

AFTER THE **DNR**

Surrogates Who Persist in Requesting Cardiopulmonary Resuscitation

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In 2006, Massachusetts General Hospital adopted a policy to support doctors who had judged that CPR would not benefit a patient in their care and wanted a DNR order in place, even in the face of objections from the surrogate decision-maker. Although some surrogates ended up accepting the DNR order, others continued to resist. Here's what MGH learned about them.

Some health care organizations allow physicians to withhold cardiopulmonary resuscitation from a patient, despite patient or surrogate requests that it be provided, when they believe it will be more harmful than beneficial.¹ Such cases usually involve patients with terminal diagnoses whose medical teams argue that aggressive treatments are medically inappropriate or likely to be harmful.² Although there is state-to-state variability and a considerable judicial gray area about the conditions and mechanisms for refusals to perform CPR, medical teams typically follow a set of clearly defined procedures for these decisions.³ The procedures are based on the principle of nonmaleficence and typically include consultation with hospital ethics committees,

reflecting the guidelines of relevant professional associations.⁴

At some hospitals, the procedures are articulated in policies about life-sustaining treatment. Sometimes called unilateral do-not-resuscitate (DNR) policies, these guidelines have been the subject of debate among experts and professional associations connected to questions about medical futility, resource allocation, and patient autonomy.⁵ Rather than removing a surrogate whom a medical team judges unable to make decisions about CPR consistent with the patient's best interests, the policies take choices about CPR out of the domain of shared decision-making.⁶ Most scholars and professional organizations agree that such policies should be invoked only following consultation with the hospital's ethics committee or through another clear and transparent process.⁷ For example, the American Medical Association's *Code of Medical Ethics* states, "If a patient (either directly or through an advance

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directive) or the patient's surrogate requests resuscitation that the physician determines would not be medically effective, the physician should seek to resolve the conflict through a fair decision-making process, when time permits."⁸ *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment* do not address this issue directly, although they emphasize the importance of communication in cases in which health professionals believe CPR is medically inappropriate.⁹ And the major North American and European critical care societies recently issued joint guidelines endorsing a procedural approach to resolving conflict over potentially inappropriate treatment, including CPR.¹⁰

Ethical debates about when CPR can and should be limited tend to rely more on discussions of theory, principles, and case studies than systematic empirical study of the situations in which such limitations are applied.¹¹ Sociologists of bioethics call for empirical study of these and related ethical conflicts, arguing that what ethicists and health professionals believe they are doing when they draft policies or invoke principles does not always mirror what is happening on the ground.¹² "As the field of bioethics grows and solidifies its position in the biosciences," sociologist Ray DeVries argues, "the skills of social scientists will become more important: expansion of the terrain of bioethicists will require more sociologists in bioethics . . . to evaluate the success of bioethical policies and interventions."¹³ This sort of research might best begin with qualitative case studies, as John Evans suggests, and culminate in larger nationally generalizable research studies.¹⁴

In this article, we begin the task of modeling the empirical analyses sociologists call for, focusing on a cohort at Massachusetts General Hospital (MGH), a large academic medical center in Boston. Cases in which physicians decide not to offer CPR because there is medical consensus that resuscitation would be more

harmful than beneficial pass through the hospital's ethics committee, called the Edwin H. Cassem Optimum Care Committee. Ethics committee involvement is recommended by a section of the hospital's life-sustaining treatment policy entitled "Doing No Harm." The committee originally identified the need for this policy after early experience with a broader "Resolving Intractable Conflict" policy, which focused on *any* disagreement about life-sustaining treatment, including CPR. While the Resolving Intractable Conflict policy was sometimes effective, its implementation often further polarized health care teams and surrogates, entrenching conflict instead of mollifying it.¹⁵

This paradoxical effect and the high rate of patient death during the

The policy was framed around the idea that physicians are not obliged to offer or provide life-sustaining treatments that have no clinical indication or reasonable likelihood of providing benefit to the patient given his or her prognosis.

time in which the requirements of the policy were implemented in specific cases led to the development of the separate Doing No Harm policy to address medical orders for DNR but not for current or ongoing life-sustaining treatments. The policy was framed around the idea that physicians are not obliged to offer or provide life-sustaining treatments that have no clinical indication or have no reasonable likelihood of providing benefit to the patient in the context of his or her prognosis. Rather than encouraging physicians to seek court permission to remove surrogates believed to be making decisions about CPR contrary to the patient's values or best interests, the policy provided a mechanism for physicians not to offer CPR.

