

Addressing Futility: A Practical Approach

OBJECTIVES: Limiting or withdrawing nonbeneficial medical care is considered ethically responsible throughout most of critical care and medical ethics literature. Practically, however, setting limits to treatment is often challenging. We review the literature to identify best practices for using the definition of futility as an anchoring concept to aid the ethical practice of ICU clinicians.

DATA SOURCES: Source data were obtained from a PubMed literature review.

STUDY SELECTION: English language articles were chosen based on relevance to medical futility ethics, end-of-life care in the ICU, or communication and conflict mitigation strategies.

DATA EXTRACTION: Independent evaluation of selected articles for recurrent content themes as relevant to our clinical case were compared among authors and based on consensus, quantitative and qualitative data from these sources were referenced directly.

DATA SYNTHESIS: When life-sustaining treatment is unlikely to achieve a meaningful benefit such as symptom improvement, continued care may be discordant with the patient's goals. Institutional and cultural norms, unconscious biases, and difficulty with navigating conflicts all influence how un(comfortable) clinicians feel in setting limits to futile care. Defining futility in light of the patient's goals and values, focusing on outcomes rather than interventions, and being proactive in communication with families are the staples of medically meaningful critical care. Palliative measures should be framed affirmatively, and clinicians should be transparent about the limits of medicine.

CONCLUSIONS: Clinicians have an ethical obligation not to provide futile care. To practice accordingly, we must clearly understand the nature and forms of futility. Armed with this understanding, our discussions with family and surrogates in the ICU should fundamentally comprise 1) eliciting the patient's values and goals, 2) communicating which interventions serve those values and goals and which do not, and 3) offering only those interventions whose likely outcomes are in line with said values and goals.

KEY WORDS: end-of-life care; ethics at the end of life; futility; goals-of-care; nonbeneficial care

An estimated 20% of Americans die in the ICU, and more than 20% of ICU care is administered to patients with poor prospects for survival or functional recovery (1). Intensive care that is unlikely to confer a meaningful patient benefit is frequently provided even when a patient's previously stated preferences to the contrary are known (2). For patients and families, "doing everything" understandably may seem like the best course of action when shared decision-making is accomplished through conversations such as the one illustrated above. With little understanding of the limits of medical therapy, a loving husband is asked to abandon efforts to sustain his wife's life. With little insight into her patient's values and goals, a physician is pressed to continue administering vasopressors and mechanical ventilation to a patient for whom they will serve no long-term benefit.

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CASE

Physician: “Mr. Smith, your wife is very ill. She suffered extensive brain damage when her heart stopped a week ago, and it is highly unlikely she will ever regain brain function. Right now, intensive life support is keeping her alive, including medicines to maintain her blood pressure and a breathing machine. Now, her kidneys have failed as well. Should we start dialysis if her kidneys do not improve?”

Mr. Smith, tearfully: “Of course, Doctor. Won’t she die if you don’t? I love her. We have been married fifty-four years. . .”

Physician: “And do you want us to continue with the blood pressure medicine if her blood pressure drops further? If her heart stops, do you want us to try and restart it?”

Mr. Smith, now very distraught: “Doctor, I want you to do everything.”

When healthcare providers fail to be proactive and intentional about life-sustaining treatments, there are consequences. Patients may receive care discordant with their goals and spend their final hours, days, or weeks receiving interventions that cause pain and suffering and prevent a “good death.” Families and surrogates may experience confusion about what decisions are theirs to make, feel burdened by the implications of withdrawing or withholding care, and, if resuscitation efforts are aggressive, may lose the chance to be with their loved ones in the final moments of life. Healthcare costs are significantly higher when patients who prefer comfort measures receive intensive care inconsistent with their goals (3). Finally, healthcare teams experience moral distress from reaching communication impasses with families, from feeling disempowered to voice concerns, and from providing sham or unnecessary resuscitation efforts (4, 5). We review the concept of medical futility and suggest a practical framework for directing therapy to patients’ goals of care amid prognostic uncertainty.

DEFINING FUTILITY IN THE PRACTICE OF MEDICINE

Medicine is a moral endeavor and practitioners of medicine act as moral agents. With significant advancements in our technological capability to prolong life in increasingly more dire clinical situations (e.g., extracorporeal membrane oxygenation) comes greater responsibility to exercise moral agency in deploying, withholding, and withdrawing these

interventions (6). As Jonsen et al (7) rightly postulate, healthcare providers have a moral obligation to the goals of medicine—that is, they should seek to cure, relieve symptoms or improve function, prevent illness or untimely death, avoid harm, or ease suffering near time of death. Many have argued that prolongation of life “in itself” is not a proper goal of medicine and that life-sustaining treatments that are not also meant to cure, relieve, or comfort should be discontinued. For a critically ill patient, treatments that delay death—such as dialysis, mechanical ventilation, repeated transfusions, and parenteral nutrition—may actually compound the suffering wrought by the patient’s disease and impede efforts to palliate and humanize the patient’s end-of-life experience. Thus, such treatments often run counter to the goals of medicine.

