# Ethical Perspectives on the Management of Status Epilepticus

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# Disclosures

- none

# Outline

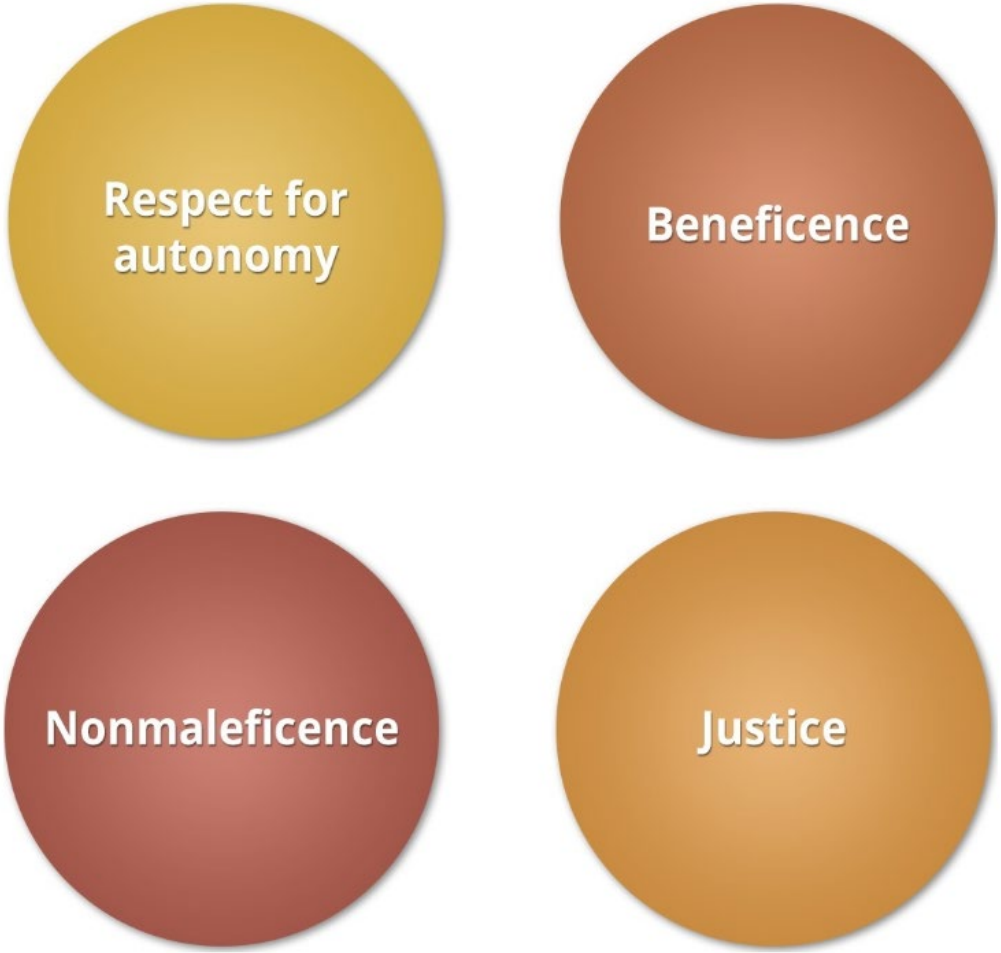
- Brief review of clinical ethics
- Highlight potential decision points in SE
- Review a case
- Review EOL care in SRSE

# Modern Hippocratic Oath

- I will apply, for the benefit of the sick, **all measures which are required**, avoiding those twin traps of overtreatment and therapeutic nihilism

- -Dr Louis Lasagna, 1948

# Basic Principles in Ethics




Childress and Beauchamp 2013

# Four Box Method

- Patient Preference
  - Informed consent
  - What motivates patient?
  - Ask patient why?
- Medical Indications
  - Diagnoses?
  - Goals of treatment?
  - When would tx not be indicated?
  - Probability of success?
- Quality of Life
  - Burden of treatment?
  - How to judge?
  - Biases regarding goals?
- Context
  - Conflict of interest?
  - Allocation of scarce resources?
  - Legal issues
  - Religious issues
  - Public health issues

# SE: Why do people die?

**Table 1**
Causes of death in a representative sample of status epilepticus studies 1998–2019 (variable seizure classifications and degrees of refractoriness).

