Palliative Care in the Neuro-ICU: The Crystal Ball of Prognosis

Jennifer A. Frontera, MD, FNCS
Associate Professor of Neurology
Cleveland Clinic

Tuesday, February 16, 2016

Center to Advance Palliative Care™
capc

Integrating Palliative Care Into the Care of Neurocritically Ill Patients: A Report From the Improving Palliative Care in the ICU Project Advisory Board and the Center to Advance Palliative Care

Jennifer A. Frontera, MD, FNCS[1]; J. Randall Curtis, MD, MPH[2]; Judith E. Nelson, MD, JD[3]; Margaret Campbell, PhD, RN, FAAN[4]; Michelle Gabriel, RN, MS[5]; Anne C. Mosenthal, MD, FACS[6]; Colleen Mulkerin, MSW, LCSW[7]; Kathleen A. Puntillo, RN, PhD, FAAN[8]; Daniel E. Ray, MD, MS, FCCP[9]; Rick Bassett, MSN, RN[10]; Renee D. Boss, MD[11]; Dana R. Lustbader, MD, FCCM, FCCP[12]; Karen J. Brasel, MD, MPH[13]; Stefanie P. Weiss, MA[14]; David E. Weissman, MD, FACP[15]; for the Improving Palliative Care in the ICU Project Advisory Board

Crit Care Med 2015

Clinical Setting and Population

TABLE 1. Common Adult Neuro-ICU Diagnoses and Outcomes

Condition	Incidence in the United States (Annual)	Mortality Rates (%)		Functional Independence at 3–12 Mo (%)
		In-Hospital	30 D	
Traumatic brain injury	2,500,000 (98)	7.5 (98)	21 (99)	25–32[a] (100–102)
Ischemic stroke	795,000 (97)	4.3–70 (98, 103)	16–23 (104, 105)	50 (106–108)
Anoxic brain injury	424,000 out-of-hospital cardiac arrests (109)	52–90[b] (98, 110)	25–40[c] (111, 112)	48–55[c] (111, 112)
Status epilepticus[d]	200,000 (113)	14–50 (114, 115)	19–65 (116–118)	42 (119)
Intracerebral hemorrhage	63,000 (120)	30 (98)	34–50 (120–123)	12–39 (123)
Subarachnoid hemorrhage	25,000 (124)	20–26 (98, 124–127)	45 (98, 124–127)	16–55 (128, 129)

[a]Among patients with severe traumatic brain injury.

[b]Overall 90% mortality including those who do not survive to hospital admission (109).

[c]Among patients who underwent targeted temperature management. Mortality rates are higher and functional outcome worse in patients with pulseless electrical activity/asystole arrest compared with ventricular fibrillation/ventricular tachycardia arrest.

[d]Patients with refractory status epilepticus (continued seizures after two antiepileptic drugs have been administered) have higher mortality rates and worse functional outcomes.

capc Center to Advance Palliative Care

Trajectory of Illness in the Neuro Critically Ill

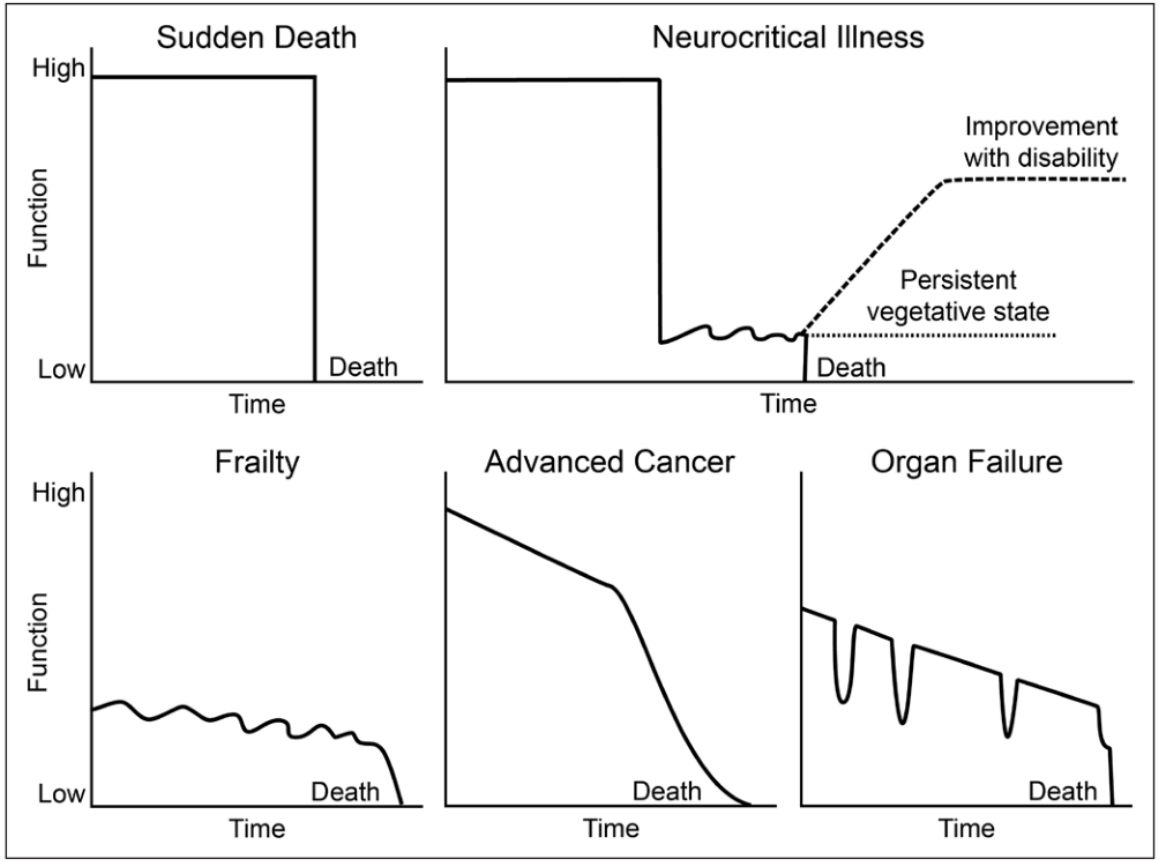


Figure 1. Distinctive trajectories of neurocritical illness. This figure demonstrates trajectories for patients without limitation of life-supporting therapies. Onset of neurocritical illness is often sudden, with precipitous decline from a normal baseline. However, most neurocritically ill patients do not progress to cardiovascular death or brain death, but survive with disability.

