

PULMONOLOGY AND RESPIRATORY MEDICINE Book Chapter

Survivors of Acute Lung Injury and Acute Respiratory Distress Syndrome

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Education and support during recovery in acute respiratory distress syndrome survivors

Survivors experience physical disability in the form of muscle wasting and weakness, and diminished ability to exercise up to about five years after discharge from the ICU. In addition, they also sustain important neuropsychological issues including depression, anxiety, memory loss, and difficulty with concentration. Fewer than half of all ARDS survivors return to work within the first year following ICU discharge, two-thirds return to the work force at two years, and 77% of all ARDS survivors return to work at about five years. Return to work has been shown to be inversely related to the severity of depression experienced by ARDS survivors, but despite this, most survivors continue to report functional limitation measured as distance walked in 6 minutes and a reduction in their physical quality of life.

In the recent stroke literature, the Timing it Right (TIR) framework has provided a construct in which to examine the changing needs of stroke caregivers from acute care, through rehabilitation, and back to community living [1]. The framework consists of five-distinct phases that consider the timing, setting, focus of care, support needs, and modifiable outcomes for each phase. Anyhow, clinical team has adapted the TIR framework to reflect the dominant phases of recovery for ICU survivors. The adapted five phases include:

- The critical illness event and ICU care.
- b. Period of stabilization on the general ward.
- c. Preparation for return to community living.
- d. First few months of home adjustment.
- e. Longer-term adjustment to community living.

The frame work emphasizes four aspects of support: informational, emotional, instrumental (e.g. tangible assistance from health care professionals, training to self-care), and feedback from others about how they are managing.

It was indicated that the support needs of ARDS survivors did change across time and with expert clinical input it identified the key phases of recovery that ARDS survivors typically experience, and used these to guide in practice. Throughout each of the five phases of recovery it is identified informational, emotional, and instrumental needs. During the critical illness event and ICU care, survivors identified emotional comfort and knowledge transfer to family members as the most important features of this phase. Caregivers were identified as the primary source of information for patients once they left the ICU. The period of stabilization on the general ward was characterized by fear for their health and well-being because of decreased surveillance and the realization of the seriousness of their illness. As survivors were preparing for return to community living they wanted to ensure that appropriate resources were available to them in the community. During the first few months of home adjustment, ARDS survivors did not begin to realize the long-term sequelae, which they nor their family members were prepared for. As a result, survivors felt they needed more support in the community, and more information to assist in their adjustment to living at home. During this phase, they were also interested in learning more from others who had a similar experience. After a longer-term adjustment to community living, survivors were concerned about the long-term consequences of ARDS, the prevention of future negative health events, and concern regarding return to work. They were unsure of where to find additional information, and wanted additional clinical care and psychological counseling. They appreciated any ongoing support provided by family members and friends.

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It was found that early support needs were largely characterized by information needs surrounding their illness event, diagnosis, and prognosis. Family members played an important role in obtaining this information and sharing it with survivors when they moved to the general ward. In previous researches, the use of diaries in fulfilling informational needs in the ICU has shown some positive impact on early post-ICU recovery. This has further translated into a decrease in incidence of post-traumatic stress disorder in the survivors over the longer term. Emotional needs were predominantly characterized by fear, frustration, and emotional distress. Many of these emotions were drawn from lack of familiarity in an environment and transitions to areas with less medical surveillance. Patients were unaccustomed to the sudden decrease in monitoring and assistance as they progressed through these early phases. These findings are not new, and in fact support findings seen in previous studies in coronary care unit patients. More recently, Field and colleagues looked at the experiences of ICU patients and the stress associated with relocation to the general ward. They noted that in addition to the physical and emotional difficulties relating to their illness and ICU care, communication, feeding, nursing care and support also contributed [4].

