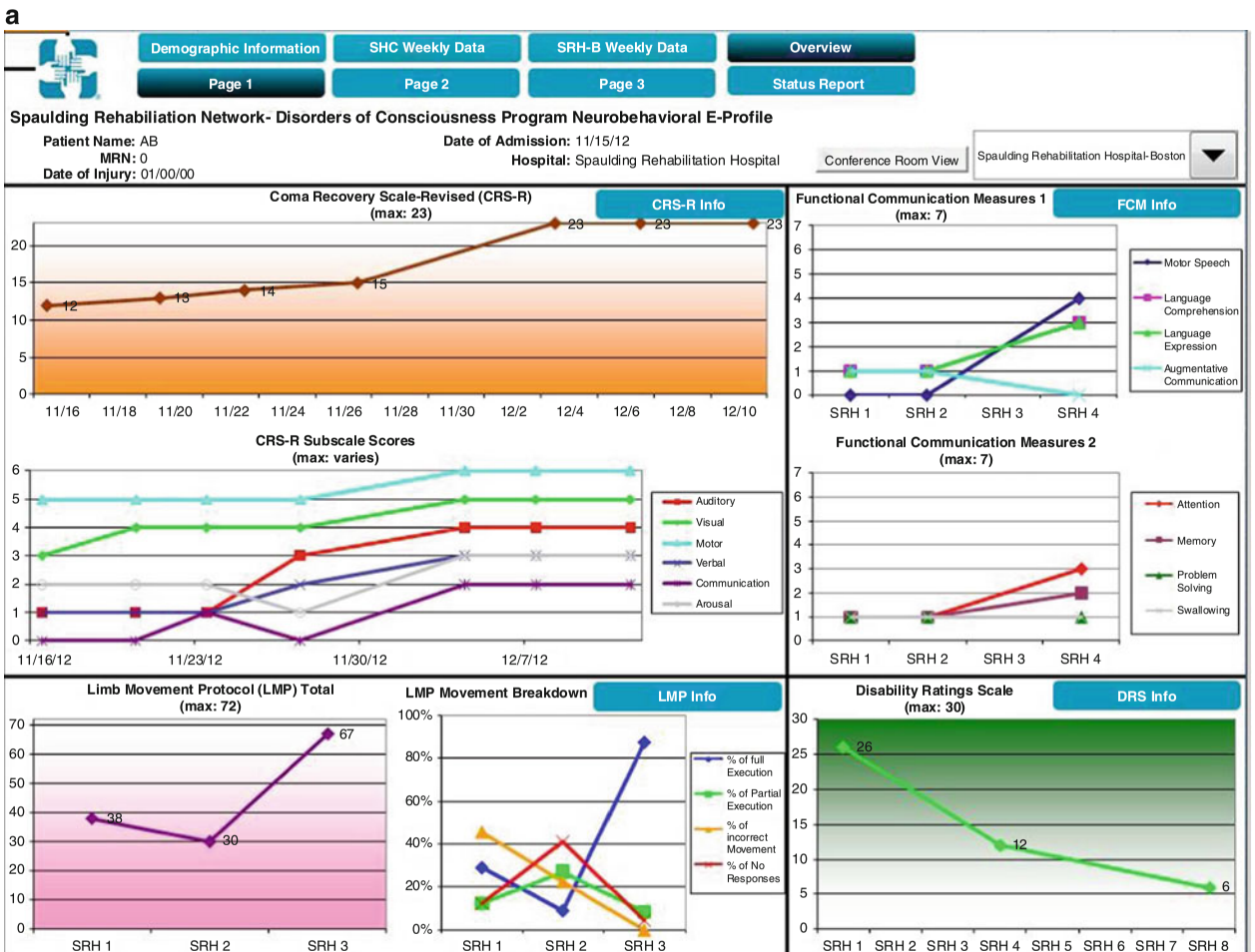

Fig. 5 *DOC COMPASS eProfile* illustrating AB's performance across all 8 core measures. Panel (**a**) shows weekly scores on the CRS-R (broken down by specific subscales), LMP (broken down by response category), FCM, and Disability Rating Scale. Data show concurrent improvement in performance across these measures beginning during the second week of the program. Panel (**b**) shows performance on the Cognitive Impairment (CAP-CI) subscale of the Confusion Assessment Protocol and the

Fig. 5 (continued) Galveston Orientation and Amnesia Test (GOAT). The trend lines for these two measures are inversely related—CAP-CI scores increase as cognition improves, while GOAT scores decrease as disorientation and posttraumatic amnesia resolve. Marked improvement in verbal fluency is also noted on the Controlled Oral Word Association Test (COWAT), which is administered when intelligible speech reemerges. In panel (**c**), average daily scores on the Agitated Behavior Scale are

