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ACUTE LUNG INJURY AND ACUTE RESPIRATORY DISTRESS SYNDROME REQUIRING TRACHEAL INTUBATION AND MECHANICAL VENTILATION IN THE INTENSIVE CARE UNIT: IMPACT ON MANAGING UNCERTAINTY FOR PATIENT-CENTERED COMMUNICATION

Case Scenario and Literature Review

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Running Head: ALI and ARDS in the Intensive Care Unit
Abstract

A 56 year-old male presented with symptoms of pneumonia and findings consistent with acute lung injury (ALI). Deterioration of respiratory function occurred over the first 24 hours of hospitalization leading to placement in an intensive care unit (ICU) followed by tracheal intubation and mechanical ventilation (ETMV). At that time criteria defining acute respiratory distress syndrome (ARDS) were present. The palliative medicine service was asked to address concerns expressed by the patient’s spouse reflecting uncertainty regarding outcome expectations.

When interacting with families of incapacitated critically ill patients, clinicians are advised to employ a patient-centered communication process to alleviate family distress and facilitate making necessary decisions in a shared manner. Acknowledging and confrontiong the uncertainties of a critical illness is an essential component of patient-centered communication. Addressing and managing uncertainty for this case scenario requires consideration of both short-and long-term outcomes including mortality, ventilator independence, and adverse effects on quality of life for survivors. In this paper, ALI/ARDS requiring ETMV in the ICU was used as a focal point for preparing a prognostic assessment incorporating these issues. This assessment was based on a review of recently published literature regarding mortality and ventilator independence of survivors for adult patients receiving ETMV for ALI/ARDS in the ICU. In the studies reviewed, long-term survival reported at 60 days to 1 year was 50-73% with greater than 84% of the survivors in each study breathing independently. Selected articles discussing outcomes other than mortality or recovery of respiratory function, particularly quality of life implications for ALI/ARDS survivors, were also reviewed.

This case example of ALI/ARDS requiring ETMV in the ICU is used to illustrate the situation of an incapacitated critically ill patient where the outcome is uncertain. Patient-centered communication with the patient’s representative should acknowledge and address this uncertainty. Managing uncertainty consists of effectively expressing a carefully formulated prognostic assessment and using sound communication principles to alleviate the distress associated with the uncertain outcome probabilities.
Keywords:

Communication
Patient-Centered Communication
Shared Decision-Making
Prognostication
Intensive Care
Acute Respiratory Failure
Acute Lung Injury
Acute Respiratory Distress Syndrome
Mechanical Ventilation
Case Scenario

A 56 year old male without prior respiratory disease presented with fever, cough, and dyspnea resulting in hospitalization for severe community-acquired pneumonia. Oximeter readings and subjective shortness of breath worsened during the first 24 hours after admission despite increasing levels of oxygen administered by face mask. On the second day of hospitalization continued clinical evidence of increased work of breathing and poor O2 saturation readings despite a maximal rebreather O2 mask necessitated transfer to the intensive care unit, tracheal intubation, and initiation of mechanical ventilator support. Continuous intravenous sedation was implemented. Initial ventilator settings were volume assist control with a tidal volume of 6 ml/kg, FiO2 0.6 (60%), and positive end expiratory pressure of 10 cm H2O. Arterial blood gases revealed a PaO2 of 60 mm Hg (PaO2/FiO2 = 100). Extensive bilateral alveolar infiltrates were seen on chest X-ray. No clinical or echocardiographic evidence of cardiac dysfunction was detected.

During intensive care unit rounds on the third hospital day the patient’s spouse was informed of the clinical diagnosis of bacterial pneumonia with development of the Acute Respiratory Distress Syndrome. While evidencing understanding of the diagnosis and need for invasive ventilator support the spouse asked a further question: “When will the breathing machine not be needed anymore?”

The palliative medicine service representative on the intensive care unit rounding team was asked to speak further with the spouse regarding the prognosis and other outcome expectations.
Introduction