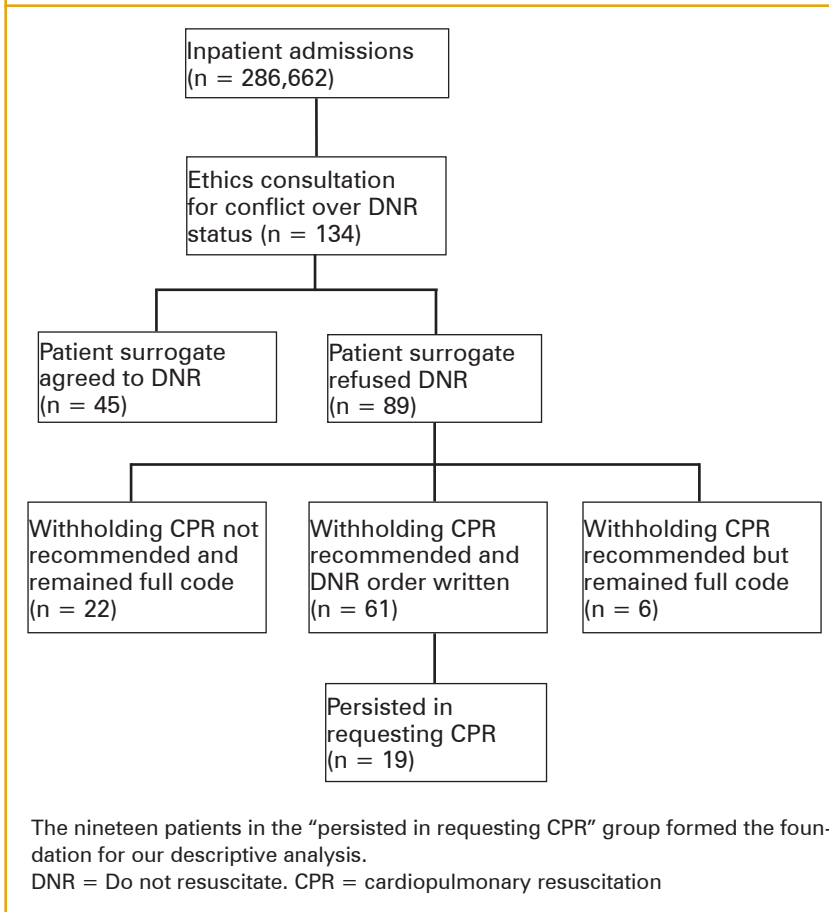
In this way, the policy reframed what was often treated as a patient or surrogate choice into a medical decision for the patient, built on evidence

of CPR's long-term ineffectiveness in conditions such as metastatic cancer, multisystem organ failure, and overall frailty accompanied by poor functional status.¹⁶ The policy was formally adopted in 2006 after being reviewed and vetted by senior physicians, nurses, the hospital's ethics committee and Critical Care Committee, the Office of General Counsel, and the Clinical Policy Committee. The policy received final approval by the hospital's Medical Policy Committee. In this way, the policy was intended to provide organizational support for physicians to enter a DNR order for seriously ill, imminently dying patients for whom they anticipated having to provide nonbeneficial CPR.¹⁷ Consistent with professional society guidelines, the policy left open the

possibility of interinstitutional transfer and extrajudicial appeal, time permitting.

Following policy adoption, when health professionals consulted the ethics committee to assess whether to apply the Doing No Harm policy, two or three committee members, depending on their availability but always led by a senior consultant with training according to the guidelines of the American Society for Bioethics and Humanities, responded.¹⁸ They reviewed the patient's medical record and helped identify the perceived ethical issues, the patient's expected prognosis, the goals of care, and the patient's values, wishes, and treatment preferences. The consultants then framed the consult question in ethical terms, conducted an ethical analysis, and discussed the benefits and burdens of CPR. Finally, they made a recommendation about the applicability of the Doing No Harm

Figure 1.
Flow Diagram of Cohort Study



policy and the appropriateness of offering or not offering CPR. The ethical analysis and recommendation were then entered into the medical record. As part of this process, ethics consultants engaged stakeholders, meeting with the medical team and surrogate(s) separately or together, as appropriate. In all cases in which the ethics committee recommended not offering CPR and a DNR order was written, this decision and its rationale were discussed in detail with the patient or surrogate, in accordance with the policy.