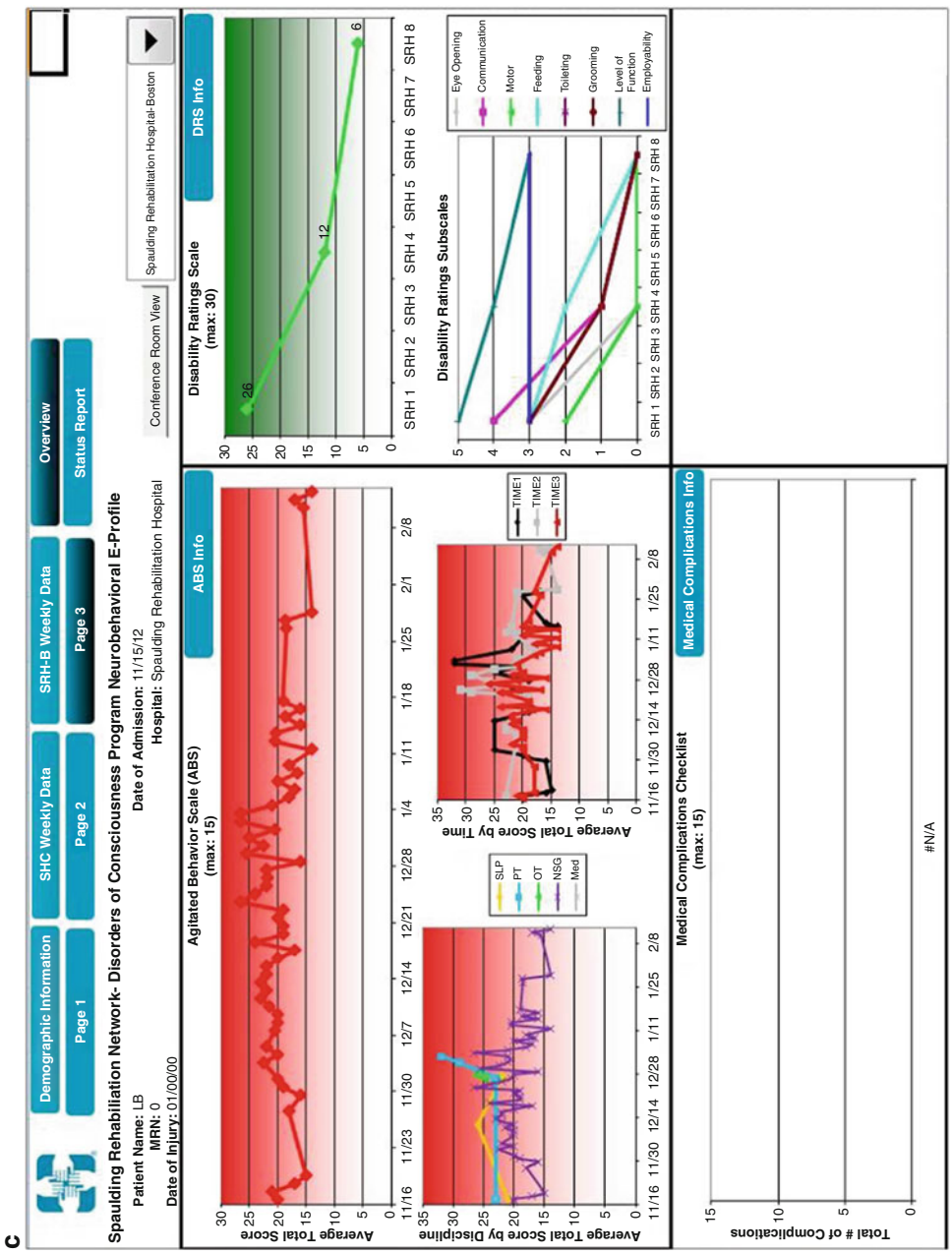

Fig. 5 (continued) initially below the diagnostic cut-off (i.e., >20), and then cross into the clinical range before eventually stabilizing at a subthreshold level. These findings reflect AB's initial disturbance in arousal, subsequent transition to hyperactive alertness, and eventual normalization in behavior

agitation, symptom fluctuation, and sleep disturbance, supporting a diagnosis of posttraumatic confusional state. Elavil was titrated up to 40 mg to reduced restlessness and address ongoing daytime somnolence.

At week 5, a follow-up team meeting was held to review the data generated by the core metrics and specialized protocols. Apart from updating AB's clinical status, the discussion focused on her rate of recovery and the best options for continued care following discharge. Review of the yes–no protocol demonstrated 70–80 % accuracy across personal information, orientation, and general knowledge questions, signaling readiness for formal communication training. A communication training protocol was developed for pilot testing in weeks 6–8.