Most neurologically Injured make maximal spontaneous recovery over 3 - 12 months

Lack of recovery during hospitalization may not accurately predict future outcome

capc Center to Advance Palliative Care

PROGNOSTICATION

Pros and Cons of Prognostication

Helpful Prognostic Signs:

- Loss of brainstem reflexes/prolonged herniation
- Diffuse cortical infarction
- Degenerative diseases (advanced dementia, prion disease, Huntington's etc)
- Poor baseline functional status prior to catastrophic neurological insult
- Age

Limitations in Prognostic Scales:

- Most outcome scales including patients with withdrawal of life-sustaining therapy
- ? Self fulfilling prophecy
- Are the outcomes clinicians think are important also important to patients?
- Dichotomized outcomes - rather than patient-centric reported outcomes
- Limited generalizability- studies exclude sickest patients
- Challenging to account for "response shift" or patient's ability to adapt/reframe perceptions of quality of life

capc Center to Advance Palliative Care

TABLE 3. Selected Prognostic Scales Commonly Used in Neurocritical Illness

Condition	Prognostic Scale	Scoring	Outcome Measure(s)	Pros and Cons
Traumatic brain injury	Glasgow Coma Scale (17)	3 (worst)–15 (best)	Mortality, functional outcome	Widely used and simple, but the verbal score cannot be assessed in intubated patients, and brainstem reflexes and breathing patterns are not assessed as part of the GCS
	Full Outline of Unresponsiveness score (90)	0 (worst)–16 (best)	In-hospital mortality	Has good intrarater and interrater reliability and distinguishes among patients with the lowest GCS scores. Not widely used, and predicts only mortality, not functional outcome
	Marshall classification of head injury on head CT (91)	I–VI	Intracranial pressure, functional outcome	Widely used and has been found to predict increased intracranial pressure and outcome, but focuses primarily on CT findings and does not incorporate examination or other prognostic factors
Subarachnoid hemorrhage	Hunt-Hess Grade (20)	I (best)–V (worst)	Mortality, functional outcome	Commonly used in the United States, the Hunt-Hess grade is one of the strongest predictors of outcome after subarachnoid hemorrhage. It does not distinguish well between moderately injured grade 3 patients
	World Federation of Neurologic Surgeons Scale (94)	1 (best)–5 (worst)	Mortality, functional outcome	Commonly used in Canada and Europe, World Federation of Neurosurgeons Score combines the GCS score with the presence or absence of a major neurologic deficit. It is similar to Hunt-Hess scale in predicting outcome (148). Does not distinguish outcome well among grade III patients and there is variable application of what constitutes a "major neurologic deficit"
Intracerebral hemorrhage	Intracerebral hemorrhage score (18)	0 (best)–6 (worst)	Mortality	Widely used and simple scoring system. Focuses on mortality only and confounded by withdrawal. Not validated in a separate cohort
	FUNC score (21)	0 (worst)–11 (best)	Functional outcome	Incorporates premorbid cognitive function and strongly predicts long-term functional outcome. In multiple cohorts, no patient with a FUNC score ≤ 4 achieved functional independence, while > 80% of patients with a FUNC score of 11 were functionally independent at 3 mo. Not widely used
Anoxic brain injury	American Academy of Neurology prognostic guideline (149)[a]	Poor outcome predicted by the following: Myoclonus status epilepticus (24 hr) Absent median somatosensory-evoked potentials N20 bilaterally (24–72 hr) Neuronal-specific enolase > 33 µg/L (24–72 hr) Examination with absent pupil or corneal responses; extensor or no motor response (72 hr)	Mortality, functional outcome	Provides a time-based guideline for prognostication with low false-positive rates at each step. Does not account for the improved outcomes with hypothermia/induced normothermia. Guidelines are nearly a decade old (149)
Spinal cord injury	ASIA (96)	A (worst)–E (best)	Motor and sensory function	The ASIA scale was not originally developed as a prognostic scale, but does correlate with functional outcome (96)

GCS = Glasgow Coma Score, ASIA = American Spinal Injury Association Scale.
[a]Applies to patients who have not undergone therapeutic hypothermia/induced normothermia.

TBI: Glasgow Coma Scale

Verbal	Score
Alert, oriented and conversant	5
Confused, disoriented, but conversant	4
Intelligible words, not conversant	3
Unintelligible sounds	2
No verbalization	1
Eye Opening	
Spontaneous	4
To verbal stimuli	3
To painful stimuli	2
None	1
Motor	
Follows commands	6
Localizes	5
Withdraws from painful stimuli	4
Flexor posturing	3
Extensor posturing	2
No response to noxious stimuli	1

PROS:
Widely used simple

CONS:
Cannot fully assess intubated patients

capc Center to Advance Palliative Care

Coma: FOUR Score

Eye opening	Score
Eyelids open or opened, tracking, or blinking to command	4
Eyelids open but not tracking	3
Eyelids closed but open to loud voice	2
Eyelids closed but open to pain	1
Eyelids remain closed with pain	0
Motor response	
Thumbs up, fist or peace sign to command	4
Localizing to pain	3
Flexion response to pain	2
Extension response to pain	1
No response to pain or generalized myoclonus status	0
Brainstem reflexes	
Pupil and corneal reflexes present	4
One pupil wide and fixed	3
Pupil *or* corneal reflexes absent	2
Pupil *and* corneal reflexes absent	1
Absent pupil, corneal and cough reflex	0
Respiration	
Not intubated, regular breathing pattern	4
Not intubated, Cheyne-Stokes breathing pattern	3
Not intubated, irregular breathing	2
Respiratory rate above ventilator set rate	1
Respiratory rate at ventilator set rate or apnea	0

PROS:

- Good reliability
- Distinguishes between those with lowest GCS

CONS:

- Not widely used
- Predicts mortality but not functional outcome

capc Center to Advance Palliative Care

SAH: Hunt-Hess Grade

GRADE	CLINICAL EXAM	MORTALITY	GOS
1	Asymptomatic, mild headache, slight nuchal rigidity	1%	4
2	Cranial nerve palsy, moderate to severe headache, severe nuchal rigidity	5%	4
3	Mild focal deficit, lethargy, confusion	19%	3
4	Stupor, moderate to severe hemiparesis, early decerebrate rigidity	42%*	2*
5	Deep coma, decerebrate rigidity, moribund appearance	77%*	2*

PROS:

- Commonly used in U.S.
- Strong predictor of functional outcome

CONS:

- Does not distinguish outcome well for moderately injured HH3

capc Center to Advance Palliative Care

SAH: World Federation of Neurosurgeons Score

GRADE	GCS SCORE	MAJOR FOCAL DEFICIT (aphasia, hemiparesis)	%MORTALITY	GOS
1	15	Absent	5	4
2	13-14	Absent	9	4
3	13-14	Present	20	3
4	7-12	Present or Absent	33*	2*
5	3-6	Present or Absent	77*	2*

PROS:

- Good at predicting functional outcome

CONS:

- Interrater variability in what constitutes “Major focal deficit”
- Does not distinguish grade 3 outcomes well

capc Center to Advance Palliative Care

ICH Score

GCS Score	ICH Score Points
3 - 4	2
5 - 12	1
13 - 15	0
ICH volume	
≥ 30 cm^3	1
< 30 cm^3	0
IVH	
Yes	1
No	0
Infratentorial location	
Yes	1
No	0
Age	
≥ 80 yr	1
< 80 yr	0

Mortality
0 = 0%;
1 = 13%;
2 = 26%;
3 = 72%;
4 = 97%;
5, 6 = 100%

PROS:
Widely used
simple

CONS:
•Focuses on mortality
•Confounded by withdrawal
•Not validated in separate cohort

capc Center to Advance Palliative Care

ICH: FUNC score

Component	Points
Age (years)	
<70	2
70-79	1
≥80	0
ICH Volume (mL)	
<30	4
30-60	2
>60	0
ICH Location	
Lobar	2
Deep	1
Infratentorial	0
Glasgow Coma Score	
≥9	2
≤8	0
Pre-ICH cognitive impairment	
No	1
Yes	0
Total Score	**0-11**

FUNC score ≤4
None achieved functional independence,

FUNC score = 11
>80% were functionally independent at 3-months.