As part of a broader empirical project, we reviewed existing data available in the patient’s medical record and notes from the ethics consultation about all ethics committee consults between 2007 and 2013 (see figure 1).¹⁹ A little less than half of these cases (n = 134 [42.7 percent]) involved disagreement between

health professionals and patients or surrogates about whether to provide CPR in the event of cardiac arrest. In approximately a third of the cases involving disagreement (n = 45), the patient or surrogate agreed to a DNR order after the initial ethics consultation without the invocation of the Doing No Harm policy. In the remaining eighty-nine cases, the ethics committee recommended offering CPR in twenty-two (24.7 percent of the cases). In the other sixty-seven cases (75.3 percent), the ethics committee recommended not offering CPR. In sixty-one (91 percent) of the cases in which the ethics committee recommended not offering CPR, the medical team implemented the recommendation and informed the surrogate that a DNR order would be written. In six cases, the physicians refused or decided not to order the recommended DNR. We found

no relationship between age, race, or functional status and the ethics committee’s recommendation regarding CPR. Patients who were not offered CPR were more likely to be critically ill. The ninety-day mortality rate among patients who were not offered CPR was 90.2 percent, and all of the longer-term survivors experienced complete dependence in their activities of daily living.

Surrogates involved in the sixty-one cases in which a medical DNR order was written had multiple responses. Some apparently accepted the order quietly, at least according to the account in the medical record. In other cases, they refused to accept a less aggressive approach when CPR was no longer being offered, perhaps because, earlier in the hospitalization, when the patient’s prognosis was different, surrogates were directly asked whether they wanted CPR performed.²⁰ Many of these surrogates struggled with the DNR order but eventually accepted it. In nineteen, or approximately one-third, of the cases in which a DNR was ordered, surrogates did not accept the order and had an ongoing conflict with the medical team.²¹ It is these nineteen cases we analyze in detail, not as a complete evaluation of the Doing No Harm policy but as a description of the patients and surrogates who continued to object once the policy was invoked.

Because of the small number of cases, standard quantitative comparisons did not identify significant sociodemographic or clinical differences between patients and surrogates who accepted or rejected the decision not to perform CPR once the policy was invoked. To better assess these differences, we inductively analyzed ethics committee notes and medical records of nineteen patients whose surrogates did not accept the decision to withhold CPR. While additional data are needed that enable the surrogates to speak directly to researchers rather than through medical records or notes, we began this analysis based on the resources available. The

institutional review board at MGH approved the study.

Continued Conflicts

Almost all of the nineteen patients whose surrogates did not accept the decision to withhold CPR were intubated, sedated, or otherwise unable to participate in treatment decisions. The demographic characteristics of these patients and surrogates are summarized in table 1.²² Surrogate decision-makers in these cases were almost all immediate family members, typically an adult child and less frequently the spouse. Family dynamics were often complex, including adult children in conflict, multigenerational living arrangements, caregivers who had left paid work to care for the patient, and adult siblings both present and at a physical distance trying to make decisions together. Several broad themes emerged as we analyzed these cases.

Persistent surrogates. First, the surrogate decision-makers in these cases were what we term “persistent surrogates.”²³ They persistently requested CPR following the physician-ordered DNR despite unanimous agreement among the patient’s care team that CPR would be nonbeneficial or more harmful than beneficial. Ethics notes indicated that these surrogates were often not amenable to what the staff considered reasonable discussion about the patient’s situation. In interactions regarding treatment in the hospital, they sometimes identified favorite nurses and physicians and rejected clinicians who shared what the surrogates perceived as “bad news,” often accusing them of giving up or blaming them for setbacks in illness or treatment. Many resisted or declined social work or chaplaincy support for themselves or their loved one. Ethics notes suggest that these surrogates were either a constant presence at the patient’s bedside or a rare presence with only occasional, short visits to their loved one. While we do not know how the surrogates would describe these situations themselves,

Age in years	75.7 ± 3.4
Number of females	9 (47.4%)
Number of nonwhites	8 (42.1%)
Number whose primary language was not English	3 (15.8%)
Number born outside the United States	9 (47.4%)
Number who resided at home prior to admission	8 (42.1%)
Number who were completely or partially dependent prior to admission	17 (89.5%)
Median number of those with major medical comorbidities on admission (with the interquartile range)	3 (2-4.5)
Days from admission to ethics consultation	15.3 ± 6.4
Number seen by one of these consulting services:	
medicine	13 (68.4%)
general surgery	4 (21.1%)
other	2 (10.5%)
Number hospitalized in an intensive care unit	10 (52.6%)
Median number of life-sustaining treatments at the time of consultation (with the interquartile range)	3 (2-4.5%)
Number with official health care proxy documentation	6 (31.6%)
Number whose surrogate decision-maker was	
an adult child	11 (57.9%)
a spouse	7 (36.8%)
other (parent, sibling, friend, legal guardian)	1 (5.3%)
Number who had more than four meetings held	7 (36.8%)

staff members described the surrogates as being unaware of or unable to respond to the patient’s physical pain, often objecting to pain medications, or appearing unable to acknowledge the patient’s impending death.

