MINIMAL COMPETENCY RECOMMENDATIONS FOR PROGNOSTICATION

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Disclosures

- None
Overview

- Need for prognostication versus risk of error
- What factors to consider for prognostication
- Communicating (diagnosis &) prognosis to caregivers, families and professionals
- Making prognostic statements
- Cases
Rush to prognostication

- Abundance of discussion early; failure to update
- Rush to prognosticate
  - Need/desire to predict early (first 48 hours)
  - Rarity of discussions when more predictable (after 1 year)
Misinformation Abounds

- Misapplication of literature to BI → decisions
  - Palliative Care quoting ICU outcomes as BI outcomes
  - Trauma conflating WOC w/ “end” of life” care costs
  - For some conditions, coma is a sign of deterioration.
  - **In BI, coma is simply the starting point.**

- Family & patient anger

- Were these incorrect comments really said, or, did families not misunderstand?
  - “what you have now is what you got”
  - “he will always be a vegetable”

- Resident 2 years after WOC recommendation

- Organ donation referral trigger
Families describe predatory behavior; still angry years later

Henry Beecher (1970): utilitarian organ retrieval policy:
• Those who have lost consciousness to help “those who could be helped” (i.e.: people with BI cannot be helped)

People with severe TBI seen as organ donors before we determine likely trajectory or ready to contemplate WOC
• Most eventually recover with outcomes of Good to SD

Conversations with families about organ donation prior to this is misleading and sends wrong message that medical professions believe efforts are futile
Prediction Accuracy Study
Hammond, et al. (unpublished)

- 4 individuals with severe TBI examined at 48 hours & 6 month (GOS, FIM, SWLS)
- 30 physicians made 6 month predictions
  - Trauma Surgery 9; PMR 15; NS 5; Palliative Care 1

**Poor accuracy**
- Actual 6-month outcome was much better than the more pessimistic predictions
- More accurate when the actual outcome was poor

**Relevance of experience**
- Attending more accurate than residents
- More accurate with greater years of practice (in all 4 cases)
- Sample size not large enough to look at specialty
Self-Fulfilling Prophecies

- In-hospital TBI death in Canada
  - 68% of TBI mortality in acute care due to WOC
  - WOC most important predictor of in-hospital TBI mortality, negating all other factors in predictive model

- Physician Survey of Clinical Vignettes
  (neurology, neurocritical care, NS, trauma. Anesthesia/critical care)
  - Predictions were overly pessimistic
Barriers, Bias & Misinformation

- Provider views, values, training, experience
  - Longterm brain injury f/u experience
  - Understanding literature (BI vs ICU literature)
- Inaccuracy of DoC diagnosis: 15-43% inaccuracies
  - Predictions depend on correctly diagnosed DoC
- Consumer views, values, expectations, understanding
- Clinical translation of research
  - Research based on short-term, but applied to longterm
    - Not even long enough to assess permanence of vegetative state
  - 70-80% predictive value doesn’t = 1 person’s outcome
- Outcome measurement
  - Non-specific
  - Broad categories and lumping
  - Misperceptions
Glasgow Outcome Scale

- **Dead (1)**
- **Vegetative State (2)**
  - Cannot obey simple commands or say words
- **Severe Disability (3)**
  - Minimally Conscious state
  - Assistance of another person needed essentially every day for some ADL, or,
  - Not able to shop without help, or,
  - Not able to travel locally without help

- **Moderate Disability (4)**
  - Not able to work to prior capacity, or,
  - ↓ social & leisure, or,
  - Psychological disruption with family/friends ≥1 week

- **Good Recovery (5)**
  - Social & leisure activities resumed, and,
  - Psychological disruption with family/friends <1 week

Lumped: Poor: D VS SD; Favorable: MD GR
Potential Prognostic Tools

- Time of prediction: 24-48 hours, 3 months, 12 months
- Time of Outcome: 6 month, 12 month, lifetime
- Varied outcomes in question: emergence from VS or MCS, global (GOS, DRS), communicate, walk, exercise, drive, live independently, work, family, socialize, intimate partner, normal life, fatigue, depression, irritability, initiation, cognition
Clinical Use of Prognostic Tools

- **Accuracy & precision**
  - Best: 79% PPV with SD combined with D & VS

- **Odds ratios and CI:**
  - Not always published or calculable
  - CL often wide indicating limited precision for clinical application
  - Isolated/specific variables & very specific circumstances (e.g. AAN/ACRM/NIDILRR guidelines DOC 28 days post)