PROS:
Strongly predicts long-term functional outcome

CONS:
Not widely used

Spinal Cord Injury: ASIA

A	Complete Lesion: No motor or sensory function below the neurological level through sacral segments S4-S5.
B	Incomplete Lesion: Sensory, but not motor function is preserved below the neurological level and includes S4-S5.
C	Incomplete Lesion: Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3. Voluntary sphincter contraction may be present.
D	Incomplete Lesion: Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more.
E	Normal

PROS:
widely used, simple

CONS:
Not originally developed as prognostic scale, but correlates with functional outcome

How good are clinicians at prognosticating?

Withdrawal of Life-Sustaining Therapy in Patients With Intracranial Hemorrhage: Self-Fulfilling Prophecy or Accurate Prediction of Outcome?

Jonathan M. Weimer[1]; Amy S. Nowacki, PhD[2]; Jennifer A. Frontera, MD, FNCS[1]

Retrospective analysis of prospectively collected data
383 SAH, SDH and ICH patients

7% underwent withdrawal of life sustaining therapy (WOLST)

Multivariable models developed in maximally treated patients
Applied to generate probability of in-hospital death or 12-month death or moderate-severe disability (mRS 4-6) in WOLST cohort

Sensitivity analysis in propensity score-matched patients from the max therapy cohort

Crit Care Med 2016

Models Predicting Outcome

TABLE 2. Prediction Model of In-Hospital Death Derived From Maximal Therapy Patients

Variables	OR (95% CI)	p
Admission Glasgow Coma Scale	0.65 (0.55–0.76)	< 0.0001
Absence of surgical intervention	30 (8–121)	< 0.0001
Vasopressor use	29 (6–135)	< 0.0001
Renal failure	12 (3–53)	0.001
History of cardiovascular disease	4.4 (1.4–13.8)	0.01
History of chronic obstructive pulmonary disease	4.7 (1.1–19.5)	0.03
Intercept = −1.54		

OR = odds ratio.
c-statistic = 0.96, Hosmer-Lemeshow goodness-of-fit test $p = 0.98$.

TABLE 3. Prediction Model of 12-Month Death/Severe Disability (Modified Rankin Scale 4–6) Derived From Maximal Therapy Patients

Variables	OR (95% CI)	p
Age	1.07 (1.04–1.10)	< 0.0001
Admission National Institutes of Health Stroke Scale	1.12 (1.07–1.17)	< 0.0001
Brainstem herniation	29 (5–175)	0.0002
Type of bleed		0.001
Intraparenchymal hemorrhage vs SDH	4.7 (1.9–11.6)	
Subarachnoid hemorrhage vs SDH	1.4 (0.5–3.5)	
Arrhythmia	6.4 (1.9–21.8)	0.003
Premorbid modified Rankin score	1.53 (1.13–2.08)	0.006
History of diabetes mellitus	2.5 (1.1–5.6)	0.03
History of cancer	2.5 (1.1–6.0)	0.03
History of chronic obstructive pulmonary disease	4.1 (1.1–15.5)	0.04
Intercept = −7.11		

SDH = subdural hemorrhage.
c-statistic = 0.92, Hosmer-Lemeshow goodness-of-fit test $p = 0.95$.

capc Center to Advance Palliative Care

Weimer Crit Care Med 2016

Probability of in hospital death or mRS 4-6 at 12 monts

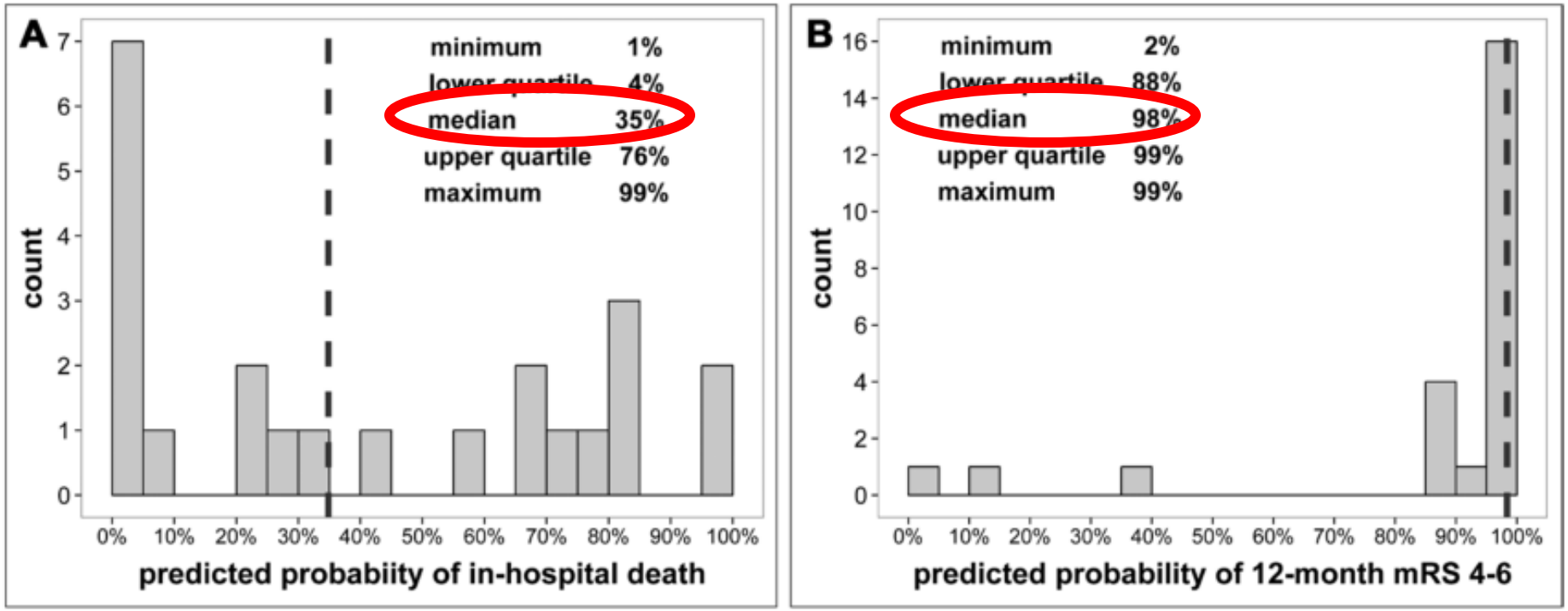


Figure 1. Distribution of predicted probability of in-hospital death (**A**) and poor 12-month outcome modified Rankin score (mRS) of 4–6 (**B**) for withdrawal of life-sustaining therapy patients had they continued maximal medical and surgical therapy.

