Resuscitation Preferences in Community Patients With Heart Failure

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Background—Little is known about the resuscitation preferences of patients with heart failure, how they may change over the course of the disease, and their association with mortality.

Methods and Results—We enrolled consecutive Southeastern Minnesota residents with heart failure from October 2007 through September 2011 into a longitudinal study. Information on resuscitation preferences (Full Code or do-not-resuscitate [DNR]) was obtained from medical records through April 1, 2013. Of 608 patients enrolled, 237 died during follow-up. At enrollment, most patients (73.4%) were Full Code, whereas at death, most (78.5%) were DNR. The independent predictors of DNR status at enrollment were advanced age, chronic obstructive pulmonary disease, previous malignancy, and decreased mobility. Patients who were DNR were at increased risk of death (unadjusted hazard ratio, 2.03; 95% confidence interval, 1.48–2.73; P<0.001), but this risk did not persist after adjusting for age, comorbidity, and self-perceived general health (hazard ratio, 0.97; 95% confidence interval, 0.74–1.30; P=0.83). Of 481 patients who were Full Code during follow-up, 22 (4.6%) received cardiopulmonary resuscitation for an in-hospital cardiac arrest. Eight patients survived to hospital discharge; only 2 (9.1% of those receiving cardiopulmonary resuscitation) made a complete recovery and returned home. The median time from a final decision to be DNR until death was only 37 (7,70) days.

Conclusions—The resuscitation preferences of patients with heart failure seem to be driven by the decline in clinical status that often accompanies advanced age and multimorbidity. Furthermore, these data suggest that electing DNR status does not independently affect a patient’s risk of death. (Circ Cardiovasc Qual Outcomes. 2014;7:00-00.)

Key Words: cardiopulmonary resuscitation ■ epidemiology ■ heart failure ■ survival

Nearly 5% of the 5 million Americans living with heart failure (HF) have end-stage disease that is refractory to medical care (stage D HF).1 End-of-life care for patients with HF is of particular importance because patients often experience repeated hospitalizations and a progressive decline in quality of life as they approach death.2,3 Although HF confers a prognosis worse than many cancers,4 patients with HF are known to receive life-sustaining treatments, such as mechanical ventilation and cardiopulmonary resuscitation (CPR), and to request do-not-resuscitate (DNR) status later in their disease course compared with patients with cancer.4 Understanding patients’ preferences regarding resuscitation is important in providing patient-centered care in alignment with patients’ treatment goals. However, little is known about the resuscitation preferences of patients with HF, how they may vary by health status, and change over the course of the disease. Furthermore, it is unclear whether a DNR preference is associated with increased mortality in HF because disparate associations have been reported in trial populations.5,6

Our goals were to evaluate the resuscitation preferences of patients at study enrollment, describe changes in resuscitation preferences over time, and assess how resuscitation preferences related to survival.

Study Design
This study was a cohort study conducted in Southeastern Minnesota. This area is relatively isolated from other urban centers, and few providers, the largest of which is the Mayo Clinic, deliver the vast majority of medical care to local residents. The Rochester Epidemiology Project,9 a medical record linkage system, allows the indexing of medical care for residents of Southeastern Minnesota, thus enabling the comprehensive capture of health-related events for the community’s residents.

Patient Population
Potential patients with HF were identified using natural language processing of the electronic medical record text.10 After a clinical visit, documentation is transcribed and appears in the electronic record <24 hours, making prompt identification of patients with HF possible. The search was restricted to patients aged ≥20 years who were residents of Olmsted, Dodge, and Fillmore Counties in Minnesota. Medical
WHAT IS KNOWN

- Patients with heart failure often experience repeated hospitalizations and a progressive decline in quality of life as they approach death.
- The resuscitation preferences of patients with heart failure may change over the course of the disease.

WHAT THE STUDY ADDS

- Three quarters of community patients with heart failure elect do-not-resuscitate status before death, and changes in resuscitation preference are often made in the hospital in the final days to weeks of life.
- A do-not-resuscitate preference is not an independent risk factor for death.
- Although in-hospital cardiac arrest requiring cardiopulmonary resuscitation in patients who are Full Code is uncommon, survival with good neurological recovery is rare when it occurs.

records were then reviewed by experienced research nurses to determine whether patients had active HF meeting Framingham criteria. Patients were approached to provide consent to participate in the study from October 10, 2007, through September 20, 2011, which includes responding to psychosocial questionnaires. Hospitalized patients were contacted in the hospital, and patients seen in the outpatient setting were approached at their next scheduled clinical encounter. All patients provided written authorization to participate in the study, which was approved by the Mayo Clinic Institutional Review Board.

