October 1, 2013

Specialized Early Treatment for Persons With Disorders of Consciousness: Program Components and Outcomes

Ronald T. Seel, *Shepherd Center*
Jennifer Douglas, *Shepherd Center*
Andrew C. Dennison, *Shepherd Center*
Sarah Heaner, *Shepherd Center*
Kathryn Farris, *Shepherd Center*, et al.

ACRM
AMERICAN CONGRESS OF REHABILITATION MEDICINE

Archives of Physical Medicine and Rehabilitation

journal homepage: www.archives-pmr.org

Archives of Physical Medicine and Rehabilitation 2013;94:1908-23

ORIGINAL ARTICLE

Specialized Early Treatment for Persons With Disorders of Consciousness: Program Components and Outcomes

Ronald T. Seel, PhD, Jennifer Douglas, MS, CCC-SLP, Andrew C. Dennison, MD, Sarah Heaner, MPH, Kathryn Farris, OTR/L, Catherine Rogers, PhD

From the Crawford Research Institute or Brain Injury Program, Shepherd Center, Atlanta, GA.

Abstract

Objectives: To describe a specialized early treatment program for persons with disorders of consciousness (DOC) that includes family education; to identify rates of secondary conditions, imaging used, and selected interventions; and to evaluate outcomes.

Design: A single-center, retrospective, pre-post design using electronic medical record data.

Setting: A Commission on Accreditation of Rehabilitation Facilities–accredited, long-term acute care hospital that provides acute medical and inpatient rehabilitation levels of care for people with catastrophic injuries.

Participants: Persons (N=210) aged 14 to 69 years with DOC of primarily traumatic etiology admitted at a mean ± SD of 41.0±27.2 days postinjury; 2% were in coma, 41% were in the vegetative state, and 57% were in the minimally conscious state.

Interventions: An acute medical level of care with ≥90 minutes of daily interdisciplinary rehabilitation and didactic and hands-on caretaking education for families.

Main Outcome Measures: Coma Recovery Scale–Revised, Modified Ashworth Scale, and discharge disposition.

Results: Program admission medical acuity included dysautonomia (15%), airway modifications (79%), infections (eg, pneumonia, 16%; urinary tract infection, 14%; blood, 11%), deep vein thrombosis (17%), pressure ulcers (14%), and marked hypertonia (30% in each limb). There were 168 program interruptions (ie, 139 surgeries, 29 nonsurgical intensive care unit transfers). Mean length of stay ± SD was 39.1±29.4 days (range, 6–204d). Patients showed improved consciousness and respiratory function and reduced presence or severity of pressure ulcers and upper extremity hypertonia. At discharge, 54% showed sufficient emergence from a minimally conscious state to transition to mainstream inpatient rehabilitation, and 29% did not emerge but were discharged home to family with ongoing programmatic support; only 13% did not emerge and were institutionalized.

Conclusions: Persons with DOC resulting primarily from a traumatic etiology who receive specialized early treatment that includes acute medical care and ≥90 minutes of daily rehabilitation are likely to show improved consciousness and body function; more than half may transition to mainstream inpatient rehabilitation. Families who receive comprehensive education and hands-on training with ongoing follow-up support may be twice as likely to provide care for medically stable persons with DOC in their homes versus nursing facility placement.

Archives of Physical Medicine and Rehabilitation 2013;94:1908-23

Disorders of consciousness (DOC) are medical conditions that arise from various etiologies in which the duration of impairment may be a brief period (ie, seconds, minutes, or hours), they may be a transient stage of recovery (eg, days or weeks after severe brain injury), or they may be a chronic, stable condition.[1] Consensus-based guidelines from the Multi-Society Task Force on Persistent Vegetative State and the Aspen Workgroup define 3 ascending DOC levels: coma, the vegetative state (VS), and the minimally conscious state (MCS) (table 1).[2-4] Persons in coma are unresponsive and unarousable with no spontaneous eye opening, sleep/wake cycles, or observable evidence of self-awareness or environmental awareness.[5] In the VS, persons display spontaneous eye opening and sleep/wake cycles, but observable signs of purposeful behavior (eg, language comprehension, behavioral response to stimuli) remain absent.[6] In the MCS, persons demonstrate minimal but definitive behavioral evidence of awareness; conscious behavior is often subtle and inconsistent, and must be systematically differentiated from reflexive or random behavior.[3,4] For complete DOC guideline criteria and detailed differential diagnostic considerations, sources are available.[4,6] The most common causes of DOC in adolescents and adults are traumatic brain injury (TBI) and hypoxic-ischemic encephalopathy; other DOC etiologies include cerebrovascular

No commercial party having a direct financial interest in the results of the research supporting this article has conferred or will confer a benefit on the authors or on any organization with which the authors are associated.

0003-9993/13/$36 - see front matter © 2013 by the American Congress of Rehabilitation Medicine
http://dx.doi.org/10.1016/j.apmr.2012.11.052

injury, central nervous system infections, tumors, poisoning, and neurodegenerative disorders.[7]

Long-term outcomes for persons with DOC range from moderate to very severe disability and vary based on etiology and early rate of recovery.[7-11] Persons with DOC caused by TBI generally have a better prognosis than persons with other etiologies.[7,12,13] Two recent prospective studies[14,15] indicate that persons with severe TBI, including persons with DOC, who receive early and continuous rehabilitation beginning in the acute medical level of care have better outcomes than those who do not receive early rehabilitation. Further, prospective longitudinal research[16] indicates that persons with DOC caused by TBI who receive early rehabilitation show improved command-following at discharge and improved functional cognition and decreased supervision needs across 1-, 2- and 5-year postinjury follow-up. Given these encouraging findings and considering the long-term health care system costs for very severe disability and nursing facility (NF) placement, it is critical to establish effective, early DOC treatment models after intensive care that can facilitate recovery of consciousness and physical function.[17] An effective, early DOC treatment model would likely need to address at least 3 essential aspects of care.

First, basic care and secondary medical conditions that emerge or linger after intensive care would need to be managed.[5,18] If not treated successfully, secondary conditions can progress to more serious complications with substantial associated health care costs.[12,19] Neurologic complications (eg, hydrocephalus, subdural hematoma, infections) must be detected and treated appropriately to reduce the risk of further disability and NF placement.[5,12,19] Dysautonomia (ie, sympathetic storming) is common, can be difficult to treat, and often requires multimodal interventions (eg, environmental modification, medications, intrathecal baclofen [ITB] trial/pump). Persons with DOC are dependent for all basic care activities, often require assistive equipment for feeding and breathing, and have limited self-initiated movement. They are highly susceptible to infections of the respiratory and genitourinary systems, which can become chronic, damage organs, or become life-threatening. Inactivity and physical deconditioning increase the risk for developing deep vein thrombosis (DVT) that may require inferior vena cava (IVC) filter placement, and pressure ulcers that may require costly muscle flap or skin graft surgeries. Hypertonia in 1 or more limbs is also common; early treatment using multimodal approaches can often manage spasticity and prevent contractures, particularly in the lower extremity, and reduce the need for costly tendon-lengthening surgeries.

Second, providing accurate assessments of DOC level and treatments to facilitate conscious recovery is critical. Diagnostic errors can have severe adverse consequences for persons with DOC including pessimistic prognoses, reduced access to rehabilitative treatment when it should be indicated, prolonged treatment when it should be contraindicated, and inappropriate medicolegal judgments or NF placements.[4,6,11,16,20] The American Congress of Rehabilitation Medicine (ACRM) recommends the use of standardized assessment measures with item content that covers consensus-based DOC diagnostic criteria because they provide more sensitive and reliable diagnoses than unstructured approaches.[21-25] Clinicians with training and experience with persons with DOC would likely be better able to administer recommended measures, differentially account for diagnostic confounds (eg, intraday fluctuations in arousal; underlying sensory, motor, and/or language deficits; effects of sedating medications), and derive accurate diagnoses.[25]

Third, facilitating patients' safe discharge to a private residence versus an NF placement is critical. When patients are medically stable but do not emerge from DOC, many families desire to care for their loved one at home. Providing comprehensive education, hands-on training, and ongoing programmatic support after discharge helps families with life care planning, identifying and responding to emerging medical conditions, and reducing NF placement. Further, ongoing supports help families manage the emotional burden of care that often includes prolonged grief, anxiety, depression, and social isolation.[26,27]

This study describes our efforts to establish a specialized early DOC treatment program for patients and their families, and evaluate the model's effectiveness. First, we present the program's components using the World Health Organization's *International Classification of Functioning, Disability and Health* (ICF) framework.[28] We include data on the types and frequencies of diagnostics, procedures, and program interruptions and their causes (ie, surgeries performed, nonsurgical complications requiring intensive care unit [ICU] transfers). Second, we report data on infections and secondary conditions on admission and acquired during their program stay. Third, we evaluate patients' functional outcomes including mental, respiratory, hypertonia, skin, and self-care. Global outcomes including emergence into consciousness, length of stay (LOS), charges, and discharge disposition are also reported. Last, we discuss and recommend necessary components for an effective, specialized early DOC treatment model and the benefits for patients, families, and health care system cost avoidance.

