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Chronic Critical Illness: The Limbo Between Life and Death

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"Come, Friend, you too must die. Why moan about it so?
… Death and the strong force of fate are waiting."
Homer, The Iliad

This is to acknowledge that Dr. Ruggiero does not have any financial interest or other relationships with commercial concerns related directly or indirectly to this program. Dr. Ruggiero will be discussing off-label uses in her presentation.

Purpose and Overview

The purpose of this presentation is to describe the entity of chronic critical illness (CCI) to both general and subspecialty practitioners, using a patient case as an example. This presentation will discuss the outcomes and epidemiology of CCI with special attention placed on prognostic variables which can be utilized to aid the practitioner in family discussions. The pathophysiology of CCI is complex and affects multiple organ systems. This presentation will review a number of the pathophysiologic changes seen in CCI and will provide an overview of symptom burden and barriers to effective communication in patients with CCI. Finally, this presentation will offer suggestions to improve the symptom management and improve communication in a multi-disciplinary setting for patients with CCI.

Objectives

1. To describe the entity of Chronic Critical Illness (CCI)
2. To describe the epidemiology and outcomes of CCI in both the acute and long-term acute setting
3. To describe the available prognostic variables which can be utilized to predict outcomes for patients with CCI
4. To review the pathophysiologic profile of the chronically critically ill
5. To review the available data on communication in CCI and to propose methods for improvement

Biosketch

Dr. Ruggiero is an Assistant Professor of Internal Medicine in the Pulmonary and Critical Care Division at UT Southwestern Medical Center. She has been a member of the faculty since 2011. She graduated with an undergraduate degree in Biology summa cum laude from Loyola University in Baltimore, Maryland. She went on to graduate with honors from Georgetown University Medical Center in Washington, D.C. Dr. Ruggiero did her Internal Medicine residency here at UT Southwestern where she also completed her fellowship in Pulmonary and Critical Care Medicine, while also earning her Master's Degree in Clinical Science. Her research interests include ICU and sepsis mortality outcomes. She is also extremely passionate about her involvement in graduate medical education and resident training.

Chronic Critical Illness

Chronic critical illness (CCI), a term first used in 1985, has gained momentum in the past decades in terms of both popularity and prevalence [1, 2]. It is loosely defined as the group of patients who require the intensive care setting for weeks to months; its hallmark is prolonged mechanical ventilation (MV) [2, 3]. However, the entity of CCI encompasses much more than the need for prolonged MV. It is a complex syndrome that encompasses multiple organ systems, and includes metabolic, endocrine, immunologic, and neuromuscular abnormalities [3, 4]. Physiologic abnormalities and organ dysfunction are persistent and cause prolonged weakness, malnutrition, poor wound healing, and recurrent infection [3]. The clinical course for an individual who suffers a traumatic cervical injury and requires prolonged MV is very different from an individual who narrowly survives a prolonged episode of septic shock complicated by ongoing renal dysfunction and delirium superimposed upon his or her underlying comorbidities.

Unfortunately, no consensus definition exists for CCI, which limits the ability to compare literature in the field, outcomes across centers, and development of prognostic variables. Although investigators have defined CCI in a variety of ways, these definitions typically center around days requiring MV with arbitrary cutoffs at 4, 7, 10, 14, 21, or 28 days [3]. The extremes of these values likely skew the data that is available; four days is likely too short (given that the average number of days a patient is intubated in the intensive care unit (ICU) is 4.7 days) and 28 days is likely too long to make practical decisions in the acute care setting. The best clinical definition perhaps lies somewhere in the middle [1]. Other investigators have used the decision to perform a tracheostomy as the transition between acute and chronic critical illness. This definition is practical because it provides ease of retrospectively searching for DRG codes that are linked to tracheostomy (DRG 483, 551, 552) and because critical care practitioners perform a tracheostomy primarily in patients who are thought "neither to wean nor die" in the near future [1, 2, 5]. Most recently, in 2004, the National Association for Medical Direction of Respiratory Care, defined prolonged MV as patients requiring greater than 6 hours of ventilation per day for greater than 21 consecutive days [6]. In the past decade, either this definition or the decision to perform a tracheostomy has been frequently utilized to define CCI.

The modern ICU is more effective at managing acute illness and many patients who would have succumbed to their acute illnesses in prior decades are now surviving; some of these individuals are adding to the growing population of the chronically critically ill [3, 5]. It is estimated that 40% of patients admitted to the ICU require MV and that 5-10% of all ICU admissions develop CCI [1-3]. In the United States, CCI affects up to 250,000 individuals per year, a number that is rapidly growing as baby boomers enter their seventh decade. The growth of long term acute care facilities (LTACs) in the 1980's has resulted in a transition of care out of acute care facilities for the vast majority of these patients in the past three decades [4]. From an economic standpoint, the costs are significant. The health care costs of this population while in the ICU are estimated to be as high as $24 billion annually [1].

This staggering figure does not represent the true financial burden, with the associated loss of productivity of individuals and their families and the cost of care outside of the ICU. The cost of treating patients with CCI accounts for greater than one-third of total inpatient care and up to one-half of ICU resources [1, 3].

