

Health Service Cost and Use Associated with Advance Directive Documentation among
Patients with COPD

By

BRANDON DUCK

B.S.N. (San Diego State University) 2007

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

Nursing Science and Health-Care Leadership

in the

OFFICE OF GRADUATE STUDIES

of the

UNIVERSITY OF CALIFORNIA

DAVIS

Approved:

Janice F. Bell, Ph.D., M.P.H., M.N., Chair

Jeri L. Bigbee, Ph.D., R.N., F.N.P.-B.C., F.A.A.N.,

Deborah Ward, Ph.D., R.N., F.A.A.N.

Committee in Charge

2015

Acknowledgements

I would like to express my sincere appreciation to my thesis chair Janice Bell for her guidance and patience throughout my thesis writing process. I would also like to thank my family and my fiancée for their support through my pursuit of the MS in Nursing Science and Healthcare Leadership. Additionally, I am grateful to the Betty Irene Moore Foundation for their generosity that has enabled me to pursue my graduate degree in nursing at UC Davis.

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Abstract

Little available research has focused on the question of whether advanced-care-planning has the potential to impact health-care related spending especially in patients with chronic and incurable conditions such as Chronic Obstructive Pulmonary Disease (COPD). The purpose of this secondary data analysis was to investigate the prevalence of Advance Directives (ADs) documented in the electronic health records, compare healthcare spending between individuals with versus those without ADs on file, and examine socio-demographic variables as potential predictors of having documented ADs on file for patients with COPD in a large tertiary academic medical center in 2012 and 2013. This retrospective cohort study used financial, socio-demographic, and hospital encounter related data extracted from electronic health records. Among the 342 inpatient records included in this study less than 24% had ADs on file despite documentation of greater than 95% of patients being provided information on ADs on admission. Mean annual charges for COPD patients with ADs were \$164K versus \$97K for COPD patients without ADs. Patients with ADs were also statistically more likely to be white and 65 years of age or older. Higher costs, older age, and more frequent hospital admissions with longer stays among patients with ADs suggest that patients may postpone completion of ADs until such time as more costly care is required. Analyses examining costs associated with ADs, adjusted for age are indicated. . Interventions are also warranted to educate

patients about ADs earlier in their illness trajectories, and to develop culturally sensitive approaches to address racial/ethnic disparities in rates of AD completion.

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Introduction

By 2060, the US population of adults age 65 or older will more than double to over 90 million ¹. As medical care and treatments have advanced and health promotion efforts have improved, people are living longer and surviving acute traumatic injuries or medical events, thus the population of older adults living with chronic illnesses has increased. Approximately half (117 million) of US adults have at least one of 10 chronic conditions (i.e., hypertension, coronary heart disease, stroke, diabetes, cancer, arthritis, hepatitis, weak or failing kidneys, current asthma, or chronic obstructive pulmonary disease [COPD]) ². Not surprisingly, health care expenditures are significantly higher in this group: 84% of all health care spending in 2006 was for the 50% of the population who have one or more chronic medical conditions ³. The US has the most costly healthcare system in the world, per capita, and the cost for healthcare in the United States continues to rise each year ⁴. The U.S. health system spends a higher portion of its gross domestic product than any other country but ranks 37 out of 191 countries according to its performance ⁵. While people in the U.S. now live longer and with more chronic conditions, the quality of healthcare performance does not justify the high price tag. It is becoming exceedingly important to find solutions that will improve health, healthcare performance and also decrease healthcare spending.

A significant share of healthcare spending is attributed to end-of-life treatments and care, especially in patients with chronic diseases ⁶. Last-year-of-life healthcare expenses accounted for 22% of all healthcare expenditures in a 1992-1996 current beneficiary survey of US adults at least 65 years old ⁷. Sometimes end-of-life care is

planned and supports patient wishes, such as hospice care, while other times interventions are “heroic” in nature and inappropriate given the severity of the patient’s condition.