- **Applicability depends on population & timing**
  - Etiology: TBI vs non-traumatic
  - LOC: VS vs MCS
  - Acute versus rehab
  - Some valuable predictors not available early (e.g: PTA)

- **Global outcomes (emergence, GOS, DRS) vs specific outcomes (physical, social, emotional, memory, work)**
Etiology

**Traumatic**

- **Class I Evidence (BTF 2001)**
  - **GCS**: Step-wise with lower GCS
  - **Age**: Continuous & step-wise with increasing age; 70% PPV
  - **Absence pupillary responses**: 70% PPV of SD/VS/D
  - **Hypotension/hypoxia**
    - SBP < 90mmHg: 67% PPV of SD/VS/D
    - SBP < 90mmHg combined with hypoxia: 79% PPV of SD/VS/D
  - **CT Scan abn** (compression, effacement, blood in basal cisterns, extensive traumatic SAH): 70% PPV of SD/VS/D

**Non-traumatic**

- Worse prognosis & shorter time course
- Impact of on etiology
- Duration of coma, motor fxn, eye signs (Levy 1981)
  - Normal eye or motor signs at 1-3 days: 30% MD/GR
- **Age**: inconsistent
Level of disordered consciousness

Vegetative State

- Difficult to predict
  - May have severe cerebral hemisphere damage with relatively intact brainstem
    - Key predictors misleading
- When is persistent VS permanent?
  - TBI: 12 months
  - Anoxic: 3 months
  - Possible later, generally to Severe Disability

Minimally Conscious State

- Better outcome than VS
  - DOC accuracy critical
    - 15 – 43% inaccuracies
- When is MCS permanent?
  - No guidelines for time to emergence from MCS
- Good outcomes possible!
  - 20% RTW or household Independent
  - 19-36% functional Independence (by Y5)
Outcome Comparison: VS vs MCS at 1 mo

MCS (n=40):
OR 11.0 traumatic (vs NT) better than SD at 12 mo (95% CI 1.9 – 63.2) (moderate)

VS (n=45):
OR 6.7 traumatic (vs NT) better than SD at 12 mo (95% CI 0.3 – 129.4) (low; insufficient)

Traumatic (n=60):
OR 13.75 MCS (vs VS) better than SD at 12 mo (95% CI 3.9 – 48.3) (moderate)

Non-traumatic (n=25):
OR 9.1 MCS (vs VS) better than SD at 12 mo (95% CI 0.4 – 212.7) (low; insufficient)

2 NT MCS had mod-severe disability
**Traumatic VS** emergence within 12 mo if in VS ≥ 28 days

- ↓ chance of emergence (moderate confidence)
  - Hydrocephalus in **late** phase (Sazbon 1990)
    - OR 16.32, 95% CI 5.84 to 45.6
    - OR 8.1, 95% CI 3.6 to 17.9

- ↑ chance of emergence (moderate confidence)
  - 2-3 mo post: DRS <26, detect P300, reactive EEG

- Age possibly **not** prognostic
  - 2.2 years younger (95% CI -6.7 to 2.4) -- clinical utility?
  - However, studies are of young avg age; not generalizable

- Insufficient data: Initial GCS & length time post-TBI
  - Yet, much emphasis placed on iGCS in early decisions

**Non-Traumatic VS** w/in 12 mo in VS ≥28 days: insufficient
12-month Time Course for VS at 1 Month
Multi-society Task Force 1994

[insufficient data after year 1 due to small n]
Acute Vs. Rehab: Rehab is Select Group

- Achieved short-term survival to come to rehab
- Thought to have “rehab potential”
- Outcomes and predictors are different
  - Age, PTA, functional abilities more predictive; GCS, RTS, pupillary responses, glucose not predictive

Nakase-Richardson, et al TBI Model System study
- 396 individuals unable to follow commands at rehab admit
- By rehab d/c:
  - 68% regained consciousness
  - 32% did not; of those, most regained later
    - Years 1 = 59%; Year 2 = 66%; Year 5 = 74%
- By Year 5:
  - 20% living without in-house supervision
  - 19% “employable” (Disability Rating Scale)
Apply to Clinical Situation

- **Treat Aggressively**, especially during early months
  - Prevent immobility consequences
  - Screen for treatable conditions
  - Wean & trial medications
  - Revisit wishes later when prognosis more clear

- **Seek longterm BI outcome experience**

- **Get diagnosis right!**
  - Systematic exams on multiple occasions
  - Objective tools
  - Consider responses with others/family

- **Communicate accurately & understandably**

- **Update as time passes**
  - Predictors change over time
  - Progression to MCS different prognosis than continued VS
Need **staged approach** to prognostication mapping on to what is most certain at each time point informed by ....

