Rites and Responsibility for Resuscitation in Heart Failure
Tread Gently on the Thin Places

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In Celtic mythology, there are pieces of ground considered to be “thin places” where the measured world comes closest to the infinite. Such places may have been set apart for burial grounds and other ritual sites. The Celtic phrase describing them derives from the Latin *limen*, a threshold or frontier where 2 countries meet (the root of “subliminal”). As physicians, we bear the privilege of escorting patients and families over the thin places. Krumholz and his colleagues have ventured to this border to provide valuable information as we ponder our responsibilities there.

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Rights of Resuscitation

Once considered to be heroic, resuscitation has become routine. Communities are trained in CPR, defibrillators are on hand at many sporting events, and paramedics provide full advanced cardiac life support services in the home. The majority of patients admitted to hospitals seek survival, regardless of the severity of chronic illness. In 1 study, 90% of hospitalized patients expressed preference for resuscitation if their admission level of function could subsequently be restored. Of patients older than 55 years who had been discharged after an intensive care unit stay, 74% were certain that they would undergo another intensive care unit stay to prolong survival for as little as 1 month of additional life. In the current study, only 23% of patients stated that they did not wish resuscitation, and 40% of such patients subsequently changed their minds in favor of resuscitation.

As patients live longer with chronic illness, death offers a welcome end to suffering for some, who should be allowed to take that journey unhindered. The majority of patients and their families appear to be anxious primarily to avoid prolonging a vegetative existence or dependency on mechanical ventilation. Fear of constant severe pain is also a common concern. The frequency of do-not-resuscitate (DNR) orders has increased over the last decade, even before the Patient Self-Determination Act of 1991, which requires hospitals to develop written policies concerning advance directives, to seek and record information regarding advance directives from all admitted patients, to give patients written information on such directives, and to educate the staff and community.

Resuscitation in Heart Failure

The number of hospitalizations for heart failure far exceeds those for AIDS and almost equals the number for all types of cancer combined. The prognosis from the time of diagnosis for patients with heart failure has been compared with that for some types of cancer and for patients hospitalized with AIDS. Unrelieved breathlessness from heart failure can be oppressive and debilitating. Despite these similarities to other terminal illnesses, DNR orders are less common in heart failure; in 1 large experience, such orders were written for 5% of patients admitted with heart failure, 47% of patients with unresectable malignancy, and 52% of patients with AIDS.

Does the lower rate of DNR orders for heart failure indicate inadequate communication with patients with heart failure, as has been suggested? Multiple differences between heart failure and other chronic diseases may profoundly influence patient and physician decisions regarding resuscitation during hospitalization. For many patients, the course of heart failure is one of long periods of stability interrupted by brief episodes of decompensation. During those episodes, both the distress and relief can be dramatic. Many of the factors leading to hospitalization for heart failure are reversible, allowing most patients to regain and maintain freedom from the congestion that limits daily activity. Independence and the ability to care for themselves rank highly in patients’ desires for resuscitation and may explain in part the low rate of DNR orders in heart failure compared with other diseases.

Hospitalization for heart failure does not usually herald inexorable decline, as indicated both by the low in-hospital mortality rate (3.4%) compared with more than 26% for patients with other chronic diagnoses and by the lower 6-month mortality rate (22.5% compared with more than 50%). Even a cardiac arrest in the hospital does not portend end-stage disease but can occur at any time in heart failure, a condition associated with electrically unstable myocardium, rapid electrolyte fluxes during diuresis, and potentially arrhythmogenic drugs.

Comprehensive management of heart failure is recommended to include education of patients and, equally importantly, their families about what to expect as the end of life. Most death in heart failure is unheralded by narcotics, hospice care, or bedside reconciliation. In the Vasodilator in Heart Failure (V-HeFT) trials, 64% of the cardiac deaths occurred suddenly, and only 30% of those sudden deaths were preceded by any reported worsening of cardiac symptoms.
Most patients with heart failure and their families fear unexpected death more than unwanted prolongation of life.

Different DNR Decisions

The study in this issue of Circulation highlights differences between patients with heart failure and their hospital physicians regarding resuscitation. Any study of this question faces multiple limitations regarding the timing and relevance of interviews for study purposes, which the authors have enumerated well. In addition, the question to the patients in this study emphasized the breathing machine, which may trigger particular reluctance from patients whose greatest fear is “being a vegetable.” From physicians, concern has been raised regarding the impact of a DNR order on intensity of other care, an example being intravenous inotropic infusions, which in some institutions are given only in critical care units. Physicians may worry that a DNR order could be translated as “Do not treat.” Although ostensibly a binary decision, plans regarding resuscitation may be further refined in the chart as “Do not intubate” and “chemical code only,” or in verbal communication as “slow code” or “short code.” There is no easy way to analyze these local variations.

Even with these methodological constraints, the degree of concordance between patients and physicians regarding resuscitation in heart failure is encouraging. Physician agreement with the resuscitation decisions was present for 76% of all patients in this study and was 84% for patients who did not subsequently change their mind, suggesting that physicians in some cases have a more accurate perception of the patient’s ultimate wishes than the patient himself when suffering from acute decompensation. The concordance was greater than that described for the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) population with other diagnoses, although the reported frequency of explicit DNR discussion was actually lower.