List of abbreviations:

ACRM	**American Congress of Rehabilitation Medicine**
CRS-R	**Coma Recovery Scale−Revised**
CTRS	**certified therapeutic recreation specialist**
DOC	**disorders of consciousness**
DVT	**deep vein thrombosis**
ICF	***International Classification of Functioning, Disability and Health***
ICU	**intensive care unit**
ITB	**intrathecal baclofen**
IVC	**inferior vena cava**
LE	**lower extremity**
LOS	**length of stay**
MAS	**Modified Ashworth Scale**
MCS	**minimally conscious state**
NF	**nursing facility**
OT	**occupational therapist**
PT	**physical therapist**
SLP	**speech-language pathologist**
TBI	**traumatic brain injury**
UE	**upper extremity**
US	**ultrasound**
UTI	**urinary tract infection**
VS	**vegetative state**

Methods

Participants

Consecutive persons with acquired brain injury−related DOC admitted over a 6-year period from January 1, 2005, through December 31, 2010, were eligible for inclusion (N = 220). Ten patients who emerged from an MCS and transitioned to traditional

Table 1 Summary of diagnostic criteria for coma, VS, MCS, and emerged from MCS

Condition	Description of Consciousness	Visual Function	Motor Function	Auditory Function	Communication
Coma*	Persistent unconsciousness Absence of spontaneous eye opening/ sleep-wake cycle No purposeful responses to environmental stimuli	Not present, ie, eyes remain continuously closed	Reflexive and postural activity No discrete or localizing responses to stimuli	Not present, ie, no startle response to sound	Not present, ie, no expressive behavior or language comprehension
VS†	Persistent unconsciousness Intermittent arousal, ie, periodic spontaneous or stimulus-induced eye opening No sustained, reproducible, purposeful responses to environmental stimuli No voluntary activity	Reflexive startle response to visual stimuli Brief, nonpurposeful or reflexive visual fixation	Postures or withdraws from noxious stimuli Periodic nonpurposeful or reflexive activity	Reflexive startle response to auditory stimuli Brief, reflexive orienting to sound	Brief, nonpurposeful or reflexive vocalizations, crying, or smiling No language comprehension
MCS‡	Partial consciousness Inconsistent but clear and reproducible behavioral evidence of awareness of self or environment Inconsistent but clear and reproducible, purposeful responses to environmental stimuli, ie, after simple commands	Visual pursuit or sustained fixation in direct response to moving or salient stimuli Reaching for objects that demonstrates a clear relationship between object location and direction of reach	Localizing response to noxious stimuli Touching or holding objects in a manner that accommodates the size and shape of the object	Vocalizations or gestures that occur in direct response to the linguistic content of comments or questions	Intelligible verbalization Gestural or verbal yes/no responses (accuracy not required) Crying, smiling, or laughing in response to the linguistic or visual content of emotional stimuli
Emerged from MCS‡	Full consciousness Consistent behavioral evidence of awareness of self or environment, ie, functional object use or functional interactive communication		Reliable, functional object use, ie, appropriate use of at least 2 different items on at least 2 different occasions		Reliable, interactive communication, ie, accurate yes-no responses to situational orientation questions

* Plum and Posner diagnosis criteria of coma.[4]
† American Academy of Neurology Multi-Society Task Force definition of the persistent vegetative state.[5]
‡ Aspen Workgroup definition and diagnostic criteria of the minimally conscious state.[6]

rehabilitation within 7 days of admission were excluded. The final sample was 210. All data in this study are from patients' specialized early DOC treatment stays; that is, data are not reported from patients' ICU or traditional rehabilitation stays.

Interventions: specialized early DOC treatment program

Overview

Our program is designed for patients in VS and MCS, and their families. The program is funded at an acute medical level of care to treat primary and secondary conditions and provide continual skilled nursing (24h/d, 7d/wk) for monitoring and all basic care activities. Acute medical care is augmented with a minimum of 90 daily minutes of interdisciplinary rehabilitation to facilitate functional communication and recovery of consciousness, and provide mobilization therapies (eg, out of bed, daily routine, physical interventions) to promote body function and reduce complications secondary to inactivity and deconditioning. Comprehensive education, hands-on training, and case management are provided to foster family preparedness for patients' home discharge.

Our DOC program is based at the Shepherd Center in Atlanta, Georgia, which is a medical rehabilitation center that primarily treats persons who have sustained severe acquired neurologic injuries. The center has 152 inpatient beds of which 54 are dedicated to persons with brain injury. The center has onsite ICU and imaging services and is physically connected to Piedmont Hospital, a level II trauma center, which provides efficient access for patients who demonstrate rapid decline and/or require intracranial pressure monitoring or invasive procedures. Interdisciplinary team members include a physiatrist, a nurse, a dietitian, a respiratory therapist, a physical therapist (PT), an occupational therapist (OT), a speech-language pathologist (SLP), a neuropsychologist, a certified therapeutic recreation specialist (CTRS), rehabilitation technologist, a family counselor, a case manager, a disability advocacy specialist, and a chaplain. Contract staff includes physicians and medical professionals from neurosurgery, pulmonology, cardiology, internal medicine, orthopedics, and imaging who provide consultations.

Admission process

Regional access case managers identify potential admissions from intensive and acute care hospitals and coordinate referrals. Admission screening criteria target persons 14 years and older who in the access case manager's judgment have a DOC based on at least 1 of the following: Rancho level of 1 to 3 *or* MCS *or* VS *or* patient not visually tracking *or* not following commands. Other admission considerations include families' interest in having the patient discharged to their home if they do not emerge from an MCS, families' willingness to participate in education and hands-on training, and payment for services. Payers are typically managed care companies and workers' compensation. On rare occasions, Medicaid will approve the service. Patients who require intracranial pressure monitoring do not meet our admissions criteria.

Patients may be admitted to our ICU first or directly to our DOC program. In the first 72 hours after admission, the interdisciplinary team extensively assesses the scope and dynamics of persons with DOC care needs. The physiatrist, nurse, and dietitian are among the first to evaluate the patient. Secondary conditions are evaluated, and specialists are consulted as needed. Patients are treated with seizure prophylaxis when indicated using published guidelines.[29] Sedating medications are weaned as appropriate. The team establishes daily routines including a nutrition and weight maintenance plan (eg, tube feeding, intravenous nutrition, dietary modification), bowel and bladder management, weight shifts and turning schedules, skin care and/or monitoring, oral hygiene, and improving sleep cycles.[30,31] Individualized toileting routines (eg, intermittent or continuous catheterization; suppositories) are started early during the stay to promote routine void and movements that can reduce therapy session interruptions. SLPs typically administer the Coma Recovery Scale−Revised (CRS-R) 24 to 48 hours after admission to allow for sedating medications used on transfer to clear. An OT and a PT evaluate physical function and hypertonia. Pain/nociception is challenging to assess in the DOC population. When indicative signs are observed, the team uses conservative interventions, which may include positioning, modalities, and nonsedating medications.[32,33]

Acute medical management

The interdisciplinary team focuses on the treatment and prevention of secondary conditions of primarily nervous system, cardiovascular, respiratory, digestive, musculoskeletal, and skin origin. All team members are responsible for monitoring patients for signs of diminished functioning, physiological changes, infections, new or worsening symptoms, or behaviors that could indicate the presence of pain. Imaging tests are used on a case-by-case basis to identify or rule out secondary conditions and inform the treatment plan. Initial treatment approaches are typically conservative. Invasive procedures, ICU transfers, and surgeries are performed when patients' conditions are deteriorating and have not responded to conservative treatments.

With regard to respiratory care, chest x-rays are standard early after DOC program admission. Ventilator weaning is conducted after therapy hours in our ICU, supervised by the attending pulmonologist and implemented by the nursing staff. Telemetry monitoring for vital signs is used for patients with a tracheostomy as well as others at risk should an airway become compromised. Overnight pulse oximetry is used to monitor persons with obstructive sleep apnea and other respiratory conditions to help guide decisions on decannulation. When persons meet criteria, tracheostomy collar weaning involves downsizing the tracheostomy and transitioning from heat and moisture exchanger to plugging and then to button if needed before full decannulation.

Doppler ultrasound (US) of patients' lower extremities is standard; upper extremities are tested when indicated. Hematologic abnormalities, notably diabetes and sepsis, are screened and treated. With regard to digestive conditions, imaging (eg, kidneys-ureters-bladder radiography, modified barium swallow study, abdominal US/computed tomography) is frequently used, and invasive procedures are performed for feeding tube placements, replacements, or revisions.