- Time course and Markers: behavioral, imaging, neurophysiologic


Recommendation 3 (NOT FINAL):
Prognostication in patients with DoC should consider published, evidence-based guidelines or educational reports that specify the:

(a) predictors used;
(b) baseline time period & window in which the predictor(s) are applied;
(c) time period & window for interpreting the outcome of interest;
(d) outcome of interest; and
(e) the precision associated with the prognosis.

Accomplishing #3 accurately & in understandable fashion is challenging!

Recommendation 4 (FINAL):
Communication of diagnosis and prognosis should ensure that the clinical information provided (ie, diagnostic features, prognostic indicators) is understandable & the limits of certainty afforded by the available evidence described.
Use of evidence-based guidelines/reports & precision

- What we know is limited: Often highlights need to disclose uncertainty or range of possible outcomes
- May be very challenging to synthesize, apply & explain to individual patient and various factors at play
- Limited-no studies/guidelines may be available relevant to the time of your prognostication, the outcome in question, the time of the outcome in question, and the predictor factors available
  - For example,
    - Prediction at 48 hours
    - Prediction beyond 1 year
    - Specific functions after emergence
- Caution needed to not misinterpret or wrongly apply
Consider your style and approach: chart vs. family
Use language easily understood by laypersons & other physicians
  • Translate all medical terms and expressions into plain language
  • If use term VS, need to explain term
Talk to family first
  • Understand their values and concerns, determine what outcome they want to know about, collect their observations of responsiveness, ask what they have heard and think, answer their medical questions
Discussion regarding range of trajectories for outcome(s) in question
Discuss some of the factors influencing outcome:
  • Age?, anoxia, current responsiveness level, time postinjury
Communicate if limited data about the specific outcome & time
Express lack of certainty in applying to individual patient
Discuss role of time in outcome prediction
Ask what they heard you say and what questions they now have
Consider written materials to supplement conversation
Update prognosis over time
Prognostic Statements

Example: VS at 1 month

“Out of coma (eyes open) as expected. VS at 4 weeks following anoxic brain injury due to cardiac arrest. Currently fails to respond purposefully to stimuli on several examinations. (Describe the results of objective exam & explain the criteria for emergence) It is too early to determine future outcome and which functions will emerge over the next months to years. At this point, full range of outcomes are possible (death, no interaction, recovery to walk, talk, and possibly live independently). Expect some memory difficulties d/t anoxia but severity uncertain. We will learn more about his/her outcome as we observe for signs of emergence over the next few months. The types of activities we are looking for are X, Y & Z. Recommend reassessing progressively over next several months.

Of note, two Class II studies have examined prognostic factors in non-traumatic VS d/t mixed etiologies > 28 days after inciting event. There is insufficient evidence to support or refute prognostication. The value of age, etiology, and duration of VS in prognostication is unclear.
Note: Limited data available. In real life circumstance, more data would be available to you. However, I don’t believe the additional data would influence the prognostic statements.
Case 1: At 1.5 mo predict 1 year outcome

- 20 yo M MVC
- Passenger; driver (brother) killed
- Combative at scene; intubated
- ED: GCS 4; decerebrate posturing
- CT scan: diffuse axonal injury; multiple punctate lesions; bilateral ventricular hemorrhage
- 1 month: VP shunt for hydrocephalus
- Meningitis

- 1.5 months: Transferred to Rehab
  - Eyes open (out of coma)
  - No blink to threat; spontaneous eye movements but no tracking; no response to command
  - Severely increased tone throughout
  - Decerebrate posture & storming to noxious stimuli
Audience Response:
What outcome do you predict for Case 1?

a) Dead
b) Vegetative State
c) Severe Disability
d) Moderate Disability
e) Good Recovery
What outcome do you predict for Case 1?
Case 1 prognostic statement

- Predictors:
  - young age?, traumatic
  - current DoC state (VS), no blink to threat, posturing, meningitis, hydrocephalus at 1 month

- Time period for application of predictors: 1.5 months post

- Time period for outcome: 1 year

- Outcome: Family interested in longer-term (beyond 1 year), not short-term. They are hoping he will eventually understand them, be able to laugh and interact with them and his sisters. Published literature is scant regarding these specific outcomes.

