Prognostication and communication in the neuro-intensive care unit

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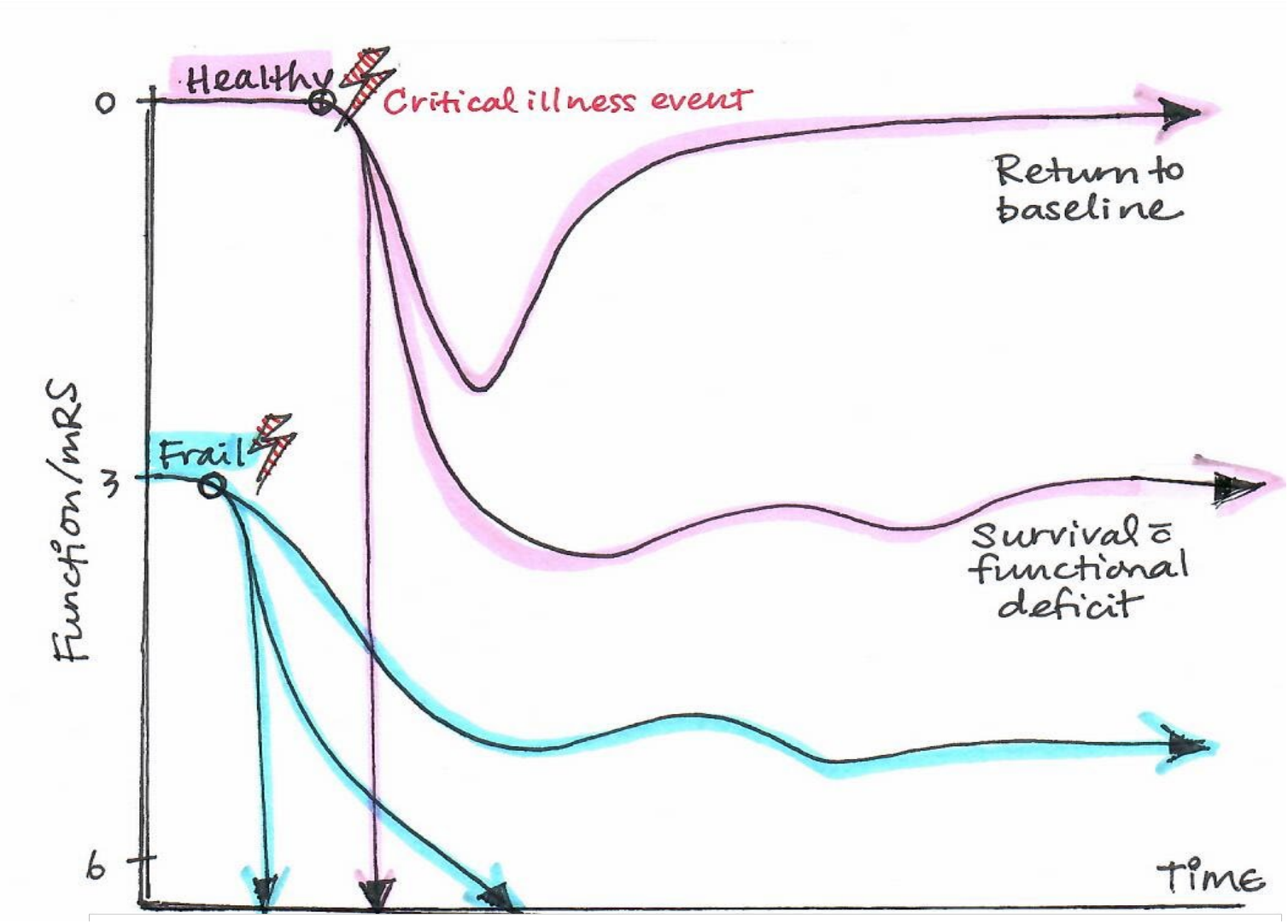
Objectives

- (1) Describe a framework for communicating information (including prognosis) to patients and surrogates in the neuro ICU
- (2) Review prognostic tools for common disease states seen in the neuro ICU

Why is this important?

- Major part of working in the ICU
- Survivors suffer from poor health-related QoL, mood disorders, and PTSD (Wendlandt)
- Physicians are overconfident in the accuracy of their recommendations (Knies)
- Open ICUs have variable practices
- Interventions to prolong life and find covert consciousness continue