Sensitivity analysis showed similar results

Weimer Crit Care Med 2016

Public (mis)Perceptions of Recovery

Center to Advance Palliative Care

Wijdicks Neurology 2006

awakening from coma

Filters

About 49,600 results

Man Awakens From Coma After 2 Months

ABC News
4 years ago • 24,010 views
Neurosurgeon detects brain activity after accident left Sam Schmid in a coma. For more, click here: ...

Teen Explains What Life is Like in a Coma

JustForMedia
6 months ago • 449,367 views
Teen Explains What Life is Like in a Coma Teen Explains What Life is Like in a Coma Teen Explains What Life is Like in a Coma ...

Man Wakes Up From 19 Year Coma

picktheparty
8 years ago • 194,875 views
Video from http://www.MyPartyPost.com It is incredible but Grzebski woke up from a coma he went into in 1988 after being hit by a ...

Mother is Awakened From Coma by her Newborn Baby

Suresh Kumar
4 months ago • 434,647 views
Shelly Ann Cawley wakes from a week long coma to meet her daughter, and guardian angel, Rylan Grace for the first time.

Miraculous moment father hugged son after teenager woke from 4 month COMA following bike crash

PatrynWorldLatestNew
2 years ago • 322,729 views
This is the moment a 16-year-old left in a coma after being knocked off his bike, woke up after four months, spoke for the time and ...

Mr. McMahon awakens from a coma

WWE
5 years ago • 767,644 views
Season 15 Clip • Raw
Mr. McMahon considers running for president More WWE - http://www.wwe.com/

Man Shot in the Head Awakens From Coma for Thanksgiving

ETNowLive26
3 years ago • 1,544 views
Benjamin Pessah, 21, takes first steps on Thanksgiving, one month after getting shot in California.

Persistent Vegetative State a.k.a Unresponsive Wakefulness Syndrome

- "Complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brainstem autonomic functions"
- Can be diagnosed if present for at least 1 month
- PVS can be judged to be permanent 12 months after *traumatic* injury in adults and children
- Permanent after 3 months in *nontraumatic* injury in adults and children
- 10000-25000 adults with PVS in US
- Cost of ~$ 7 Billion per year

AAN Neurology 1995

Criteria: Persistent Vegetative State

- No evidence of awareness of self or environment and inability to interact with others (NO COMMAND FOLLOWING)
- No evidence of sustained, reproducible, purposeful or voluntary behavioral responses to visual, auditory or tactile stim
- No language comprehension or expression
- Intermittent wakefulness and sleep-wake cycles present
- Sufficiently preserved hypothalamic and brainstem autonomic function
- Bowel and bladder incontinence
- Variably preserved cranial nerve function (pupillary, oculocephalic, corneal, vestibulo-ocular, gag) and spinal reflexes

AAN Neurology 1995

Table 1. Incidence of recovery of consciousness and function in adults and children in a persistent vegetative state (PVS) after traumatic or nontraumatic brain injury*†

Outcome and functional recovery	3 Months (% of patients)	6 Months (% of patients)	12 Months (% of patients)
Adults			
Traumatic injury (n = 434)			
Death	15	24	33
PVS	52	30	15
Recovery of consciousness	33	46	52
Severe disability			28
Moderate disability			17
Good recovery			7
Nontraumatic injury (n = 169)			
Death	24	40	53
PVS	65	45	32
Recovery of consciousness	11	15	15
Severe disability			11
Moderate disability			3
Good recovery			1
Children			
Traumatic injury (n = 106)			
Death	4	9	9
PVS	72	40	29
Recovery of consciousness	24	51	62
severe disability			35
Moderate disability			16
Good recovery			11
Nontraumatic injury (n = 45)			
Death	20	22	22
PVS	69	67	65
Recovery of consciousness	11	11	13
Severe disability			7
Moderate disability			0
Good recovery			6

Recovery from Persistent Vegetative State

Better recovery for those with traumatic injury rather than non-traumatic injury

Life expectancy for PVS 2 - 5 years

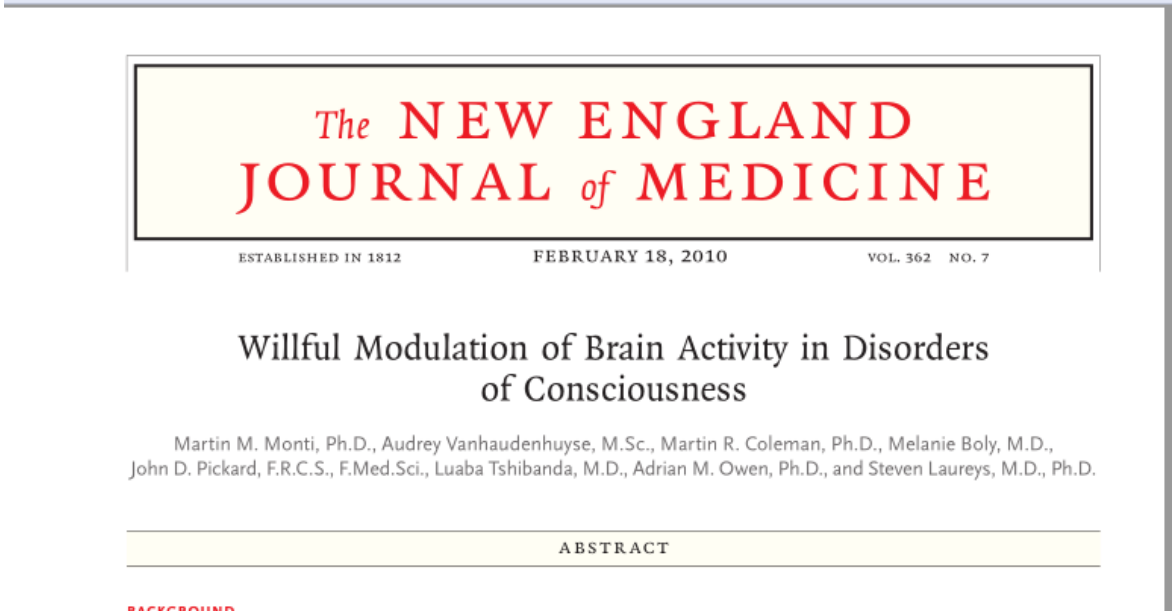
AAN Neurology 1995

capc Center to Advance Palliative Care

Minimally Conscious State

- Severe alteration in level of consciousness but may:
  - Intermittently follow commands
  - Track with eyes
  - Interact with environment
  - Have intelligible verbalization
  - Have restricted purposeful behavior
  - Have sleep-wake cycles and REM
  - Better recovery than PVS

Vegetative vs. Minimally Conscious



The NEW ENGLAND JOURNAL of MEDICINE

ESTABLISHED IN 1812 FEBRUARY 18, 2010 VOL. 362 NO. 7

Willful Modulation of Brain Activity in Disorders of Consciousness

Martin M. Monti, Ph.D., Audrey Vanhaudenhuyse, M.Sc., Martin R. Coleman, Ph.D., Melanie Boly, M.D., John D. Pickard, F.R.C.S., F.Med.Sci., Luaba Tshibanda, M.D., Adrian M. Owen, Ph.D., and Steven Laureys, M.D., Ph.D.

