

Ethical Dilemmas in the Intensive Care Unit

Treating Pain and Symptoms in Noncommunicative Patients at End of Life

Kimberly Chow, RN, ANP-BC

A large percentage of patient deaths occur during or shortly after an intensive care unit admission. Death and dying is not a new phenomenon occurring in these units; the very nature of this level of care is that patients are at their sickest and most acute phases of illness. The difference lies with advances in medical technology and pharmacologic therapies that have the potential to extend life but also fuel the fire of an already death-denying culture. As critical care teams are confronted with the increasing demands of this patient population, ethics and palliative care consultants are being called upon to assist with frequently encountered ethical and moral dilemmas. A case is presented that highlights 2 common ethical challenges seen in the intensive care unit: symptom management in the noncommunicative patient and medical futility. Steps to address concerns of nurses and outcomes are discussed.

KEY WORDS

bioethics, ICU, nursing, palliative care

Studies have shown that approximately 20% of patient deaths occur during or shortly after an intensive care unit (ICU) admission. This represents more than 500 000 patients each year who die in or after an ICU stay either with a “do not resuscitate” order in place or with full resuscitation efforts by medical and nursing staff.¹

Death and dying is not a new phenomenon occurring in ICUs; the very nature of this level of care is that patients are at their sickest and most acute phases of illness. The difference lies with advances in medical technology and pharmacologic therapies that have the potential to extend life but also fuel the fire of an already death-denying culture. As a result, prognostication—an already complex calculation—has become more difficult, impacting communication and patient care. Patients and families are now being faced with numerous decisions at a time when outcomes are uncertain and stakes are high.¹

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As critical care teams are confronted with the increasing demands of this patient population, ethics and palliative care consultants are being called upon to assist with a host of frequently encountered ethical dilemmas. It is also because of this increased demand that ICUs have become a focus of interest for many hospital-based palliative care teams. Different models have been attempted, including consultative and integrative approaches,² with the goal of improving communication, symptom management, and psychosocial support for these patients and their families who are at risk for high symptom burden and emotional distress at end of life (EOL).

Another vital component of an ethics and palliative care consultation is to provide support for staff members who accompany these critically ill patients through their journey of illness and suffering. Nurses, in particular, whose daily role at the bedside is as caregiver and patient advocate, have a high risk for burnout in cases thought to be futile. Other key sources of occupational stress leading to burnout that have been identified include a difficult workload, conflict with colleagues, inadequate staffing, emotional demands of patients and family members, ethical concerns surrounding life-sustaining therapies, and exposure to death and dying.³ These are issues that most nurses can identify with, and many have encountered at 1 or multiple points in their career. At a major cancer center, feelings of emotional exhaustion permeated the ICU from the increasing number of young adult patients admitted for acute issues that were irreversible despite prolonged, aggressive ICU management. The following case study represents one of many cases that highlight some of the ethical challenges faced in ICU settings by nurses and other team members.

CASE: SYMPTOM MANAGEMENT FOR A NONCOMMUNICATIVE WOMAN DYING IN THE ICU

L.J. was a 37-year-old woman with recurrent cutaneous T-cell lymphoma initially diagnosed 8 years prior. At that time, she was treated with multiple lines of chemotherapy and stem cell transplant, which successfully brought her into remission. She lived disease free with her husband and



child for 6 years. Shortly after her child's 10th birthday, L.J. was told she had recurrent disease when she presented with new lesions and persistent fevers. After reinitiating chemotherapy, she was admitted to the hospital for neutropenic fevers that eventually led to septic shock requiring transfer to the ICU. In the ICU, despite multiple attempts to reverse the infectious process, L.J.'s condition worsened, and she developed multisystem organ failure. She remained intubated in the ICU for weeks—requiring high levels of daily care including dressing changes for her multiple cutaneous lesions. This would cause grimacing and agitation documented by the nursing staff. In the early days of her ICU admission, L.J. was placed on continuous infusions of opioids and sedatives and prior to dressing changes would receive bolus doses as needed.