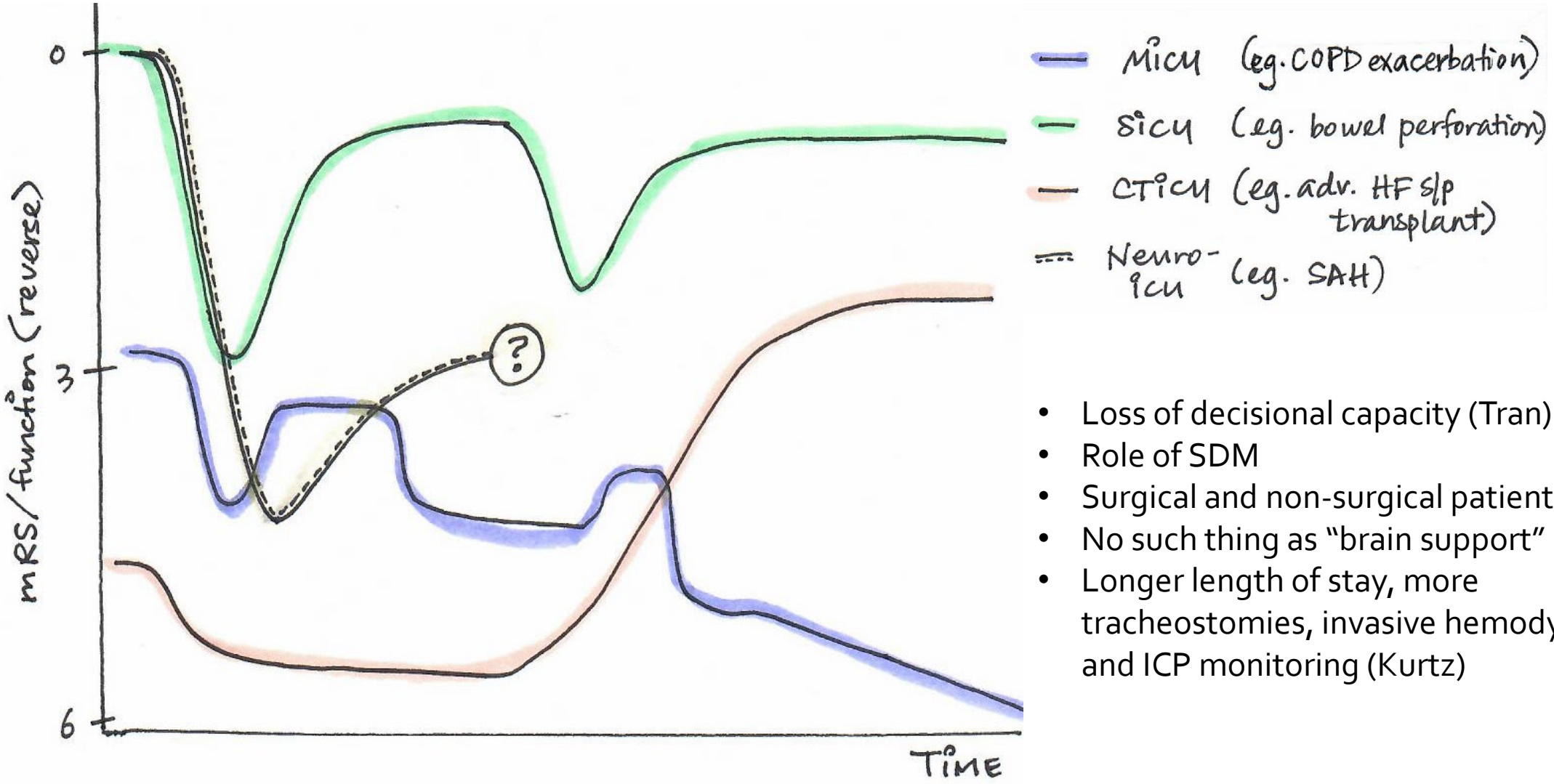
The role of uncertainty



Adapted from Montgomery et al. Crit Care Clin. 2018:34(4)

- Recovery after critical illness is very difficult to project
- New baseline in 1-2 years

Neuro ICUs are unique



- Loss of decisional capacity (Tran)
- Role of SDM
- Surgical and non-surgical patients
- No such thing as "brain support"
- Longer length of stay, more tracheostomies, invasive hemodynamic and ICP monitoring (Kurtz)

Barriers to effective communication

- Lack of formal education during training
- "Neurologists at all stages of training and practice are not comfortable with their knowledge base in palliative care" (McCovney)
- Impact of ICU structure
  - Open ICUs do not meet quality standards as often (Aslakson 2014)
  - UWH Neuro ICU is a 22-bed open ICU

Surgeon perspectives

- Special challenges in ICU with surgical patients
- Strong sense of personal responsibility for patient outcomes
- Perceive a "covenantal" relationship
- In one national survey, >40% of surgeons reported conflict with ICU physicians and RNs

Aslakson 2014

Other perspectives

Health care provider satisfaction with communication regarding prognosis

	Person Reviewed		
Reviewer	**Surgeon**	**ICU MD/NP**	**ICU RN**
Surgeon	90%	85%	85%
ICU MD/NP	23%	74%	88%
ICU RN	3%	71%	82%