Outcomes of CCI

Despite the astronomic health care costs, the outcomes of the chronically critically ill have been dismal and have not improved over time. Liberation from MV is an attractive outcome to measure and studies have shown that 30-53% of patients achieve this milestone in the acute care setting [2, 7]. While an important measure, it does not capture endpoints such as return to functional independence or mortality. Another useful outcome is one-year survival. Across the past several decades, survival has hovered at approximately 50% [1, 2, 4, 5]; which, comparatively, fares worse than most malignancies [8].

Two relevant studies describe the outcomes of CCI in the acute care setting. These are both cohort studies done in the 80's and 90's at tertiary care medical centers; even though they are a few decades old, subsequent studies have shown strikingly similar outcomes. Spicher and White retrospectively reviewed the medical records of 250 consecutive patients who required ten or more days of MV: 39% of the cohort (mean age 60) survived until hospital discharge, 28.6% were alive at one year, and 22.5% of patients were alive at two years. Age and level of function prior to hospitalization predicted survival (see Figures 1 and 2) [9].

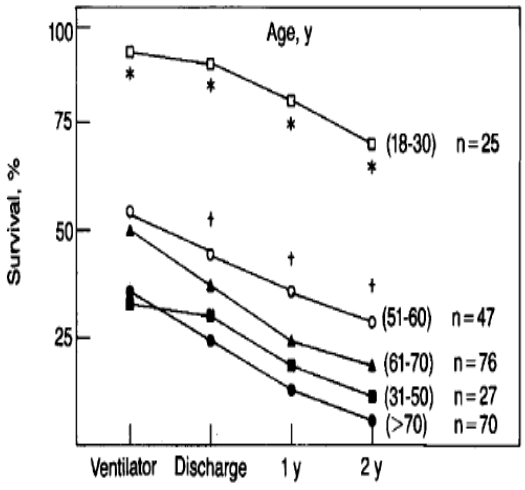

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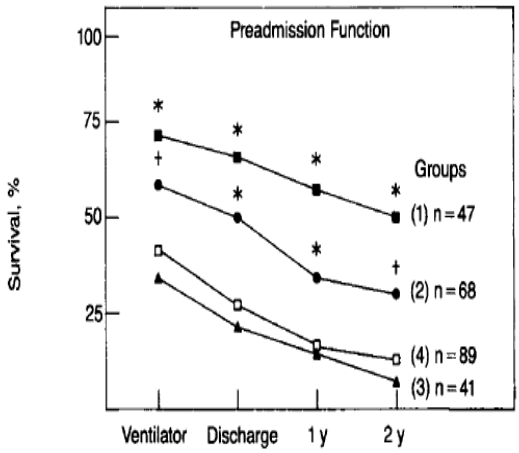
Figure 1 Comparison of survival among age groups. As seen above, survival declines with age.



[9]

Figure 2 Compares survival based on pre-admission functional status. 1 indicates no deficits prior to admission, 2, indicates mild deficits, group 3 were housebound and group 4 were institutionalized prior to admission.

In the second landmark study published in 1992, the authors evaluated the outcomes of 104 patients who required more than 28 days of MV. In this cohort (mean age 66), 60% survived to hospital discharge, and 39% were alive at one year. As expected, hospital mortality was higher in patients with respiratory failure and multisystem organ failure and lower in trauma patients [10]. Table 1 demonstrates a side-by-side comparison of these two cohort studies [3].

Table 1 Cohorts of patients with chronic critical illness from acute care hospitals

	Spicher and White [7]	Gracey et al [46]
Patients	≥ 10 days mech vent	≥ 29 days mech vent
Dates	1979–1984	1986–1988
N	245	104
Age (mean)	59.6	66.3 (SD = 15.7)
Male (%)	60.8	58.7
Diagnoses n (%)		
Previous lung disease	20 (8.1)	7 (6.7)
Acute lung disease	37 (15.1)	6 (5.7)
Resp failure w/multisystem failure		27 (26.0)
Cardiac	23 (9.4)	
Other medical		16 (15.4)
Postoperative	105 (42.6)	41 (39.4)
Trauma/burns	32 (13.1)	7 (6.7)
Neurologic	21 (8.6)	
Ventilator days mean (range)	31 (10–301)	59.6 (29–247)
Survival (%)		
Hospital	39.2	57.7
One year	28.6	38.7
Two years	22.5	35.1

[3]