ABSTRACT

54 patients (23 vegetative and 31 minimally conscious) underwent fMRI

Imagery task: hitting tennis ball Communication task: yes/no questions

4/23 (17%) PVS and 1/31 (3%) of MCS could willfully modulate fMRI

capc Center to Advance Palliative Care

Monti NEJM 2010

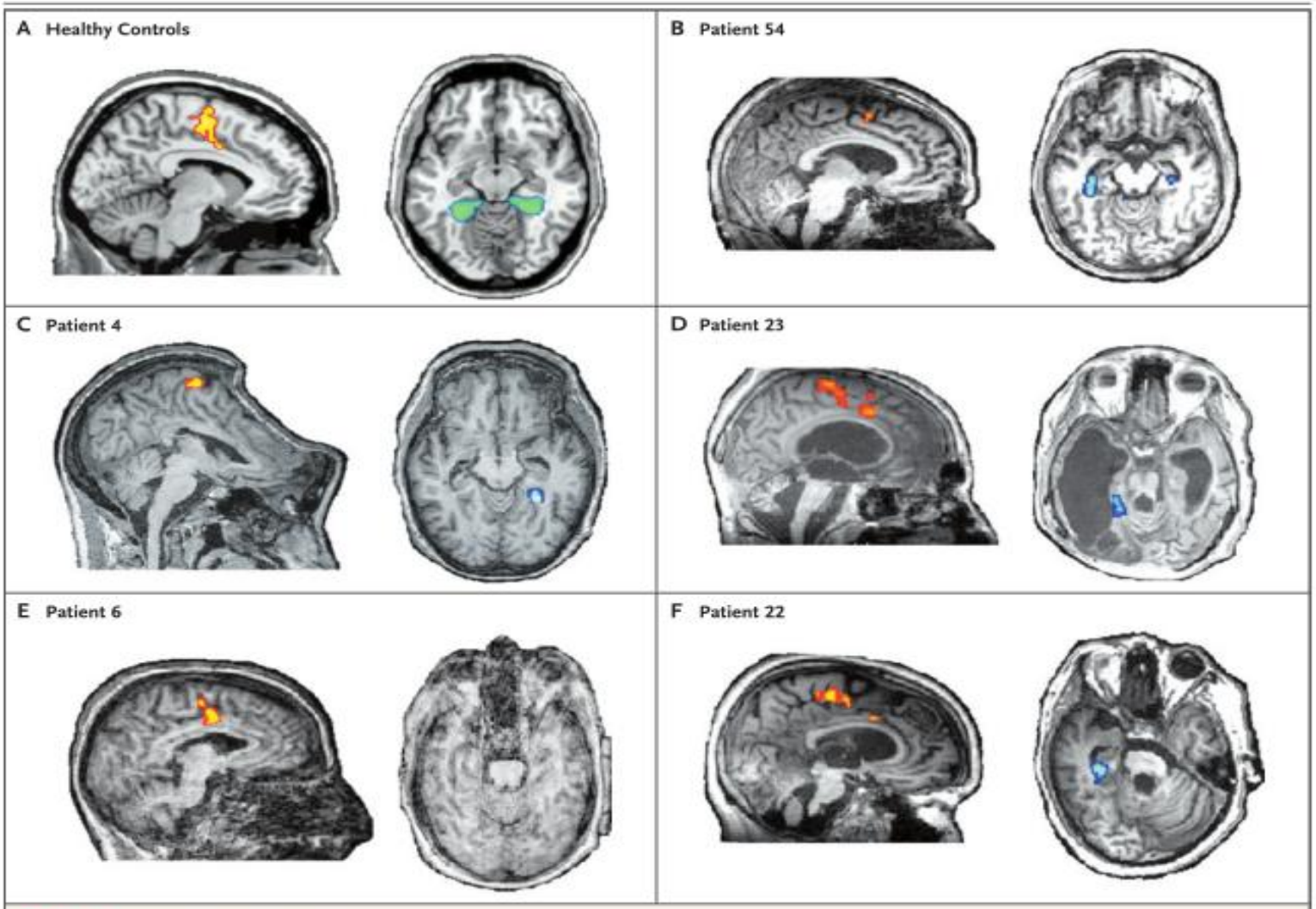


Figure 1. Mental-Imagery Tasks.

Functional MRI scans show activations associated with the motor imagery as compared with spatial imagery tasks (yellow and red) and the spatial imagery as compared with motor imagery tasks (blue and green). These scans were obtained from a group of healthy control subjects and five patients with traumatic brain injury.

(Monti NEJM 2010, Owen Science 2006,
Rodriguez Moreno Neurology 2010, Yu Neurology 2013)

Coma Mimics

- “Locked in” Syndrome
- Neuromuscular Disorders
  - Guillain Barre
  - Myasthenia Gravis
  - Botulism
- Akinetic mute
- Nonconvulsive status epilepticus
- Psychogenic unresponsiveness/Catatonia
- Medically induced coma

In General…

- Neurological recovery generally occurs over 3 - 6 months from the time of injury
- Recovery can continue thereafter with aggressive rehab

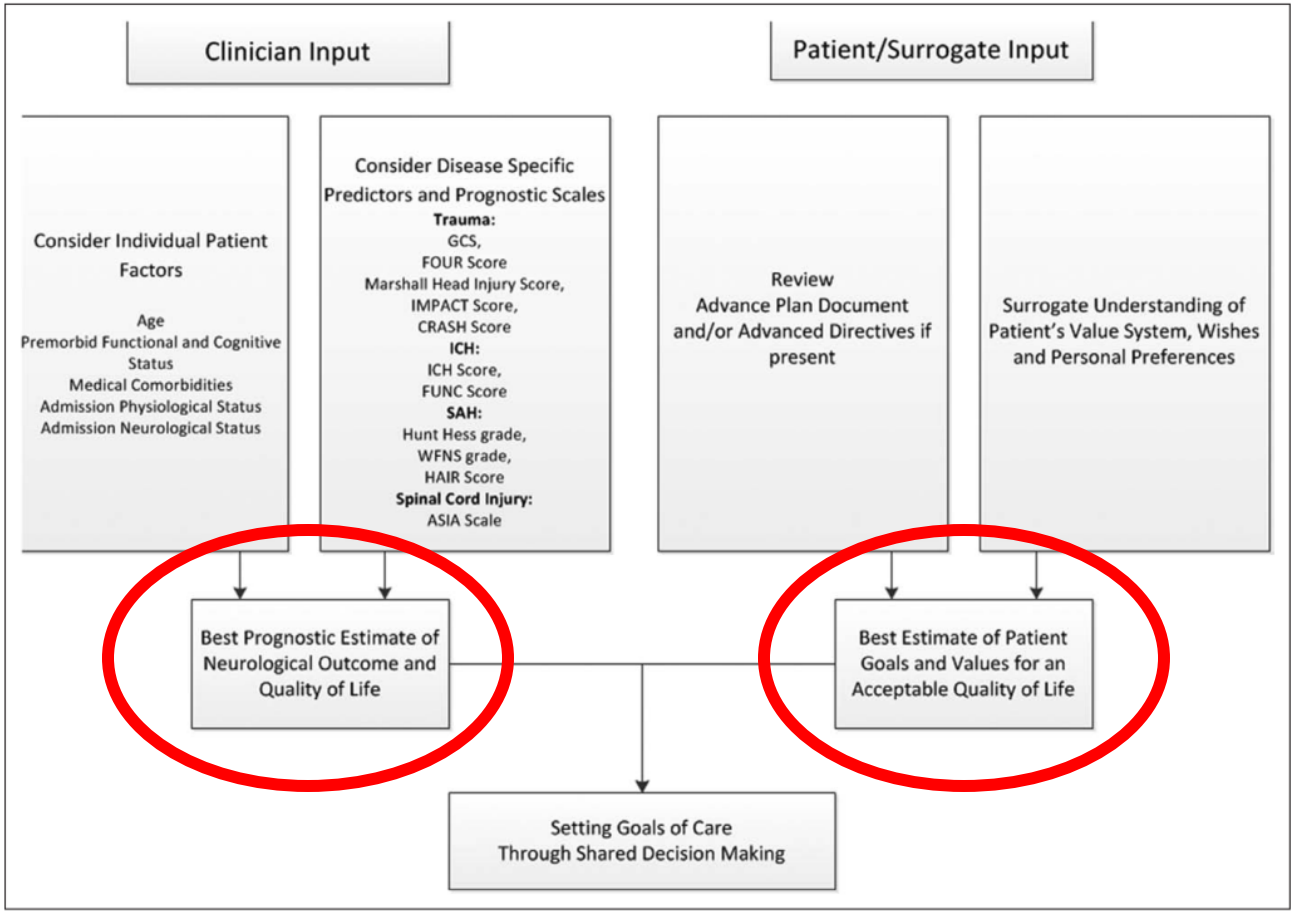
Jorgensen Phys Med Rahbil Clin Am 1999,
Hankey Neurology 2007, Cramer Ann Neurol 2008
Kong Neuro Rehabilitation 2014