Data Collection

Patient Baseline Characteristics

Patient baseline characteristics were collected from medical records. A physician’s diagnosis was used to define a history of cerebrovascular disease, chronic obstructive pulmonary disease (COPD), and malignancy. A history of hypertension was defined as systolic blood pressure >140 mm Hg, diastolic blood pressure >90 mm Hg, or use of antihypertensive medications. Diabetes mellitus was defined using American Diabetes Association criteria or use of diabetes mellitus medications. A previous history of myocardial infarction was based on standard epidemiological criteria as previously described. Estimated glomerular filtration rate was calculated based on the creatinine level at the time of HF diagnosis. Anemia was defined as hemoglobin <12 mg/dL in women or <13 mg/dL in men. New York Heart Association (NYHA) functional class was assessed using standard definitions.

The Charlson comorbidity index was used to assess the degree of co-morbidity. Resting left ventricular ejection fraction (EF) was collected from transthoracic echocardiograms performed ≤6 months before to 2 months after study enrollment. Preserved EF was defined as ≥50%. A patient’s ability to perform activities of daily living is assessed annually for all patients at the Mayo Clinic by a self-administered survey. Difficulty with mobility was defined as patient-reported difficulty with ≥1 of the following <90 days of study enrollment: dressing, climbing stairs, bathing, walking, and getting in and out of bed. Education level was obtained from the same annual survey.

Resuscitation Preference

Resuscitation preference was defined as either Full Code or DNR based on documentation in the electronic medical record. As defined at our institution, DNR status refers to withholding CPR in the setting of unconsciousness and pulselessness. A patient’s resuscitation preference is documented in the medical record by providers in both inpatient and outpatient settings and is a standard part of all hospital admission order sets. When a patient decides to change their resuscitation preference, a new order is entered electronically such that the dates of all such changes are a part of the patient’s record. Temporary changes in code status from DNR to Full Code perioperatively were determined based on manual record review and were not counted as a change in resuscitation preference.

Psychosocial Questionnaires

Psychosocial questionnaires were administered by trained research personnel after enrollment. Questionnaires included the Patient Health Questionnaire-9, Enhancing Recovery in Coronary Heart Disease Patients (ENRICHD) Social Support Instrument, and Short Form 12. For the Patient Health Questionnaire-9, patients were categorized as no depression (score 0–4), mild (5–9), and moderate or severe (≥10). Low social support was defined as an ENRICHD Social Support Instrument ≤22. Marital status was defined based on response to the ENRICHD Social Support Instrument question, “Are you currently married or living with a partner?” When the ENRICHD Social Support Instrument was not completed, marital status was defined using patient responses to an annual Mayo Clinic questionnaire. The first question of the Short Form 12, which asks patients to rate their health as excellent, very good, good, fair, or poor, was used to assess self-perceived general health. Poor physical function was defined by a Short Form 12 physical function score ≤25.

Ascertainment of Mortality

Participants were followed through April 1, 2013, for death from any cause. The date of death was determined using death certificates filed in Olmsted County, obituary notices, and electronic files of death certificates obtained from the State of Minnesota Department of Vital and Health Statistics. Patients who were alive at last follow-up were censored at the date of last medical contact. Information regarding the primary cause of death was obtained from death certificates filed in the State of Minnesota. Cause of death was categorized as cardiovascular (100–199) versus noncardiovascular (all other codes) based on International Classification of Diseases, 10th Revision.

Statistical Analysis

Differences in patient baseline characteristics by resuscitation preference at study enrollment were compared using t tests for normally distributed continuous variables or x^2 for binary variables. Logistic regression was used to examine the predictors of resuscitation preference. To obtain the most parsimonious multivariable model, all potential candidate variables (P<0.1) were included in the model and then eliminated by stepwise selection until only significant (P<0.05) predictors were retained. Kaplan–Meier curves and Cox proportional hazard regression models were used to examine the association between resuscitation preference and mortality. Data were complete for most variables (<4% missing; Table 1) with the exception of EF (6% missing), anemia (12% missing), and mobility (32% missing). Some patients (n=121; 20%) did not return for their follow-up visit to complete psychosocial questionnaires after enrollment. Complete case analysis was used in the multivariable models. A P value <0.05 was used as the level of significance for all analyses. Analyses were performed using JMP 9.0.1 (Cary, NC) and Stata/SE 13.0 (College Station, TX).

