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DO-NOT-RESUSCITATE ORDERS AMONG ELDERLY PATIENTS WITH HEART FAILURE

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Katherine Callahan

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The dissertation of Katherine Callahan was reviewed and approved by the following:

Christopher S. Hollenbeak
Professor and Department Head of Health Policy and Administration
Dissertation Advisor
Co-Chair of Committee

Yubraj Acharya
Assistant Professor of Health Policy and Administration and Demography
Co-Chair of Committee

Melissa A. Hardy
Distinguished Professor of Sociology and Demography

Lisa Kitko
Associate Dean for Graduate Education, Associate Professor of Nursing, Josiah S. Macy Jr. Faculty Scholar

ABSTRACT

The purpose of this dissertation is to contribute to the discussion about the potential impact of the advance care planning (ACP) process on end-of-life care. This dissertation aims to achieve this through three research studies that explore documentation of a do-not-resuscitate (DNR) order and patient outcomes. In the first study, the association between end-of-life care and costs is explored in the context of increasing healthcare expenditures. Although the primary benefit of ACP is that it aligns patients' wishes with the treatment they receive, a secondary benefit may be cost-savings. Data from the Healthcare Cost and Utilization Project's National Inpatient Sample is used to examine whether a documented DNR order among 700,922 hospital inpatients with heart failure (HF) was associated with costs and other outcomes between the years of 2011 and 2016. The results indicate that the presence of a DNR among this population is associated with lower total costs, a shorter hospital stay, and a higher risk of mortality, particularly when a patient with a DNR in place dies. These findings add to the evidence that ACP may aid in containing health care costs, and policies that promote ACP may not only help patients get the care they prefer but they may also lower healthcare costs

The second study in this dissertation, examines the validity of International Classification of Diseases (ICD) codes (V49.86 for ICD-9 and Z66 for ICD-10) to identify the presence of a DNR order. Elderly HF patients (N=1,719) that were admitted to the Penn State Milton S. Hershey Medical Center between 2013 and 2016 were included in this study. Merging data from the electronic medical record (EMR) and the cost-accounting database allowed a comparison between a DNR in ICD codes to a DNR present in the EMR. Measures of agreement and disagreement suggested that the ICD code for DNR presence in the ICD codes is valid and has excellent diagnostic characteristics, including sensitivity and specificity. In addition, when the ICD measures of DNR were used in analyses focused on estimating the association between DNR

and outcomes, they provided similar estimates of association compared to DNR in the EMR. This supports the use of ICD codes to identify DNR in future research studies. In addition, the use of ICD code to identify DNR will facilitate the study of ACP as ICD codes are more readily available in large, observational datasets.

The third study of this dissertation uses data from the California Office of Statewide Health Planning and Development (OSHPD) to investigate the association between a recent payment rule that provides reimbursement for physicians to have ACP conversations with their patients and DNR use among racial and ethnic minorities—groups with well documented disparities in end-of-life care. In addition, this study examines the timing of DNR orders among racial and ethnic minority groups, as early DNRs are thought to distinguish cases in which the DNR reflects patient preference regarding resuscitation on admission from those in which the DNR order results from failed salvage treatment. The results of this study suggest that although the reimbursement policy was associated with an increase ACP participation overall, the rate of increase of DNR participation was lower for racial and ethnic minorities. This paper adds to the discussion about how to best decrease disparities in end-of-life care, and suggests that reimbursement incentives alone do not appear to be enough to reduce racial and ethnic disparities in DNR participation. Future interventions may need to be multilevel and specific to the targeted group they are intended to benefit.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

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Chapter 1

Introduction

As a broad overview, this dissertation explores the written communication between the patient, their loved ones, and healthcare professionals regarding preferences for medical care that leads to high quality care at the end-of-life (EOL). High quality EOL care is incredibly complex and deeply personal; as a result, it can vary depending on individual circumstance. However, some common areas of importance to patients receiving EOL care include the avoidance of suffering, limiting burden on the family, and receiving treatment that aligns with patient values [1-3].

Having medical care that is consistent with patient preferences can be achieved through the advance care planning (ACP) process. The ACP process allows patients to think about potential medical situations and treatment options before they happen so they maintain some control and receive the care they want [4]. ACP includes conversations between the patient, loved ones, and health care professionals regarding what kind of care is wanted and unwanted should specific medical situations arise. These conversations can be formalized in legal documents that make the patient's wishes known and assign a proxy to make decisions if the patient is unable [5]. The focus of this dissertation is on the Do-Not-Resuscitate (DNR) order—one important part of the ACP process.

Patients can document their wishes in an Advance Directive, a set of legal documents that include a Living Will, a Power of Attorney form, a DNR, and other portable medical orders that vary in name depending on location. A DNR order is a legal document signed by both the patient and physician that tells all healthcare providers not to begin cardiopulmonary resuscitation (CPR) in the event of cardiac arrest. The emergency rescue technique of CPR was designed to save the life of an individual who is generally healthy; manual or machine breathing and chest compressions are completed when an individual's heart or breathing stops [6]. It is important to note that CPR is a standard procedure, so unless an individual has a written DNR, they will receive CPR if a cardiac event occurs.

However, for individuals at EOL, CPR is likely to be more harmful than beneficial; research indicates that CPR does not typically restore breathing and heart function in patients who have widespread cancer, widespread infection or other terminal illnesses. It is a vigorous emergency procedure and even if the patient survives, they may suffer broken ribs, damage to the brain or other organs, or may be permanently dependent on a machine for breathing [6]. Adverse outcomes from CPR are particularly relevant for the elderly and frail, and therefore these individuals often choose a DNR to ensure high quality EOL care where they will not receive treatment that may increase their pain and suffering and may only keep them alive for a short period of time [7].

Since 1990, the federal Patient Self-Determination Act ensures that hospitals provide patients with a description of their treatment rights, including a DNR form [8]. However, communication to patients about these rights varies between providers, and can include anything from ongoing detailed conversations about goals of care to a short packet of papers given during admission that is never reviewed with the patient or referred to again. As a result, the implementation of ACP and documentation of preferences varies across the country and patients may have very different experiences [9, 10]. Ensuring high quality EOL care is significant and timely as the US population is aging and many patients will need these services in the near future [7].

This dissertation investigates utilization of DNRs among elderly adults hospitalized with heart failure (HF). This population was chosen as the process of ACP, including the legal documentation of wishes, is particularly important for individuals diagnosed with chronic and terminal illnesses that have high rates of hospitalization, morbidity, and mortality [11]. These illnesses, of which HF is one, have an exacerbation-prone trajectory that often results in frequent hospitalizations, which is in contrast to chronic, declining trajectories more common in other terminal illnesses such as dementia. Almost 50% of individuals die within the first five years of a HF diagnosis, which presents challenges for communicating EOL wishes to family and medical teams [12]. In addition, this dissertation focuses on elderly individuals (65+) as these individuals experience the most health issues and have the most regular contact with the medical system. It is therefore likely that this population will have had more opportunities to document their preferences in an DNR order [7, 13].

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Chapter 2

Cost-savings of DNR orders among patients with heart failure in the United States.

Abstract

Background. Do-not resuscitate (DNR) orders should preclude the use of cardiopulmonary resuscitation and, consequently, may be associated with patient outcomes, including mortality, length of hospital stay, and costs among patients hospitalized for heart failure (HF).

Objectives. To examine the potential cost-savings associated with DNR orders among elderly (age 65+) inpatients with a diagnosis of HF, and the association between DNR and mortality and length of stay (LOS).

Research Design. The Healthcare Cost and Utilization Project's National Inpatient Survey was used to identify discharges of patients aged 65 and older with a primary diagnosis of HF. Linear regressions were used to estimate the association between DNRs and costs, mortality, and LOS.

Subjects. The study cohort included 700,922 hospital admissions of patients over the age of 65 who had a primary diagnosis of HF.

Measures. The diagnosis of HF and DNR status were identified using International Classification of Diseases, Clinical Modification (ICD-CM) Ninth and Tenth Revision codes.

Results. Elderly HF patients who died with a DNR had cost-savings of $5,640 ($p<0.001$). Patients with a DNR order were 8.9 percentage points more likely to die before discharge than patients who did not ($p<0.001$) and patients who died with a DNR had a significantly shorter hospital stay by 1.51 days ($p<0.001$).

Conclusions. DNR orders among elderly patients with HF are associated with cost-savings, as well as a higher likelihood of mortality and shorter LOS. Advance care planning and documentation may not only improve quality of EOL care but also help contain health care costs.

Introduction

Advance care planning (ACP) has been suggested to have the potential to reduce increasing healthcare costs in the United States [1]. Some research suggests that in addition to its primary benefit of aligning patient treatment preferences with the care they receive, ACP may contribute to cost-savings [1-3]. ACP has been defined by a multidisciplinary Delphi Panel as a "process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" [4, Pg. 246]. The process of ACP emphasizes conversations to facilitate a shared understanding between the patient, family members, and health care professionals as well as documentation of preferences in legal forms to facilitate these discussions. One piece of the ACP process is a do-not-resuscitate (DNR) order, which is a legal document that directs doctors and the clinical team to withhold cardiopulmonary resuscitation (CPR) if the patient experiences a cardiac event. It is a step further than other legal documents such as the living will/advance directive or power of attorney, which are only signed by the patient and represent general wishes. The DNR order is a specific medical order that is signed by both the patient and doctor, and implies that a conversation regarding CPR took place and the physician understands the patient's preference in the event of a cardiac event [5, 6].

The process of ACP, including the legal documentation of wishes, is particularly important for individuals diagnosed with chronic and terminal illnesses that have high rates of hospitalization, morbidity, and mortality [7]. Heart failure (HF) is one such chronic illness; almost 50% of individuals die within the first five years of a HF diagnosis, increasing importance of communicating end-of-life wishes to family and medical teams [8]. HF has an exacerbation-prone trajectory that often results in frequent hospitalizations, which contrasts with chronic, declining trajectories more common in other chronic and terminal illnesses such as dementia. Furthermore, the cost of care for HF, in general, exceeds $40 billion annually, with more than half of these expenses occurring during the last six months of life [9, 10]. Since the 1990 Patient Self-Determination Act requires that hospitals provide inpatients with advance directives, surrogate decision-making forms, and other legal forms such as DNR orders [11], the hospital setting is an ideal setting for the study of DNR and healthcare costs.

Although ACP has been promoted by some researchers and health care advocates as a partial solution to escalating health costs [3], the evidence regarding the cost-savings associated with ACP is mixed [1, 12, 13]. A recent systemic review has indicated that it was difficult to compare ACP-related cost-saving across studies because each study defined cost from a different perspective [1]. In addition, cost savings seen in prior studies may not represent real effects of a DNR if there is selection bias that has not been appropriately controlled for. Selection bias may be present when the sample selected for a study systematically excludes part of the population or when a treatment or exposure is not randomly assigned. This leads to an under- or overestimate of the true effect of a DNR on the outcomes, and does not properly account for how patients with a DNR are different from those without a DNR [14]. A DNR order is simply a legal document and is not, therefore, intrinsically cost-saving. For example, for any patient with a DNR order, if resuscitation is not required, a DNR would not alter the course of treatment or the resources used in the care of a patient. Therefore, if there are cost savings associated with DNRs, they should be observed primarily in cases where resuscitation would be required but was not attempted (e.g., cases where patients died).

Objectives

The primary objective of this study was to examine the potential cost-savings associated with a DNR order among elderly (age 65+) inpatients with a diagnosis of HF. Secondary objectives were to estimate the association between mortality and DNR and length of stay (LOS) and a DNR order among elderly (age 65+) inpatients with a diagnosis of HF. Additionally, this study sought to determine whether the cost-savings associated with a DNR order were driven by medical situations where resuscitation was required but was avoided due to the DNR order.

Hypotheses

Among elderly inpatients with a primary diagnosis of HF, the presence of a DNR order will be associated with lower total cost, greater risk of mortality, and shorter LOS. In addition, DNR-related cost-savings will be significantly greater in cases where resuscitation would be required but was avoided due to the DNR order than in cases where resuscitation would not be required.

Methods

Data Source

Data used in this observational study were from the National Inpatient Sample (NIS), Healthcare Cost and Utilization Project (HCUP), from the Agency for Healthcare Research and Quality. The NIS is a sample of discharge data from over seven million hospital inpatient stays in 48 states and the District of Columbia which participate in HCUP, covering 97% of the U.S. population [15]. The inpatient data collected by the NIS include both clinical and resource use information and are used by researchers and policy makers to estimate healthcare utilization, access, costs, quality, and outcomes at the national level [15].

Cohort

Patients in the NIS were identified with a primary diagnosis of HF using the International Classification of Diseases, Ninth, Clinical Modification (ICD-9-CM) code of 428.xx (heart failure) and ICD-10-CM code of I50.xx (heart failure). Patients under the age of 65 were excluded, as individuals in this age group are less likely to participate in ACP [10, 16].

Observations with missing patient characteristics were excluded, which further reduced the sample by <5%. The final sample consisted of 700,922 patients aged 65 or older with a primary diagnosis of HF that were admitted to the hospital between 2011 and 2016 (Figure 1).

Outcomes

The outcomes in this study were costs, mortality, and LOS. Costs were estimated from charges using hospital-specific cost-to-charge ratios and adjusted for inflation to 2018 U.S. dollars. Thus, the cost perspective is that of the healthcare system. Mortality was measured as any cause of death for all patients during the in-patient hospital stay. LOS was assessed as the number of days an individual spent as an in-patient (i.e., from admission to discharge). We only considered costs and length of stay for the initial admission; readmissions were excluded because the data do not allow linking over episodes of care.

Key Independent Variable

DNR orders were identified using an ICD-9-CM code of V49.86 (Do not resuscitate) and an ICD-10 code of Z66 (Do not resuscitate), both of which indicate DNR status.

Covariates

The analyses accounted for both patient and provider characteristics that were selected based on associations with DNR utilization identified in the existing literature [9, 17]. To control for patient characteristics, the following binary and categorical variables were used: age groups (65-74, 75-84, or 85+), sex (male or female), race/ethnicity (white non-Hispanic, black non-Hispanic, Hispanic, Asian, and other), primary payer (Medicare, Medicaid, commercial, and other), income quartile of the patient’s zip code (1st, 2nd, 3rd, or 4th), and illness severity level from all patient refined diagnosis related group (APR-DRG) categories (minor, moderate, major, and extreme loss of function).