| Year | First author | Mortality N (%) | Time mortality measured | WOLST N (% of deaths) | Causes of death in patients without WOLST |
|---|---|---|---|---|---|
| 1998 | Treiman [6] | 190 (36.7) | 30 days | NR | NR |
| 2001 | Alldredge [7] | 24 (11.7) | Hsp. discharge | NR | "Severe underlying illnesses were the probable causes of death in most patients." |
| 2002 | Mayer [8] | 14 (16.9) | Hsp. discharge | NR | "most deaths resulted from overwhelming medical complications" |
| 2005 | Holtkamp [9] | 10 (12.0) | Hsp. discharge | 0 | 4 – "persisting seizures"<br>6 – "medical complications" |
| 2005 | Rossetti [10] | 16 (12.6) | Hsp. discharge | NR | NR |
| 2007 | Koubeissi [11] | 405 (3.5) | Hsp. discharge | NR | NR |
| 2008 | Rossetti [12] | 33 (21.4) | Hsp. discharge | NR | NR |
| 2010 | Novy [13] | 21 (17.8) | Hsp. discharge | NR | NR |
| 2011 | Rossetti [14] | 9 (37.5) | Hsp. discharge | NR | Reported in 1/9 deaths – "Ileus with diffuse intestinal ischemia" |
| 2012 | Silbergleit [15] | NR | NA | NR | NR |
| 2012 | Kowalski [16] | 10 (6.9) | Hsp. discharge | 9 (90) | "Cardiac arrest," not otherwise described |
| 2013 | Hocker [17] | 20 (31.8) | Hsp. discharge | 16 (80.0) | 1 – brain death<br>2 – PRIS<br>1 – "severe pneumonia" |
| 2014 | Sutter [18] | 67 (39.2) | Hsp. discharge | 37 (55.2) | 8 – died during SE (cause NR)<br>14 – "likely from infections"<br>2 – multiorgan failure<br>1 – "could not be determined"<br>5 – "progression of the underlying pathologic condition" |
| 2015 | Ferlisi/Hocker [19] | 109 (26.4) | Hsp. discharge | 16 (14.7) | NR |
| 2015 | Marchi [20] | 67 (14.3) | Hsp. discharge | NR | NR |
| 2016 | Alvarez [21] | 52 (14.4) | Hsp. discharge | NR | NR |
| 2016 | Legriel [22] | 37 (13.8) | Hsp. discharge | NR | NR |
| 2017 | Sun [23] | 15 (6.7) | Hsp. discharge | 0 | 11 – "multiple organ dysfunction syndrome"<br>1 – "sudden cardiac arrest"<br>1 – "respiratory failure"<br>2 – "etiology of SE" |
| 2018 | Vilella [24] | 28 (31.1) | Hsp. discharge | NR | NR |
| 2019 | Hawkes [25] | 22 (9.2) | Hsp. discharge | 19 (86.3) | 3 – cardiac arrest after resolution of SE and transfer from ICU with DNR orders in place |
| 2019 | Leitenger [26] | 36 (16.3) | Within 5-year study period | NR | NR |

DNR = do not resuscitate; Hsp = hospital; NA = not applicable; NR = not reported; PRIS = propofol infusion syndrome; WOLST = withdrawal of life sustaining treatment.

Hocker, Epi and Behav 2019

# SE: Why do people die?

| | | | |
|---|---|---|---|
| Cause of SE, *n* (%) | | | 0.2281 |
| Acute symptomatic | 143(65) | 14 (58.3) | |
| Remote symptomatic | 5 (2.3) | 2 (8.3) | |
| Progressive disease | 50 (22.7) | 6 (25) | |
| Unknown | 11 (5) | 2 (8.3) | |
| Mechanical ventilation due to SE, *n* (%) | 55 (25) | 21 (87.5) | <0.0001 |
| SE Severity Score, median (IQR) | 3 (2–4) | 3 (2–4) | 0.1265 |

IQR = interquartile range, NCSE = nonconvulsive status epilepticus, SE = status epilepticus.

[a]*p* value for discharge disposition dichotomized (home vs other than home).

Hawkes, Crit Care Med 2019

# SE: Why do people die?

**TABLE 3. Outcomes of Patients With Status Epilepticus Treated With and Without Anesthetic Agents**

| Outcome | No Anesthetics ($n = 220$) | Anesthetics ($n = 24$) | $p$ |
|---|---|---|---|
| Medical complications (%) | 99 (45) | 21 (87.5) | 0.0001 |
| Length of stay, median (interquartile range), d | 7 (3.5–12.0) | 21.5 (14.0–38.0) | < 0.0001 |
| In-hospital mortality, *n* (%) | 16 (7.3) | 6 (25) | 0.0072 |
| Withdrawal of life-sustaining treatment | 13 (81.3) | 6 (100) | |
| Pulseless electrical activity arrest | 3 (18.7) | 0 (0) | |
| 90-d mortality, *n* (%) | 39 (18) | 7 (29) | 0.1415 |
| Discharge disposition, *n* (%) | $n = 204$ | $n = 18$ | 0.0003[a] |
| Home | 101 (49.5) | 1 (5.5) | |
| Home with home health | 13 (6.4) | 0 (0) | |
| Group home | 6 (3) | 0 (0) | |
| Inpatient rehabilitation facility | 27 (13.2) | 6 (33.3) | |
| Skilled nursing facility | 45 (22) | 8 (44.4) | |
| Long-term care facility | 7 (3.4) | 3 (12.5) | |
| Hospice house | 2 (1) | 0 (0) | |
| Inpatient psychiatry | 3 (1.5) | 0 (0) | |

[a] *p* value for discharge disposition dichotomized (home vs other than home).

