Determining Futility

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The challenge of determining that therapeutic intervention is futile is a recurrent ethical theme in critical care medicine. The process by which that determination is reached often involves demanding collaborative and interdisciplinary conversation and deliberation within the context of hospital policy, including ethics committee guidelines. The subsequent decision as to what happens next depends on resources, such as palliative care services, hospice, other hospital protocols, and, of course, family support.

This, in the best of circumstances, is a difficult, time-consuming, labor-intensive process. The major and common complication is conflict between the healthcare team and the surrogate; and, specifically, when the team is ready to declare "futility" whereas the family is adamantly opposed to the withdrawal of any therapy and, indeed, is looking to the medical team to suggest the next best aggressive, life-preserving intervention. This is the situation in which the physician responsible for the course of care asks, "Can doctors say 'enough'?"

Such a case came to the attention of the editor when the Columbia Presbyterian Hospital Ethics Committee actively pursued it and Dr. Kenneth Prager, its chairman, first presented it to the Metropolitan New York Bioethics Consortium coordinated by the New York Academy of Medicine in March 2002. It was so troubling and complicated and it generated such essential debate on the issue that we thought that broader exposure might benefit other ethics committees confronting the problem.

When one asks the lead question "Can doctors say 'enough'?" the sense of the question may be transformed by shifting emphasis and inflection from one of the words to another. "Can?"—is a physician empowered in an autonomy-based ethos to make these assertions of futility? "Doctors?"—is it the physician's unique role, or are there other responsible players? "Say?"—does the positive assertion and/or documentation carry special ethicolegal baggage on the spectrum from professional commitment to legal exposure? And finally, the ambiguity of "enough?," which contextually signifies the interjection "Stop." But "enough" might also mean "sufficient" in the sense that it asks that the health team be more communicative earlier on in the course of treatment. Has sufficient information been conveyed? Or more pointedly, is it really possible to fully communicate in this context? And the imperative side of "sufficient"—might the team be more directive concerning the course of treatment, in the sense of empowering or enhancing the autonomy of the decisionmakers?

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The Case: Can Doctors Say "Enough"?

Kenneth Prager

A 77-year-old woman was admitted to New York Presbyterian Hospital, Columbia Division, with intestinal obstruction. The patient had a history of multiple prior abdominal surgeries for resection of colonic polyps, partial colectomy for bowel incarceration, and small bowel obstruction. The patient underwent coronary artery bypass surgery and valve replacement 3 years prior to admission. She was very obese, was diabetic, and had peripheral vascular disease. Her mental status was normal. She was a Holocaust survivor, was married, and had one daughter.

The patient underwent bowel resection for a large villous adenoma. One month postoperatively she developed septic shock and was re-explored. An anastamotic leak was found along with multiple intra-abdominal abscesses, which were drained. She went to the surgical ICU post-op. Her subsequent hospital course was marked by severe complications. She developed multiple enterocutaneous fistulas, required ventilator support because of respiratory failure, needed regular hemodialysis, and was alimented intravenously with total parenteral nutrition because her GI tract was nonfunctional. She developed fungemia due to fungal endocarditis and required pressors most of the time because of almost continuous sepsis. A very large and very deep sacral decubitus further complicated her care. Although she would open her eyes and visually follow people in her room, she made no response to any sort of verbal or tactile stimulus. The nurses noted, however, that she would moan softly when they changed her dressings.

Despite the worsening prognosis, the patient's daughter insisted on continued aggressive care. She stated that her mother had survived the Nazi concentration camps and would survive this illness. She further said that, although her mother had no written advance directives nor a healthcare proxy, she had on several occasions commanded her daughter, "Don't let anything happen to me," which the daughter interpreted as an order to make sure everything was done to keep her mother alive. The patient's physicians felt by the fourth month of her ICU stay that there were no chances that she would leave the hospital alive, and they requested a medical ethics consultation and review by the hospital ethics committee.