- 1 yr prognosis at 6 weeks: There are still a range of possible outcomes from death or failure to interact to talking, walking, living at home, and possibly working. At 6 wks, unable to say if he will emerge VS. It will be important to revisit this question at 12 months post-injury. Meaningful prognostic factors are: TBI (+), VS (-), late hydrocephalus (-), meningitis (? -).

- Communication of dx: efforts to explain brainstem injury infuriated
Case 1: Physician Predictions for 1 year outcome

- 1 year: VS
- 10 years: VS
- Family sees responses; hopeful
- Enjoying his presence; take him everywhere
Case 2: At 1 month predict 1 year outcome

- 52 yo male MVC, unrestrained, through windshield
- $GCS_{ED} = 3$
- Pupils & oculocephalic reflexes normal
- CT scan: SAH, contusions R frontal & parietal areas
- Diaphragmatic injury & ruptured spleen
- Pneumothoarax, pleural effusion, pneumonia; prolonged ventilation
- Sacral fracture
- PMHx: Severe EtOH abuse, depression, hx TIA, several prior TBI’s
- At 1 mo post: In MCS
Audience Response:
What outcome do you predict for Case 2?

a) Dead
b) Vegetative State
c) Severe Disability
d) Moderate Disability
e) Good Recovery
What outcome do you predict for Case 2?
Case 2 prognostic statement

- Predictors:
  - traumatic, MCS, intact brainstem reflexes
  - middle-age, hx heavy EtOH abuse, prior multiple TBIs, respiratory complications & prolonged vent
- Time period for application of predictors: 1 month post
- Time period for outcome: 1 year
- Outcome: Work and living independently
- 1 year prognosis at 1 mo: Full range of outcomes are possible. Possible to emerge to live independently and work. If so, he may have some difficulty with high level cognitive functions (e.g., attention and STM). He may have some challenges with mood and/or frustration tolerance. It will be important to prevent return to substance use.
Case 2: Physician Predictions for 1 year outcome

1 year: decreased attention; anxiety & depression, improved with meds; no irritability, turned life around, stopped drinking; back together with x-wife; working; happy to be alive; GR
Case 3:
At 1 wk, 1, 2, 3, & 5 mo predict 6 mo outcome

- 17 yo male hit in chest with baseball bat resulting in sudden cardiac arrest (commotio cordis)
- Left by friends
- Resuscitation >25 minutes
- GCS 3T
- MRI c/w hypoxia
- Asked to comment on prognosis at 1st week
  - In coma: no eye opening
  - No responses elicited
Audience Response:
What outcome do you predict for Case 3?

- a) Dead
- b) Vegetative State
- c) Severe Disability
- d) Moderate Disability
- e) Good Recovery
What outcome do you predict for Case 3?
Case 3 prognostic statement

- Predictors: young age; anoxic, resuscitation time
- Time period for application of predictors: 1 week post-injury
- Time period for outcome: 6 month
- Outcome: emergence from Coma/VS

6 mo prognosis at 1 week:
- "Coma at 1 week following anoxic brain injury due to cardiac arrest. High confidence that he will emerge from coma. Unable to determine at this early point if he will emerge from VS. Too early to determine future outcome. Recommend following & reassessing prognosis at 3 months."

6 mo prognosis at 1 mo:
- Exam: Eyes open; restless, agitated; pulling tubes; thrashing violently when approached, exaggerated startle reflex
- "Out of coma as expected. Exaggerated startle. Agitated & pulling tubes. This may be a + sign. Currently fails to respond purposefully to stimuli (VS) on several examinations. (If used CRS can show the results and explain the criteria for emergence.) It is still early following the event to be able to determine future outcome and which functions will emerge over the next months to years. We will learn more as we observe for signs of emergence over the next few months. The types of activities we are looking for are X. The range of possible outcomes are death, no interaction, recovery to walk, talk, and possibly live independently. Possible difficulties with memory, balance muscle control (myoclonus). It will be helpful to update prognosis overtime. Should definitely reassess at 3 months."
Case 3: Physician Predictions for 6 month outcome

- 2 mo: Family unable take home; d/c to local NH; GOS=VS
- 3 mo: Admitted to Rehab: Following commands inconsistently; exaggerated startle; frequent myoclonic movements; GOS=SD
- 4 mo: Following commands consistently; aphasic; communicates w/ hand gestures; GOS=SD
- 5 mo (rehab d/c): talking appropriately w/ prompting; eating & peg removed; walking and transfers with moderate assistance. Discharged to NH. GOS=SD.
- Projected 6 mo outcome: SD; 2 years: GOS ≥SD

