ISSUE: The family of a dying patient is requesting care that is all risk and no benefit. How should I handle requests for potentially inappropriate care?

Evolving Thoughts on Futility

Current law and culture in the U.S. support the process of shared decision making, in which the medical team and the patient are actively involved in making medical decisions. Neither the clinician nor the patient are granted sole decision-making powers. Rather, the clinician formulates a treatment plan based on risk-benefit analysis, and offers the patient available and appropriate treatment options based on the patient’s expressed or implied goals of care. The patient may then decide to accept or reject the treatments, but it is not up to the patient to decide what care is appropriate. In the neurocritical care unit, the patient is commonly unable to participate in medical decision making due to neurologic illness or injury; for simplicity, this chapter will refer to the “patient,” even though the decision-maker may be the patient’s surrogate or the patient’s family, with or without input from the patient.

Medical futility should be reserved to describe the uncommon situation in which a patient requests interventions that cannot accomplish the intended physiologic goals (ex: prolonged resuscitation efforts with no return of spontaneous circulation). A clinician is not required to make any intervention that is not expected, based on clinician’s judgement, to provide meaningful benefit as defined by the patient’s own value set, and is therefore medically futile. In fact, clinicians should not provide futile interventions based on principles of non-maleficence and because of a professional obligation to steward medical resources responsibly.

Some hospitals have a process for declaring interventions futile. At a minimum, the clinician should thoroughly and directly explain the reason(s) upon which futility is determined to the patient, and document that clearly in the medical record. Additionally, the clinician should arrange for emotional support of the patient and family.

What is Potentially Inappropriate Care?

More commonly than requesting futile interventions, patients may request care that is potentially inappropriate. Potentially inappropriate care should be used to describe therapies that the clinician believes may have some chance of achieving the physiologic goals desired by the patient, but has overriding ethical reasons to reject the therapy. For example, starting dialysis on a patient with profound, irreversible neurologic damage will allow for clearance of toxins, but would not return the patient to a functional state of health. The Society of Critical Care Medicine supports that ethical reasons to reject therapies as inappropriate may include the following (Kon 2016):

- Inability of the patient to survive outside of an acute care setting
- Severe neurologic deficits such that they will not be able recognize the benefits of treatment

The treatment of pain and suffering should not be withheld on the basis of futility or held as potentially inappropriate.

There are several reasons that patients may request care that a clinician does not think is reasonable:

- The clinician is in a better position than the patient to understand the risks and benefits
- The patient may be willing to accept risks that the clinician is not, without understanding the clinician’s duty of non-maleficence and to distribute health care resources responsibly
- The patient may be in denial about the trajectory of illness, without understanding the clinician’s duty to distribute health care resources responsibly
LEGALLY PROSCRIBED OR DISCRETIONARY TREATMENTS
On occasion, patients or families will request care that the clinician should not provide or can choose not to provide based on existing law. Clinicians should not provide treatments that are legally prohibited (“legally proscribed”). Clinicians should not feel forced to provide treatments that they are allowed to refuse by law, judicial precedent or widely accepted policies (“legally discretionary”). An example of care that is legally proscribed in some areas but legally discretionary in others is physician-assisted suicide. Clinicians should take care to ensure that they are correctly understanding and applying the relevant law or policy, if this is to be used as a basis for refusal. When in doubt, the hospital’s legal counsel should be consulted.

REQUESTS FOR INAPPROPRIATE OR FUTILE MEDICATIONS
End of life (EOL) care is commonly associated with challenging polypharmacy issues. Providers may often struggle with the dilemma of continuing evidenced based medicine practices. However, life extending drugs including those for chronic therapies that aid in prolonging life are usually not appropriate in this setting. In addition, medications utilized for primary and secondary prevention should be appropriately evaluated. If the time to achieve therapeutic benefit is longer than the patient is expected to live, the medication should be eliminated. At the same time, there should be clear and open communication that drug discontinuation is not necessarily withdrawal of care. In addition, reason for drug discontinuation should be discussed with the patient.

Pharmacists can play a critical role in avoiding or eliminating unnecessary medications due to their expertise in medication therapeutics, pharmacokinetics, and pharmacodynamics. These pharmacotherapy interventions often result in less adverse effects to the patient.