Neuromusculoskeletal and movement-related imaging tests are common given the traumatic nature of most injuries, the need for fracture management, the discovery of previously undiagnosed fractures, and hypertonia. An interdisciplinary approach is used for the treatment of hypertonia. The Modified Ashworth Scale (MAS) and goniometer for passive range of motion are used to assess symptomatic limbs and serially evaluate intervention effects.[34] Serial casting, splinting, and stretching/passive range of motion are routinely used as a first-line treatment for both upper and lower extremities, with casts reapplied every 3 to 5 days.[35-39]

Table 2 Rehabilitative treatments reported by ICF activities and participation

ICF Activities/Participation	Assessments	Primary Interventions
D1. Learning and applying knowledge	Basic watching and listening ability; visual and auditory tracking	Establishing appropriate environment and reducing distractions Repetition to encourage habitual or conditioned responses
D3. Communication	CRS-R, level of consciousness Sensory screen Identify intact/effective modes (gestures, vocalizations, verbalizations, eye gaze) Assistive technology consult	Medication Multisystem stimulation; sensorimotor stimulation; visual and auditory input; occlusion techniques; amplifiers Augmentative assistive communication devices Cause/effect switch use
D4. Mobility	Optimal positioning including head, back, arm, and leg supports Seating clinic; specialty cushion, padding	Positioning and facilitation (bed and wheelchair); sitting balance Weight-bearing activities; neuromuscular developmental activities/ proprioceptive input Strengthening neck, trunk, extremities; modalities Assistive mobility equipment orientation
D5. Self-care	Grooming (eg, face washing, hair/teeth brushing); bathing; dressing; eating; toileting; transfers	Orientation to activities Appropriate hand and body positioning Functional object recognition and use; hand-over-hand repetitive training
D7. Interpersonal interactions & relationships	Observation of social interactions	Encourage family and friend interaction with patient using optimal communication strategies
D9. Community, social, & civic life	Observation of patient interactions and the community environment	Orientation to community outings; managing (over)stimulation Managing care in community activities (eg, restaurant)

NOTE. The ICF activities D2 (general tasks & demands), D6 (domestic life), and D8 (major life areas) do not apply to the DOC population at this level of care.

Oral medications (eg, dantrolene sodium, baclofen oral suspension) may be used when hypertonia is systemic. Botulinum toxins are used to treat severe or worsening cases; nerve blocks are used primarily as a treatment/diagnostic for contracture severity.[39-43] When conservative treatments are ineffective and the risk of contractures becomes high, ITB trials are tested and if the results are encouraging, ITB pumps are placed. Lastly, skin care and pressure ulcer prevention are closely monitored and treated aggressively.[44]

Rehabilitative treatments: functional communication and recovery of consciousness

The interdisciplinary treatment team uses an integrated approach to deliver rehabilitative treatments with an emphasis on facilitating recovery of consciousness and improving patient positioning and mobility (table 2). Repetition is frequently used to develop habitual responses. Promoting arousal and interactive communication is interspersed across all therapies and interactions with patients. Stimulant medications, when not contraindicated, are prescribed early in the treatment course. Amantadine hydrochloride is routinely used as a first-line treatment to promote faster recovery of consciousness.[11,45] Amantadine is used alone or in combination with other medications; administration is titrated slowly.

The team formally assesses patients with the CRS-R.[46,47] SLPs document patient scores weekly. The CRS-R rate of improvement during the first 2 weeks in our DOC program is used as a general benchmark to estimate when the person might emerge from consciousness and to inform discharge planning. The CRS-R is also used to guide treatment interventions. For example, the team identifies the modalities and levels in which the patient is most responsive and then targets therapeutic treatment on behaviors at the next ascending level of difficulty. During therapies, the staff presents repetitive stimulus opportunities on intact sensory modalities to increase response consistency. Visual sensory stimulation may include use of computer programs, bright objects, pictures of familiar people, and mirrors to reflect their whole body and face. Auditory sensory stimulation may include using an iPod[a] to present familiar sounds, voices, and music. Functional interaction may include command-following, self-care, and functional object use. Tactile stimulation may include moving patients to be prone, side lying, or seated on mats. The CTRS introduces music and pet therapies in an attempt to engage recognition and responses from the patient. Multisystem stimulation, when not contraindicated, is routinely used for persons in VS and MCS throughout the DOC program. For example, a person in MCS with some head control might be placed on a tilt table or standing frame while selecting named

Table 3 Family interventions reported by ICF learning activities and environmental factors

ICF Activities/Environment	Assessments	Primary Interventions
D1. Learning and applying knowledge	Family understanding of DOC and medical conditions Ability and willingness to provide hands-on patient care and management Family preparation for home placement	CRS-R assessments, level of consciousness, managing expectations, prognosis Interacting with patient (eg, optimal modes, appropriate content, allowing time to respond), sensory stimulation Bowel and bladder (eg, verbalize program, catheter use, cleaning techniques, suppository use, indicators for medical consult) Skin care (eg, checks, prevention techniques, turn schedule, positioning, wound management) Nutrition/tube feeding (eg, regimen, caloric intake measurement, medications, tube cleaning and maintenance, nutrition adjustments, indicators for medical consult) Respiratory care (eg, CPR, tracheostomy site care, deep suctioning techniques, use of Yankauer tube, clean replace equipment) General medical monitoring (eg, vital signs; seizures, pain management; signs, symptoms of storming) Transfers (eg, lifting body mechanics, positioning, Hoyer equipment, manual use) Hypertonia (eg, PROM exercises, identify spasticity/tone, splint schedule/ application/removal, indicators for medical consult) Other ADLs (eg, bathe, groom, dress, oral care)
E1. Products & technology	Nutrition and medication needs Assistive technology consult, seating clinic; vehicle evaluation Evaluation of home modifications needed for patient access and basic care	Medical care plans (eg, prescription list, nutrition plan, home care instructions from all disciplines) Obtain and maintain appropriate wheelchair, AAC devices, tub/toilet equipment, Hoyer lift, bed Modifications (eg, vehicle, community access, home equipment, structural modifications)
E2. Natural environment & human-made changes to environment	Evaluation of environmental modifications needed for patient stimulation and rest	Managing environment/stimulation/rest to optimize patient behavior and safety
E3. Support & relationships	Family and personal support system; self-advocacy and patient advocacy	Social media (eg, Shepherd Cares page; Facebook), community outreach Personal care and respite arrangements Professional and peer counseling, support groups
E4. Attitudes	Family and support system attitudes and understanding of DOC	Training on communicating needs and expectations to the wider family and community

(*continued on next page*)

Table 3 (*continued*)

ICF Activities/Environment	Assessments	Primary Interventions
E5. Services, systems, & policies	Rehabilitation, home or NF discharge plan Support services needs assessment	Medical supports (eg, home health care, single service outpatient, follow-up physician appointments) Disability planning (eg, onsite advocacy specialists, life care planning, case management, telehealth) Community resources, services (eg, vendors, transport, counseling)

Abbreviations: AAC, augmentative and alternative communication; ADLs, activities of daily living; CPR, cardiopulmonary resuscitation; PROM, passive range of motion.

objects/people or demonstrating object function during an automatic motor activity (eg, brushing teeth, feeding).

Rehabilitative treatments: mobilization and activities

Initiating patient mobilization and activities helps restore bodily integrity and reduces the risk of complications (eg, infection, DVTs, skin breakdown).[30,48] For patients who reach MCS, increased time is spent on delivering therapies targeted at increased mobility and self-care activities (see table 2). Families identify activities and interests that are familiar to the patient to include in the treatment plan. The interdisciplinary team attempts to engage patients in repetition tasks related to self-care, sitting balance, transfers, and community mobility. Planned rest (ie, back to bed) is scheduled between therapies to lessen fatigue and overstimulation. When patients are medically stable and can tolerate extensive stimulation, the team engages the patient and family in community outings. The combination of hypertonia management, physical therapies, and repetitive self-care activities delivered at the acute medical level of care also facilitates patients' functional readiness to participate in traditional rehabilitation, which can lead to more efficient and effective utilization of therapies, shorter rehabilitation stays, and cost savings for the payer.[14,15]

Family education

Comprehensive education and training is provided to all families, individualized based on each patient's level of consciousness, secondary conditions, and estimated disposition (table 3). Temporary housing in the center's 84-unit family living center is provided to facilitate family members' engagement and participation in education and training. Methods used include didactic classroom training, medical conferences, hands-on training, staff modeling of techniques, train the trainer, and supervised family-led overnight stays in the transitional living apartment and community outings. For medical care topics that may be covered, see table 3.

Case management is critical to successful home placement, reduced caregiver burden, and reduced risks of rehospitalization and NF placement.[30] Case management helps families to proactively anticipate the patient's needs on return home; identify and coordinate durable medical equipment, assistive technology, and home modification needs; establish instrumental and emotional community supports; and, identify and link families to local medical services. A disability advocacy specialist works with the family to compile, complete, and submit Supplemental Security Income and Social Security Disability Insurance applications as necessary.

Discharge planning

The case manager coordinates discharge decisions with the treatment team, family, and payer. Criteria for transition to traditional TBI rehabilitation include recovery of consciousness and the ability to participate in 3 hours of rehabilitation. Recovery of consciousness and rehabilitation readiness criteria generally consider functional object use and consistent, accurate functional communication per Aspen Workgroup guidelines.[4] For persons who do not emerge from an MCS, staff and family collaboratively decide whether to discharge to the home setting based on the patient's medical acuity, the family's ability to provide care, and access to NF placement.

LOS is determined on a case-by-case basis in coordination with the family and the payer. The patient's medical stability and anticipated or actual recovery of consciousness are the primary drivers of LOS. Persons who have not emerged from an MCS and are discharged home typically have a stay of at least 4 to 6 weeks in order to ensure medical stabilization, deliver family education and training, and implement recommendations for assistive technology, durable medical equipment (eg, appropriate wheelchair type, hospital bed, respiratory needs), and home modifications.