The “goals of medicine” framework helps us distinguish between the two interrelated definitions of futility. “Quantitative futility” refers to physiologic ineffectiveness; a proposed intervention is futile in the quantitative sense if it has an exceedingly low likelihood of achieving the stated physiologic goal—that is, it “won’t work.” The evaluation of success is based on physiologic reasoning or clinical data. It is thus generally accepted that such interventions (cardiopulmonary resuscitation [CPR] on a decapitated patient, antibiotics for viral pneumonia, or liver transplantation for a patient with multisystem organ failure) should not be performed.

This article concerns the more ethically provocative question of “qualitative futility,” which asks whether an intervention reasonably achieves a proper goal of medicine and provides a benefit of value to the patient. Dialysis may replace kidney function and prevent death from electrolyte imbalance, but for a patient with a devastating neurologic injury, dialysis may not ease suffering, resolve the underlying insult, or lead to a desired discharge and may be thus considered futile in the qualitative sense.

Because “qualitative futility” requires a normative assessment of the benefits derived from an intervention, much more ethical and legal controversy exists surrounding whether healthcare providers should be able to make such judgments. States and many hospitals have policies either affirming or denying providers the right to withdraw life-sustaining treatment against a patient’s wishes based on a professional assessment that continued care would be futile. The vast majority

of polled Americans would prefer to die at home (not in the ICU) and many would want aggressive care discontinued if they were unlikely to make a meaningful recovery (8). In the same way, death and organ damage are irreversible outcomes, so also invasive treatments can irreversibly do harm—they often subject patients to prolonged pain and suffering and can stand in the way of a peaceful death. Some have recommended using the terms “potentially inappropriate” or “non-beneficial” instead of “futile” to describe treatments to capture the subjectivity and sensitivity of making decisions to withdraw such care (9). In this article, we use the term “futile” to refer to interventions unlikely to provide a qualitative benefit, as it more clearly conveys the patient’s prognosis and acknowledges the limits of medicine.

ADDRESSING BIAS AND THE CULTURE OF MEDICINE

While theoretically, we may accept that provision of futile care is ethically unjustifiable, in practice, these judgments are clouded by societal norms and other biases. The most codified example is CPR, which per policy in most American hospitals is performed by default unless a do not resuscitate (DNR) order is explicitly requested or consented to by the patient or surrogate. This special handling of CPR in American medicine is reinforced by misleading media portrayals of CPR as a magic bullet that frequently restores dying patients to their former health and by public CPR campaigns that promote the notion that chest compressions should always be initiated (10). Patient families’ misconceptions and expectations surrounding CPR in some cases lead to medical teams performing limited resuscitation for the family’s benefit, even when it is most certainly futile. These “slow codes” are deceptive and engender significant moral distress for care providers (5). In contrast, CPR in the United Kingdom is far less “ensconced” in the public psyche and physicians are legally empowered to sign a DNR order against the wishes of patients and surrogates if resuscitation is deemed unlikely to succeed (11). This difference at least in part stems from the relative moral weight our respective cultures place on the individual versus the community (12).

In addition to larger cultural values, provider team ethos and the institutions of medicine themselves

pattern our ethics and thereby instill systemic bias—for example, it may seem more acceptable to limit such interventions as dialysis, percutaneous gastrostomy, or tracheostomy because these interventions are customarily managed by a consult service as gatekeeper. Primary ICU providers, by contrast, have reported feeling more immediately accountable to patients and therefore less empowered than their nephrology or surgery counterparts to limit access to intensive interventions (13).

The presence of disparities and bias in intensive and palliative care is an area of active research. Providers should recognize that disparities and bias “do” exist and “can” impact the aggressiveness of care at end-of-life (14, 15). Perceptions by peers and institutional emphasis on quality-improvement efforts also bias providers toward life-sustaining therapies even when they are contrary to patients’ state goals. Some ICU providers may feel obligated to avoid ‘failures’ or, depending on institutional policies, may even be hesitant to withdraw life-sustaining care out of concern for outcomes reporting and legal liability (4). Depending on institutional policies, providers may also be hesitant to withdraw life-sustaining care out of concern for outcomes reporting and legal liability. A particular kind of bias is “surgical buy-in,” a well-described practice pattern in which surgeons are less likely to withdraw care for patients who have undergone difficult procedures and following elective operations that become complicated by surgical error (16, 17).