Chronic Obstructive Pulmonary Disease (COPD) is a chronic costly condition with overall expenditures in 2010 estimated at approximately \$49.9 billion ⁸. COPD is a progressive debilitating disease that makes breathing difficult and can often lead to respiratory failure requiring hospitalization and invasive therapies including intubation and mechanical ventilation ⁹. COPD is a progressive condition and there is currently no cure. The disease is complicated and has a variable course from one patient to another ¹⁰. Patients suffering from COPD may undergo numerous hospitalizations and require various costly and invasive inpatient and outpatient therapies and interventions to stabilize their condition ¹⁰. Respiratory compromise is often significant requiring multidisciplinary symptom management to achieve optimal outcomes ¹⁰. In a retrospective survey of informants, more than 95% of people who died with COPD experienced breathlessness and fatigue or weakness either some of the time or all of the time, over the last year of their lives ¹¹. Pain and low mood were also reported in this population some of the time or all of the time by 70% and 77% of respondents, respectively. Two thirds of the patients died in the hospital where the majority of services are focused toward physiologically restorative therapies, and the lack of palliative care services received by patients and families highlighted the need for end-of-life care planning ¹¹. Little is published, however, about the extent to which patients with COPD have formally documented their wishes for invasive therapies with advanced directives and whether such documentation is associated with reduction in unnecessary treatment and subsequently reduced costs.

It is reasonable to promote interventions that improve quality and decrease costs associated with caring for patients with COPD at the end-of-life. One way to avoid performing expensive invasive therapies and providing care to individuals who do not want such care is to encourage patients to plan in advance and openly communicate their thoughts and wishes with their families and providers. In many cases, valuable healthcare resources are spent on patients who do not want the care or interventions to the extent they are provided, and in many circumstances patients are unable to express their wishes when they are gravely ill. In addressing these problems, obstacles exist when individuals have not previously communicated their wishes explicitly, and their medical conditions preclude this communication at the time invasive therapies and care is being provided. Significant cost savings may be realized and patient self-determination rights upheld if those who feel strongly about avoiding extensive and invasive medical therapies under certain conditions and situations effectively communicate their wishes and subsequently those important wishes are respected. The initial purpose of this study was to address the importance of preemptive advance care planning to potentially discover topics that might lead to real discussions among patients and their providers. A better understanding of end-of-life care decisions and associated expenditures could help to inform future interventions to decrease health care costs and improve care in this chronically ill patient population.

Background

An advance directive (AD) is a legal document that delineates an individual's preferences and wishes about advanced care planning; what a person would want done under certain circumstances if they become unable to communicate their wishes, and who

they want making medical decisions on their behalf if needed ⁹. Ideally, an AD is filed prior to an occurrence of a healthcare crisis or inpatient admission. These situations may prevent a person from being able to make informed decisions about their own healthcare, including making known their wishes regarding lifesaving or sustaining interventions and treatments. ADs provide the means for people to communicate their wishes to loved ones, family, friends, and healthcare providers and thereby avoid confusion and misunderstanding. A benefit to the individual filing an AD is the ability to make health care preferences and wishes clearly known and understandable. A benefit to the family and care providers is the cognitive and emotional support that comes with understanding the individual's preferences and decisions about medical therapies, plans of care, and end-of-life care ¹².

In a 2013 survey, two thirds of adults in the United States reported they believed that under certain circumstances a patient should be allowed to die, as opposed to health care providers doing everything possible to save a person's life ¹³. The proportion of Americans reporting that they have given a great deal of thought to their own wishes for end-of-life medical treatment (37%) was roughly the same as it was in a similar survey in 2005 ¹³. Approximately one third of adults (35%) say they have put their wishes for end-of-life decisions into writing, whether in an informal document (e.g., letter to a relative) or a formal, legal one (e.g., living will or health care directive). The rate of documenting advanced care planning is also about the same as it was in 2005 at around 20% ¹³.

Studies have shown that effective advance care planning improves outcomes for patients and families, including having their wishes known and followed ¹⁴. Detering et al. (2010) conclude that advance care planning can improve end-of-life care, patient and

family satisfaction, and reduce stress, anxiety, and depression in surviving relatives. End-of-life care planning, however, continues to be underutilized by the majority of the public, even by those with chronic incurable illnesses ¹⁵. Some studies have also suggested the potential for healthcare spending reductions associated with effective end-of-life care planning ¹⁶. A call for action is needed given dramatically rising healthcare costs in the US ⁴, significant expenses of end-of-life care ⁷, and the moral dilemma of performing invasive medical therapies that patients may have not wanted had they previously indicated their wishes.

Literature Review:

The purpose of this study is to examine the prevalence and predictors of having advance directives (ADs) formally filed among patients admitted to the hospital with COPD, and to compare health care use and costs between COPD patients with and without ADs. A search of the literature was conducted using the databases of PubMed, CINAHL, and Google Scholar. The key words/terms used to search the literature databases on this topic were: 1) advance directive, 2) cost saving, 3) COPD (Chronic Obstructive Pulmonary Disease). Based on the results of this search, 16 articles were identified investigating end-of-life care planning in general, cost savings or cost reductions associated with end-of-life care planning, and end-of-life care planning with COPD patients specifically.

