Establishing Goals of Care for the Chronically Critically Ill

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Learning Objectives

• Define the chronically critically ill.
• Describe symptom burden in the chronically critically ill.
• Discuss effective communication between provider, patient, and caregivers to establish goals of care and maximize quality of life.
• Discuss resources for promoting effective establishment of goals of care.

What is Chronic Critical Illness?

• Complex syndrome of physiologic abnormalities, organ dysfunction, and neuroendocrine and immunologic dysfunction.
• Patients who survive the life threatening phase of critical illness, but have prolonged hospitalizations due to dependence on critical care support services.
• First coined in 1985... “to save or let die” (Girard & Raffin)

Defining Chronic Critical Illness

• Prolonged mechanical ventilation, with higher incidence of respiratory failure and failure to wean.
• Prolonged ICU care (weeks to months)
• > 3 co-morbid conditions
• Poor functional status upon admission to ICU
• Multiple organ dysfunction

Outcomes of Chronic Critical Illness

• High mortality rates (39 – 79%)
• <10% at home with independent functional status at 1 year.
• High readmission rates to acute care setting.
• Account for 6 – 10% of all ICU patients annually and consume 30 – 50% of ICU resources
• Annual costs of care estimated to be $24 billion
Outcomes of CCI

- Surviving to hospital discharge does not guarantee a smooth post hospital trajectory of care.
- Older individuals at higher risk of complications and re-hospitalization


- 40 – 50% experienced pain at the highest levels
- >60% experienced dyspnea both with full ventilation and weaning.
- 60% with psychological symptoms.
- 84% alive at hospital discharge, but more than half died before 3 month follow-up.

Symptom Burden of CCI (Nelson et al 2004)

- Of survivors, 32% dependent in all ADL's
- Measure Motor Scores (13 – 91 = range) decreased from 75.2 on admission to 46.1 at 3 months, and 57.4 at 6 months.

Symptom Burden of CCI (Nelson et al 2004)

Clinical Features of CCI

- Profound weakness secondary to myopathy, neuropathy, loss of lean body mass, increased adiposity, anasarca.
- Neuroendocrine changes -> loss of pulsatile secretion of pituitary hormones -> low target organ hormone levels -> impaired anabolism.
- Increased vulnerability to infection
- Brain dysfunction
- Skin breakdown
What’s Wrong With This Picture?

• Definitions in the literature all relate to ICU patients.
• Syndrome of chronic critical illness has well documented emotional, social, and financial burdens for individuals, caregivers, and the health care system.

Considerations re: CCI

• Greater attention should be given to symptom management.
• Establish treatment plans & clear goals of care based on careful assessment of benefit & burden.
• Survival of the critical period is not the only consideration.
• The time of a critical illness is not appropriate for establishing goals of care.
• Is this really the tip of the iceberg?

Deficiencies in Provider-Patient-Family Communication

• Clinical outcomes poorly understood by patients & family decision makers
• 80 and 93% of respondents received no information re: functional dependency and discharge or about expected 1 year survival. (Cox, et al)
• Families also disagreed when prognosis was given.

Advanced Care Planning: What Do We Know?

• Patient Self Determination Act
• Mean age of those with advanced directives (57 yrs) was higher than those without (52 yrs)
• 21% of pts in an inpatient RCU had appointed a surrogate (Camhi et al 2009)

Barriers to Advanced Care Planning

• Time
• Unrealistic hopes for patient survival
• Misinterpretation of DNR
• Fear of taking away hope
• Lack of knowledge & understanding re: hospice/palliative care
• Fear of litigation

ELISABETH KUBLER ROSS’ 5 STAGES OF DYING

1. DENIAL
2. ANGER
3. BARGAINING
4. DEPRESSION
5. ACCEPTANCE
Deficits in Law Prior to Act 169 in PA

- Patients without an AD with POA specified had no legal decision maker.
- AD only applied to limited circumstances.
- DNR orders not transferrable.
- No provision for non-family surrogates.
- POA authority unclear.
- Lacked protections for disabled.

Overview of Act 169

Major components
- Living wills
- Health care powers of attorney and health care agents
- Health care representatives (e.g., close family member)
- Out-of-hospital DNR orders
- POLST

Overview of Act 169 (cont’d.)

Key changes
- Health care power of attorney
- Clear rules governing decision-making for incompetent patients
- Special rules for artificial nutrition and hydration
- Protections for the disabled
- Expanded immunity protections for physicians and other health care providers

Triggering Events

End-stage medical condition:
- Incurable and irreversible;
- in an advanced state;
- will result in death, despite medical treatment

Permanently unconscious:
- Total and irreversible loss of consciousness and capacity for interaction with the environment

Life Sustaining Treatment

Life-sustaining treatment
- Merely prolongs the process of dying or maintains the patient in a permanently unconscious state
- In advance health care directive, includes artificial nutrition and hydration only if the directive specifically provides

Key Medical Determinations

Second opinions
- No longer required by new law
- Possibly will be required by terms of advance directive
- May be helpful when there is a question
Priority List for Surrogates

1. Current spouse and adult child of another relationship
2. Adult child
3. Parent
4. Adult sibling
5. Adult grandchild
6. Close friend

Effective Use of AD’s

• Merely providing information re: advanced directives results in no significant increase in the completion of the documents. (Bricker et al 2003)
• Requires ongoing, conversation to elicit values, preferences of the patient & family.
• Requires ongoing conversation as the disease follows its trajectory.

Comfort Initiative

• Communication
• Orientation & opportunity
• Mindfulness
• Family
• Oversight
• Reiterative messages
• Team

(SPIKES)

• SETTING and listening skills
• Patient’s PERCEPTION of condition
• INVITATION from patient to give information
• KNOWLEDGE in giving medical facts
• EXPLORE emotions and empathize as patient responds
• STRATEGY and summary

(Purpose of POLST)

• To provide a mechanism to communicate patient preferences for end-of-life treatment across treatment settings.

Resources to Facilitate ....

• POLST
• Hospice
• Palliative Care
• High Mark Advanced Illness Services
### Rationale for POLST

- AD may not be available when needed
  - Not completed by most adults
  - Not transferred with patient
- AD may not have prompted needed discussion and/or may not be specific enough
  - No provision for treatment in the NH or home
  - May not cover topics of most immediate need
- AD may be overridden by a treating MD
- AD does not immediately translate into MD order.

### What is POLST?

- A physician/nurse practitioner order
- Can be completed by any provider but must be signed by MD, DO or NP
- Complements, but does not replace, advance directives
- Voluntary use, but provides consistent recognized document.

### Key Points

- The population of CCI is larger than the literature implies.
- More aggressive symptom management is needed for this population to ensure QOL
- Clarify goals of care along the entire disease trajectory
- Use POLST
- Use hospice & palliative care interdisciplinary services

### Conference Evaluation

Online evaluations at:  
[www.pacnp.org/conference](http://www.pacnp.org/conference)