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Resolving Medical Futility Disputes

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Conflicts over end-of-life treatment are common. One category of such conflict is the medical futility dispute. Typically, in a medical futility dispute the surrogate decision maker wants to continue aggressive treatment for a patient but healthcare providers determine that such treatment is inappropriate. In this article we discuss: (1) the types of medical futility, (2) how medical futility disputes can be prevented, and (3) how such disputes can be resolved.

Two Types of Medical Futility Disputes

There are two types of futility: physiologic futility and futility as understood as a lack of benefit. Physiologic futility refers to something that cannot achieve the intended goal. For example, in the treatment of a common cold, antibiotics would be physiologically futile. The common cold is caused by a virus, and antibiotics are ineffective against viruses. Therefore, antibiotics are futile in the treatment of the common cold. But while physiologic futility offers scientific certainty, it applies to few cases of treatment conflict.

The probability of a treatment's effectiveness is often higher than zero. Therefore, the more relevant type of futility is futility understood as a lack of benefit. There is some chance that the treatment might work to some degree. But, for critically ill patients, the likelihood is often very low. Is the treatment worthwhile? Is it indicated? Answering such questions requires a value laden, benefits vs. burdens judgment.

One more precise definition of futility identifies medical treatment that:

- has no realistic chance of providing a therapeutic benefit that the patient has the ability to perceive or appreciate, such as merely preserving the physiologic functions of a permanently unconscious patient; or
- has no realistic chance of returning the patient to a level of health that permits survival without acute level of care or hospital setting; or
- has no realistic chance of meeting the patient's own goals as evidenced by an advance directive or other clear and convincing evidence.

A Medical Futility Case Study

Clinical examples of medical futility that fit this definition can be found in Intensive Care Units (ICU) across the country. Here is a case in point. AH, 96 years old, is admitted to the emergency department from her nursing home with complaints of shortness of breath and weakness. She has a history of dementia, breast cancer and has a stage III sacral decubitus ulcer. AH is admitted to the medical floor where her health continues to deteriorate. She is found to be in renal and cardiac failure. She has bilateral pleural effusions and becomes acutely dyspneic and hypoxic requiring intubation.

AH is transferred to the intensive care unit where her decision maker refuses to allow a biopsy of the pleural fluid. Providers suspect that the effusion is malignant. AH had refused to have her breast cancer treated 20 years ago when it was first diagnosed, so the decision maker surmised that she would not want to have it treated now. AH had an advance directive that stated: "I want my life to be prolonged as long as possible within the limits of generally accepted health care standards." Despite the apparent contradiction between refusing to treat the malignancy and wishing all medical interventions to preserve life, other treatments were aggressively pursued.

AH remained a full code after progressing to complete renal failure requiring dialysis. She remained a full code even after progressing to long-term respiratory failure requiring mechanical ventilation including tracheostomy. AH was unresponsive to stimuli except deep pain and having severe generalized weeping edema with ubiquitous skin breakdown. Her cancerous breast had become a macerated open wound. She required artificial nutrition through a PEG tube, however she was unable to absorb the nutrition due to her poor health and suffered malabsorption diarrhea worsening her skin breakdown.

In short, there was no medical intervention that was going to cure AH. Medicine was not going to be able to return her to her previous state of health. Medicine was not even able to prevent her imminent death. AH's decision maker, however, insisted on continued aggressive care, ventilation, dialysis, antibiotics, tube feeds, dressing changes and attempted cardiac resuscitation.

Based on our working definition of futility, one might reasonably conclude that continuing aggressive treatment for AH is futile. No medication or treatment has any realistic chance of providing a therapeutic benefit that AH has the ability to perceive or appreciate, based on her vegetative neurologic condition. Medicine was indeed merely preserving the physiologic functions of an unconscious patient. Additionally, there was no realistic chance of returning AH to a level of health that would permit survival without an acute level of care (in her case, critical care).

One may wonder, however, if continued aggressive care would meet the patient's own goals as evidenced by her advance directive. Even if it truly were AH's intent to continue futile care, is it appropriate to utilize extraordinarily expensive resources when no benefit can be realized? What can the bedside nurse who is dealing with an unreasonable family member do to advocate for her patient, whom she believes is suffering with every nursing intervention; turning, suctioning, dressing changes etc?

Resolving Futility Disputes through Consensus Building

Once on this road, it is indeed a very difficult journey. Like elsewhere in healthcare, prevention is the best alternative. We suggest utilizing the following strategies to prevent and/or informally resolve conflict with families and decision makers.