Types of surgical ICUs: cardiac, trauma, transplant, vascular, general

Demographics: 40 ICU RNs, 39 ICU physicians, 4 NPs, 20 surgeons

Aslakson 2010

Definitions

Surrogate decision makers
Advanced care planning
WI rules and laws

Types of advanced care planning documents

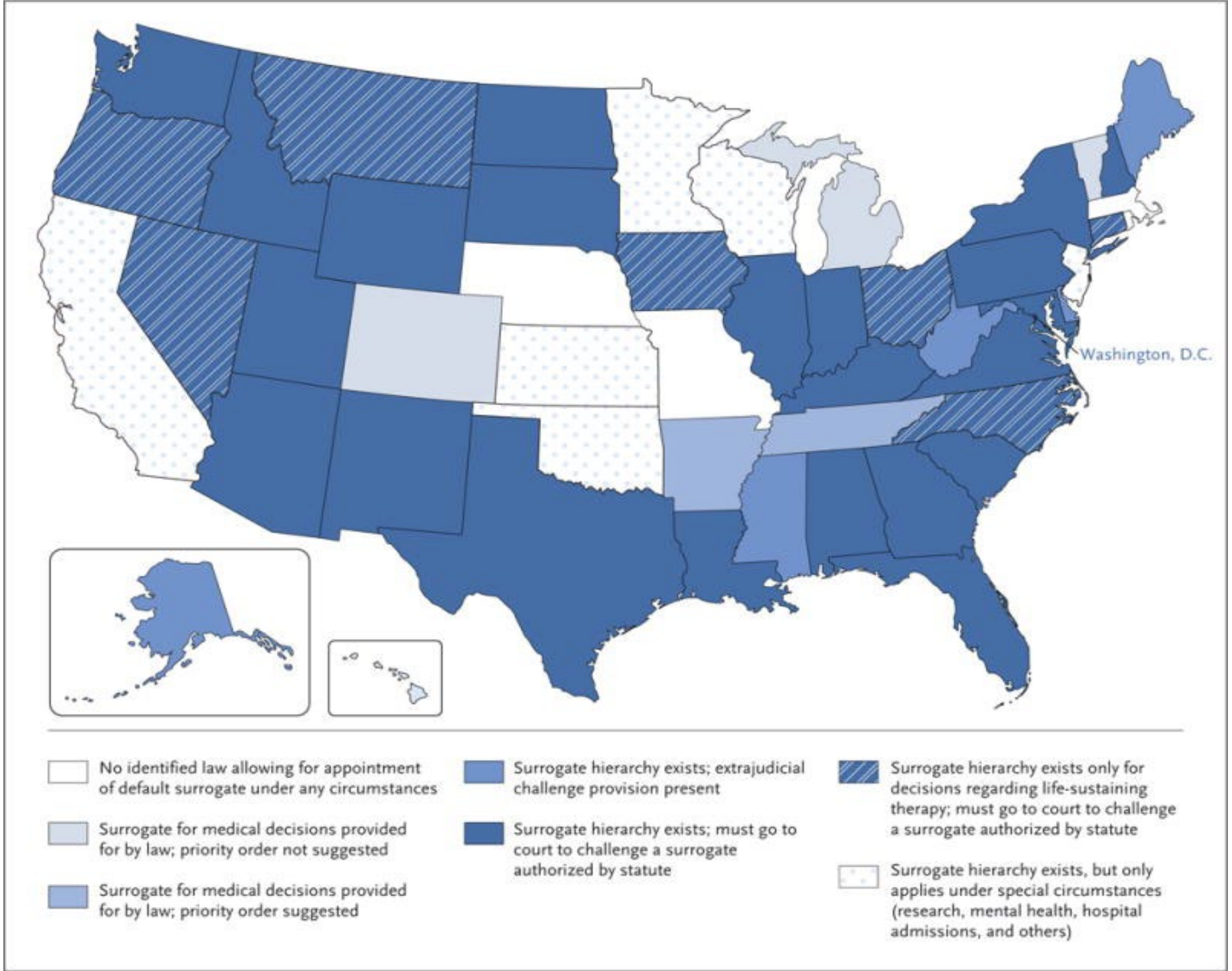
Name	Purpose	Application	Items covered	Creating parties	Jurisdiction
Living will	Patient's future preference regarding desired treatment or those to be withheld/ withdrawn	If patient is not felt to be able to regain decision making capacity	CPR Mechanical ventilation Artificial nutrition/hydration (ANH) Dialysis Organ donation Provisions for type, duration, severity of illness	-Patient -Lawyer	Some states may not recognize documents prepared in other states
POLST MOLST	A standing medical order regarding resuscitation, intubation, artificial nutrition and hydration (ANH)	Follows patient across healthcare settings. Effective once signed by a provider	DNR DNI Duration and acceptability of ANH	-Patient -SDM -Physician, PA, NP	States without: AK, AL, AR, MS, NE, SD

Adapted from Cai, Table 1

Other definitions

Name	Purpose	Application	Items covered	Creating parties	Jurisdiction
HCPOA, HCP, Durable medical POA	Designates a person to have broad authority to make healthcare decisions for a patient	If a patient is unable to make or communicate a choice about a decision	Resuscitation, treatment, procedures, medications Access to PHI Authorize admission, discharge Organ donation	-Patient -Lawyer can draft -Witnesses	Specific form requirement: IN, NH, OH, TX, WI Witness specifications: CA, CT, DE, NY, VT
Legal guardian, conservator	Gives a person or organization legal authority and duty to care for another person + finances (sometimes)	Prolonged or permanent incapacitation. Effective upon court appointment	Daily care, maintenance, support of ward (housing, meals, medication, all healthcare decisions)	-Court appointment if no next of kin (NOK) available	NE, MO, MA legally require NOK to become court appointed guardian if no HPOA

Adapted from Cai, Table 1



DeMartino Figure 1

Surrogate decision makers

- Willing and able to make decisions
- Available in a timely fashion
- Principles
  1. ACP documents: living will, POLST
  2. Specific conversations
  3. Substitutive judgement
  4. “Best interest” of patient (used by legal guardians)

Let’s start the conversation

How to talk to families

How do we start?