Advance Directives among Patients with Chronic Conditions

A study regarding documentation of advance care planning for community-dwelling elders found “38% of surveyed patients had thought about limiting the aggressiveness of medical care” ¹⁵. However, only 24% of surveyed patients stated that

they had spoken to their provider about this issue. The vast majority of respondents (88%–93%) preferred to die rather than remain permanently in a coma, on a ventilator, and/or with a feeding tube. Regardless of respondents' specific preferences, only 15%–22% of them had their preference information documented in their medical records ¹⁵. Therefore, among the population that is stimulated to think about end-of-life care issues, two thirds believe that care should be limited under certain circumstances, but only about one third has considered what that means for their own personal preferences or wishes. Furthermore, only one quarter of the population has raised the topic of end-of-life care planning with their health care providers , and at most a fifth of the population has documentation on file of their preferences or wishes, related to intrusive and invasive medical therapies to extend or sustain life ¹⁵.

In relation to costs, one study found no significant cost savings associated with advance directives in patients with end stage renal disease ¹⁷. A second study published in 1994 showed no Medicare spending difference among patients over 65 with and without advance directives ¹⁸. However, a major limitation of the second study was possible under-reporting of AD documentation during hospitalization since the study was based on chart review prior to the availability of electronic medical records. In another study Yung concluded “Community-dwelling elders' preferences for end-of-life care are not consistent with documentation in their medical records. Electronic health records and standardized data collection for end-of-life care could begin to ameliorate this problem (2010, p. 866).” Although no conclusive studies were found documenting the percentage of individuals who have expressed their end-of-life medical care preferences with their

families, the Pew Research Center study does show that two thirds of the population expresses a preference for limited care and treatments in some circumstances (2013).

Advance Directives: Who Uses Them?

The characteristics of individuals who typically file formal advance directives inform our understanding of why, how, and for whom the process of completing and documenting this form of care planning is important. While most studies on the completion of advance directives focus on rates of completion, one study on demographic characteristics found ADs become more commonly utilized as the age, education and income of the person increases ¹⁹. Additionally, individuals who are single (versus married) and who report non-white (versus white) race/ethnicity are less likely to have filed an AD to indicate their wishes ¹⁹. There were no significant differences, however, in the likelihood of filed ADs by gender.

Advance Directives and Chronic Obstructive Pulmonary Disease (COPD)

Chronic Obstructive Pulmonary Disease (COPD) is a progressive disease which eventually leads to respiratory failure; it is also the third leading cause of death in the United States ⁸ and the fourth leading cause of death in the world ²⁰. In 2011, nearly 13 million U.S. adults (aged 18 and over) had a diagnosis of COPD; furthermore, nearly 24 million had evidence of impaired lung function suggestive of COPD and possible under diagnosis of this condition ⁸. In addition to its high prevalence, COPD is costly with overall expenditures in 2010 estimated at approximately \$49.9 billion—including \$29.5 billion in direct health care expenditures, \$8 billion in indirect costs (i.e., unachieved

potential income based on decreased productivity or premature death) related to morbidity and \$12.4 billion in indirect costs related to mortality costs⁸.

Along with the tremendous financial costs associated with COPD treatment, the physical and emotional costs of the condition are profound. COPD is a severe disease in terms of morbidity, mortality, and the need for invasive therapies during exacerbations of disease conditions. In its later stages the disease is associated with severe respiratory distress often requiring hospitalization and invasive therapies including intubation and mechanical ventilation due to respiratory failure⁸. These costly interventions require intensive care and the circumstances create stressful and painful experiences for patients²¹, not to mention for their families. Many hospitalized patients experience anxiety and require sedation, pain medication, and physical restraints to allow their bodies to comply with mechanical ventilation and prevent breathing tube dislodgement²¹. Numerous studies have demonstrated the long term undesirable effects of sedation and Intensive Care Unit (ICU) stays, such as delirium and psychosis²². In some cases, when mechanical ventilation is required for more than a week or two, patients may require additional measures such as a tracheostomy (a surgical procedure to create an opening through the neck into the trachea or windpipe)²³. In summary, COPD is associated with a significant fiscal, social, and emotional impact on patients, families, the health care system, and society.