Furthermore, while for certain clinical situations (e.g., laparotomy in critically ill patients [18] or intensive multiple organ support in acute-on-chronic liver failure [19]), the use of risk-calculators based on large national datasets aid us in identifying defensible cutoffs at which an intervention is not medically justified, for many other clinical situations the assessment of likelihood of benefit is necessarily based on a provider’s anecdotal experience and clinical plus ethical judgment. When considering valve replacement for an IV drug user, a surgeon’s assessment of relapse risk is subject to prior patient experiences and personal views about substance users’ deservingness of high-cost and limited resources (20). Making such treatment decisions based on concerns that the benefit to the patient is too small to warrant expenditure of public resources is highly controversial. However, studies have shown that physician rationing of care at the bedside may be

inevitable and may in fact be masked by invoking the more acceptable rationale that futile care does harm to patients (21).

Significant provider bias may exist regarding what constitutes “quality of life.” Because of this concern, disability rights advocates have significant concerns about granting physicians unilateral decision-making authority on issues of medical (22). Indeed, physicians significantly underestimate quality of life following spinal cord injury (SCI) compared with actual SCI patients (23). Oklahoma legally prohibits providers from denying life-sustaining treatments “on the basis of a view that treats extending the life of an elderly, disabled, or terminally ill individual as of lower value... or on the basis of disagreement [over] the trade-off between extending the length of the patient’s life and the risk of disability (24).”

PATIENT-CENTERED AND GOAL-DIRECTED APPLICATION OF FUTILITY IN PRACTICE

Situations of prognostic uncertainty viewed through various lenses of bias, and further clouded by families’ grief, indeed make for challenging ethical and medical decision-making. Our approach to these difficult scenarios is anchored in pinpointing, to the best of our ability, the patient’s own definition of acceptable quality of life. We view shared decision-making as the integration of equally important but separate spheres of expertise. Patients and surrogates are the experts regarding the patient’s values and goals, while providers are the experts regarding the powers and limitations of clinical medicine. We argue therefore that providers have an ethical duty to set limits when a patient’s stated goals are unattainable to avoid the provision of nonbeneficial care. Thus, the overall priorities for communication with the patient and family should be 1) to elicit the patient’s values and goals and 2) to communicate which medical interventions are appropriate and likely to satisfy those goals and values and which are not. A structured conversation guide such as “best-case, worst-case scenario” (25) may be helpful; we provide our own template in **Appendix A** (<http://links.lww.com/CCX/A1000>) (26). Providers should start by asking patients or surrogates to describe their understanding of the situation and give them an opportunity to ask questions. The discussion should then turn to clarifying what constitutes quality of life for the patient.

The possibilities run the gamut from living independently, attending a grandchild’s wedding, or being able to see and hear. If possible, providers should attempt to have at least one private discussion with the patient, as in some cases, patients may acquiesce to caregiver wants and needs. If the patient cannot participate, surrogates should represent the patient’s values and goals according to the substituted judgment principle.

Once goals of care are delineated, providers should address whether the stated goals are likely to be attainable and the associated degree of certainty. Rather than focusing solely on the possible interventions themselves, physicians should use everyday language when describing the consequences of both success and failure. Instead of simply summarizing “she will die without a feeding tube and dialysis,” the provider should illustrate how “after the gastrostomy tube procedure she will not be able to eat on her own or enjoy food, and having her blood filtered will make her feel very tired and possibly depressed much of the time.” And if the family had previously expressed that the patient’s core goals are her independence and vigor, the provider should communicate that the interventions required to keep her alive would likely not result in those goals being achieved.

In turn, physicians should share that beneficence and nonmaleficence are core features of ethically grounded patient care and that provision of care that does not achieve an outcome acceptable to the patient conflicts with their fiduciary obligations as physicians. In our own practice, we find that asking intervention-rather than goal-focused questions is often counterproductive and that physician recommendation of either proceeding with or foregoing an intervention is well-received by families when framed in the context of patients’ goals.

Any intervention, ongoing or planned, should be routinely framed as a “trial of treatment” that is subject to ongoing reconsideration, making ultimate decision-making an iterative process. As the benefit afforded by the intervention wanes, providers should explain to caregivers and surrogates both that the trial may be failing and that the lived experience of these interventions may be painful and cause suffering to the patient. Pilot studies of a structured time-limited trial approach (where surrogates and clinicians agreed to trial a treatment or procedure for a set period of time and decided in advance how to proceed should the

patient not improve) have shown promise at reducing nonbeneficial care in medical ICUs (27).

