Background  Chronic critical illness (CCI) was first coined in 1985 (1). Although it does not have a single accepted definition, most authors apply CCI to patients who survived an initial critical illness with mechanical ventilation or other intensive care therapies, but remain dependent on these technologies beyond 14 days neither improving nor imminently declining (2). The usual CCI patient does not have respiratory failure in isolation. Instead, many have protracted comorbidities such as neuromuscular weakness, debility, delirium, skin breakdown, and edema. Palliative care clinicians may be asked to help in complex medical decision-making for CCI patients in various care settings. These decision points include whether to consider a tracheostomy for long-term ventilation or whether to withdraw long-term ventilator support in a patient at a long-term acute care hospital (LTACH) or ventilator weaning facility. This Fast Fact reviews the long-term outcomes and palliative care challenges for CCI patients.

Prevalence  Approximately 5-10% of patients who require mechanical ventilation develop CCI (3,4). It can emerge from a critical illness of any reason, including medical (e.g., pneumonia), surgical (complications after an operation), a stroke, or a trauma. Risk factors for developing CCI have not been clearly established (5). Of note: CCI does not apply to all patients on long-term mechanical ventilation as some were never critically ill. For example, a patient with amyotrophic lateral sclerosis who electively pursued a tracheostomy and mechanical ventilation.

Outcomes  For many CCI patients, proceeding to tracheostomy and long-term ventilation represents a fundamental decision point, often 14-21 days after critical illness presentation. Uncertainty in identifying which CCI patients will eventually functionally recover makes this decision challenging. When leading these discussions, clinicians should be aware of the following outcomes data:

- **Mortality in CCI is high.** A meta-analysis of patients requiring mechanical ventilation for > 14 days, who were either admitted to a ventilator weaning unit or had a tracheostomy found that the pooled mortality at 1 year was 73% in the US (7). Patients >65 years of age; patients who continue to require dialysis or vasopressor support at 14-21 days; and patients with thrombocytopenia and acute kidney injury are at even greater 1-year mortality risk (8).

- **Long-term functional outcomes in CCI are poor.** In the US, < 50% of patients ventilated for >14 days are ever weaned from the ventilator (7). A single-institution, US-based prospective study found that only 15% of the 203 patients studied at a respiratory care unit for ventilator weaning were functionally independent after 6 months. At 6 months ~2/3 patients had died, and most of the survivors had profound physical, cognitive, or communication deficits (9).

- **Symptom burden in CCI is high.** In a prospective cohort study of 36 participatory patients requiring tracheostomy and admission to a respiratory care unit for ventilator weaning, 44% experienced high intensity pain, 80% reported unsatisfied thirst, > 60% reported dyspnea, and > 60% reported worry or sadness frequently or almost constantly (6).

Communication  Most CCI patients are unable to engage in medical decision making, and family members or friends are used as surrogates. Unfortunately, current research indicates neither patients nor surrogates are well-informed about realistic long-term outcomes of CCI.

- In one study, a majority of patients reported receiving no information about choices other than continuing mechanical ventilation, financial burdens for the family, and expected functional and cognitive status after hospitalization, even though >90% or participants rated these topics as important (10). About 93% of patients reported that they did not receive information about 1-year mortality risk, even though 74% rated this as important (10).

- In another prospective study, only 26% of CCI surrogates reported that physicians discussed prognosis, functional limitations, quality of life, or expected caregiving needs (11). Among these surrogates, 93% expected their loved ones to survive 1 year and 71% expected their loved one to have no major functional limitations; the physicians expected similar outcomes only 44% and 6% of the time, respectively (11).
Recommendations  Considering the poor outcomes and the communication deficiencies involved with CCI patients, we empirically recommend the following:

- Hospitals should implement policies and practices to improve patient and surrogate knowledge about CCI outcomes, as well as alternatives prior to tracheostomy placement such as the discontinuation of life-prolonging technologies and the allowance of a comfortable death (9,10) so that these goals of care discussions are not needlessly deferred to LTACH or ventilator weaning facilities.

- Ideally, inter-disciplinary palliative care teams should be available to support clinicians in leading these discussions not just at hospitals and ICUs, but LTACHs and ventilator weaning facilities as well.

- Patient preferences, values, and meaning should be ascertained and utilized in CCI decision-making.

- Despite pressure to hurry the decision-making process, palliative care consultants should avoid acting as agents of the primary team’s agenda, especially during the initial encounter. Rather, a pause to complete an independent clinical and prognostic assessment is essential.

- Palliative care clinicians may help certain CCI patients and surrogates by offering to make a medical recommendation. If there is still difficulty deciding on an acceptable care plan, a time limited trial of continued endotracheal mechanical ventilation may be reasonable, as long as there are clearly defined targets when tracheostomy placement or comfort care would be pursued.

References

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Authors’ Affiliations:  Park Nicollet Methodist Hospital, St. Louis Park, Minnesota; University of Minnesota; Minneapolis, Minnesota

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