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Conflicts in Goals of Care at the End of Life

Are Aggressive Life-Prolonging Interventions and a "Good Death" Compatible?

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Recent medical literature reports increased utilization of the intensive care unit (ICU) at the end of life, even for patients who are considered terminally ill, and the overall ICU adult mortality rate ranges from 10% to 29%. Therefore, ICU nurses require a level of comfort in caring for patients and families at this vulnerable time. At times, ongoing aggressive life-prolonging interventions for a terminally ill patient can create ethical conflicts and moral distress for nurses. This leads to the question: Can this level of treatment be compatible with a ''good death?'' Medical recommendations are made based on the patient's goals of care, appropriate treatment options, and associated benefits and burdens. How then should nurses respond when a patient or family does not agree with these medical recommendations? Through a case study, this article explores the moral and ethical conflicts that often occur in the ICU setting at end of life and aid to empower the ICU nurse to care for patients in a way that honors the patient's wishes and maintains a healthy nurse-patient relationship.

KEY WORDS

ethics, goals of care, good death, palliative care

The intensive care unit (ICU) is a site of care that can create great uncertainty for patients with a poor or terminal prognosis and their families. The usual culture of an ICU is one of restoring homeostasis with rapid responses and aggressive measures to help patients recover. But when a patient presents with what will likely be a terminal situation regardless of medical intervention, many providers want to support the patient and family into accepting a peaceful end-of-life experience and foregoing life-prolonging treatments. This can lead to ethical conflicts when clinicians and patients/families do not agree on the appropriate course of care. A case study will be used to explore the nebulous and personal definition of a "good death" and how clinicians can be confident knowing they provided the very best patient care at the end of life within an ethical framework.

> L.S., a 38-year-old man with stage IV colorectal cancer was admitted to the ICU with dehydration and acute renal failure following a fourth cycle of salvage chemotherapy. He had previously been treated with surgical resection at the time of diagnosis 3 years prior, radiation therapy, and multiple courses of chemotherapy. Over the past 36 hours, however, he had become acutely ill with anorexia, nausea and vomiting, and altered mental status with a creatinine of 3.8 mg/mL. He requires vasopressor support, intravenous antibiotics, and bilevel positive airway pressure support. His oncologist reports in his admission note that L.S. had not tolerated the salvage therapy well, his performance status had been worsening (Eastern Cooperative Oncology Group performance status 3), and he had lost 25 lb over the past 3 months. L.S. is obtunded now and without obvious distress or discomfort. He has a wife, 3 young children under 12 years, who were all in attendance with their community pastor at the time of admission and made it clear they wanted "everything done to save him."
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> Twenty-four hours after admission to the ICU, L.S. continues to decline. He attempts to wake up and communicate with his family, but he is very lethargic and agitated. He is hemodynamically unstable and requiring blood transfusions. During multidisciplinary rounds, the primary ICU nurse requests a palliative care consult to help support the family and "make them understand L.S. is dying." A family meeting is held with all family and their pastor to review the current status, a poor prognosis for survival, and recommendations to shift to comfort-directed care. It has been determined that none of L.S.'s conditions are reversible, and his decline is due to the progression of his terminal cancer. His wife wants to keep L.S. a full code blue and reports L.S. told her to always "do everything you can to keep me alive for my kids." She shares that L.S. has been told by his oncologist that he is terminally ill, and the

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oncologist has recommended hospice to him several times, but L.S. has refused. He has told his family he wants to "go down kicking," and she feels it is his way of showing his family he did all he could to live for them. She feels obligated to honor his wishes.

After 5 days in the ICU, L.S. continues to decline overall. He is now less responsive, requiring increasing vasopressor support, and has been intubated. He is having frequent cardiac arrhythmias. The staff is growing resentful of the wife for not agreeing to shift his goals of treatment to comfort despite the medical team's advice. In fact, most of the staff request to not be assigned to him because they feel they are inflicting harm to him. During the night shift of day 5, L.S. goes into cardiac arrest, prompting a code blue to be called. Four rounds of advanced cardiac life support are provided, and he does not respond. The chaplain and charge nurse are with the wife and children to keep them updated and supported. The attending physician comes to tell her he wishes to cease attempts at resuscitation because L.S. is not responding to the treatment, and the wife agrees. L.S. goes into asystole almost immediately after the cardiopulmonary resuscitation (CPR) attempts are stopped.