Results

A total of 827 patients were approached for inclusion in the study, and 608 patients were enrolled from October 10, 2007, through September 20, 2011 (73.5% consent rate). The baseline characteristics of the study population are shown in Table 1. Patients were elderly (mean age, 74.0 years), 54.9% were men, 49.9% had preserved EF, and 65.3% reported NYHA functional class III or IV symptoms. Patients who did not consent to participate in the study were more often older (78.6 versus 74.0 years of age) and women (53.4% versus 45.1%).

Resuscitation Preferences at Enrollment

At study enrollment, most (446 of 608; 73.4%) patients’ documented resuscitation preference was Full Code. A total of 93
(15.3%) patients were DNR, and 69 (11.3%) had no documented resuscitation preference. Patients who requested DNR status were more often older and more frequently had comorbidities including COPD, a history of malignancy, and renal insufficiency (Table 2). Patients who elected DNR status were less often married/living with a partner and more often had poor physical function and limited mobility. There were no differences in resuscitation preferences at enrollment by education level, social support, depression, and self-perceived general health. Patients who were DNR less often reported NYHA functional class III or IV symptoms compared with those who were Full Code. In multivariable analysis, the independent predictors of DNR status at enrollment were older age, COPD, a history of malignancy, and decreased mobility. The c-statistic for the model predicting DNR status including these 4 variables was 0.80. By comparison, the c-statistic for the model including all of the factors shown in Table 2 was 0.82, indicating that age, malignancy, COPD, and decreased mobility provided the majority of predictive power to the model.

Resuscitation Preference and Mortality
After a mean follow-up of 2.7 (maximum 5.5) years, 237 of 608 (39.0%) patients had died. In total, 72 of 237 (30.5%) decedents were hospitalized at the time of death, and the proportion was similar in patients with preserved and reduced EF. Among those hospitalized at the time of death, 46 of 72 (63.9%) were cared for in an intensive care unit during the hospitalization, and 28 of 72 (38.9%) were intubated and received mechanical ventilation. The Kaplan–Meier predicted 2-year mortality was 22% and 47% in patients who were Full Code and DNR at enrollment, respectively (P < 0.001). Patients who were DNR were at increased risk of death compared with those who were Full Code (unadjusted hazard ratio, 2.03; 95% confidence interval, 1.48–2.73; P < 0.001). Adjusting for age and comorbidity (Charlson comorbidity index) attenuated this association (hazard ratio, 1.45; 95% confidence interval, 1.05–1.96; P = 0.026). However, further adjusting for self-perceived general health eliminated any association between resuscitation preference and death (hazard ratio, 0.97; 95% confidence interval, 0.74–1.30; P = 0.83). Information on the cause of death was available in 226 of 237 patients who died. In total, 119 of 226 patients (52.9%) experienced a cardiovascular cause of death, whereas the others had a noncardiovascular cause of death. A noncardiovascular cause of death was more common in patients with preserved EF compared with reduced EF (55.3% versus 33.8%; P = 0.013).

Changes in Resuscitation Preference Over Time
From enrollment to last follow-up, 226 of 608 (37.2%) patients’ resuscitation preference had changed. In total, 181
patients became DNR and 35 became Full Code. Overall, 274 (45.1%) patients were DNR at some point during follow-up, 28.8% of whom changed back to Full Code at least once after being DNR.

Resuscitation Preferences at the End of Life

Patients who died during follow-up (n=237) were older and more often had comorbidities such as COPD and chronic kidney disease. Most patients who subsequently died were Full Code at study enrollment (n=162 of 237; 68.4%), whereas at death, most (n=186 of 237; 78.5%) were DNR. The median (25th, 75th percentile) time from a final decision to be DNR until death was only 37 (7, 170) days, and 25.5% of patients elected to be DNR before a week of death. There were no differences in the proportion of patients who were DNR at the time of death in those with preserved and reduced EF. Most (84.8%) DNR decisions were made in the hospital. For DNR decisions made in the hospital, 58.0% were at hospital admission, whereas the remaining 42.0% changed from Full Code to DNR later in the hospitalization. Hospitalizations where DNR decisions were made were most often for noncardiac reasons (53.6%), rather than acute decompensated HF (33.9%) or other cardiac issues (12.5%). The primary team was most often a noncardiology internal medicine service (61.6%). Palliative medicine consultations were obtained in 103 of 237 (43.5%) patients a median (25th, 75th percentile) of 40 (6, 146) days before death. In total, 92 of 237 (38.8%) patients were enrolled in hospice a median (25th, 75th percentile) of 30 (6, 68) days before death, and 30.0% of patients enrolled in hospice a week before death. Patients with preserved EF more often enrolled in hospice compared with those with reduced EF (45.0% versus 31.9%; P=0.003), although this association did not persist after adjusting for age. Most (90%), but not all, patients who enrolled in hospice were DNR. Among the 237 patients who died, 40 (17%) had an implantable cardioverter defibrillator, of which 45% had their implantable cardioverter defibrillator therapies deactivated a median (25th, 75th percentile) of 9 (2, 51) days before death.