STRATEGIES FOR ESTABLISHING GOALS OF CARE

Integrating IDT

- Common message from all caregivers (huddle)
- Neuro team (neurologist, neurointensivist/critical care, neurosurgeon, endovascularist, epileptologist, trauma surgeon)
- Palliative care team
- Combine specialist (palliative care) and generalist (intensivist) models
- PT, rehab MDs, neurses, SW, ethics, pastoral care, case management, music/pet/art therapy
- Physicians should establish a therapeutic relationship with families from the time of admission

Shared Decision-Making Model



Practitioner Variability

➔ The Optimist

- Avoid emotionally laden conversations
- Maintain hope for recovery
- Feelings of professional failure

Goal is to provide best estimate of likely outcome Acknowledging uncertainties in prognostication

➔ The Pessimist

- Surveys suggest physicians overly pessimist with neuro injuries in 1st 72 hours
- AHA recommends deferring new DNR within 24-72 h of ICH or within 72h of cardiac arrest (4.5-5 optimally if targeted temp. management)

capc Center to Advance Palliative Care

The Goals of Care Discussion

TABLE 4. Steps in Discussing Goals of Care (54, 150)

Step 1	Introduce	After ensuring a quiet setting where all participants can sit down, introduce the members of the clinical team and their roles. Ask family to introduce themselves and their relationship to the patient
Step 2	Empathize	Express empathy and acknowledge that this is a difficult time and a challenging conversation. If the family is too emotionally overwhelmed to absorb and use information, continue responding empathically to the emotion before presenting information and decisions
Step 3	Inquire, inform, process emotional reactions	Inquire into the family's current understanding of the patient's condition. Clarify any gaps in understanding and update the family. Use of brain images may be useful for receptive families. Use of lay-person terminology is essential (e.g., bleeding in the brain, dead brain tissue). Allow families time to absorb information and ask questions
Step 4	Understand the patient's values	Review advance care planning discussions and written advance directives, if available, with the family, and seek out information about patient and family values that can guide decision making
Step 5	Present prognosis	Present the medical team's assessment of the patient's most likely prognosis in terms of future cognitive and functional outcome, acknowledging limitations and uncertainty in prognostication. Acknowledge the resulting emotional reactions to this information
Step 6	Present broad care options	Offer possible pathways of care that are clearly delineated. In the right context, care focused entirely on comfort should be presented as an alternative to continuation of intensive care therapies. This approach may become more acceptable over a series of iterative discussions
Step 7	Family decision making	Given the clinician's best estimate of the patient's long-term cognitive/functional outcome, and understanding the patient's values, ask the family to reflect on how the patient, if able, would decide in the present circumstances. If the family is receptive, the clinician can offer a professional recommendation based on best medical evidence and experience
Step 8	Match care goals to medical plan	Adjust the care plan to match goals including review of current interventions, medications, and cardiopulmonary resuscitation/do-not-resuscitate status. Ask about specific goals of importance, such as living until an upcoming life event, or returning to home rather than a facility
Step 9	Reflection and questions	Ask the family to summarize their understanding of the conversation. Reflect back what you hear the family saying and summarize. Allow time for questions and offer the family time to discuss and consider the options
Step 10	Follow-up and document	Make yourself available for follow-up conversations and questions. Document the results of the meeting in the medical record. Discuss plans with team members not present for the meeting

capc Center to Advance Palliative Care

Frontera Crit Care Med 2015

Communicating Goals of Care

1. Introduce
   - Sit down, explain your role and those of the rest of clinical team, meet family members, and identify NOK/POA

2. Empathize

3. Inquire, Inform
   - Determine what the family currently understands about the patient's condition.
   - Clarify any gaps in understanding
   - Use lay terminology
   - Show brain images
   - Allow for questions

Communicating Goals of Care

4. Understand patient's values

- Review advance directives with family
- Family is asked to review patient's values systems and thoughts about what constitutes an acceptable quality of life
- Clinician may ask: "What would your loved one want us to do if he/she were able to tell us?"
- "The most important thing is for us to respect your loved ones wishes, to the best extent we can understand them"

5. Present Prognosis

- Communicate concrete skills and ADLs patient may or may not regain
- Most likely outcome
- Present limitations in prognostication, no absolutes

Communicating Goals of Care

6. Present broad care options
   - Offer clearly delineated pathways of care
   - Partial treatment options can be confusing and prolong dying process
7. Family Decision making
   - Family must merge most likely prognosis with patient's known value system for an acceptable quality of life
   - If family receptive, clinician can offer professional recommendation
   - Often iterative conversations
   - Allow for time to make decision
8. Match care goals to medical plan
   - Review current interventions meds
   - Clarify DNR/DNI orders, pressors, antibiotics, nutrition/hydration status

Communicating Goals of Care

9. Reflections and Questions

- Ask family to summarize, reflect back

10. Follow-up and Document

- Make yourself available
- Document for the care team that comes after you and discuss with rest of team

Common Family Questions

- What is a sign of neurological recovery?
  - Saccades, tracking, command following
  - BEWARE: grasp, triple flexion, reflexes