Postdischarge programmatic support

Families who take their loved one with DOC home receive telehealth support biweekly for 3 to 4 months (ie, 6–8 telehealth visits total). Telehealth helps the family to monitor recovery of consciousness including supervising and providing feedback on family administration of the CRS-R. Medical conditions commonly addressed include hypertonia management (eg, the splints no longer fit because of weight gain; improvement or worsening of tone; skin problems) and feeding tube issues (eg, tube is blocked, skin irritation at insertion point, cannot deliver certain medications down the tube, tube is becoming loose). Telehealth also assists with practical issues such as making recommendations for easing the burden of patient care or equipment and supply issues (eg, wrong equipment delivered; supplies have not arrived). Telehealth is essential to meet caregivers' information and communication needs, prevent serious complications, avoid unnecessary emergency department visits, and reduce health care system costs associated with rehospitalizations or NF placement.[26,27]

Measures

The CRS-R[46] is a bedside assessment tool for differentiating levels of consciousness. It is composed of 6 subscales—auditory, visual, motor, oromotor/verbal, communication, and arousal—with 23 dichotomously scored items.[47] The item content of the CRS-R allows for tabulating a total score of 0 to 23, identifying ascending levels of conscious behavior/ability, and using a combination of items to differentiate VS from MCS from emerged from an MCS based on The Multi-Society Task Force on Persistent Vegetative State and Aspen Workgroup criteria.[46] An ACRM practice parameter recommends use of the CRS-R based on its standardized administration and scoring procedures, item content, and interrater and test-retest reliability.[25,46,49]

The MAS is a 6-point rating scale that is used to assess muscle spasticity, with ratings from 0 ("no increase in muscle tone") to 4 ("affected part rigid in flexion or extension").[50] The MAS measures muscle resistance in velocity-dependent movements, passive joint range of motion, and muscle strength. The MAS has acceptable interrater reliability and has been used as a primary outcome measure in hypertonia clinical trials.[36,51]

Skin breakdown (ie, pressure ulcers) was recorded based on wound consult reports and coded in the medical record as stage 2, 3, or 4 based on standard protocol.[44]

Self-care activities assessed throughout the stay are face washing, hair brushing, dressing upper extremity, eating, teeth brushing, bathing, dressing lower extremity, and toileting. Therapists use 4 rating categories to denote patients' level of dependence (ie, dependent, maximum assist, moderate assist, minimum assist).

Charge data were electronically pulled from hospital administrative data for the dates in which patients were treated in our DOC program and include all billable charges (eg, daily rates, procedures, medications). Data represent actual charges without time value of money or inflation adjustments.

Data collection

The study design is a single-center, retrospective, pre-post analysis of patients' DOC program stays using standardized variables in the electronic medical record data supplemented with abstraction of select data variables from text located in either electronic or paper clinical reports. Families provided consent at admission for deidentified medical record data to be used for research and program evaluation purposes. The host institution's research review committee approved the study. All data were collected from the electronic and paper medical records by 4 trained abstractors. Data prospectively recorded in the electronic medical record include weekly CRS-R scores, respiratory function, MAS, and self-care activities. Demographics, injury type, days from injury to program admission, LOS, payer, discharge disposition, diagnostic imaging, surgeries, procedures, nonsurgical interruptions, pressure ulcers, and infections data were abstracted from the electronic or paper medical record.

Ninety-six percent of admission CRS-R scores were rated within 4 days of DOC program admission. If the CRS-R discharge evaluation was not completed (n=60) and the last available score was rated more than 4 days before discharge, then an SLP (J.D.) reviewed the discharge clinical notes to determine whether there was definitive behavioral evidence of improvement or decline between the last CRS-R rating and discharge. CRS-R discharge scores for 18% of the sample (n=38) reflect behavioral evidence from the discharge clinical notes.

Table 4 Patient characteristics (N=210)

Characteristics	Values
Age (y)	28.1±13.0
Sex (men)	70
Race	
White	80
Black/African American	14
Unknown/other	6
Hispanic ethnicity	5
Health insurance payer	
Managed care	71
Workers' compensation	21
Military/Tricare	5
Self-pay	1
Medicaid	1
Primary brain injury type	
Traumatic	86
Vehicular	(76)
Falls/flying objects	(11)
Violence	(6)
Pedestrian	(4)
Sports	(3)
Other	(1)
Anoxic	12
Cerebrovascular accident/other acquired	2
Transferring facility level of care	
Acute care	88
Long-term acute care hospital	10
Other (eg, NF, VAMC, home)	2
Initial admission level of care	
ICU	34
Specialized DOC program	66
Days postinjury at DOC program admission	41.0±27.2
8–21	19
22–28	22
29–91	52
92–171	7
Level of consciousness	
Coma	2
VS	41
MCS	57

NOTE. Values are mean ± SD or percentages.
Abbreviation: VAMC, Veterans Affairs Medical Center.

Statistical analyses

All data entry and analyses were conducted using the SPSS version 15.0.[b] Descriptive statistics were calculated for patient and injury characteristics, imaging, on-floor procedures, ICU transfers, surgeries, infections, CRS-R subscale and total scores, respiratory functioning, MAS scores, skin breakdown, and self-care activities. Wilcoxon signed-rank tests were calculated to compare DOC program admission and discharge scores on ordinal-based measures including CRS-R subscales, MAS, and self-care activity scores. Findings were considered statistically significant using an alpha level of $P<.05$.

Table 5 Number of imaging studies and treatments reported by ICF functions and structures

ICF Functions and Structures	Total No.	% Patients
Mental/nervous system		
imaging/diagnostics		
Brain/head: CT (94), MRI (46), EEG (45)	185	57
ICU transfer, N-S		
Fever/storming	6	3
Seizure	3	1
Hydrocephalus	2	1
Surgeries		
Cerebral shunts: VP (10), VP revision (4), LP (1)	15	7
Puncture: lumbar (11), dural (1)	12	5
Subdural hygroma drainage	3	1
Cranioplasty	3	1
Abscess drainage/debridement	2	1
Nerve decompression	2	1
Cervical arachnoid cyst	1	<1
Sensory Systems		
Surgery		
Eye surgery	1	<1
Cardiovascular, hematologic, immunologic, & respiratory systems		
Imaging		
Chest: x-ray (520), CT (1)	521	73
DVT lower extremity, Doppler US	182	71
DVT upper extremity, Doppler US	69	24
Bronchoscopy/laryngoscopy*	28	10
Cardiovascular: ECG (26), carotid, artery US (2)	26	10
Procedures		
Blood transfusion	12	4
Intubation	1	<1
ICU transfer, N-S		
Cardiovascular	8	4
Respiratory	8	4
Sepsis	1	<1
Surgeries		
Tracheal resection, excision of stenosis	6	3
IVC filter placement	3	1
Other (ie, tracheotomy, chest tube, arterial)	3	1
Digestive, metabolic, & endocrine systems		
Imaging		
KUB/abdominal: x-ray (74), US (13), CT (9)	96	27
Modified barium swallow study	17	8
Endoscopy (4), FEES (4)	8	4
Feeding tube NOS	5	2
Surgeries		
Feeding tube placement/revision	32	12
Abdominal (ie, GI, Ex-Lap, bone flap removal)	3	1
Genitourinary & reproductive systems		
Imaging		
Genitourinary: US (6), CT (1)	7	3
ICU transfer, N-S		
Renal failure	1	<1
Neuromusculoskeletal & movement-related systems		
Imaging		
Extremities/hips: x-ray (269), CT (3), MRI (3)	275	56
Spine: x-ray (91), MRI (9), CT (6)	106	31
Skull/facial/jaw: x-ray (18), CT (4)	22	9
EMG	5	2
ITB pump dye study	3	1
Procedures		
Botox injection	78	36
Baclofen trial	52	23
Nerve block (phenol, 10; marcaine, lidocaine, 9)	19	9
Surgeries		
ITB pump placement	30	14
Hardware removal	9	4
Achilles' tendon lengthening	5	2
Other: orthopedic, skull, laminectomy	3	1
Skin & related structures		
Surgeries		
Skin flap surgery	6	3

Abbreviations: CT, computed tomography; ECG, electrocardiogram; EEG, electroencephalogram; EMG, electromyogram; Ex-Lap, exploratory laparotomy; FEES, fiberoptic endoscopic evaluation of swallowing; GI, gastrointestinal; KUB, kidneys-ureters-bladder; LP, lumbar-peritoneal; MRI, magnetic resonance imaging; N-S, nonsurgical; NOS, not otherwise specified; VP, ventriculoperitoneal.

* FEES swallow studies evaluate vocal cords (voice) and swallow (digestive); bronchoscopies/laryngoscopies/evaluate vocal cords (voice) and airway for obstruction (respiratory).

Results

Patient and injury characteristics

Patient and injury characteristics are described in table 4. The sample was predominately young (mean age ± SD, 28.1±13.0y), men (70%), and white (80%) who almost exclusively had commercial payers (98%). Most (76%) sustained a traumatic etiology secondary to motor vehicle collisions, and 81% were admitted >21 days postinjury. Based on the CRS-R, 2% were in a coma, 41% were in VS, and 57% were in MCS.