Acute lung injury (ALI) and its physiologically more severe subset, acute respiratory distress syndrome (ARDS), occur in a variety of clinical situations and identify patients at significant risk for mortality and other adverse outcomes.\(^1\) ALI and ARDS share a common pathophysiology. An inflammatory process, whether occurring in the lung or elsewhere, incites a cytokine-mediated response which in the lung manifests as a loss of the integrity of the alveolar-capillary interface, abnormal gas exchange, and adversely altered lung mechanics. The clinical findings are acute hypoxemia and bilateral lung infiltrates on chest X-ray in the absence of congestive heart failure. These characteristics form the basis for the definition and clinical diagnosis of ALI/ARDS.\(^2\) The severity of the hypoxemia indicated by the arterial oxygen level in mmHg to fraction of inspired oxygen ratio (PaO\(_2\)/FiO\(_2\)) distinguishes ALI from ARDS. In ALI the PaO\(_2\)/FiO\(_2\) is less than 300 while a more severe gas exchange abnormality, PaO\(_2\)/FiO\(_2\) of less than 200, leads to a diagnosis of ARDS. All but the most fleeting cases will require ventilator support to allow management of the primary inciting event and hopefully resolution over time of the damage done to the lung by the inflammatory process. Most often invasive ventilator support after tracheal intubation (ETMV) is required.\(^3\)

Following the initial description of ARDS as a distinct clinical syndrome over 40 years ago,\(^4\) early reports described the short-term mortality as greater than 50%.\(^1\) The short-term mortality rate for ALI/ARDS is usually measured at the time of hospital discharge, intensive care unit (ICU) discharge, or at 28-30 days from the time of admission or diagnosis. Enhanced understanding led to a consensus definition for ALI/ARDS in 1994 focusing efforts to characterize improved management strategies.\(^2\) A refinement of the definitions for ALI and ARDS not to mention a paradigm shift in management principles took place with an early publication of the ARDS Network (ARDSnet) of the National Heart, Lung, and Blood Institute in 2000.\(^5\) The short-term mortality benefit of a lung-protective ventilator strategy as outlined in this publication was widely accepted and these principles applied over the subsequent years.\(^6,7\) While other interventions for severe cases, for example extracorporeal membrane oxygenation (ECMO) and high frequency oscillation (HFO),\(^8\) remain potentially useful and under investigation the ARDSnet
ventilation guidelines remain the only proven strategy with regards to ventilator management to reduce mortality.\textsuperscript{9,10} Advances in other aspects of critical care medicine have also benefited patients with ALI/ARDS over the last two decades.\textsuperscript{11,12} A systematic review of studies up to 2006 described a pooled mortality for ALI/ARDS of 43\%.\textsuperscript{13} Similar pooled data are not available for long-term mortality or independence from ETMV as a separate outcome. Increasing attention is being paid to the physical, neurocognitive, and psychological sequelae for ALI/ARDS survivors.\textsuperscript{14}

The straightforward query asked by the spouse of the incapacitated intensive care unit (ICU) patient requiring tracheal intubation and mechanical ventilation (ETMV) for acute respiratory distress syndrome (ARDS) described in the case scenario triggers a complex set of considerations for the palliative care practitioner. Questions that reflect the uncertainties faced by patients and families during a critical illness are ranked by them as among the most common and important:\textsuperscript{15,16}

“Will he/she get better?”

“What are the chances that he/she recovers?”

“When will he/she be able to breathe on his/her own?”

“Will he/she have any aftereffects?”

Formulating responses to these questions and communicating them in an effective manner is an integral part of patient-centered communication and shared decision-making, the preferred models for interacting with families of incapacitated critically ill patients.\textsuperscript{17,18} Patient and family-centered communication requires that clinicians engage in a partnership with patients and/or their surrogates to develop care plans that are consistent with patients’ values and goals. General communication techniques (e.g. empathic statements, active listening, attention to emotion, and eliciting questions) allow the medical provider to develop a shared understanding of the patient’s experiences with illness, decision-making preferences, prognostic awareness, and values and goals in the context of a life-limiting illness to better inform medical recommendations.\textsuperscript{19,20,21}

Acknowledging and confronting the uncertainty inherent in a clinical situation such as that described in the case scenario is necessary for effective patient-centered communication to take
place. Potential benefits are enhanced quality of the shared decision-making process as well as more effective immediate coping and reduced long-term residual emotional implications for the family members serving as surrogate decision-makers and informal caregivers. Addressing uncertainty as part of patient-centered communication requires the consideration of both short- and long-term outcomes. Increasingly recognized for the ALI/ARDS patient is the importance of incorporating into this discourse not only the mortality risk but also survivorship issues including a variety of potentially adverse effects on quality of life (QOL) for the survivor and their caregivers.