Commentary

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This case has come to mediation and the ethics committee has been called. Committee members should hear the opinions of the physicians, nurses, and the surrogate. The family's cultural and religious beliefs should be explored and their own authority figures, such as a rabbi or elder, called on if available. Psychiatric, chaplaincy, patient advocate, and social work involvement should be called on if they can facilitate communication and the development of compromise solutions. Once familiar with all aspects of the case,

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*The opinions expressed are those of the authors and not of Memorial Sloan-Kettering Cancer Center or of the MSKCC Ethics Committee on which all three serve.

the committee should concentrate on defining ethically valid goals of care, exploring whether the patient should remain in the ICU, how a transfer should be managed, whether cardiopulmonary resuscitation (CPR) should be performed when she dies, and whether it would be acceptable to forgo further escalation of care. In this case, the primary ethical conflict is between the surrogate's autonomy and the physician's authority to override it on the grounds of medical futility.

In this consultation, only a daughter is mentioned. Spouse or siblings are either nonexistent or emotionally excluded. This one individual bears the full burden of accompaniment and is the de facto surrogate. But solo or not, legally designated or not, she does not function in a vacuum and remains subject to family traditions and expectations, in this case the patient's status as a Holocaust survivor. This history does not change medical reality, but its profound impact makes communication with the surrogate more challenging because survival in such families carries a powerful emotional charge. As experienced by the survivors themselves, it is conveyed to their children as a key source of meaning, a raison d'être in both the literal and existential senses. The children are sensitized to their parents' plight and ill prepared for the "letting go" needed to accept the parent's death without feeling responsible or guilty. In the light of such a past, hope may prevail over reality and life may be valued regardless of its perceived quality. This surrogate may be responding to her mother's stated intentions, but she may be acting out a family scenario that locks her into standing pat, so as to demonstrate filial loyalty and give meaning to her mother's historical suffering as well as her own. It would have been helpful if a caregiver had conveyed an understanding, hence a sharing, of her special burden.

By the time we learn about the case, the patient has occupied an ICU bed for months. Many caregivers, at the bedside hour after hour, may feel a sense of professional disenfranchisement and a mix of anger and anguish. Surrogates can experience the medical staff as deeply supportive or very troubling but never neutral because they scrutinize and overinterpret caregiver words and behaviors. Here no subtlety is needed. We assume that the physicians have stated they believe there is no chance of hospital survival and that advanced life support is prolonging her mother's death. It is our experience that the bedside ICU nurse has usually reached this opinion before the physician team. The surrogate's position and that of the medical team are so orthogonal that outside intervention may be needed to heal the empathy rift and allow the surrogate to find an acceptable way to change her stance. A mental health professional may be needed, given that the surrogate's mindset is anchored in a complex intergenerational trauma.

Turning to the caregivers, there are three factors that might be thought to alter medical decisions. The first is covert resource allocation. There is no longer as much denial about the need for careful allocation of limited resources. Physicians do not make the rules but must work under them without doing violence to their code of ethics. It is a fiction to demand that they be oblivious. The ICU is a unique case because beds are often in short supply, and triage about whom to admit and whom to transfer is part of the daily routine.[1] It is medically guided allocation in its most obvious form. No mention is made of the issue in the case presentation, but one expects the staff to be processing it at all decision points. A crowded ICU with patients needing admission could certainly alter the balance. But the decision process must be transparent, consistent, and accountable. Over 4 months it seems probable that the ongoing care of this intubated patient may have compromised that of another individual.

Another factor that may affect staff attitudes is fear of litigation, which leads to retaining patients in the ICU so as to avoid lawsuits. Sensitivity to this fear varies among institutions. Caregivers may grumble but seldom take a strong stand, because they lack institutional support.

The third factor could be called battle fatigue. Caregivers providing what they think is morally questionable care, feel professionally disenfranchised and experience a mix of anguish and anger, which demand careful self-awareness when dealing with the surrogate. Their skill in restoring health to patients suffering from erstwhile fatal diseases may seem miraculous to the lay public and support the proxy's tendency to "pray for miracles." Correcting that misconception is at the core of their communication task. Fortunately, their expertise helps the patient survive long enough to give them time to hold regular discussions about treatment options and prognosis. Given time and accurate empathy, most surrogates come to realize that technology and hope do not ensure a good outcome, and a day comes when goals change from cure to palliation. Ideally, ongoing reassessments prevent the conflict we address here, but not always.