But what about those individuals who survive critical illness and are discharged from the ICU to an LTAC? The advent of LTACs has shielded the majority of physicians as well as families from many of the sequelae of CCI [11]. Oftentimes, after an episode of critical illness, many patients undergo tracheostomy and

percutaneous endoscopic gastrostomy tube placement and then are transferred to a weaning facility or LTAC for further ventilator management. How do these patients who survive a prolonged ICU hospitalization fare after transfer to one of these facilities? Carson et al described the outcomes of 133 mechanically ventilated patients admitted to an LTAC from acute care hospitals. The main outcomes were survival, ability to liberate from MV, and functional capacity at one year. On average, patients were aged 71, came almost exclusively from medical ICUs, and required 25 days of MV prior to transfer. The majority of the patients had their index admission for lung disease (46%), cardiac disease (16%), or neurologic disorders (15%). Of the 133 patients enrolled into the study, sixty-six (50%) died while hospitalized at the LTAC. Fifty-one patients (38%) were liberated from MV. Thirty patients (23% of the original cohort) were alive at one year. Eleven patients (8% of the original cohort) were "oriented, ambulatory, and independent" at one year [12]. As in the study by Spicher and White, age and pre-hospitalization function predicted survival. They demonstrated that individuals greater than 65 years of age with dependence for ADLs, as well as patients over 75 regardless of their level of dependence had greater than 93% mortality at one year. Other studies of either hospital based weaning facilities or LTACs show similar mortality outcomes (Table 2) [12]. Similarly, across several studies, between 8-12% of chronically critically ill patients are alive and independent at one year [13]. In other words, of the next 100 patients who obtain a tracheostomy for prolonged MV, approximately 10 of them will be alive and functional at home in one year's time.

It is important to note that studies have shown that functionality does not always translate into quality of life among survivors. Interestingly, surveys indicate that responses regarding quality of life are typically more positive than would be expected after life-threatening events that leave patients with poor functional capacity, especially in the elderly population. Mankind has an amazing ability to adapt.

Table 2 Outcomes from cohorts of patients from ventilator weaning hospitals

	Gracey et al [46]	Scheinhorn et al [16]	Latriano et al [18]	Bagley + Cooney [17]	Seneff et al [39]	Carson et al [27]
Type of unit	VDU	RWC	RCF	LTAC	LTAC	LTAC
Selection criteria[a]	Strict	Moderate	Moderate	Limited	Minimal	Minimal
N	132	1,123	224	278	1702	133
Age, years ± SD (range)	68 ± 12	69 ± 13	67 ± 17	67 (21–99)	71	71 ± 12
Days MV in ICU	35 ± 26	Median 33 (0–395)	23 ± 19		21	Median 25 (9–123)
Acute lung Dz[b] (%)	1		23.6	45		41
Chronic lung Dz[b] (%)	13		19.2	19		22
Postop (%)	63		21	31		5
Albumin		2.61 ± .60	2.78 ± .49		80% < 3.0	2.3 ± .60
(A-a)DO_2		119.7 ± 73				144 ± 87
Weaned (%)		55.9	51.3	38		38
Survivors weaned (%)	87	78.4	93.8			70
Hospital survival (%)	91.2	71.2	50.4	52	49	50
1 year survival (%)	76	37.9			6 month 33%	23

[1]

Prognostic variables

While the outcomes are grim and have not improved over the past several decades, 50% mortality at one year is not considered futile care even by the worst standards. A recent study done at Duke University set out to create a prognostic model to predict one-year mortality for patients who required prolonged MV. The purpose of this study was done with the intent to aid practitioners, patients, and their surrogates in difficult decision making as patients transition from acute to CCI. Three hundred consecutive patients who required greater than 21 days of MV were enrolled from all ICUs. The first 200 patients were used to develop the predictive model, and the last 100 patients were used as the validation cohort. On day 21 of MV, medical records were reviewed for demographic and clinical data as well as pre-morbid conditions. Surrogates were interviewed to ascertain patient's pre-admission functional capacity. Patients were followed throughout their hospital course and telephone interviews were then performed at 3, 6, and 12 months. One-year mortality was 51% in the developmental cohort and 58% in the validation cohort. Logistic regression was performed for variables obtained at day 21 of MV. The authors found that the combination of age greater than 50, platelets < 150, requirement of vasopressors, and hemodialysis had 99% specificity for predicting death at one year. One point was assigned to each of these values to create a ProVent (Prognosis for Prolonged Ventilation) score. Patients with a score of 2 had 88% mortality at one year and patients with a score of 3 or 4 had a one-year mortality of 97% [14]. See Table 3.

Table 3 Prognostic Model of One Year Mortality in Patients Requiring Prolonged Mechanical Ventilation

*Pro*gnosis for *Pro*longed *Vent*ilation (ProVent) Score

Provent Score	Development Set			Validation Set	
	n (%)	Predicted 1-year Mortality 95% (CI)	Observed 1-year Mortality	n (%)	Observed 1-year Mortality
0	41 (21)	0.12 (0.06, 0.21)	0.15	14 (14)	0.14
1	98 (50)	0.44 (0.36, 0.53)	0.42	42 (42)	0.43
2	26 (13)	0.83 (0.71, 0.90)	0.88	21 (21)	0.86
3	22 (11)	0.97 (0.90, 0.99)	0.95	13 (13)	1.0
4	9 (5)	0.99 (0.97, 1.0)	1.0	8 (8)	1.0

[14]

Data on functional status was available for 57% of survivors at one year. While 40% of survivors with scores of 0 were functional at one year, 0% of patients with ProVent scores of greater than or equal to 2 were both alive and independent at one year [14]. This is useful for a multitude of reasons: it is the only prognostic study in this patient population that has been validated; it is a model with high specificity; it is easy to calculate; and it can aid tremendously in conversations with families when discussing expectations and outcomes.