- Early formal meetings are better (Knies)
- Agency for Healthcare Research and Quality (AHRQ) "Care and Communication Bundle for ICU" (Aslakson 2014)
  - SDM and code status before 48h
  - Social work and spiritual care support before day four
  - Interdisciplinary family meeting by day five

How do we start?

- Regarding patients with neuromuscular respiratory failure and locked-in states
  - Address the patient
  - Speech-language pathology colleague involvement early
  - Augmentative and alternative communication (AAC) tools

How do we start?

- The first meeting should occur within 48-72h
  - Break bad news, full medical update
    - ~75% of patients were independent prior to admission (Tran)
  - Begin to elicit patient and family values/perspectives
  - Provide time
- Formal GoC meeting should happen within the first two weeks, before major decisions need to be made

The GoC meeting

Preparation	During meeting	Wrap up	Post meeting
-Set date, time, private location -Identify consultative teams who should attend -Bedside RN, SW, CM -Interpreter? -Pre-meeting huddle: confirm all teams agree re: patient status, treatments offered, range of prognosis -Determine roles -Anticipate challenges and conflicts	-Intersperse family and team -Offer to phone-in others -Introductions, set goals -Invite questions without answering right away -Medical update—start from beginning -Pause for questions, concerns -Explore prognosis (best case-worst case, most likely) -Paint a picture of recovery, including disposition post-ICU -Function oriented -Explore patient preferences -Treatment options (further neurosurgery, trach, G tube) -Questions, concerns, fears: name emotion, validate -Offer CM/SW services -Decision? If not, time limited trial -Code status	-Assure family they will be updated -Assurance of patient needs being vigilantly attended to -Ensure ICU contact information is provided to all -Arrange a follow up meeting	-Debrief with team, in particular learners. What went well? What was difficult? -Enter EMR orders -Write a good-quality family meeting note -Check in with yourself. This is exhausting work

Adapted from Cai Table 2, Knies Table 5

A “time limited trial”

- Used when a decision cannot be reached at the first GoC meeting
- How will progress be measured? – be specific
  - e.g. 96h evaluation of caloric intake/dysphagia improvement after stroke, before G tube decision is finalized
- Timeframe for the next meeting
- Not a binding contract
- Limitations: rapid patient deterioration

Language and word choices

- Use
  - Patient and family first names
  - Functional outcome includes …
  - Life prolonging (vs life sustaining)
  - Redirecting care
  - Allowing natural death (when explaining comfort care)
  - Other: explicit empathetic statements, time for silence and listening

- Avoid
  - Nonsurvivable injury (overly confident)
  - Poor prognosis (vague)
  - Good/bad quality of life (provider judgement)
  - "in a meaningful way"
  - Withdrawal of life sustaining treatment (WLST) (poor connotation; used in the literature)

Pitfalls- what you say and what they hear

- Teach-back method
  - Only 14% of providers check SDM understanding of prognostic info (Knies)
- Conflicting treatment preferences
  - SDMs feel pushed toward comfort care, never the other way around (Tran)
- Percentage quotes
  - "Chance of survival of 5%" (provider) → "40% chance of survival" (SDM)
  - Numerical prognostic statements are no better than qualitative statements in conveying the prognosis (Cook)

Pitfalls- one meeting is not enough

- Fewer than three family meetings during an ICU stay was predictive of dissatisfaction (Weber)
  - Does this vary geographically?
  - "No pre-existing characteristics…were predictive of dissatisfaction"
- Less than 60% of families of NICU patients were satisfied with (1) frequency of communication, (2) inclusion, (3) support during decision making and (4) control over care (Hwang)
  - Single center NICU vs MICU study
  - Every family is different on the "shared decision making" spectrum

Disease specific considerations

Prognostic calculators and caveats

Common diagnoses and outcomes

Condition	Incidence in U.S. (annual)	Mortality Rates (%)		Functional Independence at 3-12 months (%)
		In-Hospital	30-Day	
Traumatic Brain Injury	2,500,000 [97]	7.5% [98]	21% [99]	25-32%* [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%^ [98, 110]	25-40%** [111, 112]	48-55%** [111, 112]
Status Epilepticus^^	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]

*Among patients with severe traumatic brain injury

^Overall 90% mortality including those who do not survive to hospital admission [109]

**Among patients who underwent targeted temperature management. Mortality rates are higher and functional outcome worse in patients with PEA/asystole arrest compared to Vfib/Vtach arrest.

^^Patients with refractory status epilepticus (continued seizures after two anti-epileptic drugs have been administered) have higher mortality rates and worse functional outcomes.