After L.S. is pronounced, the family is appropriately grieving, but the wife states to the nurse she feels comfortable that she followed his wishes and "gave him every chance to live." The next morning at shift change, the nurses discuss the events of his arrest and case. Many staff are angry that "she put him through that." There is a great deal of sadness and frustration expressed by all of the staff surrounding the case.

Because of the dissention among staff, the nurse manager schedules a debriefing the following morning for the staff. A facilitator from the hospital's Employee Assistance Program and the unit chaplain lead the discussion to allow the staff to verbalize their feelings and emotions. By the conclusion of the session, everyone felt they at least understood the choices of the patient and family even if they did not personally agree with them. All agreed that they wanted more education and support surrounding difficult cases and ways to help themselves cope with providing care at the end of life.

According to the nursing and medical literature, most patients with advanced illness state they would want to die at home in the presence of family and with a focus on their comfort; however, only 25% of those patients will die at home, 25% in a nursing home, and the remainder will die in an acute care setting.[1,2] More specifically, more than one-third of patients with advanced cancer in the United States spend their final days in the ICU receiving life-prolonging measures including ventilator support, artificial nutrition, and CPR.[3] Less than 50% of these patients with cancer will receive hospice services, and most that do receive services for only a matter of days.[1,4] There are many factors influencing these statistics including the patient's age, social situation, religious beliefs, and if he/she has had conversations about his/her end-of-life preferences and wishes.

It is reported that up to one-fifth of patients with metastatic cancer receive chemotherapy in the last 14 days of life.[1,5,6] With rising health care costs, this trend is receiving more attention, and efforts are being made to decrease this rate when there is no documented benefit for the patient. Oncologists are often criticized for continuing this aggressive treatment when the patient is nearing the end of his/her life, but many times this is a patient choice and desire to "fight to the end."[5]

When the patients and/or the medical specialists want to continue all efforts to prolong life, even in a terminal situation, many conflicts can arise within and for the ICU team. End-of-life care and the continuation (or discontinuation) of aggressive measures have been cited as 2 of the most prevalent conflicts in the ICU that lead to staff burnout and poor quality of care. Intensive care unit nurses specifically are faced with a challenge of maintaining treatment delivery and providing honest communication and emotional support to the family.[7] This can lead to an internal struggle for the nurse who may be feeling he/she is hurting versus helping the patient. This type of conflict can lead to feelings of powerlessness and will ultimately lead to less than optimal health care delivery.[8,9] The term "moral distress" has been used to describe this human response, and it has been shown to lead to staff burnout, high staff turnover, and compromised patient care.[10] Conflicts and distrust between nurse and physician can also arise if there is a feeling that the patient and family have not been fully and accurately informed of the terminal prognosis and perhaps have been given false hope. When this occurs, nurses may feel the patient and family are not making informed choices about their goals of treatment when they choose to seek end-of-life care in an ICU versus choosing a more peaceful setting for their care.[5]

ETHICAL PRINCIPLES

Difficult cases, such as the one presented here, occur daily throughout all health care settings. As we explore each of the ethical principles, autonomy, beneficence, nonmaleficence, and justice, it is important to note that neither principle is more important than the other.[11] For example, a patient's right to self-determination (autonomy) does not carry more influence than the medical team's responsibility to "do no harm" (nonmaleficence).[11] While we rely on these principles to help sort out ethical conflicts, there is no guarantee that they can provide clear answers. That is largely because of the fact that each case and subsequent dilemmas stem from the patient's unique culture, values, beliefs, and personal preferences; therefore, there is no uniform solution to apply to all cases. Ethical principles must always be applied within the patient's personal context, not that of the physician or nurse caring for the patient. Practitioners must be sure to not interject their opinion on how the case should be managed; instead, they must adhere to standards of health care appropriate for the situation. An approach cited in the literature, known as the "4 Box Model," may serve as a useful guide to clinicians when ethical conflicts arise. This model encourages the utilization of the elements of medical considerations (diagnosis, prognosis), patient preferences, quality of life, and contextual features (conflicts of interest, legal issues, etc) when examining a complex medical case to help organize priorities and facts of a case. The emphasis remains intact that no one element holds more weight than another.[11]