Guidance for future interventions was provided because it considers a broad spectrum of needs as they occur across the recovery trajectory. Through the interviews it was found a persistent need for information regarding the diagnosis and prognosis of ARDS throughout all the phases of recovery. This finding suggests that critical information needs that are not met early on in the recovery period persist throughout the care continuum until they are appropriately met. In the later phases of recovery, disease-specific information lessens and is replaced by needs surrounding resources on access to community care. Inconsistencies in the delivery of information were common suggesting that the delivery or transfer of knowledge from the health care team to the patients is variable. Emotional needs during the later phases were mixed. The anticipation of returning home brought with it challenges including difficulty coping with independent living, having unrealistic expectations for recovery, and coping with change in the relationships with their family caregivers. Re-integration back into the community ultimately determined the success of this phase. Instrumental needs during the later recovery phases focused on rehabilitation, vocational training, and access to care. Many survivors required ongoing reassurance about their health status and believed that in the future, there would be a need for more rehabilitation, psychological counseling, and medical follow-up. These qualitative findings are consistent with quantitative data of lower functional status and quality of life in ARDS survivors.

Family members acted as advocates for the survivors and this suggests that a family-centered approach towards care and recovery in the ICU would improve gaps in knowledge and care for the patients. Targeted interventions have been shown to improve functional performance and reduce hospital readmissions and health care costs. Many studies have largely helped to reduce anxiety and stress in the caregivers, and provide a source of communication between health care teams and family members of patients with critical illness. It was found that patients felt that ICU follow-up services were important and contributed to their recovery in a positive way. It also provided the patients with an opportunity to give feedback and receive information on their health status. However, the use of a self-help rehabilitation manual in addition to standard follow-up care found improvements in physical recovery and depression, but no difference in symptoms of anxiety or post-traumatic stress disorder [9].

Psychiatric morbidity in survivors of the acute respiratory distress syndrome

Health-related quality of life (HRQoL) as a state of physical, mental and social well- being is used as a measure of a patient's self-perceived outcome after critical care. There is some evidence that survivors of severe acute respiratory distress syndrome demonstrate significantly reduced HRQoL after discharge. Their HRQoLs are comparable to those of patients who suffered from chronic illnesses such as congestive heart failure or stroke. In addition, it has been reported that after admission to the intensive care unit some patients report symptoms such as anxiety, pain and nightmares, which may develop into chronic psychiatric disorders including post-traumatic stress disorder (PTSD) and depression. It has been demonstrated in ICU patients with ARDS and sepsis that post-traumatic stress disorder has a serious effect on the self-perceived HRQoL [10]. Post-traumatic stress disorder follows traumatic occurrences outside the range of common human experience such as violent physical assaults, torture, accidents, rape or natural disasters and is characterized by a typical symptom pattern of persistence of trauma, relevant stimuli avoidance, emotional numbing and physiological hyperarousal. The investigators were characterized traumatic events in the ICU setting in detail. They include hallucinations, paranoia, ICU noise, severe sleep disruption, communication difficulties and fear of disconnection from the ventilator.

Trigger of post-traumatic stress disorder, the traumatic event

Psychiatric diagnosis of post-traumatic stress disorder according to DSM-III-R criteria requires a triggering event which must be a catastrophic stressor outside the range of usual human experience. Furthermore, the stressor should be perceived as a traumatic event by nearly everyone. Post- traumatic stress disorder has a strong negative influence on QoL. This probably reflects the importance of recollection of anxiety in the development of post-traumatic stress disorder. The lifetime prevalence for post-traumatic stress disorder in western countries is reported with 8% within higher rates in females (10–12%) than males (5–6%). However, in some populations, the prevalence of post-traumatic stress disorder is considerably higher, for example in ICU-survivors (28%).

Fear of suffocation

Disconnection from the ventilator is in many cases perceived as a life- threatening situation resulting in severe emotional stress. In another prospective clinical trial analyzing patients 6 months after discharge from ICU, it was showed that in only 41% of the patients a memory of disconnection from the ventilator was associated with stress; 53% of the patients recalled tracheal tube suction, and of these 81% associated the procedure with stress. The difficulty breathing was recalled by 68% of all patients, but the frequency of these experiences did not differ between high-scoring patients and low-scoring patients. It seems that it is not the procedure itself but rather the individual's experience of it that determines the development of psychological sequelae of intensive care treatment.