To control for co-morbidities, we included the Elixhauser Co-morbidity Index, which captures the total number of co-morbidities present from a set of thirty comorbidities identified from ICD codes and diagnosis related groups (DRG) [18, 19]. At the hospital level, we controlled for hospital size (small, medium, or large), hospital geography (urban or rural), teaching hospital status, and region of the country (Northeast, Midwest, South and West).

Statistical Analysis

Statistical analyses were performed to determine whether the presence of a DNR order was significantly associated with costs, mortality, and LOS among elderly hospitalized patients with HF, after controlling for the covariates mentioned above. They were also used to determine whether the differences in costs and LOS attributable to DNR were driven primarily by patients who died. Univariate analyses were performed to compare characteristics of patients with and without a DNR order using Student t tests for continuous variables and chi-square tests for binary and categorical variables.

A linear regression model was used to model the relationship between DNR and costs with interactions between DNR and in-hospital mortality. Primary interest was in the interaction term as we hypothesized that patients with a DNR who died would have the greatest cost savings. We present both the estimated coefficient and marginal effects, which shows the DNR effects across interactions.

It is reasonable to expect that the outcomes we evaluated can vary between patients due to hospital-specific factors, such as patient mix, size and resources. Therefore, in all our analyses, we included hospital fixed effects to address potential confounding due to time-invariant, hospital-specific factors. With the inclusion of the hospital fixed effects, we compared outcomes for patients with a DNR and those without who were admitted to the same hospital. Hospital fixed effects were used instead of random effects after a Hausman test was performed that favored hospital fixed effects [20]. We also included year fixed effects to control for secular trends in the outcomes.

A linear probability model was used to estimate the relationship between DNR and mortality after controlling for important covariates. Linear regression was also used to model the relationships between DNR and LOS with interactions between DNR and in-hospital mortality. Similar to the cost model, primary interest was in the interaction terms as we hypothesized that patients with a DNR who died would have the shortest LOS. In addition to the LOS estimated coefficients, marginal effects are presented. The mortality and LOS models also controlled for hospital and year fixed effects, as described above. Stata software (version 15.1, College Station, TX) was used for all analyses, and statistical significance was defined as $p<0.05$.

Results

Patient Characteristics

A summary of patient characteristics stratified by DNR status is provided in Table 1. Among 700,922 patients over age 65 with a primary diagnosis of HF, 92,064 (13%) had a DNR order. Elderly HF patients were more likely to have a DNR order if they were aged 85 years or above, were white non-Hispanic female, had an illness severity level of 3 (major function loss), were in the second income quartile ($25,000 - $50,000), and had Medicare as their primary insurance. In addition, patients treated at large, urban, teaching hospitals, located in the South were more likely to have a DNR order. Patients were less likely to have a DNR order if they were under the age of 85, were non-white males, had an illness severity of level of 1 (minor function loss), had Medicaid as their payer, and were treated at a small, rural, non-teaching hospital located in the West. Patients with a DNR order had approximately 3.55 comorbidities, whereas those without a DNR order had approximately 3.47 comorbidities on average (p<0.001). Compared to HF patients with a DNR, those without a DNR order spent a slightly shorter time in the hospital (5.33 vs. 5.10 days; p<0.001) and the mean cost of their hospitalization was slightly higher ($10,530 vs. $10,280; p<0.001).

Trends in DNR orders among HF Patients

The proportion of elderly HF admissions with a DNR doubled from 9.9% in 2011 to 20.6% in 2016 (Figure 2). However, 80-90% of patients did not have a DNR order.

Hospital Costs

The results from a linear regression of hospitalization costs on DNR status controlling for covariates are shown in Table 2. Elderly HF patients who died had significantly higher costs by $5,075 (p<0.001) than those who lived, and those who had a DNR order had $1,080 in lower costs than patients without a DNR (p<0.001). However, compared to patients who lived and did not have DNR order, patients who died with a DNR had the largest cost savings of $5,637 (p<0.001). This suggests that a DNR is cost-saving when a patient with a DNR has an event and the patient's wishes are honored. The marginal effects in U.S. dollars for death and DNR order on costs for elderly HF hospital inpatients is shown is Figure 3. The marginal effects indicate that patients without a DNR order who died had hospitalization costs of approximately $16,500, whereas patients with a DNR order who died had a hospitalization cost of approximately $10,500.

Several other factors were associated with costs. For example, age 85 years or older was associated with a $3,392 (p<0.001) lower cost. Black non-Hispanic race/ethnicity was associated with lower costs of $387.00 (p<0.001) whereas Hispanic ethnicity and other race/ethnicity categories were associated with higher costs (p=0.002 and p<0.001 respectively). The highest severity level of HF (extreme loss of function) was associated with largest increase in cost at $14,899 ($p<0.001$).

Mortality

Table 3 provides the results of a linear probability model of in-hospital mortality. The presence of a DNR order had a large, significant association with mortality. After controlling for patient and provider characteristics and hospital and year fixed effects, patients who had a DNR order were 8.9 percentage points more likely to die before discharge than patients who did not ($p<0.001$).

Other covariates were also associated with mortality. As expected, HF patients with the highest severity level (extreme loss of function) were 13.5 percentage points more likely to die ($p<0.001$). Further, elderly HF patients who were non-Hispanic black ($p<0.001$) or Asian ($p<0.001$) were slightly less likely to die than white non-Hispanic patients. For Hispanic and other race individuals, the differences were not significant. Between 2011 and 2016, the likelihood of death of these hospitalized elderly HF patients also decreased significantly.

Length of Stay

The results from a linear regression of LOS on DNR order controlling for covariates are shown in Table 4. Elderly HF patients who died had a longer hospital stay by 0.34 days ($p<0.001$) and those who had a DNR had a shorter hospital stay by 0.06 days ($p=0.002$). However, patients with a DNR who died had a significantly shorter hospital stay by 1.51 days ($p<0.001$). The marginal effects in days for death and DNR order presence on LOS for elderly HF patients are shown in Figure 4. The marginal effects show that among patients who died, those without a DNR order were in the hospital for almost 5.5 days, and those with a DNR order were in the hospital for a little over 5 days. Similar to the cost results, this supports the hypothesis that the DNR is associated with reductions in resource utilization only when a patient with a DNR has an event and the patient's wishes are honored.

Several other variables were independently associated with LOS (Table 4). HF patients with the highest severity level (extreme loss of function) had a longer hospital stay by 6.6 days ($p<0.001$). Being treated in a rural hospital was associated with a slightly shorter hospital stay by 0.28 days ($p<0.001$), and being admitted to a teaching hospital was associated with a longer hospital stay by half a day ($p<0.001$).

Discussion

This study suggests that for elderly hospital inpatients with a primary diagnosis of HF, having a DNR order is associated with significantly lower costs to providers, higher mortality, and lower overall LOS. In terms of cost-savings associated with DNR, although savings of approximately $5,640 per patient may seem small, there are almost 6 million adults in the United States with heart failure and total savings associated with DNR and death could be substantial [21]. The national cost-savings of DNR among those who died was estimated for years 2011 to 2016 (Figure 5). This was estimated by applying sampling weights that reflect national trends provided in the HCUP's NIS. The cost-savings were calculated by multiplying the number of DNR orders among those who died for each year by the marginal cost-saving per person of individuals who had a DNR order and died. The amount of cost-savings depends on how many patients are admitted to the hospital for HF in each year. After 2014, the cost-savings were estimated to be over $15 million each year. The results provide confirmation that the cost-savings were concentrated among HF inpatients with a DNR who died.

A major contribution of this study is that it adds to the literature that indicates that part of the ACP process, documentation of a DNR order, is cost-saving in the elderly HF population. It also focused on cost-savings among patients whose care was affected by needing to have a DNR. Thus, the results provide more information about where cost-savings occur in the ACP process.

Additionally, the results provide confirmation regarding the utilization of DNR orders by age, sex, race, and other patient characteristics among HF patients, as they are aligned with the literature [8, 9]. Similar to Phadke and Heidenreich's 2016 study of DNR orders among HF patients, we found that DNRs are more common among patients who are older in age, white non-Hispanic race/ethnicity, female, and with Medicare as the primary payor [17]. Conversely, HF inpatients who were under age 85, Hispanic, black, Asian or other race/ethnicity, male, or insured by Medicaid or other primary payors were less likely to have a DNR order. Unlike Phadke and Heidenreich's study (2016), we found comorbidity burden was similar between individuals who had a DNR order and those who did not. It is likely that the disparities between studies stem from the differences in the sample population; Phadke and Heidenreich's study (2016) used HF admissions in California, while our study used a national sample. In addition, as discussed below, differences may be due to a slightly different and more narrow definition of DNR used by Phadke and Heidenreich.

The higher mortality rate among elderly HF patients with DNR orders relative to their counterparts with no such orders is not surprising as DNR orders often coincide with some expectation of impending death and with less aggressive treatments (e.g., declining CPR). Higher mortality rates associated with DNR orders have been well documented in the literature [22]. However, our results that a DNR is associated with shorter hospital LOS and lower costs per patient contribute to the ongoing debate regarding the potential cost-savings for ACP. In a systemic review, Dixon, Matosevic and Knapp (2015) found that both observational studies and randomized controlled trials provided mixed evidence of cost-savings associated with ACP [1].

The studies chosen in their review operationalized ACP in different ways and noted studies that provided cost-savings for DNR focused on specific outcomes such as costs. Similar to our results, one study found that a palliative program with ACP components significantly decreased hospital LOS for patients diagnosed with dementia who lived in the community [1, 23]. Although our study focused on a population with heart failure the results regarding the shorter LOS were similar. It is important to note that Dixon, Matosevic and Knapp's (2015) review did indicate that cost-savings results were most often associated with low income individuals who had high support needs such as individuals with chronic illnesses living in the community. While our study focused on patients during their hospital admission not in the community, the cost-savings found in the concentration of patients with high medical needs due to age and illness type is supported by this review.

Limitations

There are several limitations to our study. First, documentation of a DNR order is only one component of the ACP process. Arguably, the most important part of the ACP process includes conversations about aligning care with treatment preferences and assigning a surrogate decision maker. Still, the DNR is an important part of ACP and carries the potential to impact resource utilization. Second, we used ICD-9 and ICD-10 diagnosis codes to identify DNR orders. Some DNR orders may not have been captured in the administrative data, and DNR orders may be under-counted in any analysis that uses ICD-9 and ICD-10 codes as proxies for DNR orders [24]. As a result, the association between a DNR order and the outcomes could be underestimated. The results of our study suggest at least a partial validation of the ICD-9 and ICD-10 codes as a measure of the DNR. Cost-savings were observed when a patient with a DNR required fewer resources, which is consistent with our hypothesis about the mechanism of cost savings.

An additional limitation of our study stems from measuring mortality as deaths from any cause. We were unable to attribute deaths to cardiac arrest or explore whether patients received CPR. The ICD codes for cardiac arrest and CPR do exist, however, they are highly variable and have not been shown to be valid or reliable [25]. As a result, this study cannot specifically attribute cost-savings to withholding CPR. Another potential issue is that the measurement of DNR orders using ICD-9 and ICD-10 diagnosis codes may miss individuals who changed their minds about their desire for life-sustaining procedures, even if their doctors believed such procedures would be futile. Furthermore, even if a DNR is in place, the physician may be unaware of it, or may ignore it. It is also possible that the DNR order may be over-ridden by family or other decision makers [26].. Our study assumes that if an individual has an ICD-9 and ICD-10 code for a DNR order, it was honored by their medical team and family members.

Other limitations to this study are common to observational studies using administrative data. The data used from the NIS were only collected during the hospital admission of a patient, which means that out of hospital mortality was not captured. In addition, although we controlled for a wide range of potential confounders, the estimates cannot be interpreted as causal.

Conclusions

ACP has been shown to be beneficial for individuals and their families, yet the uptake of the process of ACP implementation into end-of-life care has faced many challenges. A major barrier has been the time sensitive nature of the ACP process as well as the lack of training among physicians to have these conversations with patients who have complex disease trajectories requiring repeated conversations about goals of care [8]. Our study suggests that if the DNR documentation part of the ACP occurs in elderly HF patients, the most substantial cost-savings are among patients who had a cardiac event that required resuscitation and did not receive it due to a DNR order. The DNR order was also found to be associated with a shorter LOS, consistent with lower resource use. Additionally, this study suggested that a DNR order is associated with a greater likelihood of mortality, which is consistent with the literature [22]. With the increasing prevalence of chronic diseases and the aging of the population, the ACP process has become increasingly important as it may not only improve the quality of end-of-life care in elderly patients with HF, but may also help contain high health care spending, which is projected to continue to increase over the next decades.

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Table 1. Summary statistics for elderly HF patients with (n=92,064) and without (n=608,858) a DNR order.