Imaging, primary acute medical treatments, and program interruptions

In our sample of 210, secondary conditions led to 139 interruptions for surgeries and an additional 29 interruptions for nonsurgical transfers to intensive care settings. Overall, 40% of patients (n=84) had at least 1 DOC program interruption attributable to surgery (37%), a nonsurgical ICU transfer (9%), or both (6%). Twenty-three percent had program interruptions (ie, 5% nonsurgical ICU transfer, 18% surgery) because of neurologic complications. Additionally, 8% were transferred to

Table 6 Infections, positive cultures at admission and acquired during stay (N = 210)

Infection Location and Bacterial Resistance	% Admit	% Acquired
Body System		
Any infection	58	41
Respiratory		
Upper respiratory	30	12
Pneumonia	16	1
UTI	14	33
Blood	11	4
Stool	4	5
CSF, brain	3	1
Wound, skin	2	5
Ear, eye	1	3
Antibiotic-Resistant Bacteria		
Any resistant bacteria	31	16
MRSA	21	5
Pseudomonas (resistant)	7	3
Acinetobacter (resistant)	6	1
VRE	5	2
Clostridium difficile	3	5
Klebsiella (ESBL)	1	1
Klebsiella (resistant/KPC)	1	0
Escherichia coli (ESBL)	0	1
E coli (resistant)	0	1

Abbreviations: CSF, cerebrospinal fluid; ESBL, extended-spectrum beta-lactamase; KPC, *Klebsiella pneumoniae* carbapenemase; MRSA, methicillin-resistant *Staphylococcus aureus*; VRE, vancomycin-resistant enterococci.

the ICU for cardiovascular or respiratory complications, while 6% had surgery (eg, tracheal complications, IVC filter placements). Thirteen percent had feeding tube placements or revisions, or other abdominal surgeries. Neuromuscular procedures and surgeries predominately focused on extracranial injuries sustained in motor vehicle collisions and hypertonia management. Six patients had skin flap surgeries. A summary of all patient imaging tests and medical treatment received for common secondary conditions (ie, procedures, ICU transfers for nonsurgical treatment, and surgeries) is presented in table 5.

Infections, positive cultures

The frequency of infections and positive cultures is shown in table 6 along with the proportions of infections that were caused by antibiotic-resistant bacteria. Notable infections at admission include pneumonia (16%), urinary tract infection (UTI, 14%), blood (11%), and cerebrospinal fluid and brain (3%). With the exception of UTI, the frequency of new infections or positive cultures was markedly less during their DOC program stay.

Mental function outcomes

CRS-R admission and discharge subscale scores are reported in table 7. At the time of admission, 2% of patients were unarousable, 51% had no visual fixation or pursuit, and 73% had abnormal motor reactivity. Further, 78% of patients had CRS-R total scores

Table 7 Mental function outcomes based on the CRS-R (N = 210)

CRS-R Scales/Items	% Admit	% DC	*P*
Auditory			<.001
0 None	17	2	
1 Auditory startle	41	20	
2 Localization to sound	27	17	
m 3 Reproducible move to command	15	23	
m 4 Consistent move to command	1	39	
Visual			<.001
0 None	25	9	
1 Visual startle	26	7	
m 2 Fixation	17	7	
m 3 Visual pursuit	24	20	
m 4 Object localization: reaching	7	16	
m 5 Object recognition	0	41	
Motor			<.001
0 None/flaccid	16	3	
1 Abnormal posturing	28	12	
2 Flexion withdrawal	29	19	
m 3 Localization to noxious stimulation	14	6	
m 4 Object manipulation	9	7	
m 5 Automatic motor response	4	9	
e 6 Functional object use	0	44	
Oral motor/verbal			<.001
0 None	8	0	
1 Oral reflexive movement	73	28	
2 Vocalization/oral movement	18	43	
m 3 Intelligible verbalization	1	29	
Communication			<.001
0 None	90	40	
m 1 Nonfunctional: intentional	10	26	
e 2 Functional: accurate	0	34	
Arousal			<.001
0 Unarousable	2	1	
1 Eye opening with stimulation	54	16	
2 Eye opening without stimulation	42	46	
3 Attention	1	37	

NOTE. All admit versus discharge comparisons based on Wilcoxon signed-rank test. Percentages may not add to 100% because of rounding.
Abbreviations: DC, discharge; e, behavioral indicator of emergence from MCS based on Aspen Workgroup criteria; m, behavioral indicator of MCS based on Aspen Workgroup criteria.

≤10. Persons with DOC showed improvement ($P<.001$) from admission to discharge on all 6 subscales. At discharge, 53% emerged from MCS based on the Aspen criteria for functional object use (19%), accurate functional communication (8%), or meeting both criteria (26%).

Body function and structures

At admission, 79% were admitted with modifications to their airway including 57% with a tracheotomy collar, 14% with a tracheotomy hygroscopic condenser, 3% with a tracheostomy plug, and 5% receiving mechanical ventilation. Improved respiratory status ($P<.001$) was observed at discharge; 67% were within normal limits without modifications, while 3% still required mechanical ventilation.

Table 8 Hypertonia outcomes based on the MAS

MAS Ratings by Extremity	% Admit	% DC	*P*
RUE (n=182)			.010
0 Normal tone	30	32	
1 Slight increase; min resist at end range	32	38	
1+ Slight increase; min resist through ROM	9	10	
2 Marked increase through ROM	20	14	
3 Considerable increase; movement difficult	9	5	
4 Rigid in flexion or extension	1	<1	
LUE (n=184)			.002
0 Normal tone	31	34	
1 Slight increase; min resist at end range	31	35	
1+ Slight increase; min resist through ROM	11	11	
2 Marked increase through ROM	16	16	
3 Considerable increase; movement difficult	10	4	
4 Rigid in flexion or extension	<1	0	
RLE (n=196)			.291
0 Normal tone	32	27	
1 Slight increase; min resist at end range	32	33	
1+ Slight increase; min resist through ROM	9	12	
2 Marked increase through ROM	19	19	
3 Considerable increase; movement difficult	7	8	
4 Rigid in flexion or extension	2	<1	
LLE (n=198)			.212
0 Normal tone	27	23	
1 Slight increase; min resist at end range	36	38	
1+ Slight increase; min resist through ROM	10	12	
2 Marked increase through ROM	18	17	
3 Considerable increase; movement difficult	7	8	
4 Rigid in flexion or extension	1	1	

NOTE. Admit versus discharge MAS comparisons based on Wilcoxon signed-rank test; persons with hypotonic/flaccid limbs were not included in the analysis.
Abbreviations: DC, discharge; LLE, left lower extremity; LUE, left upper extremity; min, minimal; RLE, right lower extremity; ROM, range of motion; RUE, right upper extremity.

Table 9 Self-care activities outcomes

Activities, Ratings	% Admit	% DC	*P*
Face washing (n=204)			<.001
Dependent	94	65	
Maximum assist	5	21	
Moderate assist	1	8	
Minimum assist	0	6	
Hair brushing (n=203)			<.001
Dependent	95	74	
Maximum assist	4	16	
Moderate assist	1	6	
Minimum assist	0	3	
Dressing—UE (n=203)			<.001
Dependent	98	80	
Maximum assist	1	14	
Moderate assist	1	5	
Minimum assist	0	1	
Eating (n=88)			.014
Dependent	100	91	
Maximum assist	0	7	
Moderate assist	0	1	
Minimum assist	0	1	
Teeth brushing (n=87)			.001
Dependent	100	83	
Maximum assist	0	11	
Moderate assist	0	5	
Minimum assist	0	1	
Bathing (n=87)			.002
Dependent	100	87	
Maximum assist	0	13	
Dressing—LE (n=88)			.014
Dependent	100	93	
Maximum assist	0	7	
Toileting (n=88)			.157
Dependent	99	97	
Maximum assist	1	3	
Transfers (n=208)			<.000
Dependent—Hoyer	97	77	
Dependent—manual	2	10	
Maximum assist	1	8	
Moderate assist	0	4	

NOTE. Admit versus discharge self-care comparisons based on Wilcoxon signed-rank test.
Abbreviation: DC, discharge.

At admission, 10% had an upper extremity (UE) DVT, and 7% had a lower extremity (LE) DVT. During their stay, 8% acquired a UE DVT, and 7% acquired an LE DVT. With regard to the skin, 14% (n=30) were admitted with pressure ulcers: stage 2 (n=17), stage 3 (n=10), and stage 4 (n=3). One patient acquired a pressure ulcer (stage 2) during the program. At discharge, 60% (n=18) of admission pressure ulcers were healed. Thirteen patients were discharged with pressure ulcers at stage 2 (n=6) and stage 3 (n=7).

Excluding persons with flaccid tone, admission and discharge MAS scores for each extremity are reported in table 8. Overall, 45% of patients (n=208) had marked hypertonia in at least 1 extremity at admission. At discharge, patients showed improved hypertonia in their right UE ($P=.010$) and left UE ($P=.002$). No improvement or worsening of hypertonia was shown at discharge for the LE.