The pathophysiology of chronic critical illness

CCI encompasses a syndrome that includes altered pathophysiology across a variety of organ systems. This syndrome is characterized by neuromuscular weakness, impaired wound healing, loss of lean body mass, impaired neuroendocrine changes related to the loss of pulsatile secretion of anterior pituitary hormones, and increased vulnerability to infection. While a comprehensive review of the pathophysiology of CCI is outside the scope of this talk, a few of the more prominent derangements will be discussed. The constellation of systems involved is depicted in Figure 3.

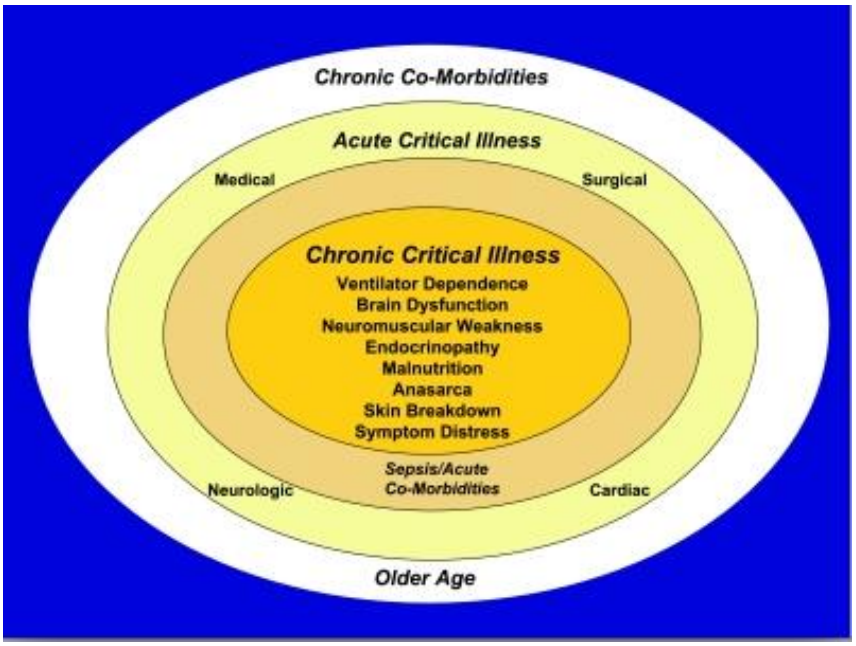


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Figure 3 The syndrome of chronic critical illness includes multiple systems and organs.

As patients cross the threshold from acute illness to CCI, organ systems are thought to lose their ability to act in a cohesive manner. When an individual is acutely ill, the activity level of organs and the neuro/hormonal/endocrine axis become hyperactive. This hyperactivity occurs early in the illness and function remains high for approximately two weeks, returning to normal once a patient fully recovers. However, in those individuals who become chronically critically ill, organ function and adaptive responses overall become depressed after several weeks. It can be said that the physiologic adaptive responses become "exhausted" after several weeks of critical illness [15] (Figure 4).

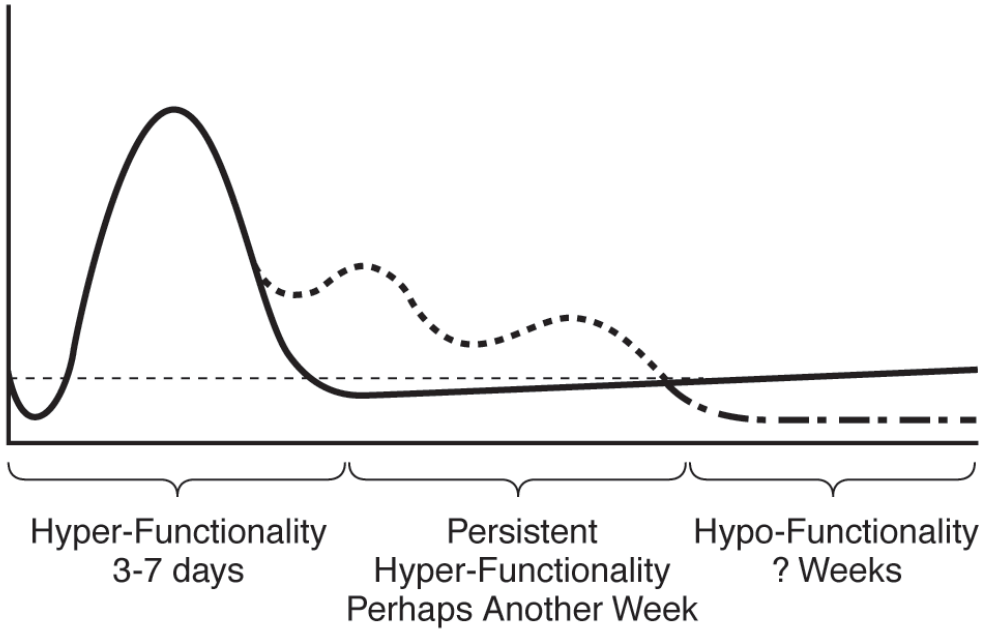

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Figure 4 This displays a schematic of the physiologic responses in the critically ill. The y-axis represents any number of physiologic or hormonal responses. The x-axis represents time. The solid line is the typical response to acute critical illness where organ function remains high for two weeks and then returns to baseline function. The dotted line represents the response when an individual becomes CCI. The initial response is similar, but after several weeks, immunologic markers and hormonal responses become depressed.