1. Develop Goals of Care. Collaborate with patients and families to develop goals of care upon admission. Once established, the patient and family should be kept abreast as to the progress towards these goals. When it is determined that patient will not be able to return to health or previous level of functioning, new goals of care should be developed in collaboration with the patient and family. Have one consistent professional be the primary communicator with the family. Teaching institutions with many residents and consultants contribute to conflicting messages and mistrust. When goals of care are agreed upon and it is clinically appropriate to do so, medically non-beneficial treatment may be limited or withdrawn.

2. Bring the Team Together to Communicate a Cohesive Message. If goals of care cannot be agreed upon, conduct an interdisciplinary meeting. Include: (1) key members of the health care team (medicine, nursing, respiratory therapy, other therapies as involved, nutrition, social work, etc.) (2) consulting physicians, (3) the patient's primary care community physician, (4) the patient and/or decision maker, and (5) other family members and support persons as requested by the family. The purpose of the meeting is to facilitate open and productive communication so that all involved clearly understand the same information. The conference should be patient-centered and should cover the following:

- A discussion of patient and family values and goals, medical status and prognosis, treatment options, the goals of medical care and the definition and implications of CPR and a DNR order.
- A consultation to the Palliative Care Team may be helpful in managing these situations and should be considered.
- A second medical opinion may also be helpful. Sometimes, conflict is related to personality or misinformation. Transfer to another physician or health care facility may be appropriate.
- If the second physician concurs that the requested treatment is medically non-beneficial, that opinion should be communicated to the decision maker.

3. Consult the Ethics Committee. If the patient and/or decision maker continues to request

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non-beneficial treatment and conflict persists, then consult the ethics committee. In an advisory capacity, the Ethics Committee should make every reasonable effort to hear all sides of the conflict, identify ethically acceptable options, and facilitate resolution of the conflict. When possible, it is preferable that the attending physician who participates in the ethics consultation should remain the attending of record until the conflict is resolved.

Resolving Futility Disputes through Unilateral Action

Fortunately, the vast majority of medical futility disputes are resolved through these measures. Providers and families almost always reach consensus. Still, in a small but significant subset of cases, conflict remains intractable. When these preventive efforts fail, an organization must assess whether it is willing to endure the possibility of legal action.

The 1996 Delaware Health Care Decisions Act (HCDA) provides that life-sustaining medical treatment may be withheld or withdrawn from incapacitated patients only with the consent of an authorized decision maker, except in three circumstances, when treatment is: (1) "medically ineffective," (3) "contrary to generally accepted health-care standards," and/or (2) contrary to the provider's "conscience." But the statute defines these terms in such a narrow way that these exceptions do not apply to most futility disputes. Furthermore, even when these exceptions do apply, the statute requires providers to continue complying with treatment decisions unless or until the patient is transferred to another provider or facility. Since such transfers are almost never found, the statute effectively requires providers to comply with surrogate requests for aggressive curative treatment that they consider non-beneficial, burdensome, and even cruel.

Many providers feel that the HCDA does not sufficiently empower them to resist inappropriate treatment demands. Indeed, providers often feel as though they are torturing the patient. Still, they usually comply with surrogate decisions for such treatment due to fear of litigation. In short, the "decline to comply" provisions in HCDA do not provide an adequate mechanism for resolving intractable medical futility disputes.

Still, a separate HCDA provision is of some use. When a surrogate makes a treatment decision that clearly contradicts what the patient would have wanted, the provider need not comply with that decision. The HCDA provides that a surrogate must make treatment decisions "in accordance with the patient's individual instructions, if any, and other wishes to the extent known by the surrogate." If the surrogate is unable to determine what the patient would have done or intended under the circumstances, then the surrogate's decision must "be made in the best interest of the patient." In other words, surrogates must make decisions that reflect the patient's values, preferences, or best interests. Otherwise, they act outside the scope of their authority. Surrogates who are not faithful agents can and should be replaced.

While effective and functional in some cases, surrogate replacement is hardly a complete solution to medical futility disputes. Most patients have not completed any advance care planning. Of the roughly 35% of Delawareans who have completed advance directives, those directives are usually unavailable when needed. And even when available, those directives usually fail to speak clearly to the patient's current clinical circumstances. In short, there is often no evidence of patient preferences. Consequently, it is impossible to demonstrate any contradiction between those preferences and surrogate decisions. While we know, statistically, that few would want to live in an extremely compromised condition, particularly if cognitively unaware, providers often do not know what any particular patient is willing to live with. In such cases, there are rarely grounds to replace a surrogate requesting treatment that providers determine is inappropriate.

Providers need to be able to "stand up" for their patients. The tough work is designing a dispute resolution mechanism that can act with the real-time speed these cases demand, yet include sufficient safeguards to ensure due process protections like neutral and unbiased adjudication.

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