Due to the complex nature of the disease trajectory and prognosis, current cancer based service models for palliative care needs are inappropriate²⁴. In a retrospective cohort study of 1098 patients who died, Goodridge concludes that although the nature of symptoms may be similar in patients with COPD and lung cancer, the healthcare needs

and disease patterns are significantly different (2008). People dying with COPD must have their needs better addressed, yet often the needed resources are not available. It is because of the complicated disease trajectory of COPD versus lung cancer that palliative care services are limited for this vulnerable group ²⁵. Services such as hospice can be limited in resources, and are often restricted to patients with more acute terminal prognoses than COPD. While COPD is progressive, even in end-stage, patients may experience periods of exacerbated symptoms followed by stabilization and vice versa ¹⁰. Relief of physical and emotional suffering and optimal quality of life are reported as being most important to patients with COPD, priorities which do not necessarily equate to the highest physiological goals ²⁵.

No studies were found on health care use and costs in patients with COPD with and without ADs. It is not known to what extent patients with COPD report having ADs on admission to the hospital, or at all. Furthermore, no studies were found to describe the socio-demographic or health characteristics that predict having an advance directive among patients with COPD. Finally, no studies of health care costs or health service use associated with having ADs in patients with COPD were found. This information is needed to plan and implement interventions, to promote education on end-of-life planning, and to inform strategies for health care cost containment.

Inadequate and poorly timed advance care planning discussions are documented problems among patients with COPD ²⁶. Discussions about advance care planning are often avoided until necessary in a crisis ²⁶. The use of a collaborative care approach with providers, patients and families demonstrates the effectiveness of utilizing resources in the proper setting and with adequate time and mental/emotional capacity to process all of

the relevant information ²⁶. This approach assists all members of the team to see the bigger picture, understand available options and make informed decisions.

A prospective survey of patients with clinically stable but severe COPD or CHF, indicated that 30 – 38% of patients did not express preference for cardiopulmonary resuscitation (CPR) and/or mechanical ventilation in the event of cardiac arrest ²⁷. In contrast, advance directives outlining these preferences were discussed with the physician specialist by only 4% and 6% of the patients with CHF and COPD, respectively. This mismatch and the rarity of these discussions in patients with stable but severe disease who are still able to indicate their preferences, underscores the need for interventions to improve advance care planning and end-of-life care communication.

In another study of patients with advanced COPD, congestive heart failure (CHF), or chronic renal failure (CRF), over a third of patients changed their minds at least once in regards to their preferences for CPR or mechanical ventilation during a year ²⁸. In this study, significant factors impacting changes in patient preferences were changes in symptoms, health status, mobility, marital status, and depression or anxiety. These findings indicate the need for regular reevaluation of patient preferences and advance care plans.

In a small qualitative study of ten patients with COPD recruited from primary and secondary care settings, patients felt they had not been given enough information about their diagnoses and prognoses ²⁹. The patients interviewed conveyed being interested in discussing general views about future care, but were concerned or uncomfortable with the traditional model of a binding ‘advance directive’. Taken together, these findings

illustrate some of the complexities in encouraging patients to complete advance directives.

Are ADs Associated with Lower Health Care Costs?

Studies by Nicholas, Langa & Iwashyna, and Emanuel & Emanuel showed no cost saving from documented advanced directives, although one study did show promise for hospital care cost savings associated with a palliative care program³⁰. In an evaluation of an interdisciplinary home-based palliative care program versus usual care among patients with cancer, CHF, or COPD, significant hospital associated cost reductions were realized and dying at home was more likely for the group in the palliative care program for all diagnoses³⁰. The group consisted of 298 non-equivocal terminally ill patients. The study by Nicholas et al. of 3302 Medicare beneficiaries who died between 1998 and 2007 did show a cost savings associated with patients who had advance directives specifying limits in care versus patients without ADs, but was unable to show conclusive cost saving benefits beyond those patients with ADs specifying limited care (2011). Although studies suggest there may be opportunities for improved quality of care and cost savings associated with advanced care planning³¹; conclusive studies to support these assertions have yet to be published.