* D VS SD (MD) (GR)
Case 4: At 48 hours predict 2 month outcome

- 19 yo in MVC
- GCS 3
- Decorticate posturing
- CT scan: SDH; shear injury; small SAH
- Left hip dislocated
- Severe spasticity
Audience Response:

What outcome do you predict for Case 4?

a) Dead
b) Vegetative State
c) Severe Disability
d) Moderate Disability
e) Good Recovery
Poll: What outcome do you predict for Case 4?
Case 4 prognostic statement

- Predictors:
  - young age, traumatic, early in time course
  - posturing
- Time period for application of predictors: 48 hours post
- Time period for outcome: 2 months post
- Outcome: Emergence to interact with others
- 2 mo prognosis at 48 hours: Too early to determine. Full range of outcomes are possible at this time. Recommend serial evaluations. Intensive treatment and rehabilitation efforts will be important to optimize outcome. Will follow to determine location and type of treatments needed, and update prognosis.
Case 4: Physician Predictions for 2 month outcome

- 1 month (rehab admission): awake and alert; waxing and waning response to painful stimuli; non-verbal; no response to command
- 2 months (rehab discharge): talking appropriately, eating, transfers with assistance, d/c to home; **short rehab stay**; GOS=SD
- Longer term outcome: Unknown; didn’t f/u (GOS ≥SD)
Case 5: At 4 weeks predict 1 year outcome

- 46 yo with hx HIV, hep C, IV drug use
- Assaulted; found down in yard by family
- GCS en route: 7; arousal to pain only
- Pupils unequal 3 and 4 mm and sluggish
- CT scan: left SDH; 2 cm midline shift; ventricular effacement, herniation

At 4 weeks:
- Max GCS: 5; arousal to sternal rub
- No responses except x1 with girlfriend
- Sclera icteric
- Acute care team requested WOC
- Ethics committee requested rehab consult re prognosis
Audience Response:
What outcome do you predict for Case 5?

a) Dead
b) Vegetative State
c) Severe Disability
d) Moderate Disability
e) Good Recovery
What outcome do you predict for Case 5?
Case 5 prognostic statement

- **Predictors:**
  - Traumatic, 1 response observed by gf, arousal to pain
  - age (46 years), herniation, unknown time down?, drug use?
- Time period for application of predictors: 1 mo post
- Time period for outcome: 1 year
- Outcome: Emergence to interact with others, longterm fxn
- 1 year prognosis at 1 month:
  - Still early in recovery to determine. Full range of outcomes are possible at this time, including full interaction. Recommend serial evaluations. Intensive treatment and rehabilitation efforts will be important to optimize outcome. Will follow to determine location and type of treatments are needed, and update prognosis.
Case 5: Physician Predictions for 1 year outcome

- At 1.5 mo post: Rehab Admit: Unresponsive
- At 2.5 months he abruptly emerged & began speaking appropriately
- 3 mo (rehab discharge): Feeding self regular diet with honey-thick liquids; Max A transfers; Max A ambulation in parallel bars; Oriented; min-mod A with reading, attn, problem solving, memory; GOS=SD
- 1 year: GOS=GR
Case 6: At 6 weeks predict 1 year outcome

- 21 yo M unrestrained passenger; T-bone MVC
- Unresponsive at scene
- GCS initially not available
- **GCS during acute care: 5-11**
- Initial CT scan: SAH; IVH
- f/u CT: bifrontal contusions & bifrontal subdural hygromas
- Multiple extremity and pelvic fractures
- **Inconsistent command following**
  - 6 weeks (rehab admission)
    - Pupils reactive
    - Oculocephalic reflexes intact
    - No response to command
    - Non-verbal
    - No spontaneous motor movements observed
Audience Response:
What outcome for do you predict for Case 6?

a) Dead
b) Vegetative State
c) Severe Disability
d) Moderate Disability
e) Good Recovery
What outcome do you predict for Case 6?
Case 6 prognostic statement

- Predictors:
  - Age?, traumatic
  - appears to be in VS at 6 weeks

- Time period for application of predictors: 1.5 mo post
- Time period for outcome: 1 year
- Outcome: emergence to interact with mother; live independently

1 year prognosis at 6 weeks:
  - It is still early in recovery. Failure to respond at this time not favorable, but in no means definitive. Traumatic etiology is promising for potential to emerge. Full range of outcomes possible. Rehabil efforts to adjust meds & look for reversible causes warranted.