Variable	Entire Sample (N=700,922)	DNR (N=92,064)	No DNR (N=608,858)	P-Value
Age	79.7	84.2	79.0	<0.001
65-74	29.7%	12.0%	32.4%	
75-84	36.5%	29.2%	37.6%	
85+	33.8%	58.9%	30.0%	
Sex				<0.001
Male	46.7%	39.2%	47.9%	
Female	53.3%	60.8%	52.1%	
Race/Ethnicity				<0.001
White Non-Hispanic	76.6%	85.6%	75.2%	
Black Non-Hispanic	12.5%	6.2%	13.4%	
Hispanic	6.6%	4.6%	6.9%	
Asian	1.8%	1.6%	1.8%	
Other	2.6%	2.0%	2.6%	
Elixhauser Comorbidity Index	3.48	3.55	3.47	<0.001
APR-DRG Severity Index				<0.001
Minor	6.5%	3.5%	6.9%	
Moderate	35.5%	26.8%	36.9%	
Major	47.1%	51.1%	46.5%	
Extreme	10.9%	18.7%	9.7%	
Hospital Death				<0.001
Yes	3.5%	12.2%	2.2%	
No	96.5%	87.8%	97.8%	
Length of Stay (Days)	5.13	5.33	5.10	<0.001
Hospitalization Cost (USD)	$ 10,500.95	$ 10,282.48	$ 10,533.98	<0.001
Zip Code Income Quartile				<0.001
Q1	30.3%	23.7%	31.3%	
Q2	26.2%	26.1%	26.3%	
Q3	23.6%	26.0%	23.3%	
Q4	19.8%	24.2%	19.2%	
Payor				<0.001
Medicare	91.1%	91.8%	91.0%	
Medicaid	1.4%	0.7%	1.5%	
Commercial	5.9%	5.4%	5.9%	
Other	1.6%	2.0%	1.6%	

Hospital Size				<0.001
Small	18.6%	19.2%	18.5%	
Medium	28.4%	29.2%	28.3%	
Large	53.0%	51.6%	53.2%	
Hospital Location				<0.001
Urban	85.6%	86.7%	85.4%	
Rural	14.4%	13.3%	14.6%	
Hospital Teaching Status				<0.001
Teaching	48.2%	50.5%	47.8%	
Non-Teaching	51.8%	49.5%	52.2%	
Region				<0.001
Northeast	21.9%	22.1%	21.8%	
Midwest	21.8%	23.4%	21.6%	
South	41.5%	33.9%	42.7%	
West	14.7%	20.6%	13.9%	

Table 2. The results of a linear regression model of total cost of admission.*

Variable	Coefficient	95% Confidence Interval Lower	Upper	P-value
Outcome				
Died	5,074.47	4,798.24	5,350.71	<0.001
DNR	-1,079.79	-1,201.73	-957.84	<0.001
DNR*Died	-5,636.99	-6,049.99	-5,223.98	<0.001
Lived / No DNR	Reference			
Age				
65-74	Reference			
75-84	-1,640.76	-1,733.38	-1,548.15	<0.001
85+	-3,392.33	-3,491.70	-3,292.97	<0.001
Sex				
Male	Reference			
Female	-570.05	-645.63	-494.47	<0.001
Race/Ethnicity				
White Non-Hispanic	Reference			
Black Non-Hispanic	-386.78	-511.47	-262.09	<0.001
Hispanic	272.91	101.99	443.82	0.002
Asian	152.30	-146.03	450.63	0.317
Other	950.16	700.94	1,199.38	<0.001
Elixhauser Comorbidity Index	-18.28	-39.99	3.43	0.099
APR-DRG Severity Index				
Minor	Reference			
Moderate	-1,944.25	-2,104.93	-1,783.57	<0.001
Major	1,718.49	1,557.29	1,879.69	<0.001
Extreme	14,898.68	14,704.91	15,092.44	<0.001
Zip Code Income Quartile				
Q1	-1,205.62	-1,335.95	-1,075.29	<0.001
Q2	-1,016.42	-1,142.02	-890.82	<0.001
Q3	-833.00	-953.88	-712.11	<0.001
Q4	Reference			
Payor				
Medicare	51.56	-271.86	374.98	0.755
Medicaid	59.28	-104.22	222.79	0.477
Commercial	-1,187.47	-1,484.95	-889.99	<0.001
Other	Reference			
Hospital Size				
Small	-1,465.37	-1,603.03	-1,327.70	<0.001
Medium	-1,406.54	-1,529.93	-1,283.14	<0.001

Large	Reference			
Hospital Location				
Urban	Reference			
Rural	189.12	28.43	349.80	0.021
Hospital Teaching Status				
Teaching	2,334.27	2,215.25	2,453.29	<0.001
Non-Teaching	Reference			
Region				
Northeast	Reference			
Midwest	-1,291.46	-2,618.43	35.51	0.056
South	-878.00	-2,513.10	757.11	0.293
West	-5,183.78	-9,181.79	-1,185.78	0.011
Year				
2011	Reference			
2012	-340.22	-1,339.56	659.11	0.505
2013	-655.24	-1,654.58	344.10	0.199
2014	-1,466.65	-2,466.28	-467.02	0.004
2015	-1,658.15	-2,656.16	-660.14	0.001
2016	-2,013.65	-3,013.54	-1,013.76	<0.001
Constant	14845.26	13073.60	16616.91	<0.001

* Model controlled for hospital fixed effects.

Table 3. The results of a linear probability model of in-hospital mortality.*

Variable	Coefficient	95% Confidence Interval Lower	Upper	P-value
Outcome				
DNR	0.089	0.088	0.091	<0.001
Age				
65-74	Reference			
75-84	0.007	0.006	0.008	<0.001
85+	0.011	0.010	0.013	<0.001
Sex				
Male	Reference			
Female	-0.006	-0.007	-0.006	<0.001
Race/Ethnicity				
White Non-Hispanic	Reference			
Black Non-Hispanic	-0.005	-0.006	-0.003	<0.001
Hispanic	-0.001	-0.003	0.001	0.209
Asian	-0.004	-0.007	0.000	0.025
Other	0.000	-0.003	0.003	0.878
Elixhauser Comorbidity Index	-0.001	-0.001	-0.001	<0.001
APR-DRG Severity Index				
Minor	Reference			
Moderate	-0.002	-0.004	0.000	0.018
Major	0.016	0.014	0.018	<0.001
Extreme	0.135	0.133	0.137	<0.001
Zip Code Income Quartile				
Q1	0.001	0.000	0.003	0.096
Q2	0.001	-0.001	0.002	0.471
Q3	-0.001	-0.002	0.001	0.248
Q4	Reference			
Payor				
Medicare	Reference			
Medicaid	0.003	-0.001	0.006	0.133
Commercial	0.024	0.022	0.026	<0.001
Other	0.061	0.057	0.064	<0.001
Hospital Size				
Small	0.003	0.002	0.005	<0.001
Medium	0.002	0.001	0.003	0.006
Large	Reference			
Hospital Location				
Urban	Reference			
Rural	0.009	0.007	0.011	<0.001

Hospital Teaching Status				
Teaching	0.000	-0.001	0.001	0.879
Non-Teaching	Reference			
Region				
Northeast	Reference			
Midwest	-0.002	-0.017	0.013	0.756
South	-0.007	-0.025	0.011	0.457
West	-0.017	-0.062	0.028	0.457
Year				
2011	Reference			
2012	-0.013	-0.024	-0.002	0.022
2013	-0.017	-0.029	-0.006	0.002
2014	-0.021	-0.033	-0.010	<0.001
2015	-0.026	-0.037	-0.015	<0.001
2016	-0.030	-0.041	-0.019	<0.001
Constant	0.0211	0.0012	0.0409	0.0370

* Model controlled for hospital fixed effects.

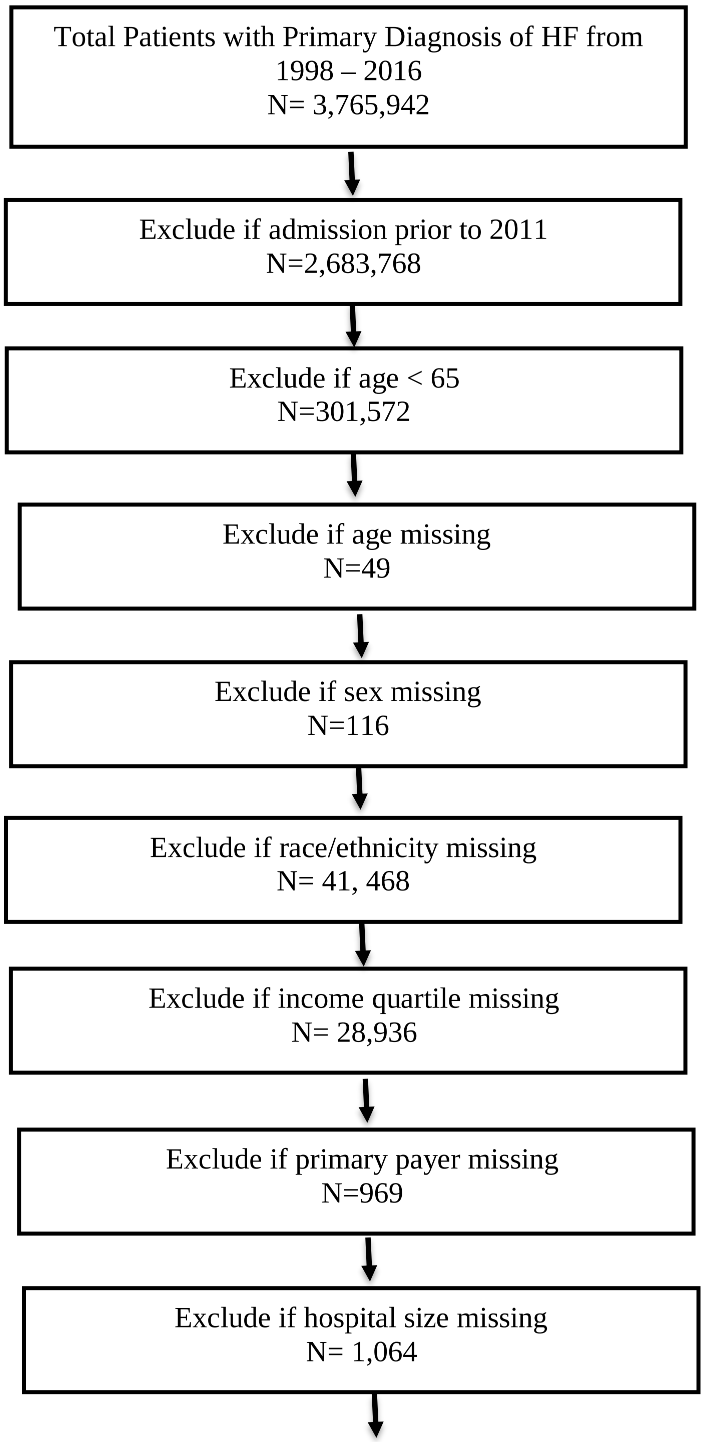
Table 4. Results of a linear regression of length of hospital stay.*

Variable	Coefficient	95% Confidence Interval		P-value
		Lower	Upper	
Outcome				
Died	0.34	0.26	0.42	<0.001
DNR	-0.06	-0.09	-0.02	0.002
DNR*Died	-1.51	-1.63	-1.39	<0.001
Lived / No DNR	Reference			
Age				
65-74	Reference			
75-84	-0.06	-0.09	-0.04	<0.001
85+	-0.21	-0.24	-0.18	<0.001
Sex				
Male	Reference			
Female	0.12	0.10	0.14	<0.001
Race/Ethnicity				
White Non-Hispanic	Reference			
Black Non-Hispanic	0.07	0.03	0.10	<0.001
Hispanic	-0.07	-0.12	-0.02	0.006
Asian	-0.14	-0.22	-0.05	0.002
Other	0.06	-0.01	0.13	0.091
Elixhauser Comorbidity Index	0.06	0.05	0.07	<0.001
APR-DRG Severity Index				
Minor	Reference			
Moderate	0.72	0.68	0.77	<0.001
Major	2.45	2.41	2.50	<0.001
Extreme	6.59	6.53	6.65	<0.001
Zip Code Income Quartile				
Q1	-0.03	-0.06	0.01	0.185
Q2	-0.05	-0.09	-0.01	0.008
Q3	-0.09	-0.13	-0.06	<0.001
Q4	Reference			
Payor				
Medicare	Reference			
Medicaid	0.55	0.45	0.64	<0.001
Commercial	-0.01	-0.06	0.04	0.737
Other	-0.02	-0.10	0.07	0.703

Hospital Size				
Small	-0.61	-0.65	-0.57	<0.001
Medium	-0.46	-0.50	-0.43	<0.001
Large	Reference			
Hospital Location				
Urban	Reference			
Rural	-0.28	-0.33	-0.23	<0.001
Hospital Teaching Status				
Teaching	0.55	0.52	0.59	<0.001
Non-Teaching	Reference			
Region				
Northeast	Reference			
Midwest	-0.19	-0.58	0.19	0.326
South	0.32	-0.16	0.79	0.188
West	-1.97	-3.13	-0.81	0.001
Year				
2011	Reference			
2012	0.04	-0.25	0.33	0.768
2013	-0.07	-0.36	0.22	0.626
2014	-0.19	-0.48	0.10	0.196
2015	-0.32	-0.61	-0.03	0.032
2016	-0.38	-0.67	-0.09	0.011
Constant	3.25	2.74	3.76	<0.001

* Model controlled for hospital fixed effects.

Figure 1. Determination of study cohort.



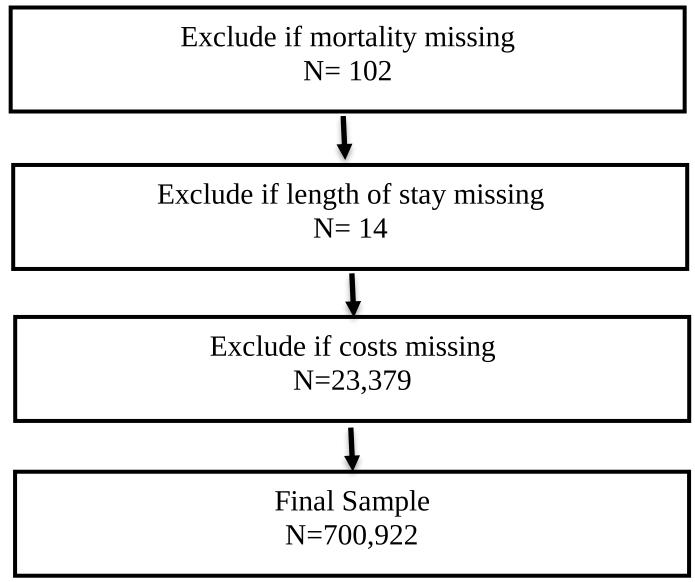

Exclude if mortality missing
N= 102
Exclude if length of stay missing
N= 14
Exclude if costs missing
N=23,379
Final Sample
N=700,922

Figure 2. Proportion of HF patients with a DNR order, 2011-2016.