Frontera 2015, Table 1

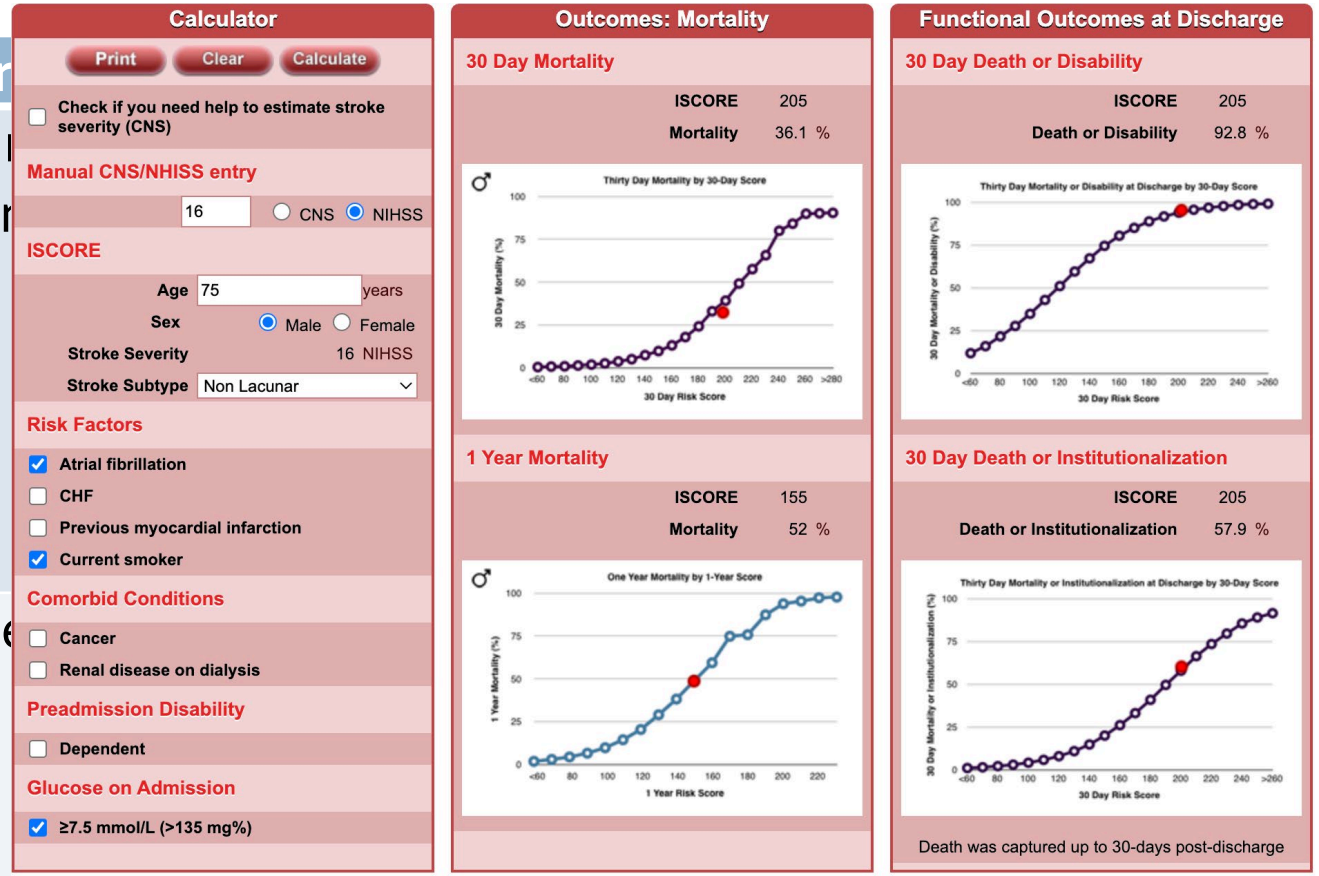
Traumatic brain injury

Adapted from Frontera Table 3, Knies Table 2

Prognostic Scale	Scoring	Outcome Measure(s)	Pros and Cons
Glasgow Coma Scale	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.
FOUR Score (Full Outline of Unresponsiveness)	0 (worst)-16 (best)	In-hospital mortality	Has good intra- and inter-rater 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 Computed tomography	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 exam or other prognostic factors.
CRASH (Country, age, GCS, pupil reactivity, major extracranial injury)	Regression based calculator	14-d mortality risk; unfavorable outcome at 6 mo	Well validated and externally compared. High income and low income country versions.
IMPACT extended (age, motor score, pupil reactivity, hypoxia, hypotension, CT classification, tSAH, EDH,	Regression based calculator	6 mo mortality and unfavorable outcome at 6 mo	Well validated and externally compared. Derived from data from the first 24 hours of admission; not for serial evaluations or updating prognosis with progression of care. Isolated head injuries only. High income countries

Ischemic stroke

Prognostic Scale	Scor
iScore (age, sex, stroke severity, stroke subtype, cardiac risk factors, preadmission disability, admission glucose, cancer, dialysis)	Regi onli
THRIVE score (NIHSS, age, history of hypertension/diabetes/atrial fibrillation)	o (be