Relevance to Nursing

Nurses are charged with promoting health and caring for many sick and dying patients, and are often required to assist in managing therapies to maintain life. It is unethical to perform invasive and painful therapies to prolong life for people who do not want that care. Knowing the inevitable symptoms and experiences of end stage COPD,

the principles of beneficence and non-maleficence should be considered when providing health care for patients in these circumstances. Beneficence is conveying compassion; taking positive actions to help others, and having a desire for good at the very core. Non-maleficence is the avoidance of harm or hurt and is central to both the oath of medicine and to nursing ethics ³². These principles are integral to patient advocacy and ethical nursing practice.

Options for COPD treatment can include expensive and invasive lung transplants and long term mechanical ventilation, or less expensive and less invasive pulmonary rehabilitation and palliative care ³³. At times it seems that healthcare has become so standardized that treatment decisions are almost automatic, based on only lab results and physiological facts. For instance, anti-infective therapies have become accepted as almost benign treatments, yet more consideration is needed in prescribing and including routine or standardized therapies in the treatment plan to be sure they are consistent with the care plan of each individual ³⁴.

Should nurses and other healthcare providers routinely provide invasive mechanically ventilation for patients with COPD who are in respiratory failure? That decision should be made by the patient in close consultation with his/her family and healthcare providers. However, it is difficult to know patients' preferences for medical treatments and interventions when they are no longer able to communicate or make cognitively sound decisions, unless they have conveyed their preferences ahead of time. Documentation of patients' preferences for such interventions through ADs, simplifies clinical decision making for families and healthcare providers, especially for the nurses at the bedside, and assures medical treatment that is consistent with the patients' wishes. It

is an ongoing ethical challenge for bedside nurses to care for critically ill patients requiring invasive treatments particularly when past clinical experiences may indicate prolongation of life without an increase in quality of life. These issues are further complicated if the patient's wishes are not known. In an overview of COPD and related literature, Urbano and Pascual (2005) state, "proper coordination of care is important in this disease, and efforts should be focused on improving quality of life and reduction of symptoms."³⁵ Research designed to understand use of ADs and associated costs among patients with COPD can inform nursing interventions in both community and inpatient settings. By identifying specific patient characteristics associated with AD use, interventions to promote use of ADs can be better targeted to specific patient groups and help nurses to focus attention where it is needed to address advanced care planning.

The current study examined health service use and costs among inpatient COPD patients with and without ADs and tested the hypothesis that costs would be lower in patients with documented end-of-life-care planning wishes. Three specific aims were examined, each pertaining to COPD patients admitted to a large academic medical center:

- 1) To determine the proportion of COPD patients with an Advance Directive on file in the years 2012 – 2013.
- 2) To compare total costs and hospital service use (ICU admissions, hospital admission, length of stay, ED visits) for COPD patients according to whether they have an Advance Directive on file. We expected lower costs and health service use among patients with an Advance Directive on file.

- 3) To examine socio-demographic variables—including sex, race/ethnicity, age, insurance status, marital status—as predictors of having an Advanced Directive documented among patients with COPD.

Methods

Design and Data Source

This retrospective cohort study is a secondary analysis of data extracted from UCDCMC electronic medical records by the Clinical and Translational Science Center (CTSC). The data set was collected through Cohort Discovery, a repository of patient information gathered from multiple sources, including electronic medical records, billing records, lab results and demographic data yielding de-identified data for research purposes. More detail about this data resource is available at:

<http://www.ucdmc.ucdavis.edu/ctsc/area/informatics/cohortdiscovery/>.

Setting and Sample

The University of California, Davis Medical Center (UCDCMC), a tertiary care center located in Sacramento, California was the setting for this study. Patients were included in the study if they were admitted to UCDCMC between 1/1/2012-12/31/2013 and had a diagnosis of Chronic Obstructive Pulmonary Disease, based on International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes 490-496. ICD-9-CM is the official system used in the United States to classify and assign codes to health conditions and related information.

The study protocol, which included retrieval and use of de-identified patient data, was reviewed by the Institutional Review Board at UC Davis Medical Center and deemed not be research with human subjects and therefore exempt from further review.

Study Variables

Dependent Variables

The primary outcome for the study was a binary measure of patients not having a signed, scanned copy of an Advance Directive (AD) attached to their electronic medical record (yes/no). For the analysis of Aim 2, the following outcomes were examined among those patients with and without an AD. Each outcome was examined over a one year period, in either 2012 or 2013. If patients had data available for more than one year, we used only 2013, as the most recent data available.