Nightmares

It was found that 74% of all patients remembered nightmares, but their incidence was comparable between high-scoring patients and low-scoring patients. It was found an unexpectedly low rate of 30% of all patients experienced nightmares, but when they did occur they had a tremendous effect on quality of life after discharge. The opinion is that the subjective perception of nightmares as a fearful experience is the crucial factor in the development of post-traumatic stress disorder after treatment on intensive care wards.

Effect of mechanical ventilation

The duration of mechanical ventilation was not associated with the severity of post-traumatic stress disorder symptoms, suggesting that mechanical ventilation itself does not affect the development of post-traumatic stress disorder. Some researchers investigated psychological effects of daily interruption of sedation. Patients without daily interruption tended to recall awakening in ICU more often than those whose sedation was interrupted daily. Moreover, study patients with a daily interruption of sedation showed significantly fewer symptoms of post-traumatic stress disorder. However, the patients did not differ in terms of HRQoL. A perception of the ICU situation that is close to reality improves the integration of treatment experiences into episodic memory, and it might prevent the formation of a memory of traumatization. It is worth repeating that weaning strategies deploying early spontaneous breathing require appropriate strategies to avoid fear, anxiety and the feeling of helplessness.

Psychiatric morbidity

Currently, there is much speculation regarding the possible cause(s) of depressive and/or post-traumatic stress disorder symptoms in survivors of critical illnesses like ALI/ARDS. One potential neurobiologic etiology of both depression and post-traumatic stress disorder in this patient population is systemic inflammation associated with ALI/ARDS and its risk factors. There is some evidence that inflammatory cytokines may play a role in the development of general medical illness-related psychopathology. For example, increased serum levels of interleukin (IL)-6 are associated with depression in patients with cancer. Also, administration of an anti-inflammatory glucocorticoid, hydrocortisone, may be associated with a decrease in the incidence of post-traumatic stress disorder in survivors of septic shock or cardiac surgery. There are other more objective explanations for post-ALI/ARDS psychopathology. For example, patients may develop post- traumatic stress disorder symptoms as a result of extremely frightening memories, such as those of severe dyspnea and/or delirium-related psychotic experiences, perhaps shaped by coincident invasive procedures. Finally, loss can be substantial in patients who survive ALI/ARDS. Many patients leave the ICU with deficits in physical and cognitive function, leading to a delayed return to work; in addition, family lives can be disrupted by prolonged hospitalizations and recovery periods. Such stress could be an understandable cause of depression/demoralization [2].

Cognitive dysfunction

Acute respiratory distress syndrome and its associated treatment may result in cognitive impairments in individual cognitive domains as well as in more global cognitive impairment. Current data indicate that ARDS patients are at risk for long- term cognitive impairments. Almost half of ARDS survivors have cognitive impairments two years after hospital discharge, with cognitive performance falling below the sixth percentile of the normal distribution of cognitive function. It was found that at hospital discharge 100% of ARDS survivors had cognitive impairments, at one year 30% had decline in intellectual function and 78% had impairments in memory, attention, concentration, or mental processing speed. It was also found that 20% of ARDS survivors rate their memory as poor 18 months after ICU discharge. Decline in intelligence in ARDS survivors comes from data showing the patients' pre-morbid estimated intelligence quotient (IQ) was significantly higher than their measured IQ at hospital discharge but improved over time to the pre-morbid level at one and two years. The finding that patients' intellectual function recovered over time does not necessarily suggest a comparable recovery in other cognitive domains, as data from patients with traumatic, anoxic brain injury, and ARDS suggest that some cognitive abilities are more likely to improve than others.