This paper will provide information and recommendations necessary to formulate and express a response to the question posed by the surrogate decision maker and informal caregiver of the incapacitated ICU patient requiring ETMV for ARDS in the case scenario. Hopefully this presentation will also offer methods for dealing with uncertainty-generated questions in other scenarios, facilitating patient-centered communication, and optimizing shared decision-making. A literature review providing current information regarding outcomes for ICU patients with ALI/ARDS requiring ETMV will be presented. Specific recommendations for expressing this information in a way to optimally manage uncertainty as part of a patient-centered communication process will then be detailed.
Literature Review: Outcome of Acute Lung Injury and Acute Respiratory Distress Syndrome requiring Tracheal Intubation and Mechanical Ventilation in the Intensive Care Unit

Studies reviewed are those reported in English from 2006 through 2010 providing absolute number data or survival/outcome graphs on mortality, both short- and long-term, as well as short- and long-term recovery of respiratory function (variously described as ventilator independence, breathing independently, breathing without assistance, or successful extubation) of adult patients receiving ETMV for ALI/ARDS in the ICU.

**Mortality and Recovery of Respiratory Function**

An ARDSnet trial studied the potential mortality benefit of using corticosteroids in cases of ARDS of at least 7 days duration.\(^2^6\) 30 day survival for the 180 patients enrolled in this trial was 77.2%. Of these 139 survivors, 93 (66.9%) were extubated and independent of mechanical ventilation. At 180 days there were 123 survivors (68.3%). 115 (93.5%) of these long-term survivors were breathing without assistance. A separate ARDSnet investigation reported on the use of pulmonary-artery catheters to determine central venous pressure in patients with ALI.\(^2^7\) Among the 1000 patients in this trial 775 (77.5%) were alive and 660 (85.2% of survivors) extubated and free of mechanical ventilation at 30 days. There were 731 survivors (73.1%) at 60 days. 690 (94.4%) of these long-term survivors were independent of mechanical ventilation.

A smaller trial by Meduri et. al. also looked at the use of corticosteroids in ARDS, this time at an early stage.\(^2^8\) Among the 91 patients entered into this investigation, 70 (76.9%) were alive and 57 (61.4% of survivors) breathing without assistance at 30 days. Follow-up at 1 year found 53 survivors (58.2%), all of whom were independent of mechanical ventilation.

A trial reported by the Lung Open Ventilation Study Investigators enrolled 983 patients and evaluated ventilator management strategies for ALI/ARDS.\(^2^9\) There were 673 survivors (68.5%) at 28 days with 417 of these survivors (62.0%) breathing independently.
At 75 days there were 496 survivors (50.5%). 417 of these survivors (84.1%) were breathing without assistance.

Finally, a recent study investigated the use of neuromuscular blockers in early ARDS.29 243 of 339 (71.7%) patients survived to 30 days. 189 (77.8%) of these short-term survivors were extubated and free of mechanical ventilation. There were 213 survivors (62.8% of the initial cohort) at 90 days, all of whom were breathing independently.

In summary, short-term survival reported at 28-30 days in these trials for patients with ALI/ARDS requiring ETMV in the ICU ranged from 68.5-77.5%. 62.0-85.2% of these short-term survivors were extubated and independent of mechanical ventilation. Long-term follow-up in these studies was reported at intervals ranging from 60 days to 1 year. Long-term survival was 50-73% with greater than 84% of the survivors in each study breathing independently.

**Survivor Morbidity**

Survivors of critical illness have been shown on long-term follow-up to have lower scores on scales correlating with quality of life (QOL) than age- and gender-matched members of the general population.31 ALI/ARDS survivors are at particular risk for an adverse impact on QOL. Physical factors can include pulmonary function impairment with exercise intolerance.32 Neuromuscular dysfunction persists in many ALI/ARDS ICU survivors whether due to critical illness polyneuropathy, critical illness myopathy, or a combination of these disorders.14 Neurocognitive aftereffects manifest as alterations of memory, attention, concentration, and executive function.33 Emotional disorders, most prominently anxiety, depression, and post-traumatic stress disorder (PTSD) are recognized as aftereffects of an ICU course with ALI/ARDS.34 Informal caregivers of ALI/ARDS survivors are at risk for emotional distress and lifestyle alterations for an extended period of time.35

The combined scores for mobility and energy as part of a QOL assessment for 38 ARDS survivors 6 months after hospital discharge were decreased compared to an age- and gender-matched reference population.36 These were correlated with mild impairments in pulmonary
function tests, decreased performance on a 6 minute walk test, and persistent radiographic
abnormalities.

The Canadian Critical Care Trials Group identified a cohort of 109 ARDS survivors
and reported on their functional outcomes in two sequential articles. At one year
persistent functional limitations and impaired quality of life indices were attributed to
muscle weakness and wasting. 49% of these patients had returned to work. 5-year
follow-up of 64 survivors documented improved but persistent impairment in exercise
capability and quality of life as well as continued increased costs and use of health care
services.