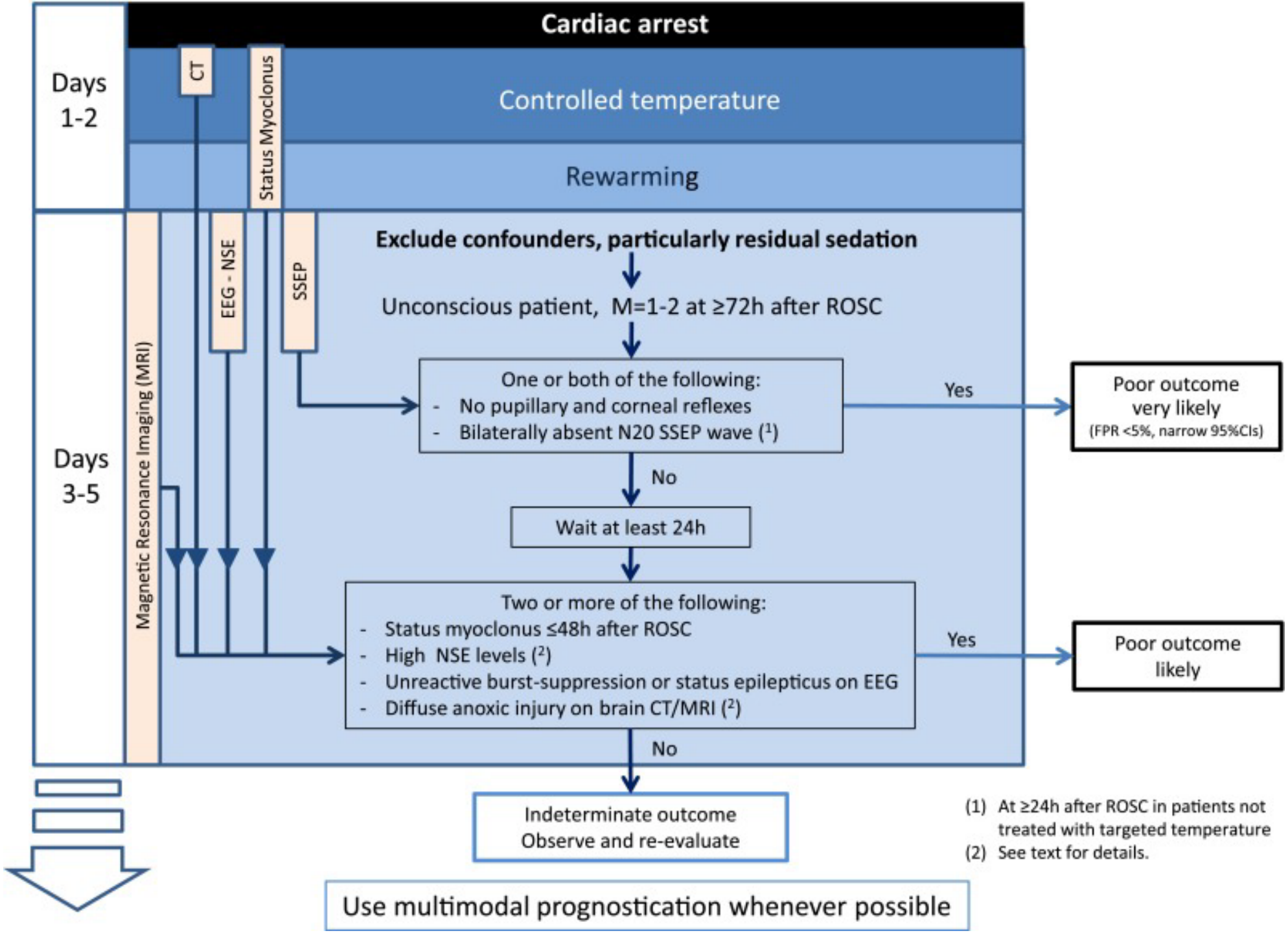


Adapted from Knies Table 2, http://www.sorcan.ca/iscore/

Post cardiac arrest

- 2006 AAN guidelines are no longer used
- 2014 European Resuscitation Council/European Society of Intensive Care Medicine guideline
  - Absent pupillary and corneal reflexes and N20 potentials at 72h robustly predict poor outcome
- 2015 American Heart Association guideline
  - Assesses prognostic modalities separately, their timing in relationship to TTM
  - The absence of pupillary reflexes at 72 hours is the only poor prognostic parameter with Class I evidence

Zhou



Sandroni Figure 1

Intraparenchymal hemorrhage

Prognostic Scale	Scoring	Outcome Measure(s)	Pros and Cons
ICH Score	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	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-months. Not widely used.

Adapted from Knies Table 2

Subarachnoid hemorrhage

Prognostic Scale	Scoring	Outcome Measure(s)	Pros and Cons
Hunt-Hess Grade	I (best)-V (worst)	Mortality, functional outcome	Commonly used in the U.S., 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 Neurological Surgeons Scale	1 (best)-5 (worst)	Mortality, functional outcome	Commonly used in Canada and Europe, WFNS combines the GCS score with the presence or absence of a major neurological deficit. It is similar to Hunt-Hess scale in predicting outcome. Does not distinguish outcome well among grade III patients and there is variable application of what constitutes a "major neurological deficit".

Adapted from Knies Table 2

Spinal cord injury

Prognostic Scale	Scoring	Outcome Measure(s)	Pros and Cons
American Spinal Injury Association Scale (ASIA)	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.