- a) Total Annual healthcare costs (\$) defined as combined bill totals (within UCDCMC)
- b) Total Annual number of intensive care unit (ICU) admissions defined as a count of all separate UCDCMC ICU admissions.
- c) Total Annual bed days for ICU defined as the total number of bed days spent in the UCDCMC ICU.
- d) Total Annual number of hospital admissions defined as the number of separate admissions at UCDCMC.
- e) Total Annual length of stay for UCDCMC hospital admissions defined as the combined days documented as an inpatient, including ICU days.
- f) Total Annual number of Emergency Department Visits defined as the number of documented visits to the UCDCMC Emergency Department.

Independent Variables

The following independent variables were examined as potential predictors of having an AD on file:

- a) Age in years as defined as age at admission, categorized into five groups: 18-34, 35-49, 50-64, 65-79, 80 or more.
- b) Race/ethnicity categorized as White/Caucasian/non-Hispanic; Black/African-American/non-Hispanic; Asian/Pacific-Islander; or Hispanic/Native-American/Unknown/Missing/Declined-to-state
- c) Gender categorized as male or female
- d) Insurance status categorized as either private, or as Public/None/Self-Pay/Other
- e) Marital status categorized as Married; or Single/Separated/Divorced/Widowed/Unknown/Missing/Declined-to-state

Statistical Analysis

All analyses were conducted with Stata (Version 13, College Station, TX). Descriptive statistics were used to summarize the study variables. Specifically, we examined the means, standard deviations, and interquartile ranges of all continuous variables and the percentages of all categorical variables. All variables were then compared statistically for the groups with and without Advance Directives using chi-square tests for categorical variables and t-tests for continuous variables. For Aim 1, the total proportion of the study sample having Advance Directives on file is reported. For Aim 2, the significance of differences in means and proportions between those with and without ADs are reported for the outcomes of interest. For Aim 3, logistic regression was used to examine having an Advance Directive (yes/no) as a function of the socio-demographic and health variables. Statistical significance was evaluated as $p \leq 0.05$.

Results

Of the 342 patients in the sample, 81 patients (23.68%) had advanced directives on file and 261 did not, indicated in Table 1. The mean annual total charges was \$113,132 for all patients with COPD, just under \$164,000 for those with ADs on file and just over \$97,000 for those without ADs. This difference in means was statistically significant ($p=0.02$) (from data analysis not presented in tables).

The socio-demographic characteristics of the study sample are presented in Table 1 according to whether or not patients had a documented advanced directive. Significantly more ($p<0.01$) adults aged 65 years and above have filed an advance directive. Patients with an AD on file were significantly more likely ($p<0.01$) to report their race/ethnicity as White than were those without an AD on file. Even though those reporting White, non-Hispanic race/ethnicity made up less than half of the study sample, they accounted for nearly 70% of the filed ADs (Table 1). There were no significant differences in the distribution of gender, health insurance status or marital status between those with and without ADs.

Table 2 depicts UCDMC hospital encounter related data associated with the patients included in this study: encounter type, annual ER visits, annual admissions, annual hospital admissions, annual inpatient days, annual ICU days and total hospital-related charges. A significantly greater proportion of COPD patients with ADs had total annual charges above \$135,000 compared to COPD patients without ADs (37% versus 21%; $p=0.02$); whereas, a smaller proportion of COPD patients with ADs had total annual charges below \$50,000 compared to COPD patients without ADs (22% versus 27%; $p=0.02$). The difference in the annual number of ICU days was statistically

significant between those with versus those without advance directives ($p < 0.01$) where patients with ADs were statistically more likely to have more instances of annual ICU days greater than 2. Compared to patients without ADs, a significantly higher proportion of those patients with ADs had 4 or more annual hospital admissions ($p = 0.02$) and 14 or more annual inpatient hospital days ($p < 0.01$).

In a fully adjusted logistic regression model, race/ethnicity and age were significantly associated with not having an AD on file (Table 3). Compared to patients who reported their race/ethnicity as White non-Hispanic, the odds of not having an advanced directive were higher for patients who report their race/ethnicity as Black non-Hispanic [OR=2.67; 95% CI: 1.23, 5.76], Asian or Pacific Islander [OR=4.17; 95% CI: 1.31, 13.12], or Other Unknown [OR=4.17; 95% CI: 1.94, 8.94]. Compared to patients who were 65 and older, the odds of not having an advance directive were higher for patients who are 65 and under [OR=0.27, 95% CI=0.15, 0.49]. The odds of not having an advanced directive on file were not different for: patients who were married versus those who were single, widowed, divorced, separated, or unknown [OR=1.34; 95% CI=0.73, 2.48]; patients who had private insurance versus those who have public insurance, none, self-pay, or other [OR=1.30; 95% CI=0.54, 3.15]; patients who were female versus those who are male [OR=0.73, 95% CI=0.42, 1.28]; and patients who visited the hospital in 2013 versus those patients who visited in 2012 [OR=1.07, 95% CI=0.62, 1.85].