Immune exhaustion

Recurrent infections are common and contribute to the cycle of CCI. Infection further weakens a compromised patient and delays rehabilitation. When a new infection arises, patients lose ground in many ways: attempts at ventilator liberation are often halted and physical therapy is often discontinued. Furthermore, CCI patients are at much higher risk of infection because of a "triple threat"; barrier breaches, resistant organisms, and immune exhaustion. Barrier breaches are found in spades in the ICU: tracheostomy tubes, bladder catheters, central venous lines, percutaneous feeding tubes, and skin ulcers offer a direct conduit for pathogens from the outside to invade the body. In addition, lack of antibiotic stewardship in ICUs and LTACs breed opportunistic and antibiotic-resistant pathogens such as methicillin resistant staphylococcus aureus, clostridium difficile, candida, pseudomonas, and other extended spectrum beta lactamase producing organisms. Lastly, these patients are postulated to be in a state of "immune exhaustion", where they are unable to mount a cytokine and inflammatory response to an acute infection. Several factors affect cellular immune function: nutritional and vitamin deficiencies, protein depletion, prior use of corticosteroids, disruptions in the hypothalamic pituitary axis (HPA) (see below), testosterone deficiency and bone hyper-resorption. Prolonged critical illness is thought to dampen the innate response to toxins by depleting immune resources; both neutrophils and NF-kappaB are down-regulated after a bout of septic shock. When added to co-morbid conditions preceding a hospital stay, these derangements render critically ill

patients literally physiologically too exhausted to mount an adequate inflammatory response to a new stressor [16].

Neuromuscular abnormalities

The two most common neuromuscular disorders in CCI patients are critical illness polyneuropathy (CIP) and critical illness myopathy (CIM). Both manifest as generalized weakness and have devastating effects on patients' return to independence. Because their symptoms and physical exam findings are similar, electromyography alone can distinguish between the two entities.

CIP is characterized by demyelination of the myelin sheath. Greater than 25% of patients who require MV for greater than 7 days will develop CIP, and the incidence ranges up to 70% in some studies [17, 18]. The development of CIP is related to both length of MV and multi-organ dysfunction [12, 18]. CIM is characterized by degeneration of muscle fibers. CIM also occurs in individuals with multi-organ dysfunction but tends to be associated with the use of high dose steroids and paralytics. The combination of these two drugs exerts a synergistic effect on the development of CIM.

Both of these neuromuscular abnormalities cause dependence on MV long after the initial pulmonary insult resolves and there are no specific treatments available. However, early and continued mobility is recommended to combat the effects of ICU acquired weakness. Based on anecdotal reports, long-term weaning is often limited disproportionally on diaphragmatic strength rather than an ongoing primary pulmonary process. The severity of CIP is directly proportional to the time it takes to liberate from MV [18]. In a study looking at patients requiring over 28 days of MV, 90% of patients that were alive at 5 years had persistent partial denervation of muscle fibers [19].

Nutrition and metabolic support

CCI patients are often in a state of catabolism, resulting in pronounced muscle wasting and hypoalbuminemia. The overall strategy of nutritional support in these patients must address these concerns. The nitrogen load of the feed must be high to minimize additional losses of lean body mass, and interruptions in nutritional support must be minimized. As with all hospitalized patients, enteral nutrition is strongly recommended over parenteral nutrition whenever possible. Hypoalbuminemia can contribute to malabsorption by causing bowel wall edema, and diarrhea is frequently seen in patients receiving tube feeds. Higher protein feeds (semi-elemental feeding) may alleviate some of the high output stools; the proteins in these feeds have already been broken down into simpler peptides and are more easily absorbed [20]. Probiotics have also been proposed to restore the normal gut bacterium in critically ill trauma patients and those with pancreatitis; no studies have been performed in patients with CCI, however [21]. Close control of serum glucose measurements are important and should be monitored by the nutritionist, the nursing staff, and the practitioner. Both hypo- and hyperglycemia can have deleterious effects. Finally, "nutritional pharmacology" incorporates

vitamin and hormonal therapies that may promote pre-CCI homeostasis. This includes vitamin supplementation, bisphosphonates for bone resorption, and testosterone when indicated [20, 22].