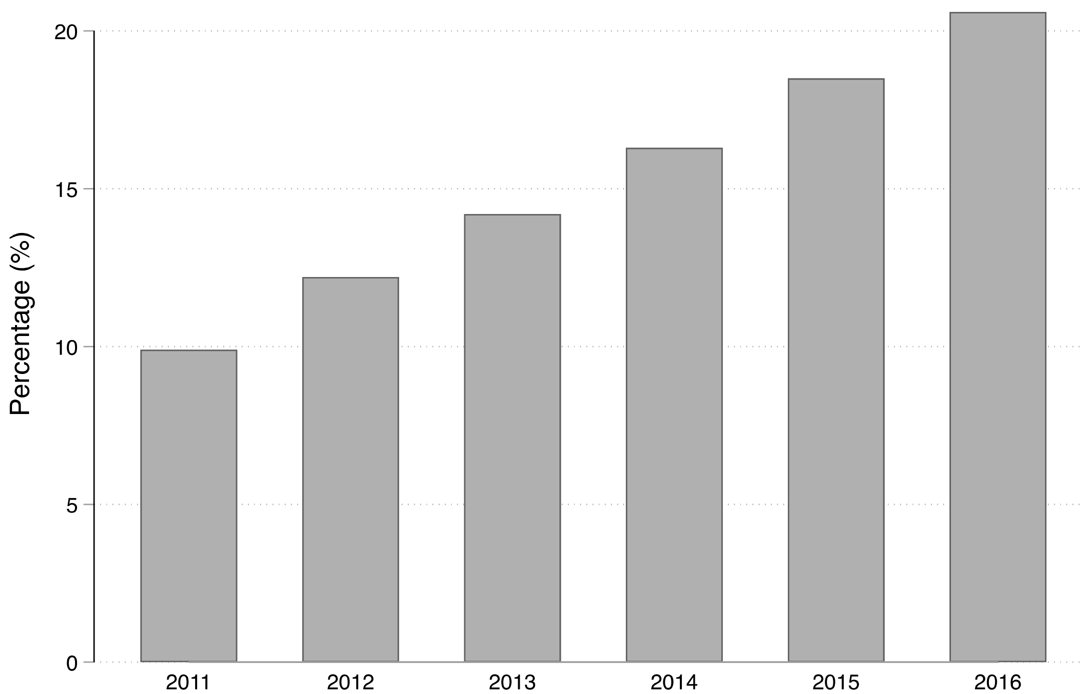


Figure 3. Marginal effects for DNR and death and total inpatient costs from regression analysis.

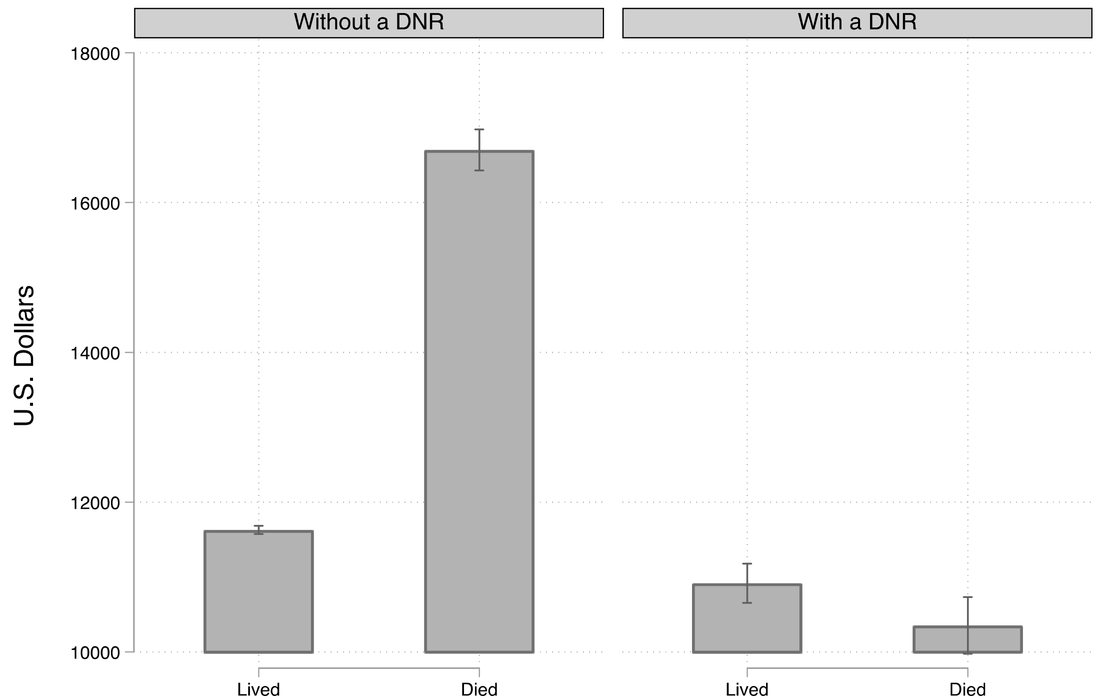


Figure 4. Marginal effects for DNR and death and length of hospital stay from regression analysis.

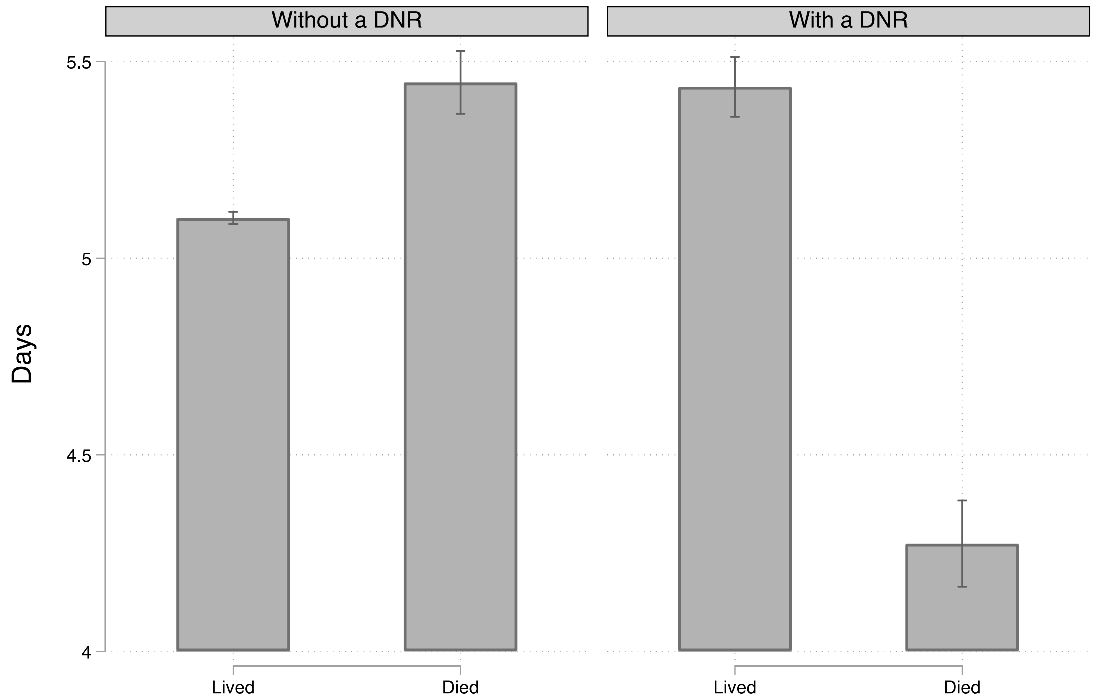
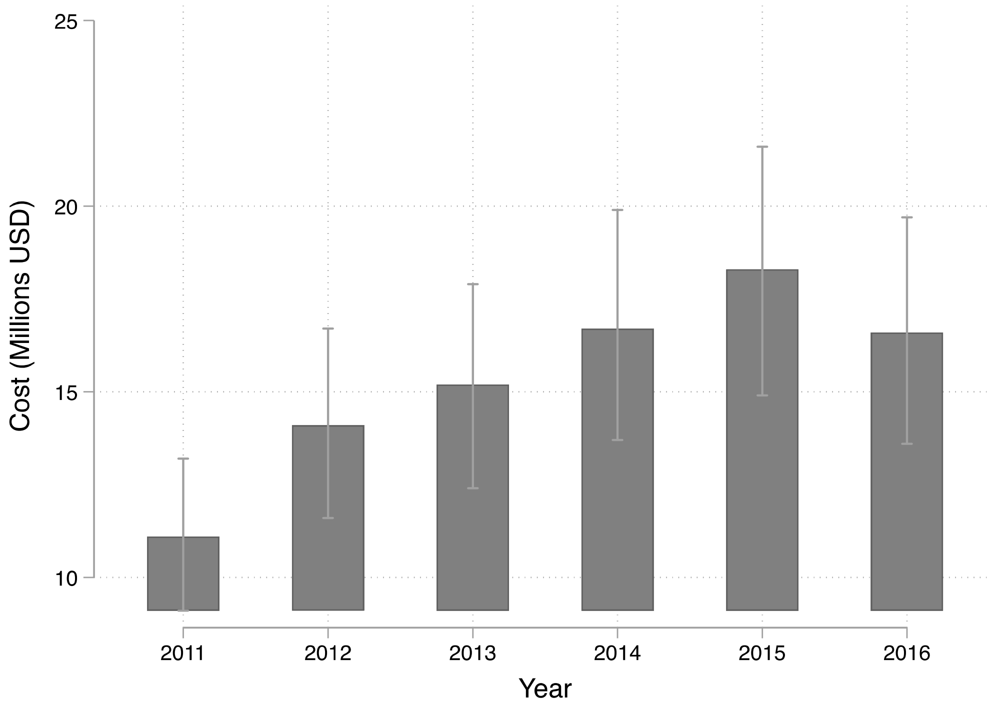


Figure 5. National estimates of cost-saving potential of DNR orders among elderly HF patients who died, 2011 to 2016.



Chapter 3

Validity of ICD Codes to Identify Do-Not-Resuscitate Orders

Abstract

Background. Observational research on the advance care planning (ACP) process is limited by a lack of easily accessible ACP variables in many large datasets.

Objectives. The primary objective was to determine whether International Classification of Disease (ICD) codes for do-not-resuscitate (DNR) orders are valid proxies for the presence of a DNR that is recorded in the electronic medical record (EMR).

Research Design. Sensitivity, specificity, positive predictive value and negative predictive value were calculated as well as measures of agreement and disagreement. In addition, estimates of the associations between DNR and mortality as well as DNR and cost were estimated using the DNR documented in EMR and the DNR proxy identified in ICD codes.

Subjects. The cohort studied included 1,719 patients over the age of 65 who were admitted to a large, mid-Atlantic medical center with a primary diagnosis of heart failure.

Measures. DNR orders were identified in the billing records from ICD-9 and ICD-10 codes. DNR orders were also identified in the EMR by a manual search of physician notes.

Results. Relative to the gold standard of DNR orders recorded in patient's EMR, DNR orders identified in ICD codes had an estimated sensitivity of 88.7%, specificity of 98.4%, positive predictive value of 96.0%, and negative predictive value of 95.3%. The estimated kappa statistic was 0.89, although McNemar's test suggested there was some systematic disagreement between the DNR from ICD codes and the EMR. Estimates of the association between DNR and mortality were very similar using the ICD DNR (8.9%, $p<0.001$) and the EMR DNR (8.9%,

p<0.001) and similar for the association between DNR and costs estimated using the ICD DNR ($-32,091, p<0.001) and the EMR DNR ($-39,940, p<0.001).

Conclusions. ICD codes provide a reasonable proxy for DNR orders, validate past research using ICD proxies for DNR, and open the door to further applied research in ACP using administrative discharge data.

Introduction

Research on issues in advance care planning (ACP) can be challenging as there are few ACP variables routinely collected in large datasets [1, 2]. Some data sets, such as the Health Retirement Study's (HRS) Exit Interview, which began conducting surveys in 1996, contain survey data on advance care planning. However, the data collected in the Exit Interview are completed with a "proxy informant" of HRS participants who have died, and this dataset is relatively small with less than 1,000 participants per year [3]. The ability to identify ACP variables in large administrative and other observational health care datasets that are easily accessible to health services researchers would be beneficial and would advance research in ACP.

One potentially important source of data is administrative discharge data, which are collected by hospitals that use them for billing, monitoring, and reporting to organizations that measure quality of care [4]. These data provide information on hospital stays and routinely include International Classification of Diseases (ICD) codes, which reflect patient diagnoses and procedures patients receive during their hospitalization [4]. Another potential source of data is claims data, which records information from third-party payers and often includes ICD codes to document diagnoses and procedures. Since 2010 there has been an ICD code for do-not-resuscitate (DNR) orders—V49.86 in the 9th revision and Z66 in the 10th revision, which began to be widely used in the US in October 2015 [1, 5]. A DNR is a signed medical order that tells healthcare providers not to begin cardiopulmonary resuscitation (CPR) in the event of cardiac arrest [6]. Although a DNR is only part of the ACP process, it can be important for patients to define their resuscitation preferences as CPR is often not beneficial for individuals at end-of-life (EOL) who are already weak and frail, such as those with severe chronic and terminal illnesses [7].

Researchers therefore have access to a proxy for DNR orders through the widely available ICD codes. This proxy may allow for research around DNR orders as part of the ACP process. For example, we recently used ICD-9 codes as a proxy for DNR orders to examine whether patients with DNR orders were more likely to be readmitted after being hospitalized in Pennsylvania for heart failure (HF) [8].

A major concern about ICD codes for DNR orders is it is not known whether they are valid proxies for actual DNR orders, and whether they reflect a patient's resuscitation preference that is recorded in their medical record. There are several reasons that the ICD code may not reflect a patient's actual DNR status. ICD codes are used by hospital billing coders in order to maximize revenues to the hospital. If the ICD code for DNR does not have revenue value in billing then hospital billing coders may not prioritize recording DNR in the limited slots available for entry. Under this scenario, DNRs could be routinely under-represented in administrative data. If the ICD code for a DNR order is not a reasonably accurate measure for the legal document that a patient signs to make their wishes regarding CPR known to the clinical team, then caution should be used in using it as a proxy for DNR, and previous studies that have used it should be interpreted with caution. However, if the ICD codes could be shown to be valid proxies for actual DNR status, then observational data sets such as administrative discharge data and claims data may be useful for EOL research.

There is some evidence that the ICD code for the DNR order is accurate [1, 6]. For example, one study found that that the ICD-9 code for the DNR order (V49.86) is moderately sensitive and highly specific among a cross-section of patients admitted to a hospital [1]. Another study that investigated the validity of the ICD-9 code among primary diagnoses of myocardial infraction, pneumonia, and heart failure (HF), suggested that the DNR proxy has a high sensitivity but only moderate specificity [6]. While these studies suggest that the ICD code provides a potentially promising proxy for DNR, there are several limitations. These studies include primary diagnoses that include many observations for which a DNR order is not likely to be relevant. For example, it is reasonable to think that discussing resuscitation preferences with a

16-year-old patient admitted with a distal radius fracture is not a high priority for health care providers. This in turn can affect the accuracy of the ICD code documented. In addition, these studies did not include data on the more recent ICD-10 codes that have been in widespread use in the US since 2015.