In this case, the primary ethical conflict is between the surrogate's autonomy and the physician's authority to override it on the grounds of medical futility. It may also be necessary to help resolve the critical ethical issue in this case: should the continuation of "aggressive" care be based on patient autonomy or on medical judgment concerning futility of care?

In principle, the conflict between patient autonomy and medically defined futility remains unresolved. Experienced clinicians are willing to commit themselves and ask others to trust their medical judgment, but many ethicists view the term futility as vague and value laden, hence unacceptable as the basis for any decision. Medical and legal institutions, repeatedly faced with situations that force a decision, have focused on more operational definitions. Although still value laden, these definitions are easier to analyze and evaluate. They include care that cannot achieve its stated purpose and care that only increases patient suffering. Short of life-sustaining measures, such care is against the patient's best interest and can be withheld from a patient. In fact, it is the physician's duty to withhold such care.[2–4] Other voices have weighed in about the right to refuse to give futile care: The American Medical Association's opinion is that physicians "are not ethically obligated to deliver care that, in their best professional judgment, will not give a reasonable chance of benefiting their patients. Patients should not be given treatment simply because they demand them."[5]

The clinical scenario suggests that further care will not restore our patient to health and will subject her to more instrumentation and possible suffering. The occasional "miracle" that puts the lie to physician predictions is not usually in the elderly, chronically ill patient. We view the risk-benefit gap as between the patient dying now or dying later. But "later" is an uncertain term in a patient with no rapidly progressive disease such as cancer. It is conceivable that with continued support, she might not die so quickly. Should this alter the decisionmaking process? Cessation of life supports in patients who are not terminal has been the cause of more concern than actively dying patients, but there are precedents for cessation of life supports with nonterminal patients as well. Great emphasis is placed on the patient's previously stated wishes and on the current ability to interact with the environment. In a recent case, a nonterminal patient's limited responsiveness made the court override his wife's wish to stop tube feedings, even though she had the support of his children and his brother. A plea has been made that, despite dramatic publicity, this decision not be extended to less responsive patients.[6]

A case might be made for the unilateral decision to withdraw mechanical ventilation or to stop dialysis. There is solid doctrinal support for the belief that withholding and withdrawing support are morally equivalent,[7] but they are not psychologically equivalent, and application of this principle at the bedside is emotionally trying and often generates controversy. Some surrogates are tormented by the thought that they are "allowing" their loved one to die. Paradoxically, being overridden by the physician may be a relief to some surrogates, but, as in this case, others may feel that they cannot—must not—give up.

Local jurisdictions can have a decisive impact on terminal care decisions. Whereas a Massachusetts court supported a futility-based decision of a physician to write a do-not-resuscitate (DNR) order and terminate mechanical ventilation of a patient against the wishes of a surrogate,[8] most physicians and healthcare facilities would be reluctant to do so without exploring all other options and would not wish to be the "test case" within a different jurisdiction. In New York,[9] Wisconsin,[10] and Michigan,[11] proof of an incompetent patient's previous wishes while competent to limit care must be clear and convincing if life-sustaining medical treatment is to be withdrawn or withheld.

New York state law offers very little guidance on the subject of medical futility outside the narrow context of decisions regarding CPR. The Committee on Bioethical Issues of the Association of the Bar of the City of New York published a "Model Policy for Conflict Resolution in End-of-Life Medical Decision Making."[12] Decisions to withhold or withdraw support, as well as initiate CPR, should be considered on a case-by-case basis. There should be attempts at negotiated conflict resolution, open communication with codification of goals of care, and, if necessary, peer review of attending-physician judgment. An ombudsman or patient representative may be required to facilitate these discussions. Ethics committee consultation, which is advisory in nature, should be sought as early as possible.