The case of Ms. Brown, age eighty-six, provides an example. This frail, elderly woman entered the hospital with deep wounds and inadequate nutrition and on large doses of opiate pain medication.²⁴ Her daughters were constantly present, and Ms. Brown deferred to them on all questions intended to assess her pain. The daughters refused some treatments for their mother’s pain on her behalf. Ethics consultants wrote in their notes, “[H]ealth professionals believe that

the mother-daughter relationship is having a negative impact on the autonomy and well-being of this patient.” Due to conflicts with teams in previous institutions, the patient had a history of being moved between health care facilities and, the team believed, not having her pain treated effectively. Ethics notes suggested that her daughters seemed unable to separate themselves from their mother and to agree to what clinicians considered to be adequate pain management. Ms. Brown’s daughters also continued to request CPR after the attending physician, critical care consulting physician, and ethics consultant suggested that cardiac resuscitation would be nonbeneficial and

harmful and decided that it would not be provided, citing the hospital's Doing No Harm policy.

In a case similar to Ms. Brown's, ethics notes also suggest that Mr. Finch's surrogate had difficulty accepting that her father, an eighty-year-old with multisystem organ failure in the intensive care unit, was dying. He had also been transferred between health care facilities during the course of multiple illnesses and chronic medical conditions. According to the ethics notes, his surrogate decision-maker did not support interventions that providers thought would address his pain. The surrogate decision-maker continued to request CPR, even when Mr. Finch was actively dying. In these cases, if surrogates had difficulty recognizing that the patient was in pain or suffering, it may be that they were less likely to perceive CPR at the end of life as being a burden or as being harmful.

The data we analyzed also suggested that some surrogates made decisions contradicting or overriding patients' stated wishes in advance directives. For example, Ms. Smith, age eighty-five, was admitted with aspiration pneumonia and a history of two significant strokes affecting her ability to communicate. She had an advance directive that provided clear guidance about how she wanted to be cared for in her final days: she did not want resuscitation or medically supplied nutrition and hydration. At both her nursing home and in the hospital, Ms. Smith had been refusing oral feeding. Marilyn, Ms. Smith's daughter and surrogate decision-maker, advocated for oral feeding, arguing that she did not believe her mother was nearing death and, therefore, the advance directive did not apply. Marilyn said that she did not want her mother to suffer and disagreed with clinicians who believed that her mother was in pain based on clinical signs. Ethics notes indicate that Marilyn pressured health care staff to continue a range of interventions and to keep her mother in the hospital rather than return her to the nursing

home, as Ms. Smith had requested in her advance directive.

While health care teams generally understand surrogate decision-makers to be individuals who provide substituted judgment for patients, some of the ethics committee notes suggest that surrogates experience this role differently. Notes suggest that some surrogates, rather than aiming to provide substituted judgment for the patient, made decisions based on ideas, fears, or values different from the patient's. These ideas included "not wanting to be responsible for the patient's death," "maintaining the life of the person I care about," and "being an advocate." Based on comments to ethics committee consultants and other staff members, some surrogates prioritized the commitments of their relational role (daughter, husband, sister, and so on) over their obligations as a surrogate decision-maker. This is not surprising, given that surrogates were much more familiar with their relational roles and had been in them much longer than in their role as surrogate decision-maker. The disconnect between what health care providers expected and how surrogates understand their role as decision-maker seemed to drive many of the conflicts around CPR both before and after the ethics committee was involved. This role strain and disjunction between what medical staff members understood surrogate decision-makers to do and the ways some surrogates experienced their roles are important and require further exploration.