In order to address these gaps, this study sought to determine the validity of ICD proxies for DNR in elderly patients hospitalized with a primary diagnosis of HF. Our sample includes both ICD-9 and ICD-10 codes for DNR, and also explores whether use of the ICD proxy produces different estimates when used as a substitute for a gold standard measure of DNR orders found in electronic medical records (EMR).

Objectives

The purpose of this study was to determine whether ICD-9 and ICD-10 codes for DNR are valid proxies for the presence of a DNR that is recorded in the EMR. We utilized data from a large, academic hospital in the mid-Atlantic region and merged billing records that contain ICD codes with data regarding DNRs documented in the EMR. In addition to comparing ICD DNR proxies to actual DNR documentation, this study also estimated the association between DNR and mortality and costs using both the ICD code DNR and the DNR recorded in the patients EMR in order to determine whether the ICD measure provides similar estimates of association relative to actual DNR documented in the EMR.

Methods

Data Source

This research used data from the Penn State Milton S. Hershey Medical Center. Billing records were obtained from the cost-accounting system (Change Healthcare, Nashville, TN), which provided ICD codes from which DNR was identified, as well as details on patient characteristics, hospital stay, and total costs. In addition, the EMR for each patient was examined, which provided physician notes that documented the patient's treatment preferences, including a DNR order. This study was reviewed and approved by the Pennsylvania State University Institutional Review Board.

Cohort

Patients admitted between 2013 and 2016 with a principle diagnosis of HF were identified using the ICD-9 code of 428.xx (heart failure) and ICD-10 code of I50.xx (heart failure). Patients under the age of 65 were excluded as older patients are more likely to participate in any type of ACP [9, 10]. The final sample included n=1,719 patients.

Outcomes

DNR proxies in ICD codes (iDNR) were identified using an ICD-9 code of V49.89 and an ICD-10 code of Z66 among secondary diagnosis codes in billing records. The actual DNR contained in the EMR (eDNR) was identified by searching the EMR, particularly physician notes, for any mention of DNR status. Secondary outcomes included in-hospital mortality and total cost of admission. Costs are estimated in the cost-accounting system using ratios of costs-to-charges at the department level and include overhead. Thus, total costs in this study represent fully-loaded operating costs for the HF admission.

Covariates

Several covariates that have been shown to be associated with DNR and were included in the analyses. To control for patient characteristics, indicators were used for age groups (65-74, 75-84, or 85+), sex (male or female), race/ethnicity (white non-Hispanic or other race/ethnicity), payer (Medicare, Medicaid, commercial, or other), and hospital admission type (elective, emergent, or urgent). To control for comorbidities, we included the Charlson comorbidity index (CCI), which is a weighted sum of seventeen common comorbidities that can be identified using ICD codes [11-13]. The CCI was transformed into categories (0, 1, 2-3, or 4+).

Statistical Analysis

In order to determine whether the iDNR predicts the presence of eDNR, the sensitivity and specificity of the iDNR was estimated relative to the eDNR as the gold standard. Sensitivity is defined as the probability that a patient has an iDNR given that patient has an eDNR; specificity is defined as the probability that a patient does not have an iDNR given that the patient does not have an eDNR. We also computed the positive predictive value (PPV), which is defined as the probability that a patient has an eDNR given that they have an iDNR, and the negative predictive value (NPV), which is the probability that a patient does not have an eDNR given that they do not have a iDNR. Additionally, these measures were computed across strata of patient characteristics, including age, sex, race/ethnicity, and comorbidities.

Two univariate tests of agreement between the two DNR measures were performed [14]. First, the level of agreement between the iDNR and eDNR was estimated using a Cohen's kappa statistic. The kappa statistic is a correlation measure with values between -1 and 1 that reflect the overall level of agreement between two predictions and is often used to measure inter-rater reliability [15, 16]. Second, systematic disagreement between the iDNR and eDNR was compared using McNemar's test. McNemar's test was used to investigate whether there are systematic differences in disagreement between the two measures. In this case, it tests whether the iDNR is significantly more likely to be negative when the eDNR is positive, or whether the eDNR is more likely to be negative when the iDNR is positive [17]. The difference between the two tests of agreement is that McNemar's test considers only the off diagonal elements in a contingency table, and the kappa statistic considers all cells of the contingency table.

After estimating agreement between the two DNR measures, we examined whether the use of each measure would yield substantially different estimates of association when used as a covariate in multivariable analysis about the associations between DNR and outcomes. The outcomes that we were specifically interested in—mortality and costs—were modeled using the iDNR and eDNR as independent variables and controlling for other covariates. Finding that the two measures yielded substantially different associations would be evidence that the iDNR is not a good proxy for eDNR. Linear probability models were used to model the relationship between DNR and mortality, after controlling for the covariates described above. Linear regression models were used to model the association between total costs and DNR after controlling for the patient characteristics. A Hausman test was used to compare the coefficients estimated for the interaction between mortality and iDNR and mortality and eDNR in the cost regressions. Stata software (version 15.1, College Station, TX) was used for all analyses, and statistical significance was defined as $p<0.05$.

Results

Patient Characteristics

A description of patient characteristics stratified by DNR status is provided in Table 1. The summary compares elderly HF patients without a DNR (n=1,186) to those with an iDNR (n=475) and those with an eDNR (n=514) across several covariates. In this sample, elderly HF patients were more likely to have a DNR (either iDNR or eDNR) if they were older, were white non-Hispanic female, had an emergency admission, and had Medicare as their primary insurance. There were no substantial differences between patients with an iDNR and patients with an eDNR. The largest difference observed was between CCI categories, where there were slightly more patients with an iDNR that had zero comorbidities compared to patients with an eDNR (32% vs.

30%). Compared to patients with DNRs, patients without a DNR were more likely to have one to three comorbidities, yet slightly less likely to have zero or four or more comorbidities.

Measures of Agreement

A 2×2 contingency table of iDNR by eDNR is shown in Figure 2. Within the sample of n=1,719 individuals there were 456 true positives (a DNR that was reflected in both the ICD codes and EMR), 1,186 true negatives (no DNR present in the ICD codes or EMR), 19 false positives (an iDNR but no evidence of DNR in the EMR), and 58 false negatives (no iDNR but an eDNR).

Cohen's kappa statistic for agreement between iDNR and eDNR was estimated to be 0.89, which suggests "almost perfect agreement" between the iDNR and eDNR [10]. On the other hand, the McNemar test suggested there were systematic differences in disagreement between iDNR and eDNR. In terms of disagreement, a false negative iDNR was significantly more likely than a false positive iDNR. However, as seen in Figure 2, the proportion of both false negatives and false positives was small.

Sensitivity and Specificity

For the full sample (N=1,719), sensitivity of iDNR was estimated to be 88.7%, which means that 88.7% of the individuals who have an eDNR were correctly documented as having an iDNR. Specificity of iDNR was estimated to be 98.4%, which means that 98.4% of patients who did not have an eDNR also did not have an iDNR. The PPV was estimated to be 96.0% and NPV was estimated to be 95.3%, meaning that among the entire sample of individuals with and without DNRs, the iDNR correctly identified who did and did not have a DNR slightly over 95% of the time. Within the subgroups of patient characteristics, the highest level of sensitivity was found among patients who had no comorbidities (91.6%) and the highest level of specificity was found among patients who had 1 comorbidity (99.3%). On the other hand, the lowest sensitivity was found among patients who had 1 comorbidity (84.9%), and the lowest level of specificity was among patients with no comorbidities (97.0%).

Mortality

The iDNR provided essentially the same estimates of the association between DNR and mortality as the eDNR. This is shown in Table 3, which provides the results of linear probability models using both iDNR and eDNR and controlling for covariates. The estimated likelihood of dying before discharge was 8.9 percentage points higher for patients with a DNR as indicated by the iDNR ($p<0.001$), and 8.9 percentage points higher for patients with an eDNR ($p<0.001$). There were other covariates that were also associated with in-hospital mortality. For example, individuals who used other pay sources including “self-pay” had the highest likelihood of dying at almost 18 percentage points ($p<0.001$) higher compared to individuals with Medicare as their payer. Age and urgency of admission were negatively associated with mortality, meaning that older age and greater urgency of admission were associated with lower risk of mortality.

Hospitalization Costs

As seen in Table 4, iDNR and eDNR provided somewhat similar estimates of the association between DNR and total hospitalization costs. Linear regression models using iDNR and eDNR as independent variables to model the association between DNR and costs suggested that after controlling for covariates, there were cost savings for patients with an iDNR order who died of $32,091 ($p<0.001$), and $39,940 ($p<0.001$) for patients with an eDNR who died. These coefficients were not significantly different from each other ($p=0.276$).

The mean cost savings for patients who died with an eDNR and no iDNR was significantly greater than the cost savings with patients who died with an iDNR and no eDNR.

Among patients who died without a DNR, costs were approximately $40,500 higher ($p<0.001$) in the eDNR model and approximately $34,000 higher ($p<0.001$) in the iDNR model. Costs were not significantly different and were similar in magnitude for patients who had a DNR and survived. This follows a similar pattern to the previous chapter for estimates of costs that have shown that costs are highest for patients without a DNR who die and are lowest for patients with a DNR who die during their hospital admission.

There were other patient characteristics associated with costs. For example, patients who were older, had a higher severity admission type, and who were non-white and Hispanic had lower total hospitalization costs. Additionally, compared to those who were insured by Medicare, patients covered by other sources had lower costs of approximately $18,000. Compared to patients with a CCI of 0, individuals with a CCI of 1 had higher costs of approximately $3,500. However, patients with a CCI of 2 or greater had significantly lower costs.

Discussion

Results from this study suggest that the ICD code for DNR is a valid proxy for the presence of a DNR order documented in the medical record. This was indicated by a high sensitivity (89%), specificity (98%), PPV (96%) and NPV (95%) relative to the gold standard of a DNR documented in the EMR. The estimated kappa statistic ($\kappa = 0.89$) also suggests there is substantial agreement between DNR in billing records and the EMR. It should be noted that the results from McNemar's test suggest a systematic difference between false negatives and false positives; however, this test only considers the off-diagonal elements of the contingency table, which were relatively small compared to the total sample (Figure 2). The sensitivity, specificity, PPV, NPV, and kappa statistic all consider the entire contingency table, and therefore together are strong indicators that the iDNR is valid. In comparison to other common ICD code proxies used in current research studies the iDNR performed as well or better [18-20].

In addition, the results confirm that the iDNR is a reasonable proxy to use in models that estimate the impact of the DNR on patient outcomes. In the model that estimated the association between DNR and mortality (Table 3), the iDNR as an independent variable produced very similar results to the eDNR (8.9 percentage points vs. 8.9 percentage points). Likewise, the model that estimated the association between DNR orders and costs (Table 4) indicated that the iDNR as the independent variable gave comparable results to the eDNR ($32,091 for iDNR, $39,940 for eDNR). Overall, these results support the use of iDNR as a proxy to measure DNR orders, validating its use in prior research and recommending it in future research.

This study makes several contributions to the literature on DNR orders and ACP. First, estimates of sensitivity, specificity, PPV, NVP, and agreement suggest that both the ICD-9 and ICD-10 codes are reasonable proxies for DNR orders recorded in patient medical records. Second, the results provide confirmation of other validation studies that have examined ICD-9 codes and similarly found that the ICD code is a reasonable proxy for DNR orders [1, 6]. Finally, the results of this study indicate that estimates of association between iDNR and patient outcomes, such as mortality or costs, are similar to those that would be obtained using eDNR.

Similar to Fonseca et al. (2018), we found the iDNR to have very high specificity at 98%. However, unlike their study, we also found the iDNR sensitivity to be high (89% vs. 69%) [1]. This may be due to differences in the sample, as we only looked at patients over the age of 65 with HF, and the Fonseca et al. study (2018) included patients at any age and admitted with any diagnosis, although the most common admission diagnoses were metastatic cancer, pneumonia, HF, acute myocardial infraction, chronic obstructive pulmonary disease, and stroke. In addition, our iDNR measure included both ICD-9 and ICD-10 diagnosis codes; Fonseca et al. (2018) only included ICD-9 codes in their proxy.

Results in this study differ somewhat from those reported in Goldman et al. (2013) who investigated the accuracy of DNR orders using administrative discharge data in California (CA).

They found that DNR orders were more likely to be recorded inaccurately as the time window increased. Our study used ICD codes that were determined after the patient was discharged, and includes DNR orders that could have been completed at any time during the hospital stay. One potential explanation for this difference is a difference in the definition of iDNR as DNR orders in CA are measured only within 24 hours of admission. They do not capture DNR orders that may have been finalized after admission and may be less accurate for patients with longer hospitalizations [6].

One piece of evidence from our study that suggested that the iDNR might not be a good proxy for eDNR was McNemar's test, which found significant disagreement between the two measures. This test compared the number of false positive results (N=19) and false negative (N=58) results and showed that the iDNR yielded systematically more false negatives. Certainly, there should be a greater expectation for false negative results since coders have a limited number of placeholders for ICD codes, and priority is given to those that result in higher reimbursement. The false positive cases are more of a puzzle. In our sample there were 19 false positive cases out of 1,719 patients, which is a relatively small proportion. Their presence raises the question, however, how a billing coder who assigns ICD codes based on a review of the EMR could indicate the presence of a DNR when our chart review did not find any evidence of a DNR in the EMR. Discussions with hospital billing coders from the Penn State Milton S. Hershey Medical Center indicated that while it is possible that these may have just been simple error, it is also possible that DNR orders were counted in false positive cases when patients received a consultation with palliative care or hospice teams, which they might interpret as having a DNR order. Another potential explanation is that coders may have observed evidence of a DNR order for a prior hospitalization and assumed (correctly or incorrectly) that the DNR order would apply to the current hospital admission [21].