We would hope that, after reviewing all pertinent information, the committee intervention would allow the surrogate and the caregivers' intentions to come together. Specific to this case, if a conflict regarding goals of care still exists after information gathering and mediation, we would advise that the ethics committee confirm that ICU care has no further impact on the patient's outcome or comfort and that it is medically and ethically acceptable to not escalate care. The patient should be transferred from ICU to general hospital care and a DNR order issued. The ethics committee would present its findings to the institution's medical director. If the medical director supports the ethics committee's recommendation, a conference is held with the ethics committee, the surrogate, and the healthcare team to present the information to the surrogate.

In New York, where CPR is the default option unless the patient or surrogate formally agrees to the writing of a DNR order or the patient leaves "clear and convincing" evidence of his or her wishes, CPR can still be withheld if two physicians determine that it is "medically futile." "Medically futile" is narrowly defined and refers to CPR that cannot be successful in restoring cardiac and respiratory function or that will be followed by repeated arrests in a short time until death occurs.[13] The law refers to vaguely defined efforts at accommodation, to be made when religious objections are involved in surrogate demands.

If the surrogate objects, the institution will transfer the patient to another facility if possible, but this is usually not a viable solution for critically ill patients. In New York, if a DNR order based on futility has been issued and the surrogate objects to it, she has a legal right to mediation. The law allows each facility to establish its own mediation process. Once a matter has been submitted to dispute mediation, the DNR order cannot be issued, or if already issued, must be suspended until (a) resolution of the dispute, (b) the process has concluded its efforts to resolve the dispute, or (c) 72 hours have elapsed.

In our experience, the mediation process often leads to effective communication and consensus between the family and caregivers such that the patient receives appropriate end-of-life care. If after 72 hours there was still an objection to the DNR order, we would maintain that the DNR order be reinstated over the objection of the surrogate. On the rare occasion that the family seeks judicial adjudication, the opinion of the ethics committee is usually given serious consideration and the courts will likely support a well-documented mediation decision.

Given the patient's incapacitated state, we would recommend caregivers defer to the proxy's opinion regarding other aspects of therapy and continue care at the current level. When the patient ultimately deteriorates, the clinical staff should be supported if they decide that there should be no escalation in care. Although many would argue that dialysis should be terminated as it is only prolonging the patient's death, with no expectation of restoring health, we would not pursue this argument. If, on the other hand, dialysis access should be lost, we believe the potential risks of replacing the vascular access would outweigh the benefit and it should not be replaced.

Ultimately, the staff should have a chance to debrief and review their common experience. It is important to notice those staff members for whom the experience was morally or emotionally more taxing than the norm and perhaps advise their supervisor about giving them support and a chance to work through their feelings. In rare cases, the qualms are strong enough that some staff members need to transfer to other units. This is a good outcome for all, not only for the caregiver in question but for the rest of the team as well, given that a commonality of purpose is an important factor in helping caregivers maintain their humanity and professional commitment when doing such difficult work.

Notes

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9. *In re Westchester County (O'Connor)*, 72 N.Y. 2d 517, 531 N.E. 2d 607, 534 N.Y.S. 2d 886 (1988).
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11. *In re Martin*, 450 Mich. 204, 538 N.W. 2d 399 (1995).
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13. N.Y. Pub. Health Law §2961(12).

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Commentary

David T. Rubin and Mark Siegler

Here is a conflict between a surrogate speaking for the patient and the healthcare team, which turns on the extent of aggressive medical care that should be delivered. The daughter, acting as surrogate decisionmaker, requests ongoing intensive medical intervention for cure, and the healthcare team, believing that cure is no longer possible, wishes to withdraw or withhold further life-sustaining therapy. The issue is further complicated because the patient is dying, she is unable to express her own wishes, and she does not have explicit advance directives. This case requires that the medical facts be clarified for the daughter and the healthcare team and that discussions proceed on the appropriate use of life-prolonging therapy, as well as requiring communication of limitations to therapy. It also requires that the ethics consultation service become actively involved to facilitate these discussions.