Limits of medical science. As they disagreed with physician's orders to not perform CPR, some surrogates made arguments about death and dying that were at odds with how death frequently happens in intensive care settings. Several said they could accept the death of their loved one if it happened "naturally" but could not make decisions to hasten their death. This was also the case when physicians explained that the decision to withhold CPR in the event of an arrest would not bring about that

arrest more quickly and would actually allow for "natural death" to occur. Probably because they were not familiar with how death happens in technologically sophisticated intensive care units or because health care providers were not able to explain it, it was not possible for surrogates to see that the "natural" deaths they wanted for their loved ones were being prevented by life-sustaining treatment. While sociologists of medicine have long described this incongruence, surrogates did not have the experience or appear to have social support in the midst of these crises to address this contradiction.²⁵

Ideas about God and religion or spirituality were also present in some but not all cases. For Mr. Green, a seventy-nine-year-old with advanced dementia, the family's religious beliefs played a role in their insistence for CPR even as he was dying. Maria, Mr. Green's daughter and surrogate decision-maker, invoked a higher power, stating that only God could decide when a person was ready to die. She saw medical interventions including CPR, however, as part of God's plan rather than as impeding a natural death. In another case, Marcy was the surrogate of her sixty-one-year-old mother who had had a devastating stroke leading to a persistent vegetative state and multiple medical complications. Marcy did not agree to a DNR order, wanting to give God as much time as possible to enact the hoped-for miracle. Attempts chaplains and others made to reframe her belief in miraculous power were ineffective.

While some surrogates presented their objections in religious terms, this was only one of many ways surrogates articulated their concerns. For example, in the case of a fifty-nine-year-old man with irreversible cardiac, renal, and respiratory failure, the patient's daughters, who were his surrogate decision-makers, said that their father asked them not to let him die. They thought it would be "okay if he died in his sleep at home" but wanted everything done for him in

the hospital and said that they “would never make a decision to end their father’s life.” The medical team did their best to communicate that their father’s condition was terminal and that they could not keep him alive. The surrogate decision-makers, however, persisted, and physicians agreed to maintain a full-code status up until the final moments of the patient’s life, at which time a DNR order was entered. The surrogates continued to resist this order when it was entered.

Similarly, the surrogate of Mr. Jones, an eighty-year-old man with irreversible respiratory failure and multiple other comorbidities, stated that she had promised her husband she would do everything she could until his heart stopped. The health care team tried to explain the situation but could not relieve his wife from the burden of the promise to her husband. She requested every possible measure and was not able to contextualize her husband’s request in the setting of his progressive, irreversible decline.

Throughout these cases, we wondered if decisions about CPR became broadly symbolic to family members, representative of more than just what would happen if the patient’s heart stopped. Chart notes suggested that surrogates felt the decision around CPR represented the medical team’s act of giving up on keeping the patient alive rather than being a decision not to escalate treatment if an arrest occurred. Many of the involved patients continued to receive extremely aggressive treatments after the decision not to administer CPR. Part of what made some surrogates reject this decision, we suspect, was the perception that the treatments patients were receiving were somehow less than what they would have received if CPR were still an option. This impression persisted in spite of clinicians’ and ethics consultants’ efforts to communicate otherwise. In contrast, surrogates who accepted the decision to limit CPR seemed to better understand that this was different from a decision to limit active

life-sustaining treatment. As evident in these examples and the research literature more generally, many persistent surrogates struggle with their role and with making any decisions other than to continue all treatments.²⁶

Recommendations

These nineteen cases suggest that, although the majority of surrogates will eventually accept a decision not to offer CPR, there are some surrogates who will persist in their request for CPR that medical providers consider inappropriate. Conversations with health professionals and ethicists across the country suggest to us that this is not an experience

surrogates were asked whether or not they would want CPR performed, we suspect that many surrogates were presented with CPR in the event of an arrest as an unrestricted option. It is unsurprising, then, that conflict might develop as health professionals’ opinions on the appropriateness of performing CPR changed. We believe that some of the cases we reviewed could have been prevented by following critical guidelines that recommend against providing an array of treatment options. Instead, clinicians should elicit information about the patient’s values and beliefs about an acceptable quality of life that could inform substituted judgment and that can be integrated into clini-

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unique to our institution and ethics committee. Addressing the suffering of patients, surrogates, and the health care staff members who care for persistent surrogates is impossible without adequately understanding these cases. Our experience suggests some strategies that may help engage with and support persistent surrogates after the DNR order is written.

Protecting patients from harm.

There is a clear role for ethics consultation and hospital policy in these challenging cases. By the time ethics consultants are involved, neither time, emotional support, nor what health professionals consider compassionate truth telling has led to a resolution. Because expectation-setting and appropriately framed discussions about CPR can be essential at the beginning of a patient’s clinical course, we recommend early ethics consultation when there are concerns about the possibility of conflict. Although we do not have data on how often during the initial days of hospitalization

cal decision-making.²⁷ In addition, having clinically engaged ethicists and ethics committee members embedded in the routine care of patients through interprofessional and unit-based ethics rounds can identify cases in a timely manner. This, in turn, can help health care providers work to set more realistic expectations for families earlier in the hospitalization.²⁸ Although ethics consultation does not always bring consensus, ethics consultants are knowledgeable about policies, empirical literature, and position statements that can direct health professionals when the clinical scenarios call for more directive resolution.