ICU-acquired weakness or critical illness neuromyopathy occurs in nearly 50% of patients
with sepsis who require mechanical ventilation for longer than 7 days and can persist up to 5
years. Evidence of physical function deficits related to ICU-acquired neuromyopathy occurred in
34.7% of ARDS survivors ventilated for 7 days or more.

Deficits in general intellectual functioning, processing speed, spatial skills, and executive
function were cognitive effects noted in 67.6% of 74 ARDS survivors at hospital discharge.
These findings persisted in 39.2% of the patients at one year and 35.1% at two years post-
discharge.

25 of 61 (41.0%) ARDS survivors reported moderate to severe symptoms of depression
when interviewed 6-48 months after hospital discharge. 51% of the group of 64 ALI/ARDS
survivors reported by the Canadian Critical Care Trials Group had at least one episode of
physician-diagnosed anxiety, depression, or both in the 5-year interval after hospital discharge.
In another report, 72.7% of 33 ARDS survivors reported multiple traumatic memories while 27.3%
of this cohort was diagnosed with PTSD.

47 informal caregivers of ARDS survivors evaluated at 2 years post-discharge evidenced
increased (compared to age- and gender-matched norms) emotional distress and alteration of
lifestyle. These findings were more likely when evidence of emotional distress was also found in
the survivor. Family mental health problems were reported in 27% of the cases from the
Canadian Critical Care Trials Group 5-year follow-up study.
In summary, ALI/ARDS survivors are at risk for physical, neurocognitive, and psychological aftereffects for several months to years after the ICU experience. Implications include an adverse impact on the ability to carry out activities of daily living, perform executive functions, demonstrate emotional well-being, and maintain employment status.
Managing Uncertainty

The case scenario being addressed presents an example of an early phase of a critical illness. A challenge for the palliative care practitioner working in an integrative or consultative relationship with intensive care colleagues is to establish an initial framework for patient-centered communication. Addressing and managing uncertainty with the patient's family is a primary focus of this effort.

The goal of the practitioner is to approach the management of uncertainty using a structure that fosters coping of the family while acknowledging that in terms of the delivery and content of these discussions "one size does not fit all". Oftentimes practitioners feel compelled to reduce uncertainty. However, uncertainty is neither inherently positive nor negative. Some families will prefer to sustain uncertainty as a source of hope while others will experience uncertainty as anxiety-provoking. Moreover, practitioners habitually provide more information and education as the best strategy for managing uncertainty. However, more information given to family members does not necessarily facilitate informed decision-making nor support coping. In some cases, more information may be detrimental if the amount or type of information exceeds an individual's ability to process it. It is paramount that communication regarding uncertainty includes a negotiation of what the individual perceives she needs to know in relation to her and to her loved one's priorities.

When communicating about prognostic uncertainty, the delivery and content of information are of equal importance. An accurate portrayal of the prognosis may help frame the uncertainties of the situation by openly acknowledging them and hopefully correcting preconceived notions that lead to excessively positive or negative expectations regarding outcome. However, the "how and what" of prognostication that a practitioner presents again requires an individualized approach. Some literature suggests that the presentation of statistical information as natural frequencies allows the formulation and expression of a prognostic assessment appropriate for the stage of the illness while other literature indicates that surrogates' understanding or estimates of prognosis do not differ when conveyed numerically versus qualitatively.
…..“is critically ill, this means there is uncertainty about what will happen. If you take 100 people in this situation about 65 people would survive to leave the hospital. Most of these, ¾, would be breathing on their own. Out of these 65 people who survive, about another 10-15 will die during the next year. Almost all of these longer term survivors will be breathing on their own” (numerical)…..

…..“there is a very real chance of survival but we cannot be certain about the outcome” (qualitative)…..

Moreover, surrogate decision-makers desire a discussion that includes quality of life indicators in addition to survival estimates.50 Prognostic assessment should also include an introduction to outcomes other than mortality and, in this case scenario, ventilator independence:

…..“we also know from experience that many people who have gone through this type of serious illness will have effects on the life they are able to lead afterwards. Physical weakness and ongoing medical problems can continue for months or even years. The trauma to a person of being this sick can cause emotional distress in the form of depression or ongoing stress and anxiety. This will also be emotionally stressful for you both now and with the challenges that can happen in the future”…..