Discussion

In a large academic medical center, we found only 23.68% of patients admitted with a diagnosis of COPD had advance directives on file in their electronic medical records. While low, this rate of AD documentation is consistent with other studies; for

example, the presence of any advance directives was 26% in 112 patients hospitalized in a cardiac care unit (CCU)/intensive care unit (ICU) in an academic medical center ³⁶. A higher rate of AD completion among patients with COPD is expected because this chronic condition is serious, incurable and often has an unpredictable and complicated course. These attributes of COPD underscore the need for advanced care planning. The low rates of documented ADs indicate a major need for new approaches to intervene and educate patients with advanced illness, and specifically with COPD, about ADs and end-of-life care planning.

Our reliance on data collected in electronic medical records (EMRs) rules out incomplete ascertainment of having an AD on file associated with review of paper records ³⁷. Our measure, however, is limited to visits within the same hospital system; whereas, ADs documentation can still get missed if a patient transfers from one facility to another in a different hospital system. This issue will become less salient as EMRs become further integrated in the future and the ability to share data between different hospital systems improves. CMS currently provides incentives and will require such integration in the future (Centers for Medicare and Medicaid services) ³⁸.

In our study, once an AD is filed in the EMR, it remains current, active, and available for providers to review in the electronic chart from one visit to the next. The ability of EMRs to carry information over from encounter to encounter would contribute to higher, rather than lower, rates of AD documentation. Furthermore, in our sample, more than 95% of the admitted patients had documentation in the EMR of having been asked if they had an AD. This high rate of patients being asked about ADs may stem from the Patient Self-Determination Act of 1990 mandate that hospitals reimbursed by

Medicare and Medicaid inform each patient about their right to a natural death³⁹. The disparity between the high rates of being asked, and the low rates of responding affirmatively to having an AD, suggests that informal discussion during hospital admissions while patients and their families are under stress is sub optimal. During this intense time, when patients and their families face so many difficult decisions, they may be unable to process information related to advanced care planning.

Although the rates of AD documentation in the current study are consistent with those of other major studies, the findings are inconsistent with studies suggesting that advanced care planning has the potential to improve patient care and reduce healthcare related expenses³¹. Our findings clearly indicate that total inpatient related healthcare costs were significantly higher in the group with documented advance directives than in the group without. One possible explanation for this finding is related to the requirement for hospitals to offer education on advance directives. A second explanation may relate to confounding of the association between AD completion and costs by age. The patients with ADs were older and therefore expected to having higher costs. Future analysis examining costs associated with ADs, adjusted for age are indicated.

The phenomenon of patients going through long involved hospitalizations with significant medical interventions before deciding to document future care wishes just prior to discharge from the hospital, may offer at least a partial rationale for the findings. A major limitation of this study was the ability to extract from the data the date at which ADs were first documented. Future research is recommended to further examine the

inpatient billing records for patients with advance directives on admissions to ascertain the timing of AD documentation.

Several findings in the current study suggest that ADs are being filed late in the COPD illness trajectory, by those patients with the most advanced illnesses. Not only were costs higher in the group with ADs compared to those without, patients with ADs were also older, and had longer hospital lengths of stay. These attributes may indicate patients with greater disease burden having ADs, as the literature indicates¹⁹ respondents with an advance directive are more likely to report having a chronic disease and a regular source of care. The finding of older age among those with ADs is consistent with prior work suggesting statistically higher rates of documentation for ADs as people get older.⁴⁰ Older adults also tend to have multiple chronic conditions, more contact with the healthcare system and increased social or family pressures to convey advanced care planning wishes. This finding only emphasizes the need to address the topic of advance care planning earlier in the course of illness and greater efforts to target the general population before the onset of illness. Advanced care planning conversations are difficult for many people⁴¹ and one possible way to increase AD documentation rates is by starting discussions before people are faced with serious injuries or illnesses⁴² that make such challenging conversations and the subsequent decision-making more stressful.