AUTONOMY

Clearly, in this case, the medical team placed significant weight on this patient's previously stated wishes and seemingly more weight than to that of the remaining ethical principles. Because the literature is clear that the likelihood of benefit of CPR in L.S.'s case was low with increased risk of harm, one could certainly argue that to offer this treatment would be nonbeneficial if not medically futile.[12] However, states have specific laws related to CPR and definitions of medical futility. These may even differ among health care institutions within the same state. The nurse must be cognizant of the laws pertinent to the where he/she practices and acknowledge how these laws impact a medical provider's practice.

While the ethical principle of autonomy seeks to support a patient's right to self-determination through informed consent or refusal, it does not demand that the physician provide treatments that are deemed more harmful or not medically appropriate.[13] Why, then, don't physicians make this decision unilaterally more often? Perhaps, it is fear of litigation from the surviving family. Even if the doctor would win such a lawsuit, he/she will still be subjected to the legal expense of judicial review. There is also potentially the fear of a fractured relationship with the patient and the family. Physicians would certainly prefer to come to a consensus opinion on such important decisions. It could also be that the physician recognizes how deeply personal these decisions are and chooses to support patient wishes even if he/she does not agree. When consensus cannot be reached, some hospital-based teams have the option of ethics committee consultation to evaluate the case, determine the medical standard of care, and either support physician decisions or make alternative recommendations. In the case of L.S., an ethics committee was not available, and the decisions had to be made between the health care team and the patient/family.

BENEFICENCE

This ethical principle demands that the medical team "always act in the best interest of the patient."[13] The nurses in this case no longer felt further life-prolonging aggressive medical interventions were in the best interest of L.S. because of his terminal illness. They also felt it would create suffering for him at the end of his life.

When members of the medical team feel such conflict, it is important to note that life-prolonging medical treatments such as CPR, defibrillation, intubation with mechanical ventilation, and prolonged artificial nutrition are "ethically neutral."[11] That means, independently, they are neither good nor bad. It is only in the context of a particular patient scenario that we can define these treatments as either "beneficial" or "harmful."[11] While the nursing team felt treatments were nonbeneficial, the patient and family clearly and consistently expressed their perceived value even after receiving full information from the medical team. This may be a good time for the nurse to ask himself/herself, "Whose life, and subsequent death, is this?" If the patient and family are fully informed and, based on their values and preferences, this is what they want this moment to look like, why is the nurse still so conflicted?

NONMALEFICENCE

Nonmaleficence is based on the Hippocratic oath of "do no harm."[11] It was clear that the nurses felt they were harming L.S. by continuing to pursue life-prolonging treatment, not only by potential physical injury but also by not facilitating a more peaceful, dignified death. As for the concern for physical injury, that is a valid concern. There are physical injuries that can occur from CPR including rib fractures, internal trauma, or neurologic injury from hypotension or hypoxia. If despite this knowledge the patient or family still wants certain treatment and it is still being offered, then there is no ethical dilemma with respect to the plan of care. However, it is hard to be the bedside nurse who actually has to perform the chest compressions when the patient codes.

In the same way that doctors are not obligated to perform medical treatments that they find unethical and can transfer the patient to another provider, so too the nurse should not be forced to perform care that he/she deems unethical. Once this conflict is identified, the nurse needs to communicate this to his/her supervisor so the patient can be assigned to another nurse.