While individual preferences for the type and content of information must be considered, avoidance of a discussion of potential outcomes and their relative risks for fear of extinguishing hope is misguided. The majority of physicians avoid discussing the prognosis when it is uncertain due to this fear.51,52,53 Most families desire prognostic information and are aware that irreducible uncertainty is present in clinical scenarios such as this.20 In fact, surrogate decision-makers’ estimate of prognosis is usually more optimistic than that of the physician and based on more variables than just the medical facts.47,54 Hope is a dynamic construct. It is sought from sources other than the physician and is engendered differently by context, time and individual.46,52

A useful strategy for managing uncertainty is to contrast the hope and worry aspects of reacting to the clinical situation. This dual agenda can be encouraged but not imposed as a framework for both understanding cognitively and coping emotionally with the inherent uncertainties already outlined.55,56 It can be used as a tool to promote prognostic awareness and
coping. Uncertainty can be presented as a joint understanding between the care team and family creating the foundation for a relationship that will be supportive and foster shared decision-making:

"We hope that a full recovery can happen.....however, we worry that surviving with ongoing problems that affect his life – or dying – are no less real possibilities. The ICU team will use all of their medical knowledge and skill to help him and hope for a good outcome while not knowing for sure whether it will work. You have the worry of what will happen to someone you care about so much, with no definite answers".....

Fostering a therapeutic relationship that leads to patient-centered communication is an essential component of acknowledging and addressing the emotional response to uncertainty. Emphasizing nonabandonment is recommended as an approach during these early discussions:57

"no matter what happens we will always do our best to make sure that he does not suffer while we are trying to make him better.....will try to help you by communicating on a regular basis; continuing to ask about the type and amount of information you prefer to hear, and do our best to provide it.....overall, we can promise to keep you informed but cannot resolve the uncertainties we have talked about.....will be here for you and call upon any resources we have available to help you cope with balancing the hopes and worries".....

Surrogate decision-makers may exhibit ambivalence or resistance to addressing the uncertainty inherent in their loved one’s clinical condition. Techniques used in motivational interviewing may prove helpful in managing uncertainty in this context. Resisting the “righting reflex” – the urge to address resistance by education or correcting perceptions – is a basic principle of this strategy.58 Instead, motivational interviewing encourages exploration of an individual’s motivations that are driving the resistance. Tools such as reflective and summative statements convey empathy, emphasize listening, and explore values and emotions that can lead to resolution of ambivalence and foster shared decision-making:
....."it seems you have a good understanding of how serious the situation is but also

frightened about what might happen and how long this might take. Do I have it right?".....
Conclusion

Outcome predictions for a person with ALI/ARDS requiring ETMV in the ICU are fraught with uncertainty. While the application of current principles for management and therapeutics offers a realistic hope for recovery of respiratory function and premorbid functional status, death or survival with significant aftereffects also occur in similar proportions. Acknowledging this uncertainty, in our scenario with the representative of an incapacitated person, is an integral component of patient-centered communication. Managing uncertainty involves addressing the cognitive and affective aspects of the response to the indefinite outcome expectations generated by a situation such as this.

There are limitations to the application of the literature review reported here to formulating a prognostic assessment. The studies analyzed present data from heterogeneous groups of patients with various precipitating events leading to ALI/ARDS and receiving different interventions. The studies in the literature review report data from the experimental and control groups in investigations of issues related to different techniques and technologies with regards to the application of ETMV for patients with ALI/ARDS. These issues are of great importance in promoting the best possible outcomes for ALI/ARDS patients receiving ETMV. The literature review used in this report allows the accumulation of a sizeable sample and a statement of a general outcome trend with some confidence but limits the ability to accurately predict outcome for an individual patient.

Analyzing the outcome possibilities for an incapacitated person with ALI/ARDS requiring ETMV in an ICU and addressing the uncertainties inherent in them with family is an example of patient-centered communication that has the potential to alleviate short- and long-term distress and improve the quality of a shared-decision making process. Managing uncertainty begins with skillfully expressing a carefully formulated prognostic assessment that includes the outcomes of highest probability and greatest importance with regards to survival and quality of life. Although there are no clear best practices for discussing uncertainty, uncertainty is inherent in the experience of families with loved ones’ in the ICU. Communicating uncertainty does not extinguish hope for most families. A discussion of uncertainty needs to be tailored to the needs
of the individual family. Applying motivational interviewing skills and the “hope and worry”
technique will aid in supporting family members as they cope with uncertainty and decision-
making for their loved one.
Author Disclosure Statement

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