Revisited at 1 year (10 year prognosis at 1 year)
  - Mom adamant he has purposeful thumb movements. On my exam: VS. I did not use VS term but described my observations to mom.
  - Limited data to guide prognostication at this point. Low likelihood for emergence. Not likely to live independently.
  - Uncontrolled late epilepsy necessitated chronic use of three sedating anticonvulsants which may be decreasing his responsivity.
Case 6: Physician Predictions for 1 year outcome

- 1 year: VS
- 10 years: VS
Case 7:
At 24 hours predict 3 week, 3 mo & 1 year outcomes

- 30 yo F
- MVC; unrestrained driver
- At scene: unresponsive; unsuccessful intubation; no peripheral lines
- En route: Asystolic arrest; CPR with bag mask started
- ED:
  - Continued resuscitation in ED for at least 30 minutes
  - Airway obtained
  - U/S: no cardiac wall motion
  - Code called
  - Later noted to have pulse
- Post-resuscitation: GCS 3T; pupils non-reactive; no gag or corneal reflexes; doll’s eyes + (present = nl for coma)
- CT scan: temporal SDH (6 mm) with mass effect; slight midline shift; diffuse edema
- Decision not to operate due to poor prognosis
Audience Response:

What outcome do you predict for Case 7?

a) Dead
b) Vegetative State
c) Severe Disability
d) Moderate Disability
e) Good Recovery
What outcome do you predict for Case 7?
Case 7: 24 hour prognosis statement:

- **Predictors:**
  - Age?; + dolls eyes (+ = presence = normal for coma)
  - Asystole with prolonged anoxia on top of traumatic BI, pupils non-reactive; no gag or corneal reflexes, failure to operate?

- **Time period for application of predictors:** 24 hours post
- **Time period for outcome:** 1 year
- **Outcome:** emergence & overall long-term function

- **Prognosis given at 24 hours:** Trauma service conveyed grave outcome with high certainty conveyed that she will never emerge to functional interaction. Family desired WOC

- **Recommend revised prognosis statement:** She is currently in coma which is expected at this early stage. Numerous factors (above) are unfavorable for emergence of responsivity & longterm function. However, 24 hours is too early to be certain of her outcome. Full range of outcomes are possible. Recommend treating and following serial exams.
Case 7: Short-term Outcome

• 1-3 weeks:
  – Family still wanting to withdraw care
  – Trauma disagreed, because began to show signs of responsiveness
  – Family threatened legal action
  – Ethics committee referral --> rehab consult requested

• 3 weeks:
  – Neurology: “VS vs MCS?”
  – Minutes later, rehab consult to see before family conf:
    • Definite purposeful movements & consistent responses to command

• Family conf held & updated status and prognosis
Case 7: 3 week prognostic statement

- Predictors:
  - Age?, emerged from MCS; current functional status
  - Asystole with prolonged anoxia on top of traumatic, pupils non-reactive; no gag or corneal reflexes; failure to operate?
- Time period for application of predictors: 3 weeks post
- Time period for outcome: 1 year
- Outcome: Emergence & Overall long-term functional abilities
- 1 year prognosis at 3 weeks: She has emerged as evidenced by current consistent responsiveness to commands and interactions with environment and others. She is neither in VS or MCS at this point. A wide range of outcomes are possible, from full recovery to upper severe disability (explain). Death, VS, and MCS are not expected outcomes. It is still rather early following the event to be able to determine ultimate extent of recovery and which functions will emerge over the next months to years. At this point, it looks like she will likely feed and groom herself, be continent of B/B, talk, and walk. It is not possible yet to tell if she will need help with these activities. Longterm it is expected that she will be fully independent with walking, talking, feeding, grooming, B/B. Although the full extent of recovery is not presently known, she may improve to be able to live independently and work. Given the anoxia, it is possible that she may have difficulties with memory and muscle control. I recommend against WOC. (Family shocked & thrilled re update, & agreed to pursue treatments.) I recommend bedside swallow eval now, and transfer to acute rehab within the next couple days.
Case 7: 3 mo and 1 year Outcome

- At 3.5-4 weeks, transferred to rehab
- 3 months (rehab discharge): GOS = upper SD
  - Talking
  - Eating
  - In PTA
  - Mod-max A transfers & ADLs
- 1 year: GOS = upper SD
  - Significant difficulty with memory
  - No motor problems
  - Not working yet
Summary of cases