Self-care activities and transfers

Admission and discharge self-care activity and transfers ratings are reported in table 9. At admission, almost all patients were dependent on self-care activities and transfers. At discharge, patients made improvements in all activities except for toileting. Patients were most able to provide modest levels of assistance on face washing (35%), hair brushing (26%), UE dressing (20%), and teeth brushing (17%).

Discharge level of consciousness, LOS, charges, and disposition

Patients' discharge levels of consciousness and associated stays, charges, and dispositions are reported in table 10. Overall, 26% of persons emerged from an MCS based on both Aspen criteria, and another 27% emerged based on 1 of 2 criteria. About 12% remained in VS at discharge. The mean

Table 10 Specialized DOC Program LOS, costs, and disposition reported by discharge Aspen consciousness levels (N = 210)

		Etiology	Admit	Admit	DOC Program		Disposition			
Discharge Aspen Level	%	Trauma	CRS-R	DPI	LOS (d)	Charges* ($)	IR	Home	NF†	Med‡
All levels	100	86	7.5±3.7	41.0±27.2	39.1±29.4	151,732±154,018	54	29	13	4
Emerged, 2 criteria present	26	94	8.9±3.3	28.3±15.8	25.6±21.7	89,040±79,580	96	0	0	4
Emerged, 1 criterion present§	27	87	8.5±4.1	40.5±19.5	33.5±21.6	116,899±93,530	82	9	7	2
MCS	35	87	6.9±3.3	46.0±28.3	48.9±34.8	200,051±190,591	22	60	14	4
VS	12	62	4.4±2.3	54.0±43.4	51.7±27.6	215,693±190,029	0	46	39	15

NOTE. Values are mean ± SD or percentages.
Abbreviations: DPI, days postinjury; IR, traditional inpatient rehabilitation program; Med, medical.
* Charges based on n = 208.
† Includes skilled nursing, assisted living, and personal care residential facility.
‡ Medical level of care and includes acute care, Veterans Administration program not specified, and long-term care hospital.
§ n = 39 met functional object use criteria; n = 17 met functional/accurate communication emergence criteria.

LOS was 39.1 days (range, 6–204d), and the mean charge was $151,732. Fifty-four percent transitioned to traditional inpatient rehabilitation, while 29% were discharged home with family and programmatic support; 13% were discharged to an NF. Persons who emerged from MCS had a shorter LOS, less charges, and were far more likely to transition to traditional inpatient rehabilitation.

Discussion

There is considerable debate regarding the treatment needs of persons with DOC and the optimal clinical care and setting to improve outcomes and reduce the risk of long-term severe disability and institutionalization.[52] Only 2 studies[12,19] were identified that provided incidence data on DOC medical acuity after intensive care within 3 months of onset. Our study replicates and extends the evidence base that persons with DOC caused primarily by a traumatic etiology have widespread secondary conditions that occur at fairly equivalent incidence rates compared with previous study results (noted in parentheses in italics) and include the following:

1. Neurologic: 73% abnormal motor reactivity, 25% dysautonomia/storming; 3% cerebral infections; 5% ICU nonsurgical transfers; and 15% cerebral shunts/revisions, punctures, and drains (*71% abnormal motor reactivity,*[12] *37% and 63% fever of central origin,*[12,19] *and 16% cerebral shunts*[12])
2. Respiratory: 74% requiring decannulation, 5% requiring ventilator weaning, 17% pneumonia, 4% nonsurgical ICU transfers, and 4% tracheal surgeries (*92% and 77% tracheostomies*[12,19] *and 30% pneumonia*[19])
3. Cardiovascular: 17% UE DVT, 15% LE DVT, 4% nonsurgical ICU transfers, 1.5% IVC placement, and 1% arterial surgery
4. Digestive: 100% enteral feeding, 100% bowel management, 47% UTI, and 12% feeding tube revisions or replacements (*100% enteral feeding,*[19] *100% bowel management,*[19] *and 53% UTIs*[19])
5. Hypertonia: 45% marked hypertonia, ie, MAS≥2, in at least 1 limb; serial casting first-line treatment; 36% botulinum toxin A; 23% ITB trial; 9% nerve blocks; 14% ITB pump placements; and 2.5% tendon-lengthening surgeries (*93% considerable hypertonia, ie, MAS≥3, in at least 1 limb*[19])
6. Skin: 14% admitted with stage 2 to 4 pressure ulcers, 3% skin flap surgeries

In our sample of 210 patients, 40% had at least 1 DOC program interruption because of either surgery or a nonsurgical ICU transfer. These data are consistent with DOC specialty program data from an acute setting in which 40% of patients also required transfer to an acute facility for temporary management of medical issues such as sepsis, status epilepticus, neurologic procedures, and/or deterioration.[19]

Despite high medical acuity coupled with low levels of conscious functioning at admission, our study provides evidence that persons treated in a specialized early DOC acute medical level of care program with ≥90 minutes of daily rehabilitation showed improvements in arousal; auditory, visual, and motor response; verbalization and functional communication; respiratory airway function; right and left UE hypertonia; pressure ulcers; and in their ability to assist with face washing, hair brushing, UE dressing, teeth brushing, and transfers. At discharge, 53% showed 1 or more signs of emergence into full consciousness, which replicates the 54% emergence rate reported by Groswasser and colleagues in a sample of 134 patients with disordered consciousness of 30 or more days.[12] Consistent with the literature, persons who emerged from MCS at discharge were more likely to have a traumatic etiology, higher admission CRS-R total scores, and fewer days postinjury than persons discharged in VS.[7-13]

Our study also provides evidence that 54% of persons treated in an early specialized DOC treatment program had sufficient medical stabilization and recovery of consciousness to transition to mainstream inpatient rehabilitation care, where they likely had further short- and long-term functional recovery and reduced disability.[16] Persons who did not emerge were 2.25 times more likely to be discharged home with family members (29%) than to an NF. Importantly, only 13% of persons receiving early specialized DOC treatment were institutionalized at discharge. This discharge to home versus NF ratio translates into significant long-term cost avoidance to the health care system. Also, persons in a specialized early DOC treatment program had no deaths and very low rates of severe secondary conditions (eg, only 1 acquired pressure ulcer [stage 2], only 7 discharged who required mechanical ventilation, and only 2 with grade 4 hypertonia), which further translates into health care system cost avoidance and reduced risk of litigation.

Based on our findings, previous study results, and consensus-based recommendations in the literature,[4,30,48,53-56] we summarize 6 essential standards of care for effective, early treatment of DOC (table 11). For each standard, we summarize primary patient- and

Table 11 Primary patient-centered outcomes and health system benefits of DOC specialty programs

Recommended Standards of Care	Patient-Centered Outcomes/Benefits	Health Care System Outcomes/Benefits
1. Optimal medical environment including: a. Medical professionals with training and experience in DOC to establish the diagnosis and coordinate clinical treatment b. Interdisciplinary team integrated in the assessment and treatment of all functions c. Onsite access to imaging, pulmonology, cardiology, neurosurgery, orthopedics, wound/ostomy, and ICU services	Accurate diagnosis of level of consciousness, prognosis, and improved recommendations for treatment Early detection/assessment/treatment of severe secondary brain complications and infections Ventilator and tracheostomy collar weaning and early detection/treatment and prevention of aspiration and respiratory infection	Reduced diagnostic errors, inappropriate referrals, and inappropriate medical-legal decisions Reduced risk of mortality, extended hospitalization, and long-term severe disability due to late identification and response to complications Reduced operational costs of ICU transfers, hospital stays, and associated costs
2. Prevent and treat secondary conditions (eg, dysautonomia, hypertonia)	Detection/prophylaxis/treatment of severe cardiovascular complications (eg, DVT) Detection/treatment/prevention of skin breakdown Improved limb functioning; prevention of tone-related complications (eg, contractures, reduced incidence and severity of skin breakdown)	Reduced risk of mortality, extended hospitalization, and long-term severe disability Reduced risk of contracture and skin surgical costs Improved rehabilitation readiness and utilization
3. Maintain bodily integrity (eg, nutrition, oral and physical hygiene, skin care, infection prevention and treatment; bowel and bladder management)	Improved nutrition management and prevention of malnutrition and muscle wasting Improved bowel and bladder management; prevention/early detection of infections/complications; reduced skin breakdown	Reduced rehospitalization and associated costs Reduced renal insufficiency and skin-/wound-related rehospitalization and costs Improved rehabilitation readiness and utilization
4. Facilitate functional communication and environmental interaction (eg, pharmacologic intervention, environmental stimulation)	Improved arousal, consciousness, and identification of intact sensory and communication modes	Reduced risk of institutionalization and long-term severe disability; improved utilization of specialized DOC program and rehabilitation services
5. Establish functional mobility (eg, postural/positioning, stretching and ROM, movement swallowing); promote self-care activities	Improved mobility, positioning, and strengthening; prevention of complications (eg, skin) Improved self-care activities	Improved rehabilitation readiness and service utilization Reduced risk of skin/wound surgical costs
6. Provide family education and support including: a. Medical information and hands-on personalized training b. Case management for life planning, products, DME, technology, community supports, and local medical services c. Disability advocacy for financial counseling d. Postdischarge programmatic support	Improved family management of DOC secondary conditions in the home and community including application of bladder and bowel program, medication administration, transfers, respiratory and nutrition programs, and identification of recovery or emergent complications Improved community support and long-term success related to financials (SSI/SSDI; medical support)	Reduced risk of mortality, institutionalization, rehospitalization, and associated costs Improved identification of rehabilitation readiness and service utilization