The other issue is the nurse's desire to facilitate a peaceful, dignified death for the patient. There is no universally accepted definition of a "good death," and there is no algorithm to follow in order to help a patient achieve it. Many articles have explored this topic and report that there are consistent themes to describe a good death, including (1) pain and symptom management, (2) clear decision making, (3) preparation for death, (4) completion, (5) contributing to others, and (6) affirmation of the whole person, but what becomes clear is that each patient's perception of a "good death" is deeply personal and is influenced by cultural and spiritual beliefs as well as past experiences with loss.[14] Essentially, patients do not define their end-of-life preferences in the same way, nor do physicians, nurses, or families.[15]

If this is what is driving the conflict for the nurse, the nurse again needs to take a step back and reflect. If we accept that the definition of a "good death" is deeply personal, then it is not for the nurse to oppose those choices simply because the patient is not dying the way the nurse thinks that they should.[15]

JUSTICE

The ethical principle of justice refers to the need to protect vulnerable populations and observe fair allocation of precious medical resources. With the rising cost of health care and hospital financial consequences of health care reform, it is imperative that the primary responsibility of this principle is to the patient, not the hospital's financial well-being.[16] That being said, this is a real issue with significant ramifications for our society. One could argue in L.S.'s case that there was perhaps injustice in the prolonged use of an ICU bed and the increased cost of aggressive care that would not change the outcome.

Unfortunately, this conflict is harder to resolve. Currently, the focus is more on the patient and family goals, and if that goal is to pursue life-prolonging measures, then that level of care is provided regardless of cost. These types of decisions should never be made at the bedside but at a state or national level. This will likely be a topic of much debate nationally as we move forward in the new era of health care reform.[11]

CAREGIVER AND FAMILY DYNAMICS

It is well documented in the literature that disorders such as anxiety, posttraumatic stress disorder, and depression are issues for families or caregivers who experience a death in the ICU setting.[17,18] What is also recognized is that family involved in any high-risk illness in the ICU or in end-of-life decision making begins experiencing distressing feelings or this anxiety in the midst of the care event. In the case of L.S., it was clear that his wife was struggling between her own anticipatory grief and the need to protect herself and her children and her need to honor her husband's stated wishes. She acknowledged to the team that because of her helpless feelings related to his disease and prognosis, she felt this was the last element of control that she maintained. It is not uncommon for nurses and team members to mistakenly see this as "selfish" and not as a coping strategy for the family. It seemed to the team that she perhaps did not understand the terminal nature of his illness and the recommended path of a comfort-directed plan of care, which then led to feelings of frustration and hostility toward her by the staff. Many people look at this as denial, but in fact it is a common way of coping or protecting one's self from the burden that is upon them.

Identifying and then resolving conflict among staff and family can be challenging. There are several different conflict resolution strategies reported in the literature including dominating, obliging, avoiding, compromising, and integrating. The nursing literature reports that nurses predominantly use avoidance as their strategy. In the case presented here, this avoidance was toward the patient's family and could potentially lead to the family feeling isolated at an extremely vulnerable time. Avoidance can also be seen as a protective mechanism for the staff to decrease the internal struggles they are going through related to a patient care plan.[19]

To decrease stress and conflict among both parties, the literature supports utilizing open and frequent communication, family meetings, and shared decision making and involving palliative care or other support services as mechanisms to prevent or reduce the incidence of posttraumatic stress disorder or long-term depression.[17] These methods of involving family from the outset of the critical illness can help them see the decline as a process or trajectory and prepare them for possibilities of recovery or an ultimate decline and death. This can help decrease or eliminate the surprise factor of the patient not responding to treatment, and support mechanisms can be put in place earlier to assist the family.[17,18]