In contemplating DNR decisions, both patients and their physicians were strongly influenced by the perceived prognosis of the disease. The greater experience from which cardiologists assess and communicate this prognosis may have contributed to the 44% lower rate of patient-physician discordance for cardiologists compared with noncardiologists. A major factor determining the physicians’ decisions regarding resuscitation were their own preferences given the same situation. This is not necessarily a shortcoming. The instinct to imagine ourselves sharing the fate of others seems in fact one to be fostered.

Direct physician-patient discussion regarding the details of resuscitation orders has been suggested as a necessary rite for compassionate care of patients hospitalized with chronic illness. In this study of patients with heart failure, slightly less than half of patients not exposed to such discussion responded that they would have preferred one. There is insufficient information regarding how patients feel after this experience, this would be predicted to result in 7 patients who preferred no resuscitation but did not occur. This would have to be weighed against a potential benefit, also unmeasured, for those patients who might be relieved that their preferences were noted.

Another strategy would be to ask all patients about their preference early during hospitalization and to abide by that preference. One potential “cost” of this strategy would be the failure to attempt resuscitation in those whose ultimate decision, although not their initial one, would have been for resuscitation. Another immeasurable “cost” is the anxiety of 894 hospitalized patients and perhaps their families, who were urged to make decisions regarding cardiac events that did not occur. This would have to be weighed against a potential benefit, also unmeasured, for those patients who might be relieved that their preferences were noted.

The weight of regret for a decision error is lighter for an unwanted resuscitation than for a failure to resuscitate someone who wants resuscitation. Based on this, a selective strategy would be to discuss resuscitation during hospitalization only with those patients whom the physician, lacking a prior chance to discuss resuscitation, believes are likely to prefer not to be resuscitated. This would potentially have caused 4 patients to be resuscitated “incorrectly.” As only 1 of 6 patients in this experience survived unwanted resuscitation, the actual “risk” of unwanted survival during heart failure hospitalization would be only 0.07%, a risk lower than that for complications of common cardiovascular procedures.

The strategies described above assume that the patient does not volunteer any information regarding prior resuscitation decisions. Although written advance directives are still relatively rare, patients in the current study who did not desire...
resuscitation were twice as likely to have discussed the issue specifically with their physicians.

The models of DNR decision-making calculations do not assign values to different scenes of death. For patients without expected recovery of cognitive function, there is increased consensus and comfort with DNR orders. For other patients, we are at times exhorted to curtail our resuscitative efforts in order to ensure “death with dignity.” Gerard Guiraudon, the noted Canadian cardiac surgeon, was overheard to answer a group of young colleagues advocating dignity, “I would feel honored if the end of my life were attended by a team of highly skilled professionals endeavoring to prolong it.” The rites of resuscitation are not the last. Regardless of the details of the final days, life and its end acquire a dignity that physicians can neither bestow nor withdraw.

Future Resuscitation for Heart Failure

In a ideal circle of care, the issues of prognosis and preference for resuscitation would initially be addressed in the outpatient setting, as recommended by multiple physician groups and revised as needed during hospitalization. The urgency of this discussion would be greater for those patients with more severe disease, those patients whom the physician believes would not want resuscitation, and perhaps for elderly patients, suggested by this study to have less predictable preferences. Interpretation of such discussion should be colored by the mood of the patient, shown to be a major factor in unstable preferences regarding resuscitation. The value of continuity in making these decisions must be considered as we anticipate the impact of dividing care between clinic physicians and “hospitalists” for a chronic illness such as heart failure.

The decisions made by doctors regarding DNR orders have not determined many outcomes in heart failure, in which the preference for resuscitation is high and the in-house arrest rate is low (4% in this study). Death from heart failure still occurs out of the hospital in the majority of cases. One important issue for improving future care, beyond the scope of the current study, is how to make information from advance directives available to paramedic response teams and emergency rooms.

Sudden death strikes as a double-edged sword in heart failure. It can fell patients at a time when they might otherwise have enjoyed longer productive lives. In the other direction, sudden death offers relief for patients whose progressive symptoms otherwise threaten to become crippling, a feature that has until now lightened the weight of this disease for the patient, family, and physician.

The advent of effective devices to treat rhythms responsible for sudden death in heart failure will diminish the dual effects of sudden death. Almost 40,000 cardioverter-defibrillators will be implanted this year in the United States alone, with an estimated 20% increase yearly for present indications. Currently, these devices are intended for patients in whom tachyarrhythmias are not incessant and heart failure is sufficiently compensated that a fatal dysrhythmia would be unwelcome. Device inactivation is now occasionally requested by patients with intractable arrhythmias causing repeated shocks, or patients with heart failure symptoms that become intolerable. Such requests will become more frequent, however, as heart failure remains a disease of progression, despite the favorable impact from optimal use of angiotensin-converting enzyme inhibitors and β-adrenergic blocking agents.

Appropriate concerns have been raised by the SUPPORT study, but current decisions regarding resuscitation have been more critical for other terminal illnesses than for heart failure, in which the majority of deaths occur out of the hospital.
When patients carry the tools of resuscitation inside them, these decisions will mandate more active intervention. Although internal defibrillation may be more difficult in settings of hemodynamic compromise, immediate success remains likely, whether or not it is welcome. Farther ahead, even greater challenges will be presented by the relentless performance of implantable circulatory support devices.

Although we do not yet know the best way to encourage effective communication between patients and physicians, the current study provides a framework that will help us to address the more complex decisions arising in the future. Patients, families, and physicians will participate to rewrite the natural history of heart failure. As we lean to break new ground beside the thin places, we shoulder more responsibility to preserve them.

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References

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