Adrenal exhaustion

Glucocorticoids have widespread metabolic, cardiovascular and anti-inflammatory effects. The adrenal axis is under the control of the HPA. Cytokines and hypotension are sensed by the nervous system and these signals are relayed to the hypothalamus. Corticotropin-releasing hormone stimulates the release of adrenocorticotropic hormone (ACTH) which acts on the adrenal to stimulate the release of primarily cortisol. Androgens and aldosterone are also under at least partial control by ACTH. This, like the rest of the HPA axis, is on a negative feedback loop and is tightly controlled when the body is in homeostasis. However, in critical illness, this feedback loop often becomes dysregulated.

Adrenal insufficiency is difficult to assess but estimated to occur in at least 30% of critically ill patients, and even more often in patients with septic shock. Adrenal insufficiency correlates with higher mortality. Additionally, those patients with initially intact adrenal function can acquire adrenal insufficiency from prolonged inflammation. This has been termed “adrenal exhaustion”; it highlights the importance of intermittent assessment of CCI patients’ adrenal function [23].

Somatotropic axis

One of the hallmarks of CCI is the loss of lean muscle mass which contributes to the inability to wean from MV and overall debility. The building of muscle is at least in part under the control of the HPA. Growth hormone (GH) is released from the anterior pituitary under control of (mainly) growth hormone releasing hormone (GHRH) from the hypothalamus. GH acts directly on skeletal muscle to promote new muscle development and also indirectly via stimulation of insulin like growth factor (IGF) from the liver.

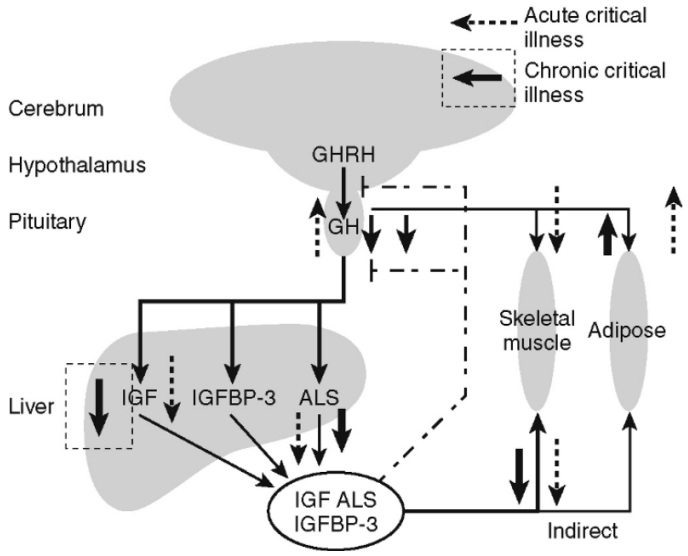

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Figure 5 Schematic illustrating the feedback loops of the somatotropic axis in acute and chronic critical illness. Once a patient becomes chronically critically ill (the solid lines), GH production is down-regulated, IGF is down-regulated and there is significant loss of muscle mass.

IGF stimulates both anabolism as well as lipolysis, acting in a negative feedback mechanism on the hypothalamus to decrease release of GHRH. In acute illness, the entire axis is depressed and receptor density decreases. Circulating IGF levels decrease which acts as a positive feedback mechanism to the hypothalamus. Therefore, in the sub-acute stages of critical illness, there are high levels of GH but low levels of IGF. GH promotes lipolysis directly, but there is no anabolic activity from IGF, which results in muscle wasting. Then in the chronic stages of critical illness, the entire axis becomes depressed. There is further decrease in the levels of IGF-1 and GH and this adds to loss of skeletal muscle and results in severe wasting [15, 24, 25].

Other

This process described above for the somatotropic axis and adrenal axis is reproduced in the entire HPA. Diurnal pulsatility of the release of hormones is lost and the tightly kept feedback loop is in disarray. This includes the thyroid axis, the production of prolactin, and the sex hormones, which results is severe testosterone deficiency [15, 24, 26, 27]. Figure 6 shows a simple schematic of the HPA.

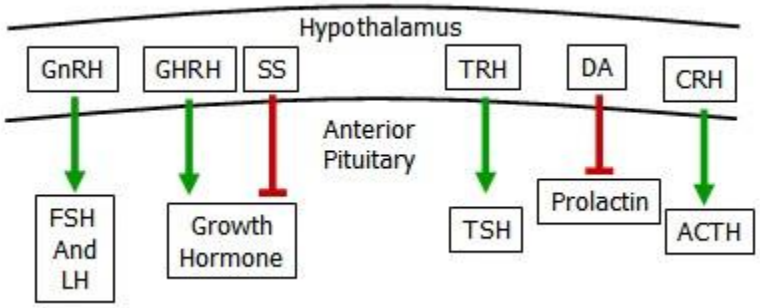


Figure 6 A simplified schematic illustrating the hypothalamic-pituitary axis.

Symptom burden of CCI

Another crucial element of CCI is the symptom burden that patients experience. Feelings of dyspnea, inability to communicate, and pain lead the list of symptoms which patients frequently report. A prospective study done in the respiratory care unit of a tertiary care hospital enrolled consecutive patients who were admitted to this unit for ventilator weaning after an acute illness. Ninety percent of responders reported at least one symptom, with a mean number of 8.6 symptoms reported. Almost half of the patients reported having either "quite a bit" or "very much" pain, 60% reported sadness and/or anxiety, and 90% of patients reported the highest level of distress due to difficulty communicating. Dyspnea was also reported in over half of patients, present both during weaning and, surprisingly, full ventilator support [28].