Limitations

The results of this study only came from patients at a single medical center. Therefore, it is possible that the use of ICD codes for DNR orders can be attributed to the practice patterns of this particular center's billing coders, and these results therefore do not reflect practice patterns at other institutions or nationally. In addition, we examined only elderly patients with HF. iDNR may be different for younger patients with HF or for patients with other chronic and terminal illnesses. Our results also may be driven by the specific practice patterns around ACP and DNR orders of physicians in this medical center.

There are other challenges to measuring associations between patient outcomes and DNR orders that are due to discrepancies between a patient's wishes and care that is actually received. A patient may have a DNR order in place and still receive CPR after a cardiac event. This may occur if the clinical team is unaware of the DNR order or if the patient's family overrides the DNR order. Family members' desire for heroic measures may be given preference to patient's wishes, particularly in hospital environments where lawsuits are more prevalent and if the medical care ends in death for the patient [22]. The greater the extent of these occurrences, the more the estimates of association between DNR orders and outcomes will be biased toward the null.

Conclusions

Using a sample of elderly patients with a primary diagnosis of HF at a large, academic medical center in the mid-Atlantic, this study examined the validity of ICD codes for DNR orders and compared their use relative to DNR status in the EMR. Results showed high sensitivity, specificity, PPV, NPV, and overall agreement. They also showed that the use of the ICD proxy provided similar estimates of association between patient outcomes and DNR status. These results suggest that the ICD codes provide a reasonable proxy for DNR orders, validate past research using ICD proxies for DNR, and open the door to further applied research on DNR orders. Additional research is needed to validate the ICD proxies in other diseases and other populations, and to find other proxies for other elements of ACP beyond DNR orders.

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Table 1. Summary statistics for elderly HF patients, stratified by DNR status in ICD codes and EMR.

Variable	**No DNR** *(N=1,186)*	**iDNR** *(N=475)*	**eDNR** *(N=555)*
Age			
65-74	42.2%	17.7%	17.7%
75-84	38.7%	32.4%	31.1%
85+	19.1%	49.9%	51.2%
Sex			
Female	43.8%	53.7%	53.7%
Male	56.2%	46.3%	46.3%
Race/Ethnicity			
White Non-Hispanic	94.1%	95.8%	96.3%
Other Race/Ethnicity	5.9%	4.2%	3.7%
Admission Type			
Elective	5.2%	3.6%	3.5%
Urgent	18.8%	15.6%	15.6%
Emergency	76.0%	80.8%	80.9%
CCI Categories			
0	29.5%	32.0%	30.0%
1	23.1%	23.0%	24.5%
2 to 3	34.4%	31.8%	31.9%
4+	13.0%	13.2%	13.6%
Payor			
Commercial	24.9%	18.5%	18.5%
Medicare	72.3%	73.7%	74.1%
Other	2.8%	7.8%	7.4%

Table 2. Summary of diagnostic characteristics of iDNR relative to eDNR, stratified by patient characteristics.

Patient Characteristics	Sample Size	Sensitivity	Specificity	PPV	NPV
Patient Characteristics					
Total	(N=1,719)	88.7%	98.4%	96.0%	95.3%
Age					
65-74	(N=597)	86.8%	99.0%	97.4%	94.6%
75-84	(N=628)	90.6%	98.1%	95.3%	96.1%
85+	(N=494)	88.2%	97.8%	94.6%	95.1%
Sex					
Female	(N=804)	89.5%	98.5%	96.2%	95.7%
Male	(N=915)	87.8%	98.4%	95.8%	95.0%
CCI Categories					
0	(N=515)	91.6%	97.0%	92.8%	96.4%
1	(N=402)	84.9%	99.3%	98.0%	93.9%
2 to 3	(N=576)	89.6%	99.0%	97.5%	95.7%
4+	(N=226)	87.1%	98.7%	96.7%	94.7%

Table 3. Results of linear probability models of mortality controlling for eDNR versus iDNR as independent variables as well as other covariates.

Variable	eDNR Model N = 1,719	P-Value	iDNR Model N = 1,719	P-Value
DNR	0.089	<0.001	0.089	<0.001
Age				
65-74	Reference			
75-84	-0.021	<0.001	-0.021	0.054
85+	-0.047	<0.001	-0.043	0.001
Sex				
Female	0.003	0.731	0.003	0.716
Male	Reference			
Race/Ethnicity				
Non-Hispanic White	Reference			
Other Race/Ethnicity	-0.033	0.107	-0.036	0.083
Admission Type				
Elective	Reference			
Urgent	-0.095	<0.001	-0.094	<0.001
Emergent	-0.121	<0.001	-0.120	<0.001
CCI Categories				
0	Reference			
1	-0.002	0.85	0.001	0.945
2 to 3	-0.020	0.08	-0.019	0.107
4+	-0.018	0.236	-0.016	0.310
Payor				
Private	0.009	0.410	0.008	0.454
Medicare	Reference			
Other	0.180	<0.001	0.179	<0.001
Constant	0.149	<0.001	0.148	<0.001

Table 4. Results of linear regression models of hospital cost controlling for eDNR versus iDNR as independent variables as well as other covariates.

Variable	eDNR Model	P- Value	iDNR Model	P- Value
Died	40,562.79	<0.001	34,132.04	<0.001
DNR	998.55	0.613	1,763.20	0.380
Died & DNR	-39,939.60	<0.001	-32,091.12	<0.001
Lived & No DNR	Reference			
Age				
65-74	Reference			
75-84	-8,803.46	<0.001	-8,801.04	<0.001
85+	-11,418.75	<0.001	-11,885.74	<0.001
Sex				
Female	-3,585.29	0.031	-3,959.44	0.018
Male	Reference			
Race/Ethnicity				
Non-Hispanic White	Reference			
Other Race/Ethnicity	-3,267.93	0.367	-3,331.53	0.359
Admission Type				
Elective	Reference			
Urgent	-18,322.04	<0.001	-17,313.97	<0.001
Emergent	-26,462.20	<0.001	-25,536.35	<0.001
CCI Categories				
0	Reference			
1	3539.77	0.114	3390.60	0.131
2 to 3	-5101.19	0.012	-5430.32	0.008
4+	-6522.70	0.015	-6955.28	0.010
Payor				
Private	-128.16	0.947	158.77	0.935
Medicare	Reference			
Other	-18,262.38	<0.001	-18,925.60	<0.001
Constant	50,091.94	<0.001	49,485.33	<0.001

Figure 1. Determination of study cohort

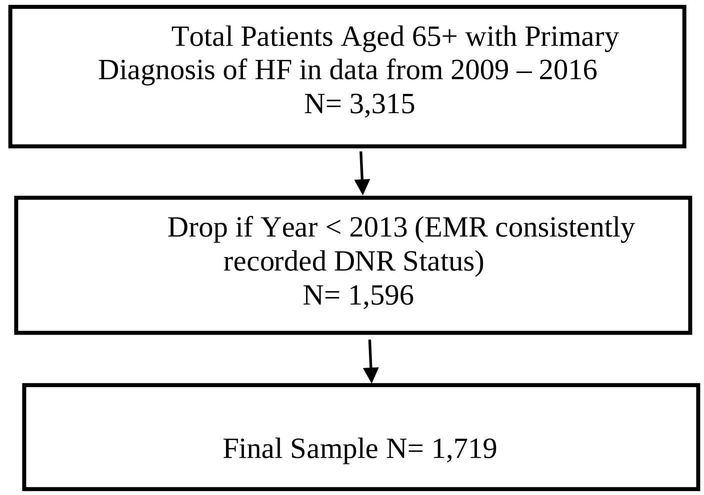

Figure 2. Contingency table of eDNR and iDNR.

		eDNR		
		DNR	*No DNR*	*Total*
iDNR	*DNR*	456	19	475
	No DNR	58	1,186	1,244
	Total	514	1,205	1,719

Chapter 4

The Affordable Care Act and Do-Not-Resuscitate Orders: Differences by Race and Ethnicity

Abstract

Background. There are significant racial and ethnic disparities in end-of-life care. The Affordable Care Act (ACA) created new payment rules that provided reimbursement for physicians to engage in advance care planning (ACP) conversations with patients. This reimbursement policy has the potential to increase ACP participation, including among racial and ethnic minority groups that have had lower ACP participation.

Objectives. To examine whether the ACP payment rules were associated with an increase in use of do-not-resuscitate (DNR) orders, particularly among racial and ethnic minority groups, among patients diagnosed with heart failure (HF) in California. A secondary objective was to investigate the timing of DNR orders among racial and ethnic groups.

Research Design. The California Office of Statewide Health Planning and Development (OSHPD) Patient Discharge Data Set was used to identify a cohort of elderly patients with a principal diagnosis of HF. Linear probability models were used to model the relationship between DNR utilization and ACP reimbursement.

Subjects. This study included 432,520 hospital admissions of patients over the age of 65 with a primary diagnosis of HF between 2012 and 2018.

Measures. DNR status was identified using International Classification of Diseases, Clinical Modification (ICD-CM), Ninth and Tenth Revision, codes. OSHPD data also contain DNR

orders that are signed within 24 hours of admission to the hospital, which allowed us to distinguish between early and late DNR orders.

Results. There was a small increase in the utilization of DNR orders overall after the ACA reimbursement policy, but the change was not significantly different for all racial and ethnic groups when compared to white non-Hispanic patients. Among individuals who had DNR orders, late DNR was more common among racial and ethnic minorities.

Conclusions. ACP payment rules provided in the ACA were associated with increased utilization of DNR, but the effect was not significantly different between racial and ethnic minorities hospitalized with HF in CA, although they were for white non-Hispanic patients. In addition, racial and ethnic minorities may be more likely to have late DNR orders, suggesting they are more likely to make this resuscitation status choice when their initial treatment plans fail. Additional efforts are needed to increase ACP participation among racial and ethnic minorities.

Introduction

The advance care planning (ACP) process can be effective in aligning patient preferences with medical care and result in higher quality end-of-life (EOL) care for the patient and greater levels of satisfaction without complicating grief for their loved ones [1, 2]. In addition to facilitating conversations with loved ones and medical providers about goals of care, the ACP process includes assigning a proxy to make decisions in case the patient becomes unable, and putting preferences into legal documents to ensure they are accurately followed [1, 3, 4].

High quality EOL care can include physical support such as pain management, and also psychological, social, spiritual and practical support. EOL care is one of the many areas in health care where significant disparities have been documented between racial and ethnic groups [3]. Several explanations have been documented for why racial and ethnic minority groups are less likely to participate in the ACP process, including trust issues with medical providers, religious factors, family decision making styles, and a lack of knowledge regarding ACP issues [5, 6].

The Patient Protection and Affordable Care Act (ACA) was implemented in 2010 and included several components with the potential to improve EOL care. In particular, beginning in January 2016, the Center for Medicaid and Medicare Services added payment rules for Medicare reimbursement for physicians to consult with patients on ACP [7]. The ACA added two Current Procedural Terminology (CPT) codes that allowed Medicare to pay $86 for every 30 minutes of ACP that occurred in a physician's office, and $80 if this conversation occurred in the hospital [8]. In addition, Medicare would pay $75 for an extra 30 minutes of ACP [8]. Prior to the implementation of these payment rules, physicians would not be reimbursed for engaging Medicare patients in discussions about their EOL care preferences, which may result in patients receiving futile medical care that is not only potentially unwanted, but also costly. Several studies have shown that Medicare spends significantly more on health care in last year of life, and the ACP process has the potential to mitigate some of this [9, 10]. In addition, these new payment rules provide an incentive for physicians to initiate and engage in EOL conversations with their patients, which may begin to break down some of the trust barriers that have kept racial and ethnicity minority groups from more fully participating in ACP [11, 12].

A few studies have examined the impact of changes to payment structures for hospice and palliative care contained in the ACA [13, 14], and one study has investigated the impact of utilization of the new CPT codes for ACP in claims data since the new reimbursement took effect [15]. However, to our knowledge, no studies have looked at the implications of the new payment rules on ACP participation for racial and ethnic disparities. This study addresses this gap by exploring the association between the ACA ACP reimbursement policy and utilization of do-not-resuscitate (DNR) orders—part of the ACP process—among racial and ethnic groups in the state of California (CA). In addition, this study examines the timing of DNR orders among racial and ethnic groups. Previous studies have indicated that patients who have signed a DNR prior to hospitalization, or within the first 24 hours of admission, were more likely to have made the willing choice for less aggressive care compared to patients who signed a DNR later in the admission, who were responding to failed or salvage treatment.

Objectives

The objective of this study was to examine the association between the new payment rules to reimburse physicians for engaging in ACP conversations, and the utilization of DNR orders among racial and ethnic groups. A secondary objective was to examine whether the timing of the DNR order differed by race and ethnicity pre- and post-reimbursement policy.

Methods

Data Source

Data used in this study were from the CA Office of Statewide Health Planning and Development (OSHPD) Patient Discharge Data (PDD) [16]. The PDD is a dataset of inpatient admissions to all licensed hospitals in the state of CA, including chemical dependency recovery centers and acute psychiatric facilities. All licensed hospitals are required by law to report their inpatient discharge data to OSHPD, with the only exception being federal hospitals. These data are used to produce reports of access, utilization, quality, and cost of healthcare in CA. OSHPD data has been used in many prior studies to examine health outcomes and resource utilization across the state [17].

Outcomes

In order to explore the association between the ACA reimbursement policy and racial and ethnic disparities in DNR orders use, International Classification of Disease (ICD) codes were used to identify the presence of a DNR, including V49.86 in the 9th revision and Z66 in the 10th revision, which began to be widely used in the US in October 2015 [18, 19]. Our previous research has validated the use of the ICD codes to identify DNR orders against the gold standard of patient's electronic medical records [20]. OSHPD data also provide a measure of early DNR that is distinct from the ICD DNR measure. DNR orders signed within the first 24 hours of a patient's hospital admission (including DNRs signed prior to admission), are considered an early DNR measure. If a patient elects to have a DNR after the first 24 hours of their admission, their request is still ordered by a physician, however it is reported as not an early DNR. The timing of the DNR is important, as research has shown that individuals who have a DNR upon admission, or who sign a DNR within the first 24 hours of admission, tend to have different characteristics than individuals who might have tried aggressive treatment initially, and then signed a DNR and opted for comfort care after aggressive or salvage treatment failed [21-23]. In this study, patients who had a DNR order in the ICD codes but not an OSHPD early DNR were classified as having a late DNR. Prior studies suggest that patients with late DNRs are more likely to have failed some initial treatment plan.