Maintaining focus on the patient, regardless of whether he or she is able to speak, is essential to the consultation process. In cases in which the patient is able to interact, we encourage ethics consultants to have at least one discussion without the surrogate directly involved. We have found that patients will often refrain from

articulating a contradictory view in the presence of a persistent surrogate and will instead acquiesce to the surrogate's point of view. Meticulous documentation of differing views is essential, including in cases in which the patient can clearly articulate a perspective aligned with the surrogate's, even if it means greater suffering. Regardless of a surrogate's objections, it is also important to observe and treat the patient's underlying pain and symptoms as either a consequence of the disease process or the patient's response to basic or invasive nursing care and interventions.²⁹

Ethics consultants can also encourage clinicians to engage other senior physicians, and, where appropriate, critical-care consultants, to provide second and third opinions. This can widen consensus or present alternative strategies for resolution. And, when consultants or clinicians invoke hospital policies, it is important to emphasize that careful thought and revision have gone into their development. These policies have usually been crafted by ethics committees, with the input of senior physicians and nurses, critical-care committees, and hospital legal counsel, and typically represent years of consensus building within the institution.

Supporting surrogates. Even if ethics consultation results in the invocation of a limitation of a life-sustaining treatment policy, we recommend that the ethics consultants remain involved. We have found anecdotally that surrogates who manifest the characteristics and behaviors we describe are often isolated within their own families and communities and are particularly vulnerable during the patient's impending death. We encourage health professionals to consider present and future coping by the surrogate. With the support of the ethics consultants, the health care team can employ compassionate interventions to support these surrogates. When invoking Doing No Harm or a similar policy, we advocate that, when informing the surrogate, the message be accompanied with

skilled, sincere, and compassionate support.

The nineteen cases we describe all involved surrogates who disagreed with the DNR order verbally and behaviorally. Rather than engaging this resistance, physicians, health professionals, and ethics consultants should set limits clearly and use nonconfrontational language, such as, "I'm sorry. I wish this could be different for your loved one, and physicians/nurses have tried their best to make him/her better, but he/she is now dying, and this is what we must do. We'll stay with you and support you." Surrogates may respond with a request to transfer the patient to another hospital. When this occurs, we recommend that physicians and interprofessional teams acknowledge that this is the surrogate's right but express hope that he or she will not exercise this option. Language such as this could be used: "You do have the right to request transfer, of course. However, we believe that your loved one is at the end of his/her life, and we believe that moving him/her would be difficult for him/her. We prefer to care for your loved one and for you here."

We have found that when physicians and health professionals affirm their desire to care for the patient and their commitment not to abandon the surrogate, it may disabuse one myth that a mistrustful surrogate carries, namely, that the decision to withhold CPR reflects an uncaring team, financial considerations, or discrimination of any kind. Setting limits in this way can take great moral courage for providers given anxiety, particularly among physicians, about litigation.³⁰ There may be a tendency for clinicians and the surrogate to fall into a polarized stance, but we advise clinicians not to succumb to this. A consciously chosen, compassionate, and nondefensive stance may be more effective. For care and communication to be as good as possible in these difficult cases, strong interprofessional teams that include social work and chaplaincy members

are needed to support physicians and nurses at the bedside.

Consistent with our policy, we believe that optimum care in these cases is best achieved with institutional policies on setting limits on shared decision-making about CPR, contingent on state law and judicial precedent, rather than removal of the surrogate in a court proceeding. Anecdotally, the former is less devastating to the surrogate and may have a more positive effect on a difficult grieving period for the surrogate after the patient's death. Surrogate removal may also represent an additional harm to the patient, particularly in cases when she or he has specifically designated the surrogate as the health care agent. If limits can be set while still allowing the surrogate to represent what he or she perceives as the patients' wishes, the patient's prior preferences in designating an agent are respected. This recommendation is best illustrated through the case of Mrs. Smith. In the final twenty-four hours of her life, Mrs. Smith's nurse addressed what she believed might be her patient's worries about her daughter and health care agent, Marilyn. The nurse stated, "Mrs. Smith, we will take care of Marilyn; don't worry." After the nurse's statement, tears trickled down the patient's cheeks—she knew about her daughter's conflict with her caregivers and seemed to acknowledge the team's efforts. Removing Marilyn as health care agent would have been an additional harm to the patient at the end of her life.