The emotional and economic burden on the families of patients with CCI cannot be overstated. Caregivers often battle depressed mood and high levels of psychological stress. In fact, depressive symptoms are often higher for the caregiver than the patient themselves. At one year, the majority of surrogates have either stopped working or markedly changed their work hours in order to care for their loved one's medical needs. The financial burden is also significant and loss of savings and/or income is common, even among insured patients [2, 29].

Greater attention needs to be given to these symptoms in the CCI population. It has been suggested that since the majority of these patients do not survive the year, the structure of care and goals should be focused on reducing distressing symptoms rather than focusing on a "cure". One significant obstacle to managing symptoms such as dyspnea and pain adequately is the perception that aggressive measures to ensure comfort may compromise rehabilitation or ventilator weaning. However, a growing body of evidence in both CCI and oncology reports that managing symptom distress poorly contributes to mortality; patients may actually have improved survival after pain, distress, and depression are treated [30]. Pain itself causes increased metabolic demands and will increase oxygen consumption, which can be an important variable during spontaneous breathing trials. Stress and depression are known to increase pro-inflammatory cytokines; it is therefore postulated that the ongoing inflammatory state that characterizes CCI may be perpetuated by psychological stress [30].

The feeling of dyspnea is multifactorial and incorporates not only the mechanical load of the respiratory muscles but also receptors in the airways and lungs, and even receptors located on the face. Dyspnea during a weaning trial is often interpreted as a failed weaning trial, even when physiologically, the respiratory mechanics are acceptable. Therefore, it is plausible that relieving the *symptom* of dyspnea may facilitate liberation from MV. A non-pharmacologic method passed down among generations of critical care physicians is the use of a fan to relieve

dyspnea. It is postulated that perhaps the cool air acts on facial receptors which play a role in the sensation of dyspnea.

Pharmacologically, there is a widespread perception that opioids decrease the respiratory drive or alter cognition to an extent that further attempts at rehabilitation are halted. However, multiple studies have demonstrated that a one-time dose of narcotics given to patients with COPD actually improves exercise tolerance and dyspnea without cognitive impairment. However, there have been no studies on the use of opioids specifically for dyspnea or to aid in ventilator weaning in patients with CCI. Conversely, benzodiazepines, frequently have been associated with delirium and have had inconsistent results in relieving dyspnea; they are best avoided if possible [30].

Pain also contributes to a large symptom burden. It is important to note that it is not always invasive procedures that cause the most pain or discomfort. Interestingly, a survey of hospitalized patients rated turning as more painful than most other procedures, all of them invasive [31].

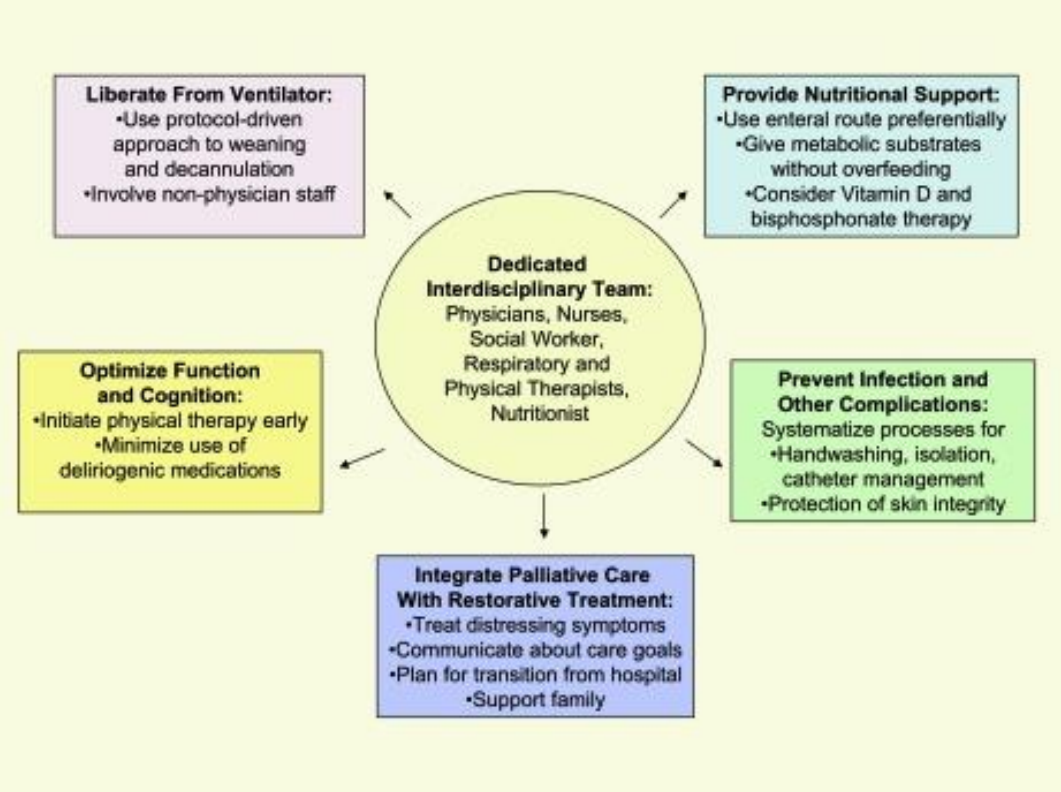
Depression must also be recognized and addressed. Although it is a common occurrence, it should never be dismissed as "normal" or "appropriate" and therefore ignored. This contributes to poor liberation from the ventilator, decreased participation in physical therapy, and impairs both social and physical function overall. As in the general population, selective serotonin reuptake inhibitors are recommended but their onset of action is gradual and care teams must be mindful of potential drug-drug interactions. For those patients where more immediate results are optimal, psychostimulants (i.e. methylphenidate) should be considered [30].