Abbreviations: DME, durable medical equipment; ROM, range of motion; SSDI, Social Security Disability Insurance; SSI, Supplemental Security Income.

family-centered outcomes and potential health care system benefits gained from early specialized DOC treatment in comparison with suboptimal care. For example, there are wide-ranging benefits to early and aggressive treatment of hypertonia, in addition to avoiding contractures and the associated high costs of tendon release surgeries. If the patient emerges from an MCS and transitions to traditional inpatient rehabilitation, the patient with managed tone will be able to participate in and benefit from an array of upper and lower extremity rehabilitation therapies related to self-care activities and transfers that would not be possible with marked tone.[57] Improved rehabilitation readiness results in better utilization of the rehabilitation benefit (eg, not spending the first 3wk on functioning vs. tone management) and health care system cost savings. If the patient does not emerge from an MCS, well-managed hypertonia increases the likelihood that the family will be willing and able to manage the patient at home by reducing caregiver burden related to patient transfers, hygiene, and dressing, as well as distress related to the physical appearance of

hypertonic limbs. Family members report treatment satisfaction and reduced burden when improvement is observed in physical function (eg, head control, reduced hypertonia, assistance with transfers) as well as communication (eg, eye contact, visual tracking, indications of approval/disapproval, communication device use) and behavior/mood (eg, smiling, decreased "agitation").[55]

The importance of establishing an early standard of care for persons with DOC is critical given the federal government's increasing emphasis on narrowing health access disparities and providing patient- and family-centered care. There remains significant disparity in access to extended acute medical and early rehabilitative treatments for persons with DOC because of intensive care system knowledge of prognosis and treatment options, specialized program availability, and third-party payer policies.[52]

After intensive care, many persons with DOC are transferred to an NF.[52] This is consistent with adult trauma population data in which only persons aged 18 to 30 years were more likely to be discharged to an inpatient rehabilitation facility than an NF.[58] Adult trauma patients discharged from intensive medical settings directly to an NF have substantial increased risks of mortality compared with discharge to rehabilitation and other settings across all adult age groups, even after controlling for severity indices including discharge functional status, brain injury severity, admission injury severity, mechanism of injury, Charlson Comorbidity Index score, and LOS.[57] Other intensive care longitudinal studies[59-61] that have also controlled for severity have reported similar high risks of mortality when patients are discharged directly to an NF, but it is unclear to what extent this risk is a surrogate marker of unmeasured severity, premature discharge for services, or difficulty providing the appropriate level of care.

Given our research findings, it is difficult to envision a standalone NF providing optimal care to persons with DOC at least within the first 3 to 4 months postinjury. Adults with DOC tend to be traumatically injured, require mechanical ventilation during their intensive stay, and have very high rates of secondary conditions early after injury, the very factors that place persons at risk for mortality in a skilled NF. It is unlikely that a standalone NF would possess or have immediate access to the level of specialization required to manage medical acuity including dysautonomia, cerebral swelling, decannulation, tracheal complications, pneumonia, UTIs, sepsis, DVT monitoring, hypertonia treatment, and pressure ulcers. It would also be difficult for an NF to operationally manage frequent, unplanned offsite transfers to acute settings for diagnostic tests or invasive interventions for these conditions. Lack of training and infrequent experience with persons in DOC would provide challenges for NF clinical staff when assessing consciousness, differentially accounting for diagnostic confounds, and observing and interpreting subtle changes that might indicate the presence of a serious condition. Future research on specialized early DOC treatment programs should examine long-term impacts, cost-effectiveness, and prediction models that match subgroups of patients with the most effective level and setting of care.

Study limitations

There are limitations to inferences that can be made from our pre-post study design when attributing patient improvement to treatment program effects. Previous research[62-64] suggests that hypertonia and pressure ulcers are unlikely to improve, and often worsen, without intervention. Therefore, it is reasonable to infer from our data that treatment contributed to improved UE tone, prevention of contractures, pressure ulcer healing, and prevention of new pressure ulcers. While natural recovery likely plays a significant role in recovery of consciousness, treatment in a specialty DOC program appears to contribute at least a small to moderate effect related to using effective interventions such as neurostimulants (ie, amantadine). Given that there is significant variation in our outcomes (ie, there is a mix of good and suboptimal outcomes reported), there should be only minor concerns related to expectation bias. Further, many outcomes were assessed by trained clinicians using measures with standardized administration and scoring procedures, minimizing measurement error attributable to reliability. Lastly, using the discharge clinical note to impute 14% of CRS-R discharge scores likely reflects behavioral observations made over a more extended time interval than from a single CRS-R administration that uses a more restricted time interval.

Conclusions

Persons with DOC remain at a high level of medical acuity after intensive care, which should be considered in order to make appropriate early discharge placements. Persons with DOC caused primarily by a traumatic etiology who are treated in a specialized early treatment program that includes acute medical care and $\geq$90 minutes of rehabilitation daily show improvement in all aspects of conscious functioning, respiratory function, UE hypertonia, pressure ulcers, and self-care activities. More than half may be transitioned to mainstream inpatient rehabilitation programs. Lastly, families who are provided comprehensive education and hands-on training with follow-up support are likely willing and able to provide care for medically stable persons with DOC in their home.

Suppliers

a. Apple Inc, 1 Infinite Loop, Cupertino, CA 95014.
b. SPSS Inc, 233 S Wacker Dr, 11th Fl, Chicago, IL 60606.

Keywords

Brain injuries; Diagnosis; Prognosis; Rehabilitation; Vegetative state

Corresponding author

Ronald T. Seel, PhD, Shepherd Center, Crawford Research Institute, 2020 Peachtree Rd, Atlanta, GA 30309. *E-mail address:* ron_seel@shepherd.org.

References

1. Bernat JL. Chronic consciousness disorders. Annu Rev Med 2009;60:381-92.
2. American Congress of Rehabilitation Medicine. Recommendations for use of uniform nomenclature pertinent to persons with alterations in consciousness. Arch Phys Med Rehabil 1995;76:205-9.