As is the case following traumatic brain injury and stroke, cognitive impairments in ARDS patients improve during the first six to 12 months post-hospital discharge until plateauing at levels typically well below baseline. Studies suggest that the cognitive impairments in survivors of critical illness are long-lasting and likely permanent. Even those patients who no longer demonstrate frank and identifiable cognitive impairment may continue to display subtle, hard-to-identify, but clinically significant deficits. The persistent effects of critical illness on cognitive function may be particularly striking in geriatric patients with preexisting mild cognitive impairment or dementia, as critical illness related neurologic insults may serve to heighten their cognitive decline and lead to what could be characterized as an [ICU accelerated dementia] Additionally, it may be that individuals with certain chronic medical conditions may be uniquely vulnerable to developing cognitive impairments due to ARDS-related insults that may interact with their pre-existing vulnerabilities. Unfavorable cognitive sequelae do not appear to be related to certain markers of illness severity scores, medical data, or age. Neither ICU length of stay, Acute Physiology and Chronic Health Evaluation II (APACHE II) scores, duration of mechanical ventilation, tidal volume, or days receiving sedative, narcotic or paralytic medications were associated with cognitive impairments in ARDS patients. The lack of relationship between cognitive impairments with some markers of illness severity suggests that the cognitive impairments experienced by ARDS survivors cannot simply be explained in terms of the degree of age or acute illness severity.

The etiology of cognitive impairment is undoubtedly multifactorial and is the subject of on-going discussion and research. Possible mechanisms may include hypoxemia, sedatives or analgesics, hypotension, delirium, and hyperglycemia – mechanisms that may be independently responsible for adverse cognitive outcomes or that, more typically, may interact with genetic and other predisposing vulnerabilities. Other potential mechanisms of cognitive sequelae include sedatives and delirium. Although delirium may be a sign of emerging cognitive impairment, it is clearly not the case that the cognitive decline experienced by large numbers of patients with delirium is solely or primarily related to pre- existing cognitive impairment or an early dementing disorder. For example, if dementia is excluded using a conservative cut-off score on the Modified Blessed Dementia Rating Scale there is found that one-third of ICU patients (all may experienced delirium) had mild to moderate cognitive impairment at six month follow-up. The high percentage of these ICU patients showing such impairment suggests that delirium is not simply a marker of pre- existing cognitive impairments.

The consequences of cognitive impairment are far reaching. There are conflicting data regarding relationships between decreased quality of life and cognitive impairment in ARDS survivors. It was found decreased quality of life was not associated with cognitive impairment whereas another studies found ARDS patients with cognitive impairment had lower quality of life compared with ARDS patients without cognitive impairment. Similarly, survivors of acute lung injury with cognitive impairment had worse quality of life compared with those without cognitive impairment, and both groups of patients had lower quality of life compared with age- and gender-matched healthy controls. Cognitive impairment is a major determinant in the ability to return to work, work productivity, and life satisfaction following ARDS. Relatively little is known about the specific impact of cognitive impairment secondary to ARDS on important daily activities. However, researchers on other populations suggests that even mild cognitive impairments can lead to signifi-

cant deficits in the completion of instrumental activities of daily living such as driving, money management, as well as the successful management of certain basic activities of daily living [5].

Strategies for prevention

It was described that the influence of delusional memories (nightmares, dreams and hallucinations) on acute symptoms of post-traumatic stresses disorder. Indeed, factual memories in particular protected against the development of acute symptoms of post-traumatic stress disorder. Even though factual memories were sometimes unpleasant, they may have helped in coping with moments of unavoidable traumatic events. Some patients benefited from social support, notably in terms of social integrity. Even though it was found no correlation between social support and post-traumatic stress disorder rate, it was demonstrated that a reduced social function in patients with post-traumatic stress disorder, which in turn led to diminished social activities and communication [8]. The compromise of social function in patients may have partly induced an avoidance of social relationships, and to some extent it may have led patients to reject the social support offered to them. Correlation between social support and severity of post-traumatic stress disorder symptoms in patients suggested that emotional support and social integration acted as factors in preventing post-traumatic stress disorder symptoms. Because membership of the high-scoring group of patients was related to disability pension, social assistance by family caregivers might be associated with a better social outcome in ARDS survivors.