- How long will my loved one continue breathing after extubation?
  - Acknowledge our limitations in predicting
  - Explain titration of meds for comfort may slow down breathing/make breathing more comfortable
  - Minutes, hours, days
  - Snoring sounds, drift into deeper coma, breathing becomes slower, oxygen gets lower and eventually death comes peacefully

WITHDRAWAL OF LIFE-SUSTAINING THERAPIES

Symptom Management during Withdrawal

- In neuro patients withdrawal typically consists of extubation of comatose patients
- Determine if family would like to be present
- Patient's typically cannot communicate discomfort but can suffer pain, anxiety, thirst etc.
- Clinicians must be vigilant for signs of discomfort
  - Tachypnea
  - Tachycardia
  - Diaphoresis
  - Posturing
  - Grimacing
  - Agitation

capc Center to Advance Palliative Care

Symptom Management during Withdrawal

- Opioid drip (Morphine, fentanyl, dilaudid)
  - Suggest Titrate to RR<20, HR<100
- Glycopyrrolate for secretions
- Anxiolytics (prn ativan)
- Discontinue all meds that do not offer symptom relief including:
  - Antibiotics
  - Vasopressors
  - DVT prophylaxis
- Antiepileptics are typically continued since seizures are perceived as uncomfortable
- Foley catheters are maintained for comfort
- Hydration and nutrition do not provide comfort and hunger is uncommon at end of life

capc Center to Advance Palliative Care

Special Circumstances: Long-Acting Sedatives

- Unnecessary to wait for washout of long acting sedatives (i.e. pentobarbital, phenobarbital) prior to withdrawal
- Ethical Principles:
  - Patient autonomy and double effect
- Withdrawal in context of sedatives is not euthanasia but allowing patient to die from underlying illness
- Barbituates actually used in past as part of comfort care regime

Organ Donation after Neurological Death

Brain Death

- Irreversible loss of brain and brainstem reflexes
- Known cause
- No confounding factors (temperature, BP, acidosis, drugs, toxins)
- Neurological exam
- Apnea test
- Confirmatory test only in special circumstances
- BRAIN DEATH = LEGAL DEATH

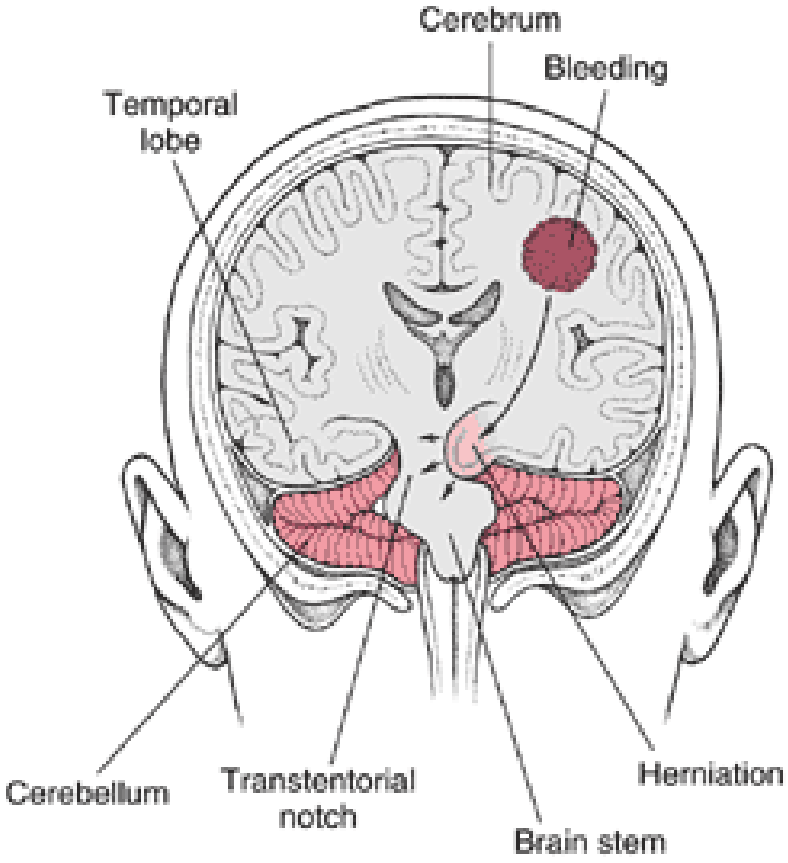
Care for the Potential Organ Donor

- Progression from brain death to somatic death results in loss of 10 - 20% of potential donors
- Intensive monitoring and care needed to preserve organs
- Aggressive management with bronchoscopy, hormonal therapy and hemodynamic monitoring and management improve organ procurement rate

(Kutsogiannis Can J Anesthe 2006)

Effects of brain death

- Medullary level of brain death produces sympathetic surge
  - Elevated MAP to maintain CPP (in face of elevated ICP)
- Cardiac stunning, myocyte necrosis
- Panhypopituitary state
- Spinal cord ischemia coincides with herniation resulting in deactivation of sympathetic nervous system



Care for the Potential Organ Donor

STEP #1: Assess hemodynamic status

- Is patient hemodynamically unstable?
- Bolus with 10 cc/kg of NS, continue to goal SBP>90 mmHg or MAP>60 mmHg and UOP>1 cc/kg/h
- Use colloids if patient actively bleeding (pRBC, FFP etc)
- Ensure central line and A line in place
- Begin vasopressors if necessary and begin hormonal therapy
- Order TTE

Care for the Potential Organ Donor- Hormonal Resusitation

STEP #2: Treat endocrine failure/ panhypopituitary state

- Synthroid drip (T4 10-30 mcg/h)
  - Watch out for afib
- Pitressin drip 25 u in 250 cc NS
  - 1 u Pitressin bolus
  - 0.5 u /h titrate to max of 4-6 u/h
- Insulin drip to maintain BG 80-150 mcg/dL
- Start 15 mg/kg Methylpresnisolone q 24 h
- For all brain dead patients

Care for the Potential Organ Donor

- DI watch:
  - Check for UOP ≥5 cc/kg/h x 2 hours
  - Urine specific gravity <1.005
  - Serum Na>145
  - Serum Osm >305
  - In absence of diuresis or contrast
- If DI detected->Pitressin 0.5 u IV titrate to UOP 1-2 cc/kg/h, max 4-6 u/h
- Avoid D5W - hyperglycemia causes osmotic diuresis and worsens problem

Organ Donation after Cardiac Death

Process

1. Decision to withdraw/withhold treatment
2. Assessment for DCD
3. Withdrawal of treatment
4. Pre-mortem interventions (morphine drip etc.)
5. Cardiac arrest and organ procurement

1. Decision for Withdrawal of Life Sustaining Therapy

- Family/patient decides based on patient wishes to withdraw care
- Occurs prior to any discussions regarding organ donation - there should be a clear separation between withdrawal and donation discussions
- Only OPO staff should approach the family for donation discussions
- DNR should be documented
- Withdrawal conversation documented

capc Center to Advance Palliative Care

2. Eligibility for DCD

- Contact Organ Donor Network (MD, RN)
- Organ Donor Network will assess patient for DCD
- Typically under age 60
- Consent done by organ donor network
- Separate consent for heparin administration (if necessary)