Cohort

This study identified admissions of patients in the PDD with a primary diagnosis of HF using the ICD-9 code of 428.xx and ICD-10 code of I50.xx (both codes signify heart failure). Only admissions between 2012 to 2018 were included to provide time before and after the new payment rule to reimburse ACP conversation went into effect in 2016. Patients under the age of 65 were excluded, as HF primarily affects older adults and individuals over the age of 65 are much more likely to engage in ACP [2]. Observations with missing covariates were also excluded, which decreased the sample by less than 1%. The final sample included 432,520 admissions of patients over the age of 65 with a primary diagnosis of HF (Figure 1).

Key Independent Variables

The primary independent variables of interest were the interactions between the post-ACA ACP payment period and race and ethnicity. The post-ACA ACP payment period was indicated by years greater or equal to 2016. Race and ethnicity were self-identified as the following groups: white non-Hispanic, black non-Hispanic, Hispanic, Asian, and other race/ethnicity.

Covariates

Several covariates were included in the analyses that have been suggested in the literature to have some association with DNR use among HF patients [24, 25]. To control for patient characteristics, indicators were used for age groups (65-74, 75-84, or 85+), sex (male or female), payer (Medicare, Medicaid, commercial, and other), illness severity levels from all patient refined diagnosis related group (APR-DRG) (no complications or comorbidity, complication or comorbidity, and major complication or comorbidity), and type of hospitalization (medical or surgical). To control for comorbidities, we included the Charlson Comorbidity Index, a weighted sum of seventeen comorbidities that can be identified using ICD codes [26-28].

Statistical Analysis

Statistical analyses were performed to determine whether the new payment rules for EOL consultation were associated with an increase in ACP participation, including among racial and ethnic minority groups. Linear probability models were used to model the relationship between DNR utilization and the timing of the payment rules and race/ethnicity after controlling for the covariates described above. Linear probability models were also used to model the relationship between late DNR orders and race and ethnicity, controlling for covariates.

We expected that outcomes could vary between patients due to hospital-specific factors. A Hausman test was performed that favored hospital fixed effects over random effects [29]. As a result, the multivariable analyses included hospital-fixed effects. Interactions between the ACA reimbursement policy and racial and ethnic minority groups were used to estimate differential associations in DNR participation after the ACP payment rules went into effect. Stata software (version 15.1, College Station, TX) was used for all analyses, and statistical significance was defined as $p<0.05$.

Results

Patient Characteristics

Table 1 presents the characteristics of the elderly HF patients (n=432,520) in the sample stratified by the presence and timing of a DNR order. There were n=100,611 patients (23.3% of the population) with either type of DNR; 73.2% of these patients had an early DNR (n=73,681), and 26.8% had a late DNR (n=26,930). Elderly HF patients were more likely to have a DNR order if they were aged 85 years or above, were white non-Hispanic, female, had an illness severity of the highest level (a major complication or comorbidity), had Medicare as their primary insurance, and were hospitalized for a medical reason (as opposed to a surgical procedure). Among individuals who had a DNR order, black non-Hispanic, Hispanic, Asian, and individuals of other race and ethnicity were more likely to have late DNR orders than white non-Hispanic individuals.

Trends in DNR Utilization

The proportion of elderly HF admissions in CA with (both early and late) DNR orders increased in many race and ethnicity groups from 2012 to 2018, including white non-Hispanic, Hispanic, Asian, and other race and ethnicity (Figure 2). However, the gap between white non-Hispanics and all other race groups remained large, from approximately 10% in 2012 to 8% in 2018. DNR utilization appeared relatively constant among black non-Hispanic patients over this time period.

Linear Model of DNR Utilization

The interaction between the implementation of the ACA payment rules and DNR participation for racial and ethnic minorities was significant, but the effect of the reimbursement was slightly lower for all racial and ethnic groups relative to white non-Hispanic patients (Table

2). This was observed for both early and late DNR measures. This implies that the ACA reimbursement policy was associated with higher DNR participation for non-Hispanic black patients, Hispanic patients, Asian patients, and patients of other race/ethnicity, but the increase was lower than that of white non-Hispanic patients. The interaction terms for Asians were not significant when the sample was all DNR orders and late DNRs, and the interaction terms for both Asians and Hispanics were not significant among early DNRs.

There were other variables with significant associations with DNR utilization. For example, patients over the age of 85 had the largest utilization (10-23 percentage points above patients under the age of 85) of DNR use ($p<0.001$). Illness severity was also associated with DNR use; patients with the highest severity (major complication or comorbidity) were 5-8 percentage points more likely to complete a DNR ($p<0.001$).

Figure 3 presents marginal effects from each of the linear probability models (all DNRs, Early DNRs, and Late DNRs), and suggests that at the margin, DNR participation for all race and ethnicity groups (white non-Hispanic, black non-Hispanic, Hispanic, Asian, and other race and ethnicity) increased following the implementation of the ACA policy for ACP reimbursement. This was also seen in the linear probability model results shown in Table 2, as during the time period in which the ACA was in effect, DNR use increased overall by 1 - 4 percentage points ($p<0.001$).

Discussion

Results from this study suggest that the 2016 payment rules for ACP was associated with greater DNR participation overall, but did not specifically increase DNR participation more for racial and ethnic minorities. In fact, the results actually suggest that the ACA reimbursement policy was associated with a slightly lower increase for racial and ethnic minority groups relative to white non-Hispanic patients. Although the ACA increased healthcare coverage among racial and ethnic minority groups, and the reimbursement policy incentivized health care providers to initiate ACP conversations, racial and ethnic disparities in utilization of DNR orders did not improve over the time period investigated in CA.

It may not be completely surprising that these new payment rules alone did not appear to reduce racial and ethnic disparities in DNR utilization. Solutions to healthcare disparities need to be multi-faceted, simultaneously targeting the person, social support, provider and policy levels, as well as be specific to the social context of targeted groups [30]. The new ACP payment provision in the ACA represents a single level intervention, and was not specific to any racial or ethnic groups.

A review of interventions developed to target health disparities indicated those that were most successful connected patients with resources that exist in their local community [30]. For example, a research team from Penn State College of Medicine partnered with 53 influential community organizations nationwide in order to provide an ACP intervention to African American communities [31]. Places of worship and local community centers were used to deliver a community-based model and was associated with high rates of ACP behavior for individuals who participated [31]. Focused interventions that involve partnerships with community stakeholders have the potential to reduce racial and ethnic disparities in ACP participation, and also make these efforts sustainable in the future [30].

Disparities in EOL care between racial and ethnic groups have been well-established and are partly explained by lower engagement in the ACP process [3]. A recent study suggested that when compared to whites, African Americans had more emergency room visits, had higher-intensity treatments, and were less likely to use hospice in the last 6-months of life [32]. The barriers to the ACP process for racial and ethnic minorities are complex and involve language translation issues, religious and spiritual beliefs about death/dying, health literacy, and decision making [33, 34]. These barriers can stem from providers who are not sensitive or understanding of their patient's culture [5, 34]. As the United States and other parts of the world are becoming increasingly diverse, it is important for providers to practice culturally humility [35]. Cultural humility is different from cultural competency, on which training is often provided or required in many healthcare institutions. Cultural competency teaches the provider about the special needs and vulnerabilities of the racial and ethnic minorities they serve. Criticism of cultural competency is that this type of approach can lead to stereotyping, assumptions, and an incorrect understanding of different cultures as a quick "one and done" check-box of knowledge. Cultural competency has not been effective in its intent of breaking down cultural barriers to quality health care [36].

In contrast, cultural humility is defined as a "life-long process of self-reflection and self-critique whereby the individual not only learns about another's culture, but one starts with an examination of her/his own beliefs and cultural identities" [35]. An individual closely examines how their own social environment has led to their experiences and biases and applies their own awareness in order to increase their understanding of others. Actions taken by health care providers toward a valid understanding of diverse cultures are particularly significant in EOL healthcare circumstances when preferences and decisions need to be made that affect suffering and length of life [37]. The importance of improving EOL care for racial and ethnic minority groups is highlighted in research that explores cultural differences in healthcare system, levels of trust, pain perception and treatment decisions [37, 38]. Even if physicians are motivated and financially incentivized to engage in an ACP conversation, mistrust toward the entire health care system may prevent many racial and ethnic minorities from engaging ACP participation [33].

Results from this study also indicated that minority racial and ethnic groups are more likely to have late DNR orders. The timing DNR orders has not only been associated with costs but also with preventing non-beneficial procedures, reduced perceived suffering, and improved quality of death [23, 39]. It has been suggested that early DNRs are better measures of participation in the ACP process as patients who possess them have the potential to have had more thoughtful conversations about their goals of care [40]. Individuals with late DNR orders frequently have had other, more aggressive treatment plans that failed, and as last resort they agree to the DNR [39, 40]. Reducing disparities in ACP participation has the potential to allow patients of racial and ethnic minorities to have more thoughtful discussions about their goals of care at a time when the patient is not in a crisis, and assure that their preferences are documented and honored.

Discussions about EOL, death, and dying remain taboo in mainstream American culture. There is a focus on medical innovations that extend the quantity of life, and as a result it can be difficult for some health care providers to have ACP conversations with their patients [2]. In a survey regarding ACP conversations with 726 physicians who see patients over the age of 65 on a regular basis, 89% of respondents indicated that it is very important to have ACP conversations with their patients [41]. However, only 29% of providers indicated that they have had specific training to engage in ACP conversations with their patients, and 44% of respondents felt that they were unsure of what is culturally appropriate for the patient and that this was a barrier to having an ACP conversation [41]. Lack of training for physicians regarding EOL communication in general is an often-cited barrier to initiating ACP conversations with patients, even if physicians indicate that they would not be surprised if a particular patient were to die in the next year [42-44]. A summary of training programs for physicians to engage in ACP conversations suggested a need to focus on what physicians can accomplish in small amounts of time with their patients [44]. This would include normalizing ACP as part of routine healthcare visits, as well as understanding patients' values and goals of care at times when they are not in the middle of a health crisis [44]. In addition, the reimbursement structure of ACP claims needs to become more flexible, as it might contribute to lower ACP participation among racial and ethnic groups if current reimbursement ACP claims occur in a way that omits certain members of the population.

A recent study that investigated healthcare provider utilization of current CPT codes for ACP claims indicated that most ACP claims occurred during annual wellness visits, which already occur at lower levels among racial and ethnic groups [15].

Limitations

There are limitations to this study. First, documentation of a DNR order is only one component of the ACP process; a lack of a DNR does not necessarily imply a lack of ACP. It is possible that a patient had an advance care plan and did not choose to have a DNR. The literature suggests racial and ethnic minorities are more likely to prefer intensive care that includes being resuscitated, it is therefore less likely to be captured by any DNR measurement [12]. It is therefore possible that more racial and ethnic minorities participated in ACP and were not captured in the data set used in this study. In addition, CPT codes are not available in this data set and we are not able to see whether physicians utilized them in discussions with patients. Our data set also does not capture outpatient visits and therefore would not include any ACP conversations had at this time. Presumably, the early DNR measure captures any DNR that would have arisen from prior outpatient visits, which mitigates this limitation to some degree.

Another limitation is that these data only capture the first few years after the ACA reimbursement policy was implemented. It is possible that physicians were not aware of the new billing code right away, and this would hinder measuring the effectiveness of new reimbursements as incentives [45]. This is reflected in the small survey mentioned above regarding the ACP conversations completed in March of 2016 [41]. While 75% of respondents indicated that the ACA reimbursement benefit would make it more likely for them to have ACP conversations with their patients, only 14% had billed Medicare at the time of the survey [41]. In addition, this dataset only captures DNR participation in the state of CA, and is not representative of the entire country.

Conclusions

The results from this study suggest that while the ACA reimbursement policy for ACP conversations was associated with increased DNR participation overall, it was not associated with increased DNR participation among racial and ethnic minorities. Additionally, the results suggest that racial and ethnic minorities are more likely to have late DNR orders, which have been associated with last resort options and not true treatment preferences. To improve the effectiveness of efforts to increase DNR participation among racial and ethnic minorities physicians and other healthcare providers need specific training in initiating ACP conversations and cultural humility to build better trusting relationships with patients of diverse cultures. In addition, discussions about quality of life, goals of treatment, and preferences in medical care need to be normalized in everyday nonemergent health care settings as a part of routine care so that patients do not see ACP as a signal that their healthcare situation is dire and postpone these conversations for too long.