With regard to psychosocial characteristics, it has been demonstrated that objective injury criteria are not correlated with the incidence of post-traumatic stress disorder in trauma patients who are evaluated during the first 3 weeks after the accident, whereas pre-trauma variables such as gender and mental health, biographical risk and stressful life events associated with post-traumatic stress disorder symptomatology are correlated. The association between high social support and fewer post-traumatic stress disorder symptoms might reflect a better social and emotional state before the ICU trauma. Central factors in the development of active coping strategies and a stable mental health status to prevent traumatization are emotional support, empathy and helpful accepting behavior of family caregivers during the life-threatening and traumatic ICU stay. Passive coping strategies, which are related to diminish social support, inhibit cognitive function and psychological recovery from a traumatic event. A meta-analysis identified a lack of social support after the trauma as one of the major risk factors for post-traumatic stress disorder. In addition, family characteristics, for example family dysfunction or instability, seem to be a risk factor for the development of post-traumatic stress disorder symptomatology. In contrast, high social support might imply good communication and a stable family network and might consequently constitute a protective factor against the development of post-traumatic stress disorder [3].

One-year outcomes in survivors of the acute respiratory distress syndrome

Patients who survive the acute respiratory distress syndrome are at risk for physical and neuropsychological complications of the lung injury itself, associated multi-organ dysfunction, and their long stay in the intensive care unit. Several investigators have evaluated morbidity among survivors using pulmonary-function tests, neuropsychological and cognitive assessments, and quality-of-life measures, and most have indicated that there is persistent morbidity after discharge from the ICU.

It was found that patients who survived the acute respiratory distress syndrome have persistent functional limitation one year after being discharged from the ICU, largely as a result of muscle wasting and weakness (Figure 1) and, to a lesser extent, to entrapment neuropathy, heterotopic ossification, and intrinsic pulmonary morbidity. It was suggested that the inability to exercise is primarily due to extra-pulmonary disease; the impression is that impaired muscle function had an important effect on the long-term outcomes in these patients. However, it is postulated that the observed muscle wasting and weakness in survivors of the acute respiratory distress syndrome is multifactorial and may be due in part to corticosteroid-induced and critical-illness – associated myopathy. The results of multivariate regression analysis support this hypothesis. At 3 months, it found that the use of any systemic corticosteroid treatment [if ever used] is the main determinant of the ability to exercise. At 6 months, the effect of the use of systemic corticosteroids is lost and the burden of illness acquired during the ICU stay and rate of resolution of illness (as reflected by the slopes of the Lung Injury Score and the Multiple Organ Dysfunction Score) become the important determinants of

exercise capacity. A variety of changes in the nerves, muscles, or neuromuscular junctions may also explain the findings of muscle wasting and weakness, such as anterior-horn cell loss as a result of hypoxic myelopathy, the polyneuropathy of critical illness, atrophy or disuse myopathy resulting from prolonged use of sedation and paralytic agents, mitochondrial myopathy, and prolonged post-paralysis syndrome.

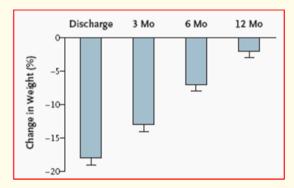


Figure 1: Mean (+SE) Change in Weight from Base Line among Patients with the Acute Respiratory Distress Syndrome at the Time of Discharge from the ICU and at 3, 6, and 12 Months (Herridge 2003).