- For many of the cases WOC was recommended. These individuals would be dead now, but Ethics Comm required PM&R consultation.
- Patients are very quickly pushed through the system with impatience to make definitive prognoses with decisions based on this.
- Ortho was more accurate than others!
- 4 cases overly pessimistic
- Yet, the 2 poor outcomes were not predicted to be poor
- How accurate were you?
- Were predictive factors helpful? Which ones?
- How did your prognosis statements hold up to time?
- Thoughts on how to best convey prognostic statements?
- Thoughts on recommendations 3 & 4?
Summary & Discussion

- Prognostic statements
  - Should consider evidence-based guidelines or educational reports that specify the
    - Predictors used
    - Time period for application of predictors
    - Time period for outcome
    - Outcome
    - Precision of prognosis

- Communication of dx & prognosis
  - Made understandable
  - Describe limits of certainty

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PROGNOSIS AFTER SEVERE TRAUMATIC BRAIN INJURY: A PRACTICAL, EVIDENCE-BASED APPROACH

Sunil Kothari
Content of all slides reproduced from:

“Prognosis After Severe Traumatic Brain Injury: A Practical, Evidence-Based Approach” by Sunil Kothari & Craig DiTommaso

Nathan Zasler, Douglas Katz, & Ross Zafonte
It seems to be highly desirable that a physician should pay much attention to prognosis. If he is able to tell his patients when he visits them not only about their past and present symptoms but also to tell them what is going to happen, as well as to fill in the details they have omitted, he will increase his reputation as a medical practitioner and people will have no qualms in putting themselves under his care.

Hippocrates
GLASGOW OUTCOME SCALE I

- Dead
- Vegetative state ("alive but unconscious")
- Severe disability ("conscious but dependent")

unable to live alone for more than 24 hours: the daily assistance of another person at home is essential as a result of physical and/or cognitive impairments.
GLASGOW OUTCOME SCALE II

• Moderate disability ("independent but disabled")
  independent at home; able to utilize public transportation; able to work in a supported environment.

• Good recovery ("mild to no residual deficits")
  capacity to resume normal occupational and social activities although there may be minor residual physical or mental deficits.
Medicine is a science of uncertainty and an art of probability.

William Osler
INCLUSION CRITERIA I

Population

- 1. Publication after 1983
- 2. Setting in North America, Western Europe, Australia, New Zealand, or Israel
- 3. Setting in either acute care or inpatient rehabilitation
- 4. Moderate and/or severe TBI (penetrating and/or closed)
- 5. Exclusively or primarily adult TBI

Predictors

- 6. Predictor variables: GCS (total), LOC PTA, age, neuroimaging (CT or MRI) and/or early neuropsychological testing
INCLUSION CRITERIA II

Outcomes

 7. Outcomes: GOS, vocational re-entry, and/or independent living
 8. Outcomes assessed at 6 months or later

Methodology

 9. Sample must represent consecutive admissions (whether done prospectively or retrospectively) or a random/neutral sampling or consecutive admissions
 10. Sample size 25
 11. Follow-up 80%
 12. Statistical analysis performed (or, if not, enough information provided to analyze oneself)
SUMMARY OF STUDIES I

GCS
• Lower scores associated with worse outcomes
• No threshold values

Length of Coma
• Longer duration associated with worse outcomes
• Threshold values:
  • Severe disability unlikely when less than 2 weeks
  • Good recovery unlikely when greater than 4 weeks
SUMMARY OF STUDIES II

PTA
- Longer duration associated with worse outcomes
- Threshold values:
  - Severe disability unlikely when less than 2 months
  - Good recovery unlikely when greater than 3 months

Age
- Older age associated with worse outcomes
- Threshold values:
  - Good recovery unlikely when older than 65 years old
SUMMARY OF STUDIES III

Neuroimaging

• Certain features (e.g., depth of lesions) associated with worse outcomes

• Threshold values:
  • Good recovery unlikely when bilateral brainstem lesions present on early MRI
Severe disability (according to GOS) is unlikely when:

- time to follow commands is less than 2 weeks
- duration of PTA is less than 2 months
Good recovery (according to the GOS) is unlikely when

- Time to follow commands is longer than 1 month
- Duration of PTA is greater than 3 months
- Age is older than 65 years
- MRI indicates bilateral brainstem injury
SPECIAL POPULATIONS: PENETRATING INJURY

- Lower GCS scores and CT findings of bilaterality or transventricular injury are associated with worse outcomes.