As L.J. continued to receive aggressive interventions in the ICU without improvements in her clinical condition or mental status, the palliative care service was consulted to assist with goals-of-care discussions. The oncology team, ICU team, and palliative care service were all in agreement that the patient's condition was irreversible, and she would likely not survive this ICU admission. Multiple meetings were held with L.J.'s husband, who was her designated health care agent, and other family members. Ultimately, L.J.'s husband understood the critical nature of L.J.'s condition and was agreeable not to attempt resuscitation should her condition worsen; however, he was not amenable to withholding or withdrawing care stating, "I can't give up on her. I'm still hoping for a miracle." An order to allow a natural death was placed in the chart, and ongoing support and daily updates were provided to L.J.'s husband. As L.J.'s condition continued to deteriorate, so did her mental status, and she was no longer exhibiting nonverbal cues of pain or agitation. The ICU team, in a final attempt to awaken L.J., slowly tapered her sedation, including opioids, without success. Despite documenting the absence of pain and agitation in L.J.'s chart using validated scales, the nurses still felt that it was their obligation to provide pain medication prior to dressing changes, as this had always been a source of extreme pain for her. Because of her tenuous blood pressure, the ICU residents and fellows on call overnight did not feel comfortable giving L.J. medications that could potentially lower her blood pressure further. The evening L.J. died, she was given a very low dose of opioid twice, spaced 3 hours apart when she had previously required almost 4 times that amount for pain management.

ASSESSING AND TREATING PAIN IN THE NONVERBAL PATIENT

In this particular case, the nurses felt there was a level of suffering that L.J. likely experienced that could not have been documented using validated pain and agitation scores. The pain being described was witnessed directly

by the eyes of the nurses performing daily care and dressing changes at the bedside. In their attempts to advocate for patient comfort and dignity at EOL, the ICU nurses felt their concerns were being dismissed by team members. Meanwhile, the ICU fellow on call worried that giving opioids in the setting of hypotension and no documented evidence of pain could potentially hasten L.J.'s death. This calls attention to one of many challenges in the ICU, which is the assessment and management of symptoms in nonverbal, critically ill patients.

Pain, as well as other symptoms, has been well documented in the ICU, so much so that guidelines⁴ have been published for assessment and ongoing management. The pain, agitation, and delirium practice guidelines for adult critically ill patients are supported by research that has identified the presence of pain in ICU patients as high as 50% at rest. Incidence increased up to 80% during the common care procedures performed in the ICU, including turning, tracheal suctioning, wound care, and placement and removal of drains and central lines. For the patients who survived ICU admission, pain was linked to greater risks for posttraumatic stress disorder when uncontrolled and reduced duration of mechanical ventilation, ICU-acquired infections, and length of stay when well controlled. For patients who are cognitively impaired, symptom experience remains less understood.^{4,5}

The Improving Palliative Care in the ICU Project⁴ has addressed relieving common distressing symptoms of pain, dyspnea, and thirst in the ICU. Evaluation of current standards and evidence supports that self-report of pain and other symptoms remains the criterion standard of assessment. When patients are noncommunicative, validated behavioral symptom assessment scores using the Behavior Pain Scale or the Critical Care Pain Observation Tool have been helpful in understanding pain levels in adult patients without brain injury. Findings of these tools, however, are still an indirect representation of a patient's true perception of pain.

Proxy assessment by either family or clinicians when self-report and behavioral assessment scores cannot be used remains somewhat controversial. Although family members have been found to overestimate pain, data suggest that report by proxy can help identify normal sources of distress for the patient and their past response to management. Clinicians should also use their experience and judgment to identify potential sources of discomfort for the patient and treat symptoms appropriately using evidence-based approaches to care.⁴

Pain and symptoms should be routinely monitored and documented. If pain is thought to be present, initiating analgesic trials is recommended using low doses of fast-acting opioids to monitor for improvement of symptoms or pain-related behaviors.^{4,6} Putting a plan of action in place and discussing this with family and bedside clinicians are essential to ensure that all parties have a clear understanding of how

symptoms will be managed. This also provides the opportunity for all members of the care team to voice any questions or concerns that may be present. In L.J.'s case, the nurses reported that she previously had severe pain with dressing changes requiring premedication and postmedication with opioids, which should have prompted an evaluation by the care provider. The nurses' concerns should have also been sufficient reason to provide an analgesic regimen that took into consideration what was needed in the past to tolerate a similar level of care.