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Table 1. Summary statistics for elderly HF patients stratified by DNR order

Variable	**No DNR (N=331,909)**	**All DNR (N=100,611)**	**Early DNR (N=73,681)**	**Late DNR (N=26,930)**
Age	78.5	85.0	85.3	84.4
65-74	35.8%	12.8%	12.0%	14.8%
75-84	37.5%	29.3%	28.8%	30.6%
85+	26.6%	58.0%	59.2%	54.7%
Sex				
Male	49.9%	42.3%	41.6%	43.9%
Female	50.1%	57.7%	58.4%	56.1%
Race/Ethnicity				
White Non-Hispanic	52.1%	71.8%	73.7%	66.6%
Black Non-Hispanic	11.0%	4.9%	4.5%	5.9%
Hispanic	22.3%	12.7%	11.8%	15.1%
Asian	10.6%	8.0%	7.6%	9.2%
Other	4.0%	2.6%	2.4%	3.3%
Category of Hospitalization				
Medical	94.4%	97.4%	97.8%	96.4%
Surgical	5.6%	2.6%	2.2%	3.6%
APR-DRG Severity				
No Complication/Comorbidity	15.5%	8.6%	9.0%	7.5%
Complication or Comorbidity	29.9%	28.1%	29.3%	24.8%
Major Complication or Comorbidity	54.6%	63.3%	61.7%	67.8%
Charlson Comorbidity Index	2.1	2.0	2.0	2.0
Payor				
Medicare	87.4%	92.7%	93.1%	91.8%
Medicaid	5.8%	2.2%	2.0%	2.8%
Commercial	5.4%	4.1%	3.9%	4.5%
Other	1.4%	1.0%	1.0%	1.0%

Table 2. The results of a linear probability model of DNR participation.*

Variables	All DNR		Early DNR**		Late DNR***	
	Coef.	P-Value	Coef.	P-Value	Coef.	P-Value
ACP Reimbursement	0.039	<0.001	0.030	<0.001	0.018	<0.001
Racial/Ethnic Group						
White Non-Hispanic	Reference					
Black Non-Hispanic	-0.056	<0.001	-0.065	<0.001	-0.024	<0.001
Hispanic	-0.044	<0.001	-0.051	<0.001	-0.019	<0.001
Asian	-0.056	<0.001	-0.065	<0.001	-0.024	<0.001
Other Race/Ethnicity	-0.043	<0.001	-0.048	<0.001	-0.013	<0.001
Reimbursement*Racial/Ethnic Group						
ACP Reimbursement*White Non-Hispanic	Reference					
ACP Reimbursement*Black Non-Hispanic	-0.021	<0.001	-0.010	0.006	-0.008	0.007
ACP Reimbursement*Hispanic	-0.012	<0.001	-0.002	0.433	-0.005	0.024
ACP Reimbursement*Asian	-0.003	0.437	-0.001	0.831	-0.001	0.706
ACP Reimbursement*Other Race/Ethnicity	-0.018	0.003	-0.015	0.009	-0.010	0.019
Age						
65-74	Reference					
75-84	0.065	<0.001	0.062	<0.001	0.027	<0.001
85+	0.233	<0.001	0.228	<0.001	0.105	<0.001
Sex						
Male	Reference					
Female	0.032	<0.001	0.034	<0.001	0.011	<0.001
Payor						
Medicare	Reference					
Medicaid	-0.021	<0.001	-0.015	<0.001	-0.009	<0.001
Commercial	-0.002	0.467	-0.005	0.048	0.001	0.670
Other	-0.016	0.001	-0.004	0.471	-0.014	<0.001
Category of Hospitalization						
Medical	Reference					
Surgical	-0.038	<0.001	-0.037	<0.001	-0.007	<0.001
Charlson Comorbidity Index	0.003	<0.001	0.006	<0.001	0.003	<0.001
APR-DRG Severity						
No Complication/Comorbidity	Reference					
Complication/Comorbidity	0.037	<0.001	0.032	<0.001	0.018	<0.001
Major Complication/Comorbidity	0.087	<0.001	0.073	<0.001	0.051	<0.001
Constant	0.012	<0.001	0.020	<0.001	-0.008	<0.001

* Model controlled for hospital fixed effects.
** Excludes patients with late DNR
*** Excludes patients with early DNR

Figure 1. Determination of study cohort

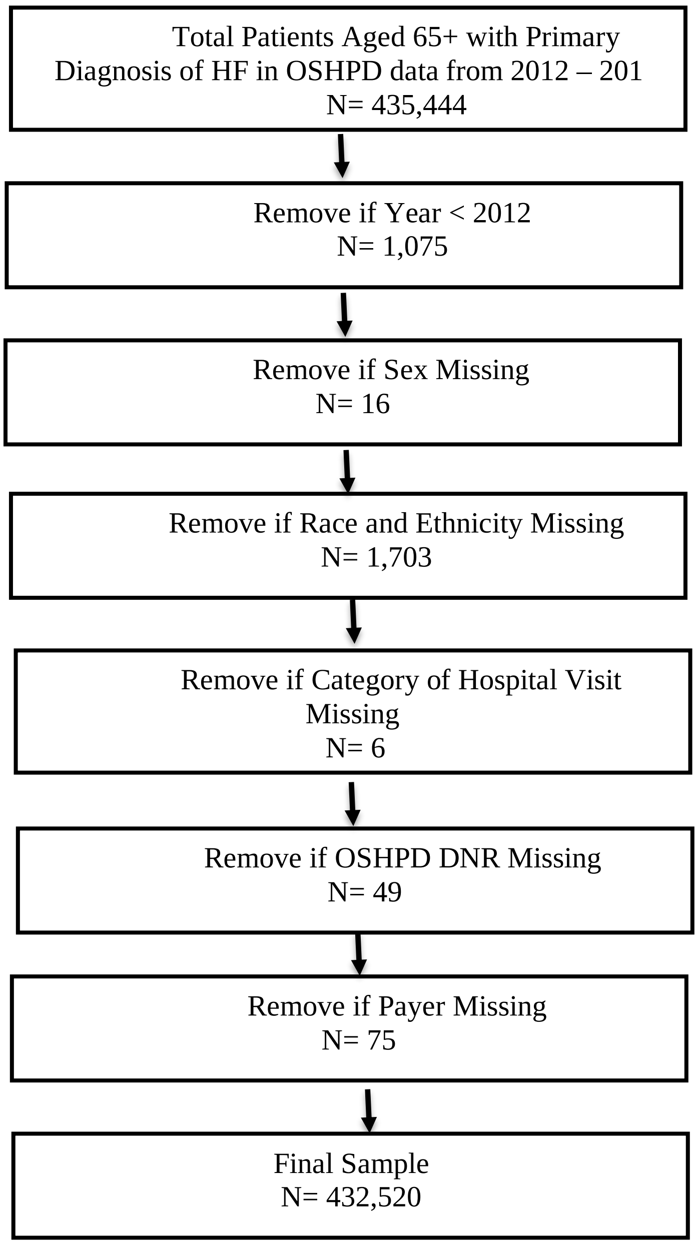


Figure 2. Proportion of patients with a DNR order stratified by race/ethnicity, 2012-2018

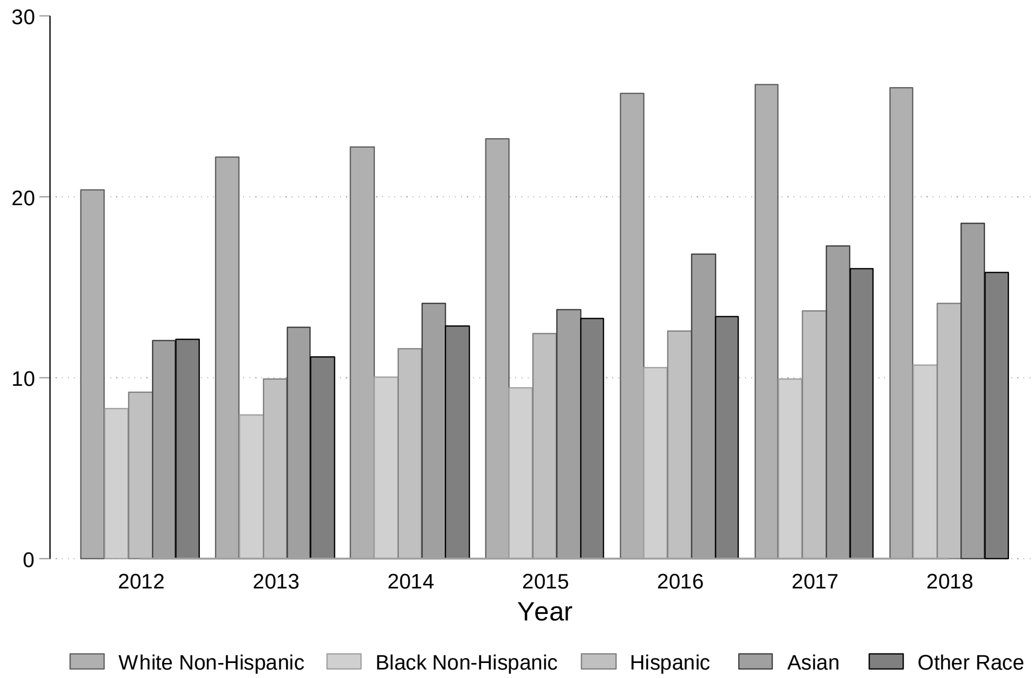
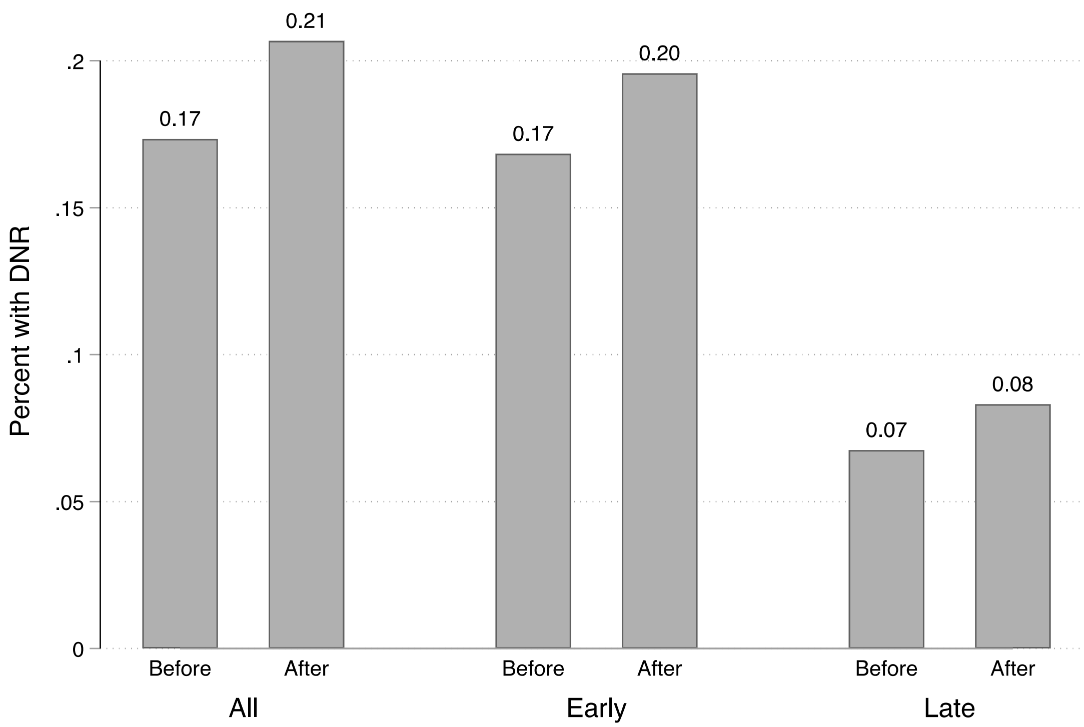


Figure 3. Marginal effect of ACP payment rule on DNR utilization, stratified by DNR timing.



Chapter 5

Discussion

The purpose of this dissertation was to contribute to the discussion surrounding DNR orders—part of the that the ACP process—and their association with patient outcomes. This was done by investigating DNR documentation among elderly HF patients in three papers that explored, 1) the association between DNR orders and hospitalization costs, 2) the validity of ICD codes for identifying the presence of a DNR order in the EMR, and 3) whether participation in DNR orders increased for racial and ethnic minorities following the implementation of new payment rules for ACP conversations created by the Affordable Care Act.

The first overarching theme in this dissertation is that it is challenging to measure and study the ACP process as its components, including conversations and legal documents, are often not available in large data sets. The lack of easily accessible and generalizable data may partly explain why the uptake of ACP has been so slow. The third chapter of this dissertation examined the validity of using ICD codes to identify one important ACP variable—DNR orders. This is significant as ICD codes are ubiquitous in many large datasets, including administrative discharge data and claims data, making this a potential source for studying the ACP process. Compared to the gold standard of DNR status documented in the EMR, ICD codes were found to be valid proxies. These results provide confirmation for research that has used ICD-based DNR measures in the past and suggests that this DNR proxy could be useful for future research.

Another overarching theme of this dissertation is that in addition to the primary benefit of ACP, which is improved EOL care for the patient and peace of mind for the family, early implementation of ACP can lead to cost savings for providers. The results from the second chapter of this dissertation, which examines a particular high medical need population that is frequently hospitalized, suggest that the use of DNR orders could saves millions of dollars every year. Additionally, normalizing discussions about preferences for care at end of life and not only during times of crisis may lead to an increase in the participation of individuals from racial and ethnic minorities. Results from chapter four of this dissertation suggested that a policy to provide reimbursement incentives was not enough to reduce racial and ethnic disparities in DNR participation. To make future ACP interventions more successful, they should be multilevel and targeted at the larger policy level, as well as specific to context to the group the interventions are intended to benefit. Healthcare providers would benefit from additional training to initiate ACP conversations as well as more practice with cultural humility with their diverse patient populations.

VITA

KATHERINE LEA (SCHLEICHER) CALLAHAN

EDUCATION

2011	M.S.W., Social Work – Practice Concentration School of Social Work McMaster University, Hamilton, ON, Canada
2010	B.S.W., Social Work – Generalist Practice School of Social Work The University of Western Ontario, London, ON, Canada
2008	B.Sc., Biology The University of Western Ontario, London, ON, Canada

PEER-REVIEWED PUBLICATIONS

2020	**Callahan, K.**, Hollenbeak, C.S., Van Scoy, L. and Kitko, L. (2020). Do-Not-Resuscitate Orders and Readmission Among Elderly Patients with Congestive Heart Failure in Pennsylvania: An Observational Study, 2011 to 2014. *Heart & Lung: The Journal of Acute and Critical Care, 49*(6): 812 – 816.
2015	Tam, D., **Schleicher, K**., Wu, W., Kwok, S., Thurston, W., and Dawson, M. (2015). Social work interventions on intimate partner violence against women in China. *Journal of Social Work*, 0(0) 1-22.

ACADEMIC HONORS

2022	Pennsylvania State University's College of Health and Human Development Funds for Dissertation Research
2021	Jewish Healthcare Foundation Feinstein Fellowship – Death & Dying
2018	Hillemeir Award (Summer Funding)
2018	Award for Excellence in Graduate Education
2017	Hugh C. Arell Memorial Prize (Best M.S.W. Thesis)
2011	The Tina and Paul Bellavia Ontario Graduate Scholarship
2011	McMaster University Entrance Scholarship
2010	Ontario Graduate Scholarship (OGS)

PROFESSIONAL EXPERIENCE

2017-22	Pennsylvania State University, Graduate Assistant
2018-20	Iris Healthcare, Planning Facilitator
2013-17	Vital Decisions, QI Specialist (2015-17); Healthcare Counselor (2013-15)
2012-13	Joseph J. Peters Institute, Partial Hospital Individual Therapist
2011-12	Defender Association of Philadelphia, Adult Social Service Social Worker
2010	McMaster University - School of Social Work, Teaching Assistant
2009-11	University of Western Ontario - School of Social Work, Research Assistant
2009-10	University of Western Ontario - School of Social Work, Teaching