The medical context of the case requires clarification. The patient has suffered severe complications after a required medical procedure. Anastomotic leaks and infection are possible complications after a bowel resection and are certainly more likely in an obese older patient with diabetes and peripheral vascular disease. Is any element of this conflict based on issues of negligence, either real or perceived? If so, this may affect the physicians' (or the institution's) willingness to force the daughter to accept withdrawal or withholding of care, and the institution's risk management and medical-legal teams should be aware of the situation. But even if there is no negligence involved, the case represents an iatrogenic (i.e., doctor-caused) maloccurrence. In such iatrogenic situations, there is a tendency on the part of doctors to try harder, to go the extra mile, because they feel "responsible" for the patient's situation.

This patient suffers from multisystem organ failure in addition to multiple comorbidities. Her prognosis as assessed by the ICU expert physicians is grave, yet the daughter does not appear to acknowledge the inevitability of this prognosis. She may be uninformed. More likely, she was informed but didn't actually comprehend or interpret the physician's dire prognosis. This lack of understanding may be a form of psychological denial. Her persistence may result in the physicians second-guessing their own assessment, although this is not made clear in the case. The difference of opinions between daughter and doctors regarding the patient's prognosis may be due to her rapid deterioration and the development of multiple complications. Both the daughter and the healthcare team may have lost sight of the "forest for the trees." When this occurs, expectations of care that independently appear reasonable (fix the decubitus ulcer, treat the fungemia, administer dialysis, feed her intravenously) are unrealistic or even untenable when considered in aggregate. Sometimes, even the physicians lose sight of the whole picture as they attempt to treat one problem after another. If the daughter is focused on the treatability of each independent problem, the primary physician or whomever she views as the team leader should inform her of the overall prognosis. Communication of this prognosis and inevitability of the patient's death is probably more difficult to discuss given the patient's apparent presurgical high-level functional status, and the fact that she is viewed by the daughter as a "survivor," not just of the Holocaust, but of many previous medical and surgical illnesses and (presumably) ICU stays. She has survived overwhelming odds and complications from acute illness before; why is this any different?

If medical cure is not possible, ongoing intensive therapy may be considered futile. The definition of futile medical therapy varies, but in this case it may be considered to be delivery of medical services that definitely will not yield their desired outcome and will not change the outcome in the short run. The healthcare team appears to believe that ongoing care is indeed futile and is recommending limitations to ongoing therapy. It is not clear from this case description that the healthcare team is recommending withdrawal of therapies or the initiation of a "comfort-only" palliative option to care, but it is assumed that would be the approach once the daughter accepts that ongoing therapy will not change the outcome.

After clarifying the medical facts, obtaining information about the patient's wishes and identifying the appropriate surrogate are the next steps in our approach to this case. The patient is married and has one daughter, yet there is no mention of explicit advance directives other than a recounting of her verbal wishes, which are somewhat vague and susceptible to various interpretations. The daughter has interpreted "Don't let anything happen to me" to mean "Do everything!" Another plausible interpretation of the same phrase might be "Don't let anyone treat me inappropriately or excessively." Additionally, in the absence of clearly documented advance directives or a legally appointed durable power of attorney for healthcare, the patient's husband should be the surrogate decisionmaker. There is no mention of his involvement in these decisions or whether he would interpret his wife's previously expressed wishes differently from the daughter. Even if we were able to identify advance directives that differed significantly from the daughter's requests, there may remain conflict, which requires mediation. Although legally we could proceed to withdraw care if the husband identified different wishes for his wife, all reasonable attempts should be made to avoid direct conflict with the identified family spokesperson and to avoid situations that lead to conflicts between family members.

What is the relationship between mother and daughter? Is the daughter expressing wishes that were shared with her 10 years ago, and she has been living far away since that time? We frequently see children who live far from their sick family members who then pursue the "stop at nothing" course of action when they have been out of touch and may feel guilty for a lack of closeness as a parent aged or became ill. Separating the daughter's personal feelings, which may color her decisionmaking, would be important in determining the true wishes of the patient and in encouraging the daughter to examine her own feelings as the first step of grieving.