In-Hospital Cardiopulmonary Resuscitation

Of the 481 patients who were Full Code at some point during follow-up, 22 (4.6%) had a cardiac arrest in the hospital and received CPR. The presenting rhythm was ventricular fibrillation or ventricular tachycardia in 7 patients (31.8%) and pulseless electric activity in 15 patients (68.2%). The majority (59%) of those with a cardiac arrest had reduced EF. Only 8 of 22 patients (36.4%) survived to hospital discharge. Only 2 patients (9.1% of those receiving CPR) made a complete recovery and were able to return home, although 1 required a short stay in a skilled nursing facility after hospital discharge. Both patients had ventricular fibrillation/ventricular tachycardia arrests. Of the remaining 6 who survived to hospital discharge, 3 experienced anoxic brain injury and have since died, 2 were discharged to skilled nursing facilities and died, and 1 is still alive in a skilled nursing facility. Although all patients were Full Code at the time of CPR, of the 8 initial survivors, 6 changed their resuscitation preference to DNR during follow-up.

Discussion

There were several important findings from this study. First, resuscitation preferences in community patients with HF changed over time. Although 73% of patients living with HF
were Full Code, most patients became DNR before death, and changes in resuscitation preference were often made in the hospital in the final days to weeks of life. Older age, COPD, a history of malignancy, and reduced mobility were the best predictors of which patients would be DNR, rather than HF-specific indicators such as NYHA functional class. A DNR order was not an independent risk factor for death, but rather the excess mortality risk was explained by comorbidity and poor health status. Finally, although in-hospital cardiac arrest was rare in patients who were Full Code, outcomes were poor when it occurred.

To date, few studies have examined resuscitation preferences in patients with HF. In general, studies that included a younger and more highly selected population had lower proportions who were DNR, whereas studies that included patients with more advanced disease had more patients who preferred DNR status. For example, only 7% of patients enrolled in the Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheterization Effectiveness trial preferred to be DNR, although patients were younger (mean age, 56 years), and by definition, patients were amenable to invasive interventions because a pulmonary artery catheter was used in the trial. In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, which enrolled patients with a variety of chronic conditions including HF in the 1990s, 23% of patients with HF reported they did not want to be resuscitated. This population was younger than our community cohort and was restricted to patients with reduced EF and advanced disease. Finally, the highest proportion of patients electing DNR status (39%) was reported in the Trial of Intensified Medical therapy in Elderly patients with Congestive Heart Failure, which exclusively enrolled elderly patients with advanced cardiac disease. Herein, in a cohort that included all community patients with HF, regardless of age, stage of disease, or EF, we found that 27% of patients were DNR at enrollment, although this proportion increased before death. In our population, even after making a decision to be DNR, 29% of patients changed back to Full Code at least once during follow-up. This frequent change of preference underscores the importance of periodically reviewing resuscitation preferences and goals of care with patients with HF over time, as strongly advocated by the American Heart Association.

Most decisions to become DNR were documented while patients were hospitalized rather than in the outpatient setting. A review of resuscitation preferences in the hospital is important. However, from patients’ perspective, hospitalization may not be an optimal time to make decisions regarding resuscitation because physical and mental dysfunction may prohibit thoughtful decision making. It is best if advanced care decisions have been previously discussed in an outpatient setting and can be reviewed and updated on hospital admission. Interestingly, the strongest predictors of DNR status in our population were older age, COPD, a history of malignancy, and reduced mobility, rather than HF-specific indicators such as NYHA functional class. These findings may suggest that end-of-life decisions in patients with HF are not disease-specific, but rather driven by the frailty and decline in clinical status that often accompanies advanced age and multimorbidity.