Finally, to provide compassionate support to surrogates, the team should sustain the caring practice until the end of the patient's life and in the surrogate's immediate transition from the hospital to a life without the patient. When the patient is actively dying, paying attention to how the surrogate is getting home and whether anyone, family or friend, can be present is of high value and may require persistence and probing on the part of a social worker, nurse, or chaplain. Assuring that the surrogate has a meal, a parking ticket or

taxi voucher, and a connection to a funeral home represents quality care.

Maintaining the integrity of the health professions. Health professionals are also stakeholders in these cases. To allow nonbeneficial or harmful treatment is to tolerate behavior that may damage the moral integrity of individual health professionals. Permitting patient suffering erodes health professionals' moral sensitivity, creating a norm of tolerance toward providing treatments that are medically ineffective, do not contribute to the patient's recovery, and impose harm without benefit. Health professionals' experience of preventable patient suffering can become normalized, subverting the reasons they entered the profession and leading to burnout and disengagement.³¹ Acknowledging the emotional distress and suffering among health care professionals in the idea of having to provide potentially nonbeneficial interventions at the end of life and the way that these feelings may drive conflict is an equally essential role of the ethics consultant. This is especially important in cases in which the committee believes that offering CPR would be inappropriate.

Resolution in these cases takes time and patience on the part of all parties. We believe that health professionals can best be supported in providing appropriate care when there is a process, guided by ethics consultants and ethics committee leadership, that aims to protect the patient from harm, treats the surrogate compassionately, and hears the voices of health professionals who aim to provide ethically responsible care. These policies, along with institutional support, allow attending physicians to be supported in the goals of their profession, to first do no harm.³²

Limitations and next steps. Our paper has several methodological limitations, including our reliance on medical records for our qualitative analysis. Although our study of the records led us to believe that there were some important themes in these cases—for example, many surrogates

seemed to have risk factors for what has been called complicated grief in the broader literature on end-of-life decision-making—we were not able to confirm these observations without direct interaction with surrogates.³³ In addition, because MGH has one of the largest and most active ethics consult services in the country, our experience may not be generalizable to smaller committees or to hospitals in states with different regulations regarding DNR orders or other institutional approaches to these conflicts. Finally, our aim was not to address broader concerns about due process and the appropriateness of having

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hospital ethics committees play the role we describe here.³⁴ Although we believe our empirical experience suggests that these committees have an essential role in conflicts over life-sustaining treatment, it is important to acknowledge that the extent and nature of this role remain in need of ongoing reflection.³⁵

Third, our emphasis was on the cases in our study cohort in which CPR was not offered. We did not explore the six cases in which physicians offered CPR despite the recommendation of ethics consultants that it would be appropriate to write a DNR order. We do not know whether health professionals offered CPR as a way of acknowledging the symbolic importance of a code, because of an emphasis on benefit to the surrogate, because they felt that they were honoring the patient's wishes, because of litigious concerns, or because of concerns about insufficient institutional support. None of these patients survived resuscitation when it was attempted, but we do not have any information as to whether surrogates derived symbolic meaning from these

codes or were more satisfied with patient care in these cases.³⁶

In keeping with professional society guidelines, however, our ethics committee does not support the use of “show or slow codes” or resuscitation efforts that are intended to benefit third parties and not to achieve the actual physiological purpose of CPR.³⁷ We are concerned that, in actual clinical practice, physicians would be unlikely to disclose that they plan on limited or partial resuscitation.³⁸ Intentionally misleading a patient's surrogate through a sham resuscitation is harmful to the surrogate and, by extension, the patient

who chose that person to represent his or her interests. Undertaking a slow resuscitation in a dying person for whom CPR has no benefit also prevents patients and families from spending their last moments together. In these cases, the focus stays on the health professionals' efforts, not the patient.

While there may be scenarios in which clinicians can fully inform surrogates that CPR is not recommended and that it will be performed only for a short time or without full effort, in our experience, surrogates do not want merely a limited attempt at CPR. At the heart of these conflicts is a persistent surrogate's request that the patient undergo every possible intervention. We find it unlikely that the surrogate would be satisfied with a simulacrum of resuscitation. Finally, we note that the attending physician involved in complex code-status questions is often not present during an actual arrest, leaving a colleague, house staff, a respiratory therapist, and bedside nurses to interpret appropriate resuscitation efforts. Since these codes are, by definition, outside of the usual scope of clinical practice,

it is unlikely that there would have been any clear consensus on starting or stopping conditions or even on what constitutes the “appropriate” administration of medications. Ultimately, we believe that show and slow codes represent one final indignity to the patient that can further undermine surrogate trust and the moral integrity of health professionals.