Communication in CCI

Communication to patients and their families is critical in all aspects of medicine but particularly at times of crucial decision making. However, we, as practitioners, can and must do better in this arena. Studies have shown that less than 40% of patients and their families who required ICU care for greater than 2 weeks had a discussion with their physician regarding prognosis and/or their preferences for advanced life support. In those situations where a discussion did occur, greater than half of surrogates reported being unable to understand the diagnosis, prognosis or treatment for their family member [32]. A study performed at a tertiary care medical center in New York interviewed patients or their surrogates 48 hours after receiving a tracheostomy for PMV. They were asked whether they had been given information regarding specific topics (why mechanical ventilation was needed, choices other than mechanical ventilation, probability of death within a year of hospitalization, etc.) and whether they felt that information was considered important. Respondents rated almost all the questions as important but reported that they received no information on greater than 50% of the questions posed [33].

Many physicians feel uncomfortable broaching these topics, which in part may be secondary to a lack of formal training in communication skills. This may also be more difficult when the "writing on the wall" is less obvious. Among physicians who work in the ICU, providers generally feel quite comfortable having discussions with families after an anoxic brain injury resulting in a persistent vegetative state or in patients with refractory shock and multiorgan system failure. However, it is much harder to have end of life discussions for those patients who are intermittently awake and alert, can show some signs of improvement, and are not dependent on multiple forms of life support. Those consulting services that do have the most experience in this arena, such as the ethics and palliative care teams, are rarely called upon in these situations. Rather, these services are consulted when there is family conflict, terminal cancer, or obviously futile care. Absent or inadequate communication, or the decision "not to decide" results on continuing advanced therapies and the plan of care takes on a life of its own [34, 35].

Interestingly, it has also been demonstrated that patients, their surrogates, and physicians have great discrepancy in their expectations regarding outcomes for patients undergoing PMV. In a recent study, 126 patients, their surrogates and ICU physicians were interviewed at the time of tracheostomy and asked about their expectations for one-year survival, functional status and quality of life. These answers were then compared to outcomes at one year. At the time of the interview, 93% of surrogates expected their family member to be alive at one year, 71% expected no major functional limitations and 83% expected a good quality of life at one year. As expected, physicians were less hopeful and expected that 43% of their patients would survive one year, 6% to be free of functional limitations, and 4% expected a good quality of life. In keeping with past studies, 70 (56%) of patients were alive at one year and 11 (9%) independent at one year. Thirty-three percent of survivors reported a good quality of life. The concordance between physicians and surrogates was very low. In addition to this disparity, only 26% percent of families reported that their physician discussed overall survival or expectations about functional dependence [29].



[2]

Figure 7 Multidisciplinary approach to the chronically critically ill

Approach to treatment

Approaches to treatment must include a multi-disciplinary team and an iterative process (Figure 7). From a medical standpoint, both protocol driven approaches and process maps of care for ventilator liberation, nutritional support, and infection prevention should be incorporated as part of comprehensive care [34]. Second, a systematic approach to recognizing and treating distressing symptoms should be a part of our process of care [28, 30].

Finally, and most importantly, communication needs to be a priority. I suggest at the time of tracheostomy or at week 2 of hospitalization, a formal discussion take place with the palliative care service, the ICU attending, the nursing staff and the family regarding expectations and outcomes in the coming year [33, 34]. Additionally, there are printed materials that have been developed that can be given to patient's families. This handout, which can be found online at MyIcuCare.org addresses questions such as: What is chronic critical illness? What is the experience like for families? Can patients live on their own after treatment for chronic critical illness? While these pamphlets cannot take the place of direct communication, they have been shown to be a useful adjunct to face to face meetings, providing families tangible information which they can digest over time, and offering a glossary of terms to increase understanding and relieve some of the psychological stress associated with this process [36, 37].

In this complex patient population, we need to call on the early tenets of our profession. *Primun non nocere* (first, do no harm) and *cura personalis*, (care for the whole person) necessitate the combined efforts of multiple care teams and the early integration of palliative and critical care.

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