Important decisions on end-of-life care were made in close proximity to death. One quarter of those who were DNR at death changed from Full Code in the final week of life, and hospice services and palliative medicine consultations were often obtained in a similar time frame. Although this may be appropriate when the patient experiences a sudden catastrophic decline in health, many of the patients in this study had lived with HF for several years and experienced frequent hospitalizations before death. Indeed, patients with HF have been shown to elect DNR status later in their disease course compared with patients with cancer. Patients with HF go through periods of slowly declining health, marked by episodes of exacerbation often requiring hospitalization, from which they often recover. In contrast, patients with terminal illnesses such as cancer often follow a more predictable progressive downward health trajectory before death. The waxing and waning pattern typical in patients with HF can make it difficult to accurately prognosticate regarding expected survival. As such, physicians are often wary of discussing prognosis and end-of-life care for fear of causing alarm and destroying hope. As a result, most patients with HF have little understanding about their prognosis.

In addition to overestimating their own survival, patients often hold erroneous beliefs regarding the likelihood of survival after CPR, which may affect their decisions regarding resuscitation preference. In 1 survey of elderly patients, 81% thought that their chance of surviving CPR and leaving the hospital was >50%, and 23% thought their chance was >90%. Herein, in-hospital cardiopulmonary arrest in patients who were Full Code was uncommon, occurring in only 5% of Full Code patients. It should be recognized that the low percentage of patients experiencing in-hospital cardiac arrest was affected by the number of patients in our study who were DNR at the time of death and thus not treated with CPR at the time of in-hospital cardiac arrest per their wishes. However, although 36% of patients experiencing cardiac arrest treated with CPR were discharged from the hospital alive, only 9% (2 patients) had a complete neurological recovery and were able to return home. Although survival after cardiac arrest may be improving over time, outcomes remain poor. In patients with advanced HF, further provider and patient education is needed so that patients may be more empowered to make informed decisions regarding their end-of-life wishes.

An issue critical to education about resuscitation preferences is their association with mortality. It has been debated whether the risk of death is higher in patients who are DNR and whether this reflects increased illness severity or differences in the aggressiveness of therapy that may influence mortality. Some studies in Medicare beneficiaries, patients with stroke, and patients with HF have found an increased risk of death in patients who are DNR even after adjusting for comorbidity, whereas others have not. We found that patients who were DNR were at increased risk for death and that the excess risk persisted after adjusting for comorbidity and age but was eliminated by further adjusting for self-perceived general health. The availability of psychosocial data in this study provides an advantage compared with previous work. Poor self-perceived general health is a strong predictor of mortality in patients with HF and may account for a degree of
unmeasured illness that is difficult to quantify using traditional risk factors. These findings are important clinically because patients may hesitate to change their resuscitation preference to DNR due to concern that they may fail to receive care that may impact their mortality, although these data would suggest that electing DNR status does not independently affect the risk of death. A change in resuscitation preference to DNR may simply be a ritual acknowledgment of impending death.34

Limitations and Strengths

There are limitations that should be acknowledged to aid in the interpretation of these data. First, resuscitation preferences were abstracted from documentation in the medical record, rather than discussing them with patients directly. Patients with more frequent contact with medical care may have increased opportunity to declare their resuscitation preferences and have them documented in the medical record. Second, the consent rate for this study was 73.5%, which is similar to other community epidemiological studies. Because nonparticipants were, on average, older than participants, the proportion of patients who were DNR at enrollment may be underestimated. Furthermore, because we included patients with complete data in our multivariable models, those with unknown resuscitation preferences at enrollment and missing mobility information were excluded from some analyses. Finally, although Southeastern Minnesota is becoming increasingly diverse, the population remains primarily white, and results observed herein may not apply to communities of varying racial and ethnic diversity. It would be of interest in future studies to examine resuscitation preferences and patterns of care at the end of life in other populations of patients with advanced HF. However, there are several strengths to these data. This cohort includes patients with HF who are elderly and have preserved EF, populations that are often excluded from HF clinical trials. They are extensively characterized and followed longitudinally for outcomes, providing an optimal framework to examine these questions.

Conclusions

Patients’ resuscitation preferences change over time, particularly as they approach the end of life. Discussion of goals of care, including resuscitation preference, should be an ongoing, iterative process, considered in the context of an individual’s specific health status, available therapeutic options, and personal beliefs.

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Disclosures

None.

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