NAVIGATING CONFLICTS

Discordance between the provider's and surrogate's best estimates of a critically ill patient's prognosis is extremely common and can be due to misunderstandings of the medical team's assessment or to fundamental differences in religious beliefs or in views of a patient's unique character strengths such as being "a fighter" (28). Proactive, intentional communication with patients and their caregivers or surrogates is essential. In ICUs, family conferences should be initiated routinely ideally before there are doubts the patient will make a meaningful recovery; palliative care consultation can be useful prior to these discussions and bedside nurses should be included (4).

Caregivers may also believe that remaining optimistic improves patient outcomes. While physician prognostication is generally more accurate, surrogates' expectations can drive shared decision-making, such as toward invasive life-sustaining treatments if prognostication is optimistic and toward palliative measures if not (29, 30). Because end-of-life situations can become quickly fraught with conflict among providers, patients and caregivers, several professional organizations have recommended early ethics consultation at any hint of conflict before it becomes explicit (9, 31). Furthermore, with frequent team turnover in ICUs, the continuity of clinical ethics or palliative care team involvement may be comforting to families. In cases where families believe that clinical outcomes are determined by a higher power, a chaplaincy consult may be useful in exploring the belief in miraculous intervention (31).

In all cases where prognosis is bleak, providers should prioritize and communicate to caregivers what the team "can" accomplish for the patient. Rather than the feared "nothing more we can do" if treatment or cure is not possible, framing the care plan in affirmative wording emphasizes that palliative interventions serve equally important goals of medicine such as providing comfort and dignity near the time of death. "We will do everything we can that will keep your husband from pain," or "we will do everything we can for your mother to make the most of time with her grandkids" reflects the medical team's focus on the patient's goals and

values and underscores that the team is not abandoning the patient. The special status of CPR in the public conscience and hospital policy should be considered proactively, as presenting CPR as a reasonable option early can influence code status discussions when prognosis worsens (31). Full code status might represent for families a more existential need, such as unwillingness to abandon a loved one. Providers should openly acknowledge these fears while clearly stating the limitations and harms of CPR. Furthermore, families should be reassured that a DNR order changes nothing about how the team will approach other aspects of care (32).

Providers whose medical judgment calls for limiting life-sustaining treatment may face resistance from families and surrogates who fear the provider is giving up on or discriminating against the patient in favor of the hospital bottom line. High-profile cases have illustrated how conflict can become intractable even despite the medical team's best intentions (33). In such cases, teams should avoid alienating surrogates from the decision-making process, chiefly because the surrogate is usually a loving caregiver who, while possibly misguided, still has the best interests of the patient at heart (31). If treatment for curative intent is not medically justified, providers should make commitments to caregivers not only to make the patient comfortable through end-of-life, but also to support the caregivers in any way possible (e.g., by facilitating family visits, providing travel and lodging support, etc.).

Family requests for inter-institutional transfer, while allowable by many hospitals as a last resort when families insist on medically inappropriate care, likely reveal that serious breakdown of trust and communication has occurred. In this case, the team should clearly express a desire for the patient to remain in their care and warn families that physically transferring a critically ill patient will inflict additional pain and suffering (31).

Patients and families are perhaps best served if institutions have formal mechanisms to support physicians' decisions to set limits on CPR and other life-sustaining treatments when such interventions are futile and if they are transparent about them. Rather than setting strict parameters on indicated interventions a priori in the absence of fully understanding each patients' goals and values, "conscientious practice policies," such as the one at Yale New Haven Medical Center, empower physicians to only provide care that serves proper goals of medicine (13). Abiding by professional oaths and

referring to them in family discussions and electronic medical record documentation leaves less room for uneven applications that erode families' trust.

CONCLUSIONS

Our case presentation illustrates several pitfalls in clinical decision-making in the ICU. Common missteps include not eliciting the patient's acceptable outcomes via substituted judgment; a focus on interventions over likely outcomes; and providing the sense of ethically comparable choices without providing the physician's professional recommendation. Goals-of-care discussions are fraught with prognostic uncertainty, cultural and individual bias, and surrogate decision makers' grief and potentially conflicting interests. Grounding conversations and recommending interventions around what outcomes (rather than interventions) are and are not acceptable to a patient allows for a more patient-centered, goal-directed, and professionally concordant ethical practice of medicine.

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