3. Giacino JT, Zasler ND. Outcome after severe traumatic brain injury: coma, the vegetative state, and the minimally responsive state. J Head Trauma Rehabil 1995;76:40-56.
4. Giacino JT, Ashwal S, Childs N, et al. The minimally conscious state: definition and diagnostic criteria. Neurology 2002;58:349-53.
5. Plum F, Posner J. The pathologic physiology of signs and symptoms of coma. The diagnosis of stupor and coma. 3rd ed. Philadelphia: FA Davis; 1982.
6. American Academy of Neurology Quality Standards Subcommittee. Practice parameter: assessment and management of persons in the persistent vegetative state. Neurology 1995;45:1015-8.
7. The Multi-Society Task Force Report on PVS. Medical aspects of the persistent vegetative state. N Engl J Med 1994;330:1499-508.
8. Levin HS, Saydjari C, Eisenberg HM, Foulkes M, Marshall LF, Ruff RM. Vegetative state after closed-head injury. A traumatic coma data bank report. Arch Neurol 1991;48:580-5.
9. Giacino JT, Kezmarsky MA, DeLuca J. Monitoring rate of recovery to predict outcome in minimally responsive patients. Arch Phys Med Rehabil 1991;72:897-901.
10. Choi SC, Barnes TY, Bullock R, Germanson TA, Marmarou A, Young HF. Temporal profile of outcomes in severe head injury. J Neurosurg 1994;81:169-73.
11. Whyte J, Katz D, Long D, et al. Predictors of outcome in prolonged posttraumatic disorders of consciousness and assessment of medication effects: a multicenter study. Arch Phys Med Rehabil 2005;86: 453-62.
12. Sazbon L, Grosswasse Z. Outcome in 134 patients with prolonged posttraumatic unawareness. Part 1: parameters determining late recovery of consciousness. J Neurosurg 1990;72:75-80.
13. Giacino JT, Kalmar K. The vegetative and minimally conscious states: a comparison of clinical features and functional outcome. J Head Trauma Rehabil 1997;12:36-51.
14. Choi JH, Jakob M, Stapf C, Marshall RS, Hartmann A, Mast H. Multimodal early rehabilitation and predictors of outcome in survivors of severe traumatic brain injury. J Trauma 2008;65: 1028-35.
15. Andelic N, Bautz-Holter E, Ronning R, et al. Does an early onset and continuous chain of rehabilitation improve the long-term functional outcome of patients with severe traumatic brain injury? J Neurotrauma 2012;29:66-74.
16. Nakase-Richardson R, Whyte J, Giacino JT, et al. Longitudinal outcome of patients with disordered consciousness in the NIDRR TBI Model Systems Programs. J Neurotrauma 2012;29:59-65.
17. Sorbo B, Rydenhag KS, Sunnerhagan M, Blomqvist S, Svensson I, Emanuelson I. Outcome after severe brain damage, what makes the difference? Brain Inj 2005;19:493-503.
18. Sazbon L, Groswasser Z. Time-related sequelae of TBI in patients with prolonged post-comatose unawareness (PC-U) state. Brain Inj 1991;5:3-8.
19. Ng YS, Chua KS. States of severely altered consciousness: clinical characteristics, medical complications and functional outcome after rehabilitation. NeuroRehabilitation 2005;20:97-105.
20. Giacino JT, Kalmar K. Diagnostic and prognostic guidelines for the vegetative and minimally conscious states. Neuropsychol Rehabil 2005;15:166-74.
21. Childs NL, Mercer WN, Child HW. Accuracy of diagnosis of persistent vegetative state. Neurology 1993;43:1465-7.
22. Andrews K, Murphy L, Munday R, Littlewood C. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. BMJ 1996;313:13-6.
23. Laureys S, Perrin F, Schnakers C, Bolya M, Majerus S. Residual cognitive function in comatose, vegetative and minimally conscious states. Curr Opin Neurol 2005;18:726-33.
24. Schnakers C, Vanhaudenhuyse A, Giacino J, et al. Diagnostic accuracy of the vegetative and minimally conscious state: clinical consensus versus standardized neurobehavioral assessment. BMC Neurol 2009;9:35.
25. American Congress of Rehabilitation Medicine, Brain Injury-Interdisciplinary Special Interest Group, Disorders of Consciousness Task Force, et al. Assessment scales for disorders of consciousness: evidence-based recommendations for clinical practice and research. Arch Phys Med Rehabil 2010;91:1795-813.
26. Giovannetti AM, Leonardi M, Pagani M, Sattin D, Raggi A. Burden of caregivers of patients in vegetative state and minimally conscious state. Acta Neurol Scand 2013;127:10-8.
27. Leonardi M, Giovannetti AM, Pagani M, Raggi A, Sattin D. National Consortium Functioning and Disability in Vegetative and in Minimal Conscious State Patients. Burden and needs of 487 caregivers of patients in vegetative state and in minimally conscious state: results from a national study. Brain Inj 2012;26:1201-10.
28. International Classification of Functioning, Disability and Health (ICF) of the World Health Organization. 2003 revision. Available at: http://www.who.int/classifications/icf/training/icfchecklist.pdf. Accessed June 20, 2013.
29. Chang BS, Lowenstein DH. Practice parameter: antiepileptic drug prophylaxis in severe traumatic brain injury: report of the Quality Standards Subcommittee of the American Academy of Neurology. Neurology 2003;60:10-6.
30. Andrews K. Rehabilitation practice following profound brain damage. Neuropsychol Rehabil 2005;15:461-72.
31. Puggina AC, Paes da Silva MJ, Schnakers C, Laureys S. Nursing care of patients with disorders of consciousness. J Neurosci Nurs 2012;44: 260-70.
32. Schnakers C, Chatelle C, Majerus S, Gosseries O, De Val M, Laureys S. Assessment and detection of pain in noncommunicative severely brain-injured patients. Expert Rev Neurother 2010;10: 1725-31.
33. Schnakers C, Chatelle C, Vanhaudenhuyse A, et al. The Nociception Coma Scale: a new tool to assess nociception in disorders of consciousness. Pain 2010;148:215-9.
34. Elovic EP, Simone LK, Zafonte R. Outcome assessment for spasticity management in the patient with traumatic brain injury. J Head Trauma Rehabil 2004;19:155-77.
35. Mosely AM. The effect of casting combined with stretching on passive ankle dorsiflexion in adults with traumatic head injuries. Phys Ther 1997;77:240-7.
36. Singer BJ, Singer KP, Allison GT. Evaluation of extensibility, passive torque and stretch reflex responses in triceps surae muscles following serial casting to correct spastic equinovarus deformity. Brain Inj 2003;17:309-24.
37. Singer BJ, Jegasothy GM, Singer KP, Allison GT. Evaluation of serial casting to correct equinovarus deformity of the ankle after acquired brain injury. Arch Phys Med Rehabil 2003;84:483-91.
38. Mortensen PA, Eng JJ. The use of casts in the management of joint mobility and hypertonia following brain injury in adults: a systematic review. Phys Ther 2003;83:648-58.
39. Verplancke D, Snape S, Salisbury CF, Jones PW, Ward AB. A randomized controlled trial of botulinum toxin on lower limb spasticity following acute acquired severe brain injury. Clin Rehabil 2005;19:117-25.
40. Childers MK, Brashear A, Jozefczyk P, et al. Dose-dependent response to intramuscular botulinum toxin type A for upper-limb spasticity in patients after a stroke. Arch Phys Med Rehabil 2004; 85:1063-9.
41. Elovic EP, Brashear A, Kaelin D, et al. Repeated treatments with botulinum toxin type A produce sustained decreases in the limitations associated with focal upper-limb poststroke spasticity for caregivers and patients. Arch Phys Med Rehabil 2008;89: 799-806.
42. Simpson DM, Gracies JM, Yablon SA, Barbano R, Brashear A. BoNT/TZD Study Team. Botulinum neurotoxin versus tizanidine in upper limb spasticity: a placebo-controlled study. J Neurol Neurosurg Psychiatry 2009;80:380-5.
43. Esquenazi A, Mayer N, Lee S, et al. Patient registry of outcomes in spasticity care. Am J Phys Med Rehabil 2012;91:729-46.

44. European Pressure Ulcer Advisory Panel and National Pressure Ulcer Advisory Panel. Prevention and treatment of pressure ulcers: quick reference guide. Washington (DC): National Pressure Ulcer Advisory Panel; 2009.
45. Giacino JT, Whyte J, Bagiella E, et al. Placebo-controlled trial of amantadine for severe traumatic brain injury. N Engl J Med 2012; 366:819-26.
46. Giacino JT, Kalmar K. The JFK Coma Recovery Scale-Revised: measurement characteristics and diagnostic utility. Arch Phys Med Rehabil 2004;85:2020-9.
47. Kalmar K, Giacino JT. The JFK Coma Recovery Scale-Revised. Neuropsychol Rehabil 2005;15:454-60.
48. Elliott L, Walker L. Rehabilitation interventions for vegetative and minimally conscious patients. Neuropsychol Rehabil 2005;15:480-93.
49. Schnakers C, Majerus S, Giacino J, et al. A French validation study of the Coma Recovery Scale-Revised. Brain Inj 2008;22:786-92.
50. Bohannon RW, Smith MB. Interrater reliability of a Modified Ashworth Scale of muscle spasticity. Phys Ther 1987;67:206-7.
51. Hinderer SR, Gupta S. Functional outcome measures to assess interventions for spasticity. Arch Phys Med Rehabil 1996;77:1083-9.
52. Berube J, Fins J, Giacino J, et al. The Mohonk Report. Disorders of consciousness: assessment, treatment and research needs. Available at: http://www.northeastcenter.com/the-mohonk-report-disorders-of-consciousnessassessment-treatment-research-needs.pdf. Accessed June 20, 2013.
53. Giacino JT, Zasler ND, Datz DI. Development of practice guidelines for assessment and management of the vegetative and minimally conscious states. J Head Trauma Rehabil 1997;12:79-89.
54. Eilander HJ, Wijnen VJM, Scheirs JGM, de Kort PLM, Prevo AJH. Children and young adults in a prolonged unconscious state due to severe brain injury: outcome after an early intensive neurorehabilitation programme. Brain Inj 2005;19:425-36.
55. Reimer M, LeNavenec C. Rehabilitation outcome evaluation after very severe brain injury. Neuropsychol Rehabil 2005;15:473-9.
56. McNamee S, Howe L, Nakase-Richardson R, Peterson M. Treatment of disorders of consciousness in the Veterans Health Administration polytrauma centers. J Head Trauma Rehabil 2012;27:244-52.
57. Dumas HM, Haley SM, Ludlow LH, Carey TM. Recovery of ambulation during inpatient rehabilitation: physical therapist prognosis for children and adolescents with traumatic brain injury. Phys Ther 2004;84:232-42.
58. Davidson GH, Hamlat CA, Rivara FP, Koepsell TD, Jurkovich GJ, Arbabi S. Long-term survival of adult trauma patients. JAMA 2011; 305:1001-7.
59. Legner VJ, Massarweh NN, Symons RG, McCormick WC, Flum DR. The significance of discharge to skilled care after abdominopelvic surgery in older adults. Ann Surg 2009;249:250-5.
60. Wunsch H, Guerra C, Barnato AE, Angus DC, Li G, Linde-Zwirble WT. Three-year outcomes for Medicare beneficiaries who survive intensive care. JAMA 2010;303:849-56.
61. Winzelberg GS. The quest for nursing home quality: learning history's lessons. Arch Intern Med 2003;163:2552-6.
62. Gormley ME, O'Brien CF, Yablon SA. A clinical overview of treatment decisions in the management of spasticity. Muscle Nerve Suppl 1997;6:S14-20.
63. O'Dell MW, Bell KR, Sandel ME. Brain injury rehabilitation. 2. Medical rehabilitation of brain injury. Arch Phys Med Rehabil 1998; 79(Suppl 1):S10-5.
64. Zafonte R, Elovic EP, Lombard L. Acute care management of post-TBI spasticity. J Head Trauma Rehabil 2004;19:89-100.