Adapted from Knies Table 2

Not discussed

- Other ICH: epidural and subdural hematoma
- Venous sinus thrombosis
- Status epilepticus
- Encephalitis
- Neuromuscular disease, locked-in states
- Integration of hospital/ICU complications, critical illness polyneuropathy, multiorgan failure

NCS position statement: devastating brain injury

- "We recommend
  - Consideration of all known prognostic variables in determining risk of death and that prognostication be based on individualized assessment of risk factors rather than on clinical scoring systems (*strong recommendation, moderate quality of evidence*)
  - Determining prognosis from repeated examinations over time (*strong recommendation, moderate quality of evidence*)
  - Applying these guidelines in the early stages of DBI treatment in order to maintain physiologic stability, even when early limitation of aggressive care is being considered (*strong recommendation, moderate quality of evidence*)
  - Using a 72-h observation period to determine clinical response and delaying decisions regarding withdrawal of life-sustaining treatment in the interim (*strong recommendation, moderate quality of evidence*)" …

Souter

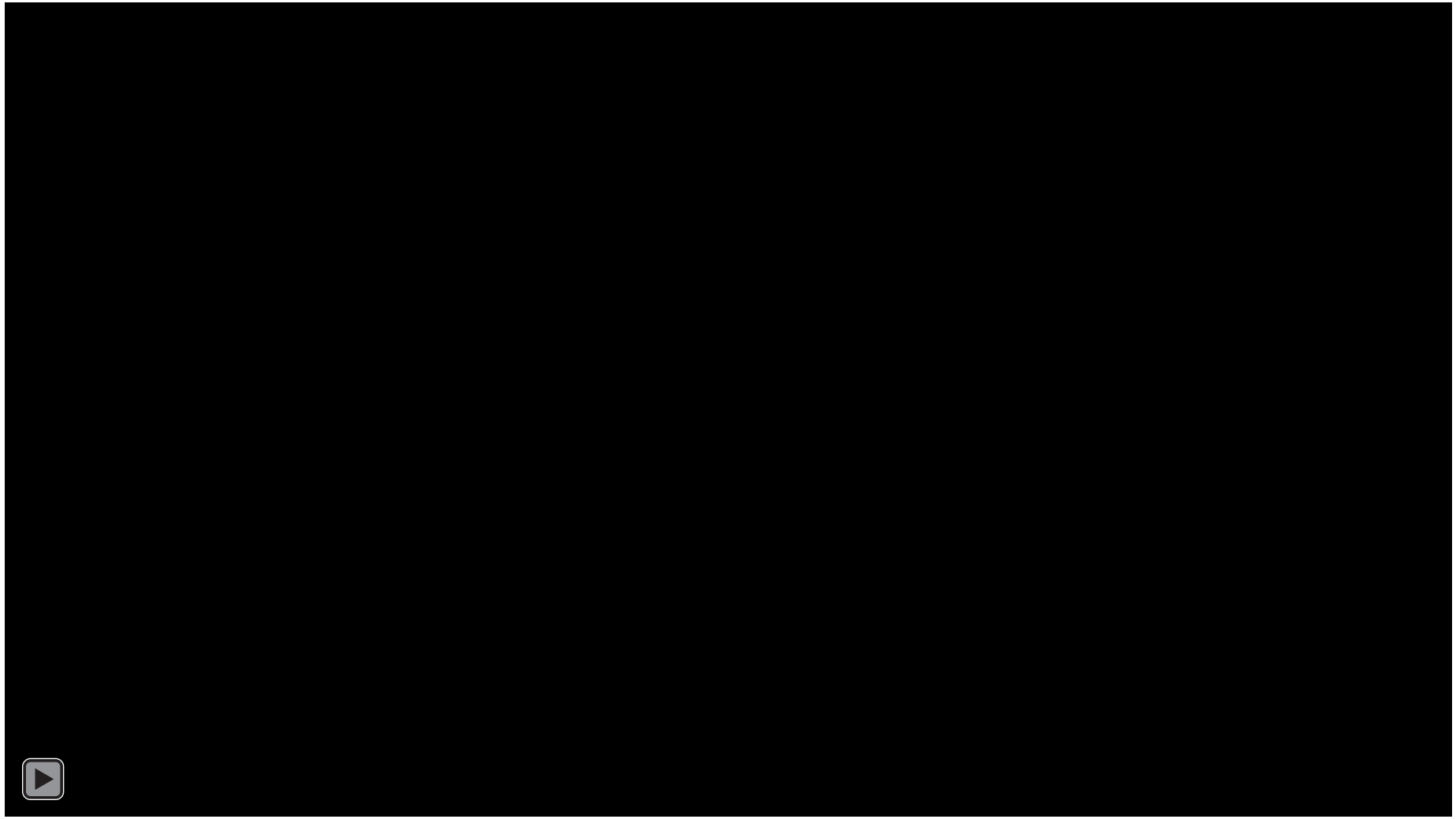
Palliative care in the Neuro ICU

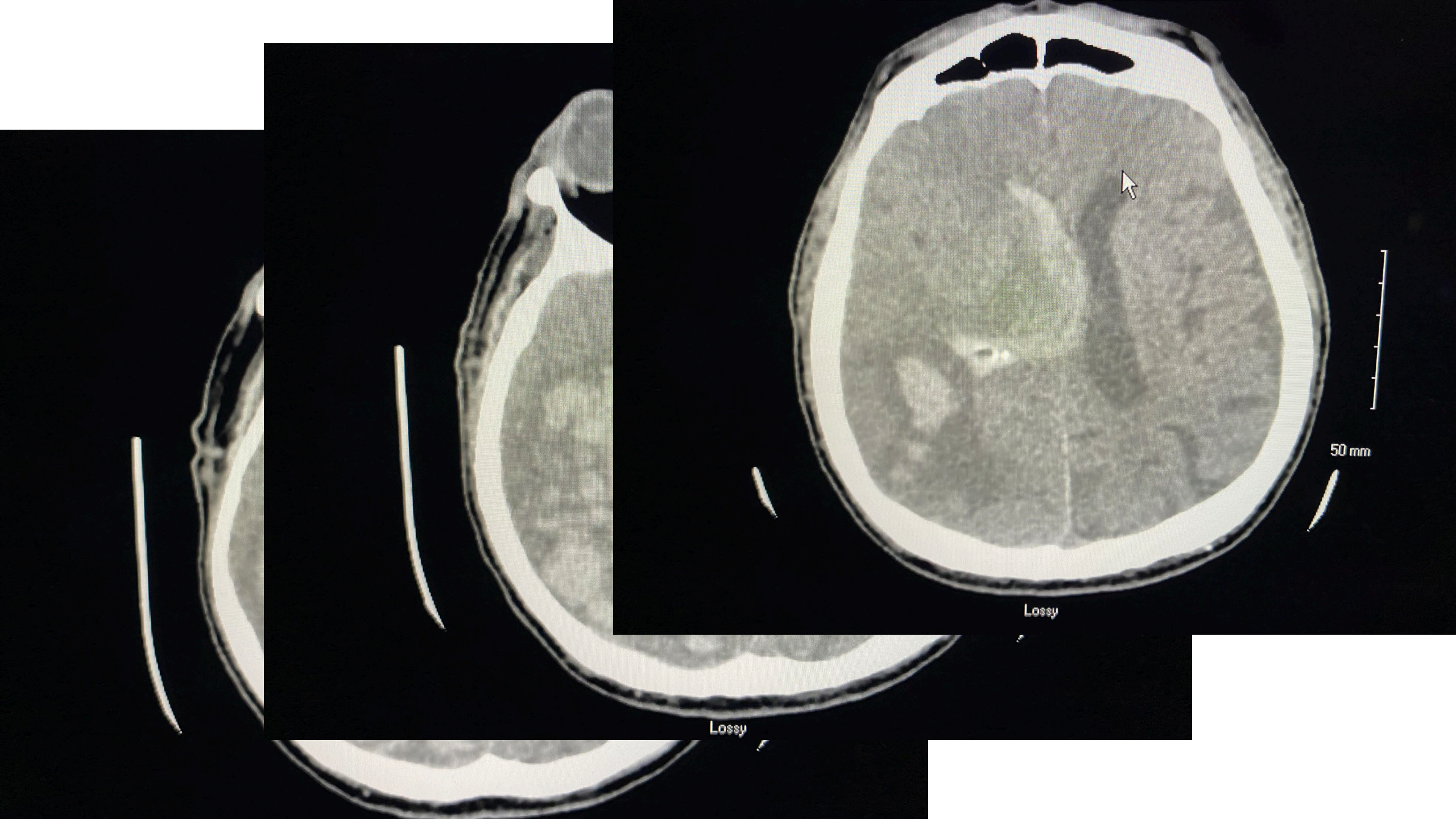
- Primary palliative care – ICU provider
- Specialized palliative care – consultative vs integrative
- Common misconceptions
  - Palliative care and critical care mutually exclusive or sequential
  - Palliative care = end-of-life or hospice
  - Palliative care will hasten death (Aslakson 2014, Table 2)
- "There are no evidence-based referral triggers identified for neurosurgical conditions" (McCovney)

Transitioning to comfort measures only (CMO)

- When to bring up?
  - As a valid alternative to life prolonging care
  - Follow family/SDM cues
- Thorough description in a gentle fashion
  - Don’t beat around the bush
- Guidance regarding symptoms to be expected, management, anticipated timeline of death
  - Anxiety, agitation – lorazepam
  - Pain and dyspnea – morphine (fentanyl or hydromorphone in ESRD)
- Continuous infusions reserved for refractory symptoms despite adequate bolus dosing (Knies)
- CMO orderset/checklist

Case




Lossy
Lossy
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Extrapolations

- Is any of this relevant to outpatient providers?
- I think so
  - Neurodegenerative diseases
  - "Soft skills" – listening, language use
  - Principles of breaking bad news, having discussions about prognosis/goals of care in the office
  - Timely offer of Palliative consultation and dispelling misconceptions
  - Social work referrals for adjunctive counseling, grief and coping resources, financial concerns

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Thank you

Questions or comments?