Whether the healthcare team should act unilaterally in the absence of approval of the daughter (or husband) remains an issue primarily of patient suffering. If the patient is suffering because of the ongoing therapy (and is reported to moan when moved), and that therapy has no chance of yielding cure, then the physicians must act in the patient's best interests and provide comfort care. The additional issues in this regard include the conflict of conscience that may be experienced by healthcare team members while being forced to provide aggressive interventions that they regard as inappropriate. If the nurses or respiratory or dialysis technicians view the ongoing extraordinary care as cruel, this may contribute to the healthcare team dynamics. The daughter and healthcare team may have unintentionally entered into a power struggle and lost sight of the fact that they have similar goals.

Once the family accepts the medical facts and the impossibility of cure, the patient's daughter and husband should be informed that withholding or withdrawing life-sustaining therapies does not mean "stopping everything." In fact, they should be informed that care never ceases. Comfort care will be started, and the family can begin the process of grieving. Aggressive therapies should be administered to treat pain, dyspnea, and anxiety, and the family should be offered the opportunity to speak with a religious counselor.

Our recommendations therefore would be the following. First, clarify the medical facts of the case and the grave prognosis by emphasizing that ongoing therapy to achieve cure is not only futile but may be causing the patient pain, dyspnea, and anxiety. If there is concern that the patient's outcome is directly related to an iatrogenic event, the risk management or medical-legal teams should be involved but also the psychological needs of the physicians should be considered. Second, clarify the issue of surrogate decisionmaking and the patient's wishes. If discrepant wishes are identified or if the patient's husband disagrees with the patient's daughter, a family meeting with mediation should occur to try to reconcile family tensions. If these approaches do not achieve an acceptable compromise, mediation should occur by the ethics consultation service. If this is unsuccessful, as a last resort, the medical team could consider a unilateral approach. This, however, invariably leaves bitter feelings for surviving family members. If agreement can be reached to switch goals of care from cure to comfort, this should be performed in an aggressive and sensitive manner. Finally, the psychological and ethical concerns of the caregivers should be considered, and other members of the healthcare team should be encouraged to participate in all elements of this conflict resolution.

What Actually Happened

The ethics consultant spoke with the daughter, who stressed that her mother had fought for survival during the Holocaust and had recovered from multiple previous medical and surgical trials. The daughter interpreted the mother's prior injunctions to her as clear evidence that she would want continued aggressive care even in her current dire straits. The daughter also felt that her mother was aware of the daughter's presence at her bedside, although the nurses were highly skeptical of this. The consultant felt that, although the patient's continued care would be considered futile if judged by the yardstick of survival to discharge, her treatment was not futile in the sense that it probably accorded with the patient's prior wishes concerning medical treatment and by the criterion of maintaining life for as long as possible because of the sacredness of life per se—values that she and her daughter held, in line with their Orthodox Jewish beliefs. The consultant also pointed out that, just as physicians accord high priority to patient autonomy when it comes to terminating medical treatment, they must equally respect such autonomy when it is used to assert a desire for continued treatment even in the face of almost certain death.

The case was presented to the ethics committee, which felt unanimously that there were no grounds at that point to go against the daughter's wishes. The committee based this on the presumption of the patient's wishes as previously expressed to her daughter. Another factor underlying the committee's recommendation was the knowledge that it was hospital policy, probably because of fears of legal consequences, almost never to go directly against a family's wishes in a situation where even "futile" care was involved. Because the committee realized that the physicians and nurses caring for the patient would feel increasingly unsettled as her condition deteriorated, they urged the doctors and ethics consultant to maintain continued contact with the daughter in the hopes that she would relent and eventually allow some limitation of treatment.

The daughter did not relent and continued to even insist on resuscitation. The patient lived for another 4 months and died, after an attempt at resuscitation, after a total of 8 months in the ICU.