Selection of medications that are individualized and align with the patient’s wishes for comfort should be a top priority. EOL therapy should ultimately have a positive impact. In the instance that a medication does not meet the aforementioned criteria, the medication’s pharmacokinetic parameters should be considered and the medication should be withdrawn in a manner to avoid potential withdrawal symptoms.

Prioritization of care should evolve from disease prevention to controlling the symptoms that may cause the patient to be uncomfortable. Pain relieving medications, particularly opioids, are considered first line therapies for pain at the EOL; however, treatment for symptoms related to shortness of breath, increased secretions, delirium, anxiety, and seizures remain controversial due to lack of evidence supporting their treatment. For instance, antiepileptic medications will not sustain life but may be administered during EOL to avoid disturbing effects associated with seizure activity.

Efforts should be made to address and alleviate symptoms in the event that either the patients or their families have concerns. Pharmacists can directly communicate with the patient or family to design an optimized regimen that aligns with both comfort and quality of life.

RESOLVING PATIENT/CLINICIAN CONFLICTS
Communication between the clinician and patient is the first step in working to resolve conflicts regarding futile or potentially inappropriate care. Start by identifying the goals of care. Clinicians should be able to communicate the prognosis (to the extent it is known) and counsel the decision makers as to whether it is reasonable to think that the goals of care can be accomplished. Clinicians should anticipate that families often need more time to come to a decision about accepting or rejecting components of a treatment plan than the medical team. Engage Palliative Care consultants if needed. If it becomes clear that the patient’s goals of care cannot be met, the Palliative Care service can offer suggestions regarding the appropriate setting and focus of care going forward.

Unfortunately, communication alone may not resolve all differences. If a futile or potentially inappropriate treatment is still requested, the hospital’s process to resolve these types of conflicts needs to be explained to the patient and then carried out per the hospital’s policies (which are
presumably in compliance with applicable laws). Specific steps may include:

- Second medical opinion from an independent clinician to assess prognosis and determine if the requested treatment is appropriate
- Ethics consult
- Interdisciplinary committee review
- Input from hospital’s legal department

In the Neuro-ICU, the severity of illness may not allow for time to work through these processes. It may be reasonable to stabilize the patient (when possible) to carry out as much of the dispute resolution process as is feasible. There are situations where a time-limited therapeutic trial of the requested treatment may be appropriate, if only to allow time for the decision makers some additional time to understand the severity of the situation. The biggest problem with this approach is that even though withholding and withdrawing treatments are ethically equivalent, clinicians and families routinely find that it is more difficult to stop a treatment in progress when compared to not initiating the treatment in the first place.

If the conflict remains intractable, the surrogates should be offered the opportunity to transfer the patient to another institution. In the United States, the only tangible form of extramural appeal (which some suggest as a component of the conflict resolution process) available to the patient or family is the court system. This is not ideal, since the legal process is slow and U.S. courts are not meant to be a source of expert medical opinions. If a decision results from a dispute resolution process, the treatment team should honor that decision, while offering emotional support and compassion to the patient and family. Such support could come from the Palliative Care team, hospital chaplains, or members of the health care team.

NEEDS OF THE NEUROCRITICAL CARE TEAM
The neurocritical care unit serves a patient population in which ethical conflicts are likely to arise. This is often a source of tension, since the severity of illness in the patient may not allow time for a conflict resolution process to play out. The health care providers in the Neuro-ICU should receive training to recognize potential ethical conflicts (for example, when a patient’s family has expectations for recovery that are not consistent with the prognosis) and understand the resources available to help resolve conflicts. Ethically complex cases can take an unusual amount of time, so staffing needs should be taken into consideration when a complicated case is encountered, similar to the approach for a medically complicated patient. One practical need is a dedicated space in which ICU family meetings can be held.

While the conflict is being resolved, clinicians may have to provide interventions they think are inappropriate or futile. This can cause moral distress to the health care providers, and they may also need emotional support. This support can similarly come from the Palliative Care service, chaplaincy, or co-workers.

REFERENCES/SUGGESTED READING