Weeks 6–8: At week 6, a follow-up family team meeting was held to review the degree and rate of progress across functional domains, and to discuss discharge recommendations. To aid the family's understanding of the clinical findings, data acquired from the *DOC COMPASS* were converted to graphics and presented as charts and figures. Discharge arrangements were initiated while the team continued to administer the core measures and specialized protocols during the last 2 weeks of the program. By week 8, AB presented with only one symptom of confusion on the CAP, indicating resolution of PTCS. Language recovery paralleled resolution of the confusional state as evidenced by improved FCM ratings across language areas and an increase in the verbal fluency score from 5 to 23 within a 4-week span (normal age-corrected mean = 45). The Yes–No Response Consistency/Accuracy Protocol was discontinued at week 7 as she achieved 100 % accuracy across all three categories of questions. The total DRS score improved to 6, suggesting ongoing functional improvement and moderate residual cognitive and physical disability. AB's *eProfile*, shown in Fig. 5, depicts her performance within each functional domain across the 8-week program. AB was discharged home upon completion of the program with recommendations for 24-h supervision and outpatient speech, physical, and occupational therapies.

Conclusion

Severe brain injury is a complex neurobiologic disorder that can result in prolonged disturbance in consciousness. Attesting to the challenges associated with this condition, diagnostic error is common and treatment practices are highly variable across patients with similar problems. The prevailing "trial and error" approach to clinical management is inefficient, impedes evaluation of effectiveness, and slows accumulation of knowledge. In contrast, a systematic, data-driven approach offers a platform to administer assessment and treatment in a more objective manner, provides the opportunity to monitor progress in real time, and generates empirical data that can be used to inform best practices.

In this chapter, we describe an operational framework for clinical management of patients with DoC designed to inform clinical practice, *in the context of clinical practice*. In this model, the clinical setting serves as an in vivo laboratory, and the rehabilitation team functions single-mindedly, directing its efforts toward a set of common goals. The assessment process is interleaved with treatment, interventions are standardized, and common outcome measures employed throughout the rehabilitation course. This approach provides a clinical roadmap designed to improve consistency of care, generates objective evidence to inform diagnostic and prognostic decision-making, facilitates caretaker education, and expands the base of knowledge concerning TBI.

References

1. Faul, M. X. L., Wald, M. M., & Coronado, V. (2010). *Traumatic brain injury in the United States: Emergency department visits, hospitalizations and deaths, 2002-2006*. Atlanta, GA: National Center for Injury Prevention and Control.
2. Posner, J. B., & Plum, F. (2007). *Plum and Posner's diagnosis of stupor and coma* (4th ed., Vol. 14, 401p.). Oxford, England: Oxford University Press.
3. Multi-Society Task Force on PVS. (1994). Medical aspects of the persistent vegetative state (1). *The New England Journal of Medicine, 330*(21), 1499–1508.