The cases reported here, in the context of a larger series, demonstrate that most surrogates at our institution accept when CPR is not offered. A small fraction of surrogates, however, do not agree with this decision. Individuals in this group manifest a constellation of characteristics and behaviors captured in the idea of a persistent surrogate. While we have described these surrogates based on information available in medical records and ethics notes, we hope this is a step toward future research that also assesses these situations from the point of view of surrogates themselves and the ongoing questions about the best approach to resolving these conflicts. Future research should also attempt to identify early predictors for this kind of ethical conflict and to work toward interinstitutional collaboration in policy development and implementation.³⁹

Notes

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16. W. J. Ehlenbach et al., “Epidemiologic Study of In-Hospital Cardiopulmonary Resuscitation in the Elderly,” *New England Journal of Medicine* 361, no. 1 (2009): 22-31; J. Tian et al., “Outcomes of Critically Ill Patients Who Received Cardiopulmonary Resuscitation,” *American Journal of Respiratory and Critical Care Medicine* 182, no. 4 (2010): 501-06. The complex and important question of fully defining burdens, benefits, and harms of CPR is beyond the scope of this paper, which primarily focuses on the utilization of the policy. Important considerations regarding the justification of these types of policies can be found in J. Billings, J. Andrew, and E. L. Krakauer, “On Patient Autonomy and Physician Responsibility in End-of-Life Care,” *Archives of Internal Medicine* 171, no. 9 (2011): 849-53; Blinderman, Krakauer, and Solomon, “Time to Revise the Approach to Determining Cardiopulmonary Resuscitation Status.”

17. The Doing No Harm policy was subsequently revised in 2014 to require rather than recommend ethics committee consultation in all cases in which physicians were considering withholding CPR from a patient who was not imminently dying. In our experience prior to this revision, the Doing No Harm policy was rarely if ever invoked without ethics committee involvement given the complexity of the ethical and legal issues involved. This revision was made primarily to emphasize the importance of ethics consultant participation in decision-making about not offering CPR.

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19. A. M. Courtwright et al., "Experience with a Hospital Policy on Not Offering Cardiopulmonary Resuscitation When Believed More Harmful Than Beneficial," *Journal of Critical Care* 30, no. 1 (2015): 173-7.

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21. Given that CPR was not offered for the patients of all of the surrogates in our cohort but the surrogates still refused to acknowledge or consent to the DNR order, when it was written, this order was, by definition, made over their objections.

22. For full definitions of the table variables, see Courtwright et al., "Experience with a Hospital Policy on Not Offering Cardiopulmonary Resuscitation When Believed More Harmful Than Beneficial."

23. We use the phrase "persistent surrogates" descriptively rather than normatively to describe surrogates who persistently and repeatedly asked for their loved ones to remain full code. While we considered other terms—"surrogate demanders," "resistant surrogates," "demanding surrogates"—we settled on this phrase as the best way to characterize these individuals

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28. L. J. Schneiderman et al., "Effect of Ethics Consultations on Non-beneficial Life-Sustaining Treatments in the Intensive Care Setting: A Randomized Controlled Trial." *Journal of the American Medical Association* 290, no. 9 (2003): 1166-72.

29. Mass. Gen. Laws, Ch. 201D, § 13, Pain Alleviation: Comfort Care Procedures.

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32. E. D. Pellegrino, "Toward a Reconstruction of Medical Morality," *American Journal of Bioethics* 6, no. 2 (2006): 65-71.

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Tomarken et al., "Factors of Complicated Grief Pre-Death in Caregivers of Cancer Patients," *Psychooncology* 17, no. 2 (2008): 105-11; R. Neimeyer, "Bereavement and the Quest for Meaning: Rewriting Stories of Loss and Grief," *Hellenic Journal of Psychology* 3, no. 3 (2006): 181-88; N. M. Simon, "Treating Complicated Grief," *Journal of the American Medical Association* 210, no. 4 (2013): 416-23.

34. See Pope, "The Growing Power of Healthcare Ethics Committees Heightens Due Process Concerns," and E. Rubin and A. Courtwright, "Medical Futility Procedures: What More Do We Need to Know?," *CHEST* 144, no. 5 (2013): 1707-11.

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