Despite recommended guidelines, these methods of evaluation when the patient cannot self-report pain or distress may not necessarily alleviate provider concerns about secondary effects of opioids. Secondary effects can include hypotension, sedation, respiratory depression, delirium, and agitation.⁴ Treating pain in the presence of physiologic instability remains a concern for many ICU clinicians, especially those in training that may not have been exposed to the full spectrum of ICU patients and outcomes. Regardless, fear of physiologic instability should never prevent clinicians from assessing and treating pain in this patient population vulnerable to suffering at EOL. Treatment of pain is not limited to opioids, and all available ICU resources must be utilized to optimize comfort. Feelings of uncertainty should prompt any clinician to seek advice from colleagues with more experience, supervisors, and/or from palliative care specialists.

MEDICAL FUTILITY

Another key ethical dilemma was the feeling of providing futile care for L.J.. "Medical futility" is a complex concept as there is no universally accepted definition. Some view care as being futile if the goals of treatment are not achievable or when a seriously ill patient has an extremely low likelihood of meaningful recovery.^{1,3} A study by Sibbald et al⁷ used semistructured interviews with physicians, nurses, and respiratory therapists in an ICU to develop a working definition of "futility" that was ultimately summarized as using considerable resources without a reasonable hope for recovery to a state of relative independence and interaction with the environment. When participants were asked why medically futile care was offered and provided, the 3 most common themes were demands from family or decision makers, lack of skilled and timely communication, and lack of consensus among team members. Although each theme can be viewed separately, it is truly the blending of all 3 that creates the perfect storm of difficult decision making in emotionally charged conditions.

Health care providers often find themselves in critical situations where choice of treatment seems to lie in the hands of the patient's family or surrogate decision maker(s). In many of these cases, individuals dictate care without any previous health care knowledge and insist on treatments that may or may not be supported by the

medical teams involved. In certain states, an agreement between 2 attending physicians that a case is "medically futile" may be enough to legally cease unnecessary, sometimes harmful, interventions. In the states that do not have this legal support, families are left with the burden of making choices based on their understanding of an extremely complex situation. Although decisions to pursue futile care against medical advice may be driven by cultural or religious beliefs and lack of critical care knowledge,⁷ one must not forget that even with a knowledgeable decision maker, sometimes choices are made in hopes of having a few more moments with their loved one. L.J.'s husband verbalized understanding of his wife's poor prognosis and did not want to see her suffer, as demonstrated by his agreement to place the "do not resuscitate" order. Regardless, his desires to continue the current measures and escalate care to a certain point were largely driven by his emotional dedication to his wife. This aspect of decision making cannot be ignored.

Gaps in understanding may be filled by initiating clear and timely communication with patients and families throughout the disease trajectory. Unfortunately, this does not happen routinely, and critical care teams are tasked with breaking bad news to patients and family members in a crisis situation. Communication is also essential between different team members to ensure that a unified message is being presented to the patient and family. This is especially crucial when a consensus on the plan of care has not been reached between providers, including the many consulting teams who can fall into a pattern of focusing on specific organ systems rather than the total patient. Differing messages from care teams can contribute to the patient's and family's feelings of mistrust for the medical system and create barriers to communication later in the ICU course. Frequent discussions and family meetings should be held with all involved parties to outline different perspectives that avoid medical jargon.

Whether clear and timely conversations could have prevented a prolonged death in the ICU for L.J. is unclear; however, dialogue should have been initiated between the ICU nurses and medical team caring for this young patient. Unfortunately, the ethics and palliative care teams were consulted late in the case when the focus of concern was primarily L.J.'s goals of care. The case also happened to take place at the beginning of an academic year when new medical residents and fellows were just becoming oriented to the hospital system. Because of this, steps were not taken to communicate with the nursing staff to get their daily perspective on patient care.