Hawkes, Crit Care Med 2019

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Hawkes, Crit Care Med 2019

# SE: Integrating SDM

- ACP in clinic for patients with severe epilepsy
- After failure of 2nd line treatment (before ICU transfer)
- After failure to wean anesthetics

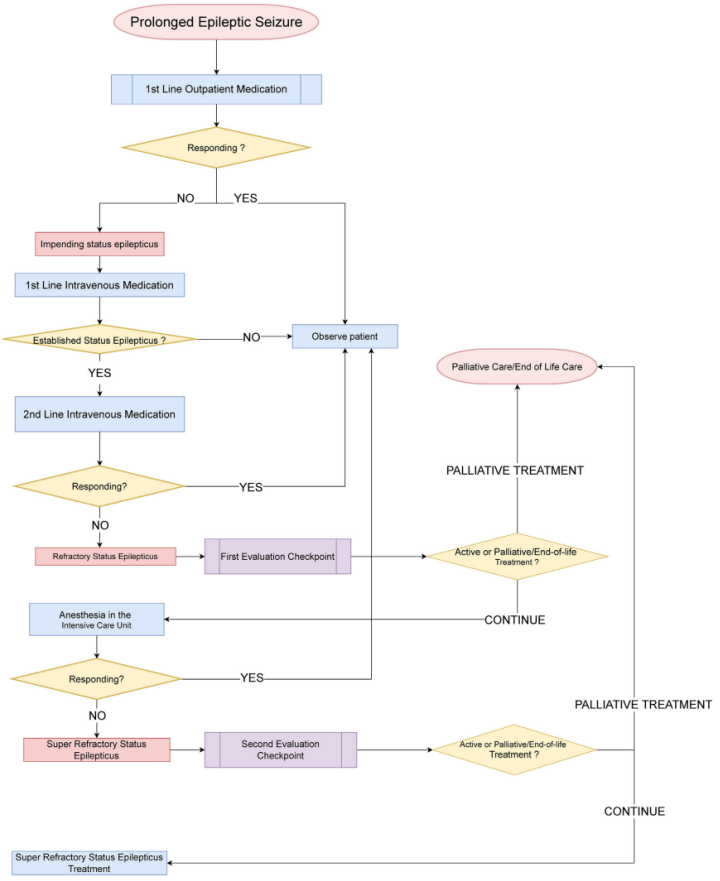


**Fig. 1.** Integrating palliative care decision-making to the status epilepticus care pathway.

Kalviainen, Epi & Behav 2023

# Case

- 20 yo with mitochondrial disease and severe epilepsy
  - VNS, 8-9 AEDs outpt, daily seizures, chronic trach/peg cared for at home
- Admitted 3/21 with fever and increased seizure frequency
- Transferred to OMC 4/5 with up to 30 seizures/day (tonic spasm, clusters of seizures q2 min for hours at a time
- No improvement after multiple rounds of abx, 7 AEDs, 2 anesthetics, VNS and ketogenic diet

# Four Box Method

- Patient Preference
  - Can patient return home?

- Medical Indications
  - What's the treatment goal?
  - What is the probability that further treatment will allow patient to become interactive and go home?

- Quality of Life
  - Can this patient improve to the point of being interactive?

- Context
  - Poor prognosis, poor access to care
  - Prolonged symptoms prior to adm
  - How other relationships affected?
  - Spiritual, social, and economic burden?

# SE: EOL care

## Principle of Double Effect

- Goal is to provide relief from distressing symptoms
- May hasten death

1. **Nature of action is morally good/neutral**
2. **Action's bad consequences are not the means of good consequences**
3. **Bad consequence is foreseen but sincerely not intended**
4. **The good consequence is of proportional value to bad consequence**

Potter, Am J Hosp & Pall Med 2021

# SE: EOL care

## Palliative sedation

- Use of sedation to reduce patient's consciousness to control refractory symptoms
- Ethically different than euthanasia/physician assisted suicide?

National Ethics Committee VA, Am J Hosp & Pall Med 2007

# SE: EOL care

## Recommendations from National Ethics Committee

- Last resort only
- For patients in final stages of dying, DNR
- Informed consent
- In conjunction with experts
- Use minimal effective dose

National Ethics Committee VA, Am J Hosp & Pall Med 2007

# SE: EOL care

- Pt maintained on all AEDs and minimal effective dose of midazolam and ketamine to prevent motor seizures
- Disconnected ventilator, patient was spontaneously breathing
- Prn opioids and bzds for symptoms of distress
- Pt died comfortably while mother laid next to her