3. OR care

- Patient will be prepped and draped prior to extubation to minimize ischemia time
- Family should be made comfortable in OR
- The organ procurement team will leave the OR after patient preparation and will not return until after death is declared and the family has left the OR
- Titration of drips should not be influenced by possibility of organ donation
- Suggested titration targets include HR<100 and/or RR<20
- The physician titrating the comfort medications SHOULD NOT be part of the transplant team.
- Any physician or staff member with ethical objections may decline to participate in DCD but should find a replacement

Time to Death from Extubation

TABLE 5. Prediction of Cardiopulmonary Arrest After Withdrawal of Life-Sustaining Therapy (Donation After Cardiac Death-for Patients in Neurocritical State Score) (84)

Component	Score
Cough	
Present	0
Absent	2
Corneal reflex	
Present	0
Absent	1
Motor response	
Flexor or better	0
Extensor or absent	1
Oxygenation index	
≤ 3.0	0
> 3.0	1
Total score	**Death within 60 min**
0	5%
1	27%
2	29%
3	52%
4	80%
5	89%

A score of ≥ 3 was associated with a 74% probability of death within 60 min, whereas a score of 0–2 was associated with a 77% probability of survival beyond 60 min.

capc Center to Advance Palliative Care

Rabinstein Lancet Neurol 2012

4. Pronouncement of Death

- 5 min. must pass after cardiopulmonary arrest before legal declaration of death (absence of arterial line waveform; PEA may occur)
- Must arrest within 60-120 min. of withdrawal
- Pronouncement of death may be made by primary care team (attending or designee), or anesthesia
- The declaring physician must not be part of organ retrieval/transplant team
- Death certificate must be filled out
- Family notified

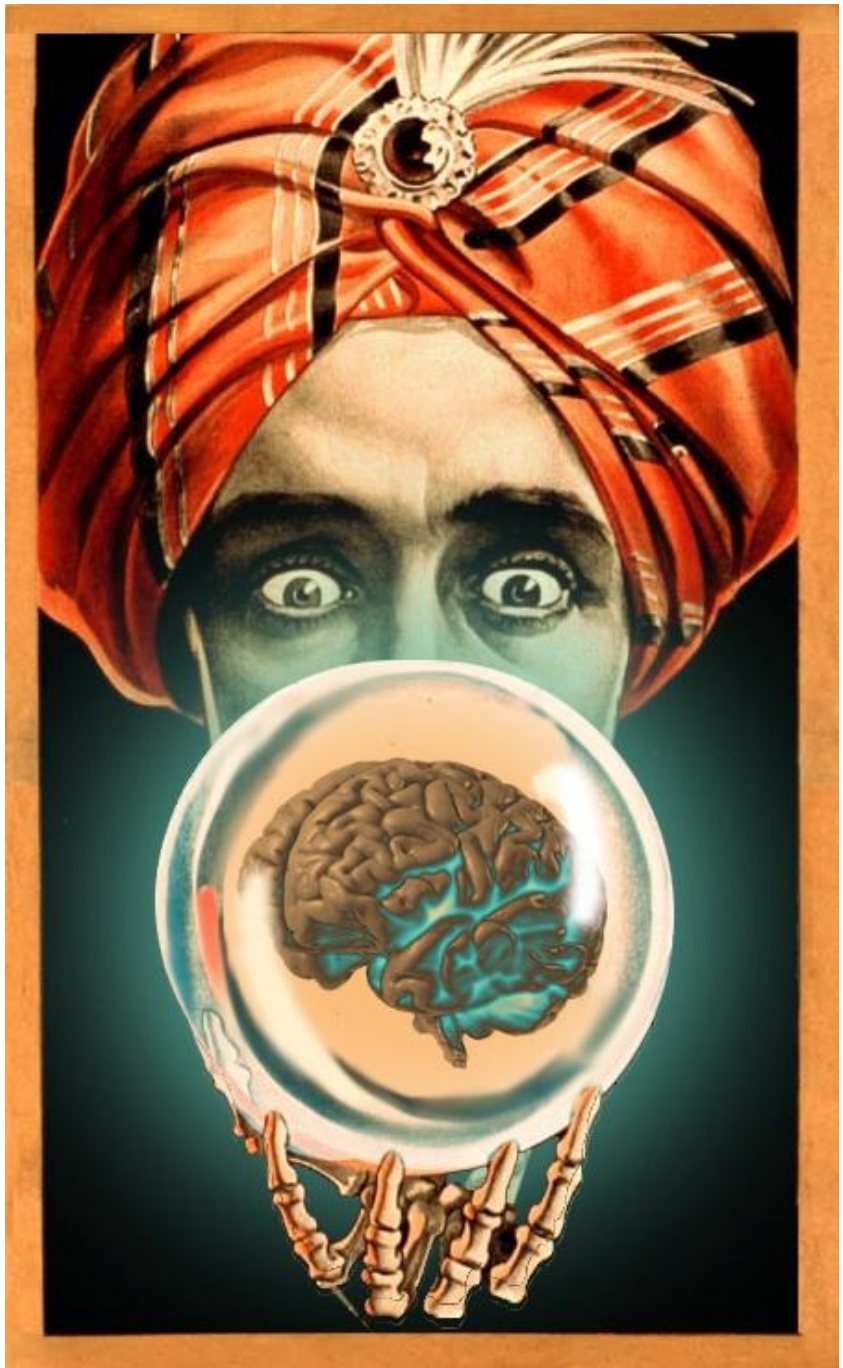
5. Patients Found Ineligible

- If no cardiac arrest in 60 -120 min. pt returns to ICU or floor bed and comfort care continues
- If pt expires in ICU or on floor primary team must declare death and fill out death certificate

Conclusions

- Prognostication is possible but practitioners should acknowledge limitations
- Medicine is a team sport (integrated model of palliative care)
- Shared decision making model
- Consider organ donation options and partner with your local organ donor network

Thanks!

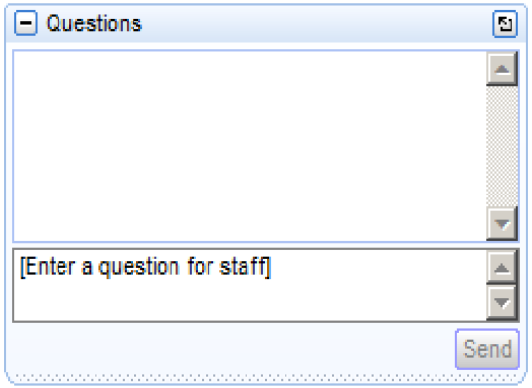


capc Center to Advance Palliative Care

Questions and Comments

- Do you have questions for the presenter?

- Click the hand-raise icon ( )on your control panel to ask a question out loud, or type your question into the chat box.



CAPC Events and Webinar Recording

- For a calendar of CAPC events, including upcoming webinars and office hours, visit
  - https://www.capc.org/providers/webinars-and-virtual-office-hours/

- Today's webinar recording can be found in CAPC Central under **'Webinars: View all 2016 CAPC Webinars'**
  - https://central.capc.org/eco_player.php?id=328