- Patients with a post-resuscitation GCS score of 8 or less are unlikely to achieve a good recovery.
SPECIAL POPULATIONS: MODERATE TBI

- > 90% of individuals who survive a moderate TBI will achieve either a moderate disability or good recovery.

- Risk factors associated with the poorer outcomes:
  - lower GCS scores (e.g., 9 or 10)
  - older age
  - abnormalities on the CT scan
SPECIAL POPULATIONS: DISORDERS OF CONSCIOUSNESS

Next section
Patients and their families will forgive you for wrong diagnoses, but will rarely forgive you for wrong prognoses.

David Seegal
General guidelines for communicating prognostic information.

- Begin with the family’s desire for information as well as their current beliefs.
- Ensure that the meaning and content of the outcomes are understood.
- Present quantitative information in a manner that can be understood.
- Foster hope.
- Pay attention to the process of communication.
Guidelines for the communication of quantitative information

• Try to use “natural frequencies” when communicating probabilistic information (e.g., “8 out of 10 people with this type of injury will make a good recovery”)

• Present information both qualitatively as well as quantitatively (e.g., “This is a very good chance of a good recovery”)

• Attempt to “frame” information in both a positive and negative manner (e.g., “This is the same as saying that 2 out of 10 people with this type of injury will not make a good recovery”)

• When possible, consider presenting the information visually

• Ask the person to restate, in their own words, their understanding of the information provided
Guidelines for the communication process

• Find a quiet, comfortable room without interruptions
• Sit close and speak face to face
• Have the family member’s support network present, if wanted
• Present the information at a pace the family can follow
• Periodically summarize the discussion to that point
• Periodically ask family members to repeat or summarize what was said
• Keep the language simple but direct without euphemism or jargon
• Allow time for questions
Predictions are difficult, especially about the future.

Yogi Berra
Content of all slides reproduced from:

“Prognosis After Severe Traumatic Brain Injury: A Practical, Evidence-Based Approach” by Sunil Kothari and Craig DiTommaso

DISORDERS OF CONSCIOUSNESS

Functional Outcomes in Traumatic Disorders of Consciousness: 5-Year Outcomes From the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems

John Whyte, MD, PhD, Risa Nakase-Richardson, PhD, Flora M. Hammond, MD, Shane McNamee, MD, Joseph T. Giacino, PhD, Kathleen Kalmar, PhD, Brian D. Greenwald, MD, Stuart A. Yablon, MD, Lawrence J. Horn, MD

Archives of Physical Medicine and Rehabilitation 2013;94:1855-60
Objective: To characterize the 5-year outcomes of patients with traumatic brain injury (TBI) not following commands when admitted to acute inpatient rehabilitation.

Design: Secondary analysis of prospectively collected data from the National Institute on Disability and Rehabilitation Research funded Traumatic Brain Injury Model Systems (TBIMS).

Setting: Inpatient rehabilitation hospitals participating in the TBIMS program.

Participants: Patients (N=108) with TBI not following commands at admission to acute inpatient rehabilitation were divided into 2 groups (early recovery: followed commands before discharge [n=72]; late recovery: did not follow commands before discharge [n=36]).
Functional Outcomes in Traumatic Disorders of Consciousness II
Whyte et al 2013

- **Interventions:** Not applicable.

- **Main Outcome Measures:** FIM items.

- **Results:** For the early recovery group, depending on the FIM item, 8% to 21% of patients were functioning independently at discharge, increasing to 56% to 85% by 5 years postinjury. The proportion functioning independently increased from discharge to 1 year, 1 to 2 years, and 2 to 5 years. In the late recovery group, depending on the FIM item, 19% to 36% of patients were functioning independently by 5 years postinjury. The proportion of independent patients increased significantly from discharge to 1 year and from 1 to 2 years, but not from 2 to 5 years.

- **Conclusions:** Substantial proportions of patients admitted to acute inpatient rehabilitation before following commands recover independent functioning over as long as 5 years, particularly if they begin to follow commands before hospital discharge.
Independence in Early Recovery Sample

(Whyte et al 2013)
Independence in Late Recovery Sample
(Whyte et al 2013)
EARLY RECOVERY: By 5 years, independent functioning ranged from 56% (problem solving) to 85% (ambulation/wheelchair).

LATE RECOVERY: By 5 years, 19% to 36% of participants were independent depending on the functional domain.
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