It was noted that decreases in the distance walked in six minutes in a survivors of the acute respiratory distress syndrome who were evaluated one to two years after they participated in a trial of mechanical ventilation. It was found that survivors of the acute respiratory distress syndrome reported an important decrement in the physical functioning domain of the SF-36 23 months after discharge from the intensive care unit. It was also demonstrated that the quality of life of these patients was compromised 6 and 12 months after hospital discharge. Impaired muscle function may explain the compromised functional ability and quality of life.

Many studies of patients with the acute respiratory distress syndrome have focused on pulmonary morbidity and have shown that pulmonary function returns to normal or is nearly normal by six months to one year, with the exception of a persistent reduction in carbon monoxide diffusion capacity. A more recent studies suggested that survivors of the acute respiratory distress syndrome have important pulmonary symptoms and may have substantial limitations as a result of pulmonary disease related to the syndrome [6].

Functional disability 5 years after acute respiratory distress syndrome

It was found that relatively young patients who survived ARDS had persistent exercise limitations and a reduced physical quality of life 5 years after their critical illness. Pulmonary function was near-normal to normal at 5 years. The decrements in quality of life and exercise capacity may have resulted from persistent weakness, as well as a spectrum of physical and neuropsychological impairments that were also documented during follow-up. These patients had modest preexisting illnesses, and most were working before their illness yet they facing health care costs at a greater rate over time than did age-matched and sex-matched healthy persons. It was also found that the cumulative costs after hospitalization were associated with the burden of coexisting illnesses at the time of ICU admission. This observation is consistent with other reports that link coexisting illness with poor clinical outcomes after ICU discharge and increased costs over time.

ICU-acquired weakness may continue to be an important contributor to long-term function and quality-of-life outcomes in survivors of ARDS. The spectrum of physical and neuropsychological impairments that compound such weakness may also contribute to these outcomes. These data are consistent with other reports of long-term sequelae in survivors of critical illness. However, it is shown that such dysfunction persists over a period of 5 years and that heterogeneous issues contribute to this reported disability over time. It is also shown that psychological and emotional dysfunction persists in both patients and caregivers for up to 5 years after discharge from the ICU.

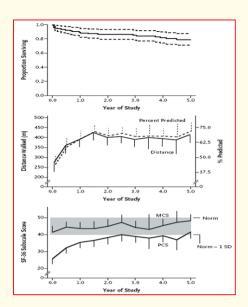


Figure 2: Survival Rates, 6-Minute Walk Distance, and Quality of Life for 5 Years after Discharge from the Intensive Care Unit. In the top graph, the solid line is the Kaplan–Meier survival curve from 0 to 5 years; dashed lines represent the 95% confidence interval. The middle graph shows the distance walked in 6 minutes in meters (solid line) and the percent of the predicted distance (dashed line). The bottom graph shows the physical- component score (PCS) and the mental- component score (MCS) on the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36); scores range from 0 to 100, with higher scores indicating better health status. Vertical bars in the middle and bottom graphs represent half 95% confidence intervals (Herridge 2011).

The decrements in the 6-minute walk distance and the score on the physical component of the SF-36 at 5 years may suggest that previously working, relatively young patients may have an irreversible decrease in function after critical illness, although this decrease is less marked than the decrements recently described in older patients with more coexisting disorders (Figure 2). Early mobility and rehabilitation are promising interventions for ameliorating such impairments, but the ability to stratify risks and tailor programs to individual needs requires further study. Recent work highlights the need to balance the potential risk of ICU-acquired weakness with the potential benefit of neuromuscular blockers and systemic glucocorticoids in severely lung-injured patients. In addition, ICU-based interventions may play a role in reducing longer-term neuropsychological disorders in ICU survivors (e.g. ICU diaries to help reduce post-traumatic stress disorder).

Through in-person follow-up it came to understand the burden on caregivers associated with the recovery of patients with lung injury. There is an emerging literature on morbidity among caregivers and the important psychological impairments sustained by family members for prolonged periods after the initial episode of critical illness. Dysfunction in these family members may also have an important negative effect on patients' recovery and rehabilitative potential [7].

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