THE ROLE OF ETHICS AND PALLIATIVE CARE

In a health care system where "medical futility" lacks clear definition and consistency in legal support for providers,



how can the large number of caregivers experiencing professional burnout and moral distress be appropriately addressed?

In many of these challenging cases, ethics and palliative care teams come together to provide the staff working with patients day in and day out with a new care perspective. The nature of bioethics is to approach individual patient cases by looking not just at what can be done, but rather what should be done.¹ Ethics consultants are often brought on board in cases where there is moral dilemma or conflicting values about patient autonomy, surrogate decision making, goals of care, and transitions to EOL care.⁸ Palliative care teams may be called upon for similar reasons, and their presence is growing rapidly as health care professionals and patients are benefiting from the added layer of physical, spiritual, and psychosocial support provided at various points along the disease trajectory. Palliative care specialists can provide guidance with difficult and complex treatment choices as well as help patients and families navigate the health care system.⁹ The 2 services have been known to work synergistically with each other to alleviate patient and family conflicts with care teams and conflicts between teams and also to provide support for staff working in an environment prone to ethical dilemmas and moral distress.

In L.J.'s case, all medical teams were on the same page about goals of care and treatment options moving forward. What was lost was the nurse's voice and concerns. The ICU nurses felt ethically challenged by this case for multiple reasons and brought this to the attention of the ethics committee and their nurse leader. As a result, a debriefing session was arranged, and members of the ethics, social work, and palliative care service were asked to facilitate. Also in attendance were multiple critical care fellows and residents, attending physicians, and chaplaincy. With strong backing by nursing leadership and the weight of the ethics consultant indicating institutional support, the nurses were given a platform to verbalize their distress with not just caring for L.J., but also the multitude of patients, young and old, who enter the ICU and remain there until death.

Some of the key challenges identified by the staff included feelings of frustration, lack of support, and the minimizing of their concerns when advocating for patient dignity and comfort at EOL. The ICU nurses bravely voiced their emotional distress about having to care for an increasing number of patients at EOL with very little support and communication from other team members. More specific to this case, nurses felt strongly that if they were obligated to provide care that they believed was "futile" to patients like L.J., they should at least be reassured that the resources necessary to alleviate the pain and suffering they had witnessed first hand would be made available. The ethics consultant played a vital role in validating many

of the nurses' concerns and reinforced that relieving patient suffering regardless of code status or goals of care is both an ethical and moral obligation of all health care providers.

RESOLVING ETHICAL DILEMMAS AND MORAL DISTRESS

As a response to staff distress, changes have been made to the ICU's approach to caring for the seriously ill with high mortality risk. Whenever a case is deemed challenging by staff members, the ICU nurse leader and social worker are notified, and a debriefing session is convened. This may be held before or after a patient's death. The meeting is scheduled to include the attending physician(s) involved in the case, palliative care, ethics, medical fellows and residents, and nurses. The case is reviewed with weigh-in from multiple parties to assess what was done, what should have been done, and how care can be improved.

At the nursing level, changes in documentation practices have been initiated to compliment the validated pain and agitation scores already in place. Nurses are now more aware of documenting additional information on past and present pain findings to support the need for optimizing patient's symptoms. In addition, the ICU nurse leader and palliative care nurse practitioner were awarded grant funding to support the designation of 4 palliative care nurse champions who will complete the End-of-Life Nursing Education Consortium critical care train-the-trainer course and develop training programs for all full-time ICU nurses to complete.

As 1 in 5 deaths will occur in or shortly after an ICU admission,¹ ethics and palliative care teams must continue to work side-by-side, using their individual strengths and expertise to provide ongoing support for this extremely vulnerable patient population. Support cannot stop with patients and family members and must also be offered to providers at every level who have willingly taken on the responsibility of accompanying patients through their journey with illness.

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