STRATEGIES FOR THE ICU TEAM

Undoubtedly, there will be patients in the ICU who will continue to wish for life-prolonging measures despite the health care team's education and recommendation to consider a more comfort-directed approach. Although this could be difficult to accept as a nurse, it could be used as an opportunity to get to know patients better and to explore what is driving that decision. Dr Timothy Quill explains that patients who say they want "everything" may or may not actually want those treatments that the physicians feel may be more harmful than beneficial.[20] Quill recommends asking patients or families questions such as "what are your biggest fears?" He states that for many patients there is a fear that if they start to set limits to their treatment, the medical team will become "less vigilant" when changes in their health develop.[20] They may have spiritual, psychological, or social stressors that are impairing their ability to cope with goals-of-care discussions. Other questions that may be helpful as nurses explore their patients' goals are to ask them to define treatment success and what are they willing to go through in order to achieve it. Be aware that they may not trust the health care system. If they are part of the population with known health care disparities or limited access to care, this is often the case. Nurses need to develop a trusting relationship with patients in order facilitate goals-of-care discussions. Reiterate to the patients that the medical team will never stop caring for them even when they cannot cure them and that there is always more that can be done to alleviate suffering. Because goals of care can and often do change over time as the disease progresses, nurses must maintain a therapeutic relationship with the patients and families in order to support them through those transitions.[17,18,20]

As shown in this case, L.S. and his wife chose a course of treatment at the end of his life that most nurses and health care providers would disagree with. However, this treatment plan was offered to him, and he made an informed decision based on his goals for showing his children he had attempted everything possible to live longer. This case also demonstrates a loss of a therapeutic relationship between nurse and family.

SELF-CARE FOR THE NURSE

Nurses must explore their own fears of death and respect that these perceptions influence their ability to care for dying patients. Is death perceived as failure? Is it the enemy? Or is it a natural part of the human physiologic experience?[10] Nurses can work through those feelings in order to be able to engage with terminally ill patients in a more meaningful way.[18] Nurses must also recognize their need for more education on this topic and seek out local resources to obtain it. That may be through formal continuing education programs or simply by reaching out to a local hospice and palliative care organization for support and training. Finally, nurses need to be sure to engage in self-care strategies including spiritual practices, exercise, and quality time with family and friends. These strategies will help process the often heart-wrenching experiences witnessed at work on a daily basis. Nurses who are able to cope with their work in this healthy manner are better able to function both professionally and personally.[18] As in L.S.'s case, nursing leadership acknowledged a need for staff support following this distressing event, and a debriefing was held to allow further exploration of feelings. There are multiple ways to hold staff debriefings, and each facility or unit may have specific methods of providing support that makes them feel supported. This enables staff to find their own closure for difficult cases and a chance to process the events in a way that is most meaningful to each unit or staff. Having a facilitator lead the session allowed for an unbiased perspective to assist the staff in processing their viewpoints.[19,20]

HOW PALLIATIVE CARE CAN HELP

Multiple studies demonstrate the benefits of incorporating palliative care principles in the ICU.[21] It is well documented that patients dying in the ICU suffer from multiple sources of physical and psychological distress, and their family members are at increased risk for prolonged grief.[18] In response to this, palliative care programs are becoming more prevalent across the country in various health care settings; however, these specialized clinicians will never be able to meet all of the needs of the chronically or critically ill patients. It is the role of all clinicians caring for patients to engage in primary palliative care. Primary palliative care is the basic skills and competencies required of all physicians and health care providers when taking care of their patients. This includes discussion and education about goals of care and management of distressing symptoms.[22] Secondary palliative care is provided by clinicians with special training, and they provide formal consultation. This is appropriate for those cases when conflict within family is high and patient symptoms are not controlled with typical measures.[22] As in L.S.'s case, secondary palliative care was engaged; however, the wishes of the patient and family were not altered. It should never be assumed that this consultation will automatically resolve any conflicting ethical issues, although this can be a great source of support to the health care team and to the patient and family to ensure that all involved are fully informed of the issues.

SUMMARY

"Meet patients where they are and take them where they want to go." This is a well-known saying among hospice providers, and it supports the concept that the end-of-life journey is unique to each individual patient. Furthermore, a "good death" is not a myth. It can be achieved, and it frequently needs to be fostered by a well-trained and caring medical team.[23] Always screen for evidence of suffering (physical, emotional, social, and spiritual) and include all members on the team (social worker, chaplain) in the plan of care in an effort to relieve suffering.[24,25] Offer education and support the patient's and family's decision once they have received the necessary information. In doing this, nurses are more likely to maintain a healthy nurse-patient relationship even in the most difficult of situations, and patients and their families can be supported through one of the most frightening times of their lives.

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