4. Quality Standards Subcommittee of the American Academy of Neurology. (1995). Practice parameters: Assessment and management of patients in the persistent vegetative state (summary statement). *Neurology, 45*(5), 1015–1018.
5. Giacino, J. T., Ashwal, S., Childs, N., Cranford, R., Jennett, B., Katz, D. I., et al. (2002). The minimally conscious state: Definition and diagnostic criteria. *Neurology, 58*(3), 349–353.
6. Sherer, M., Nakase-Thompson, R., Yablon, S. A., & Gontkovsky, S. T. (2005). Multidimensional assessment of acute confusion after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 86*(5), 896–904.
7. Sherer, M., Yablon, S. A., Nakase-Richardson, R., & Nick, T. G. (2008). Effect of severity of post-traumatic confusion and its constituent symptoms on outcome after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 89*(1), 42–47.
8. Childs, N., Mercer, W., & Childs, H. (1993). Accuracy of diagnosis of persistent vegetative state. *Neurology, 43*(8), 1465–1467.
9. Andrews, K., Murphy, L., Munday, R., & Littlewood, C. (1996). Misdiagnosis of the vegetative state: Retrospective study in a rehabilitation unit. *BMJ, 313*(7048), 13–16.
10. Schnakers, C., Vanhaudenhuyse, A., Giacino, J., Ventura, M., Boly, M., Majerus, S., et al. (2009). Diagnostic accuracy of the vegetative and minimally conscious state: Clinical consensus versus standardized neurobehavioral assessment. *BMC Neurology, 9*, 35.
11. Giacino, J. T., Schnakers, C., Rodriguez-Moreno, D., Kalmar, K., Schiff, N., & Hirsch, J. (2009). Behavioral assessment in patients with disorders of consciousness: Gold standard or fool's gold? *Progress in Brain Research, 177*, 33–48.
12. Dejong, G., Horn, S. D., Gassaway, J. A., Slavin, M. D., & Dijkers, M. P. (2004). Toward a taxonomy of rehabilitation interventions: Using an inductive approach to examine the "black box" of rehabilitation. *Archives of Physical Medicine and Rehabilitation, 85*(4), 678–686.
13. Lammi, M. H., Smith, V. H., Tate, R. L., & Taylor, C. M. (2005). The minimally conscious state and recovery potential: A follow-up study 2 to 5 years after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 86*(4), 746–754.
14. Katz, D. I., Polyak, M., Coughlan, D., Nichols, M., & Roche, A. (2009). Natural history of recovery from brain injury after prolonged disorders of consciousness: Outcome of patients admitted to inpatient rehabilitation with 1-4 year follow-up. *Progress in Brain Research, 177*, 73–88.
15. Estraneo, A., Moretta, P., Loreto, V., Lanzillo, B., Santoro, L., & Trojano, L. (2010). Late recovery after traumatic, anoxic, or hemorrhagic long-lasting vegetative state. *Neurology, 75*(3), 239–245.
16. Nakase-Richardson, R. W. J., Giacino, J. T., et al. (2012). Longitudinal outcome of patients with disordered consciousness in the NIDRR TBI model systems programs. *Journal of Neurotrauma, 29*(1), 59–65.
17. Giacino, J. T., Kalmar, K., & Whyte, J. (2004). The JFK Coma Recovery Scale-Revised: Measurement characteristics and diagnostic utility. *Archives of Physical Medicine and Rehabilitation, 85*(12), 2020–2029.
18. DiPasquale, M. C. W. (1996). J. The use of quantitative data in treatment planning for minimally conscious patients. *The Journal of Head Trauma Rehabilitation, 11*(6), 9.
19. Schnakers, C., Majerus, S., Giacino, J., Vanhaudenhuyse, A., Bruno, M. A., Boly, M., et al. (2008). A French validation study of the Coma Recovery Scale-Revised (CRS-R). *Brain Injury, 22*(10), 786–792.
20. Lovstad, M., Froslie, K. F., Giacino, J. T., Skandsen, T., Anke, A., & Schanke, A. K. (2010). Reliability and diagnostic characteristics of the JFK Coma Recovery Scale-Revised: Exploring the influence of rater's level of experience. *The Journal of Head Trauma Rehabilitation, 25*(5), 349–356.
21. Rappaport, M., Hall, K. M., Hopkins, K., Belleza, T., & Cope, D. N. (1982). Disability rating scale for severe head trauma: Coma to community. *Archives of Physical Medicine and Rehabilitation, 63*(3), 118–123.
22. American Speech-Language-Hearing Association. (2003). *National Outcomes Measurement System (NOMS): Adult speech-language pathology user's guide*. Rockville, MD: Author [Internet].
23. Strauss, E., Sherman, E. M. S., Spreen, O., & Spreen, O. (2006). *A compendium of neuropsychological tests: Administration, norms, and commentary* (3rd ed., Vol. xvii). Oxford, England: Oxford University Press. 1216p.
24. Schiff, N. D., Giacino, J. T., Kalmar, K., Victor, J. D., Baker, K., Gerber, M., et al. (2007). Behavioural improvements with thalamic stimulation after severe traumatic brain injury. *Nature, 448*(7153), 600–603.
25. Whyte, J., Nordenbo, A. M., Kalmar, K., Merges, B., Bagiella, E., Chang, H., et al. (2013). Medical complications during inpatient rehabilitation among patient with traumatic disorders of consciousness. *Archives of Physical Medicine and Rehabilitation, 94*(10), 1877–1883.
26. Sander, A. M. (2007). Brain injury and the family. *NeuroRehabilitation, 22*(1), 1–2.
27. Sinnakaruppan, I., & Williams, D. M. (2001). Family carers and the adult head-injured: A critical review of carers' needs. *Brain Injury, 15*(8), 653–672.
28. Gan, C., Campbell, K. A., Gemeinhardt, M., & McFadden, G. T. (2006). Predictors of family system functioning after brain injury. *Brain Injury, 20*(6), 587–600.
29. Bond, A. E., Draeger, C. R., Mandleco, B., & Donnelly, M. (2003). Needs of family members of patients with severe traumatic brain injury. Implications for evidence-based practice. *Critical Care Nurse, 23*(4), 63–72.
30. Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness. A practical scale. *Lancet, 2*(7872), 81–84.