This study found that race was a statistically significant factor associated with documentation rates for advance directives. White participants were more likely to have documentation for advance directives than any other racial/ethnic groups. One issue in particular that has been well documented and is relevant in this discussion is the distrust of the healthcare system by minorities, especially in the Black or African American

community⁴³. Cultural or religious beliefs may play important roles in patients' decisions to complete ADs and in other aspects of their healthcare utilization and experiences. New methods and routes of culturally sensitive education are clearly necessary to address disparities in advanced care planning given the challenges of beginning discussions about potentially limiting care under certain circumstances and conditions in hospital settings by healthcare providers with patients and families who may not trust the information they are given. Innovative outreach strategies to improve communication and education regarding advanced care planning within these groups might include engaging trusted community members and institutions including religious leaders and churches. One study found that a facilitated, asset-based approach of community engagement for end-of-life conversations and care can catalyze community-led awareness initiatives⁴⁴.

The major limitation of this study relates to the underlying data and the inability to discern when an advance directive was documented, relative to a hospitalization. It is not clear from our data, for example, if patients with advance directives on file to begin with were actually using more resources and accruing higher hospital healthcare related costs. Another limitation of this study was related to the exclusion of outpatient data due to coding inconsistencies and data incompleteness possibly related to billing processes or requirements. Outpatient clinics would be optimal locations for conversations about end-of-life issues and to assure ADs were on file before a hospital admission occurs.

Conclusion

Rates of completed and filed ADs remain low regardless of the adoption of widespread electronic medical charting that keeps a documented AD on file from visit to visit, and in the face of the Patient Self Determination Act that mandates patient

education about ADs upon hospital admission. Theoretically the use of ADs could improve quality of desired patient care and decrease healthcare spending by reducing unnecessary and unwanted care; however, little evidence exists to support these claims. Our study suggests that patients with ADs tend to be older, more critically ill and possibly in the later stages of advanced illness. New strategies are needed to promote advanced care planning among younger patients, earlier in the illness trajectory, and among racial/ethnic minority populations. Further investigation is needed to determine how best to approach the issue of increasing AD completion and documentation for all groups and improving equality at the same time. With a significant portion of the US population, the baby boomers, moving into the older age category where rates of acute illness, chronic illnesses and healthcare spending are all increasing, the time to act is now. Ensuring that people get the best health care possible is goal all providers should strive for and one of the ways to work toward this goal is by providing the appropriate care that is in accordance with patients' wishes. Nurses have the opportunity to take the lead in the screening for the presence of ADs on admission to inpatient settings, and to collaborate with community-based organizations to promote discussions and awareness of ADs and their utility. The goal of increasing resources for advanced care planning and the documentation of advance directives among the majority of the population is achievable. It will require a concerted effort and creative problem solving, but with technological advances, the right focus and visionary healthcare leadership resolving the healthcare crisis in this country is achievable, one step at a time.

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Appendices

Tables: Characteristics of 342 Patients with COPD by Documentation of
Advanced Directives

Table 1:					
Socioeconomic Categories	Advanced Directive				Significance
	Yes = 81		No = 261		P value
	#	%	#	%	
Age					<0.01
18 - 34 years	0	0.0	5	1.9	
35 - 49 years	2	2.5	26	10.0	
50 - 64 years	20	24.7	123	47.1	
65 - 79 years	35	43.2	90	34.5	
80 or more years	24	29.6	17	6.5	
Sex					0.29
Male	34	42.0	127	48.7	
Female	47	58.0	134	51.3	
Race/Ethnicity					<0.01
White, Causaian, non-Hispanic	56	69.1	102	39.1	
Black, African American, non-Hispanic	11	13.6	54	20.7	
Asian, Pacific Islander	4	4.9	23	8.8	
Hispanic, Native American, Unknown, Missing, Declined to state	10	12.4	82	31.4	
Health Insurance Type					0.31
Public, None, Self pay, Other	72	11.1	220	15.7	
Private	9	88.9	41	84.3	
Marital Status					0.91
Married	24	29.6	79	30.3	
Divorced, Widowed, Separated, Single, Unknown, Missing, Declined to state	57	70.4	182	69.7	

Table 2: Hospital Encounters among Patients with COPD (n=342) by Documentation of Advanced Directive						
	Advanced Directive					Significance
	Yes		No			P value
Medical Encounters	#	%	#	%		
Type of Encounter						
Inpatient	81	23.7	261	76.3		
ICU	15	29.4	36	70.6		
Outpatient						
Annual Number of ER Visits	81		261			0.29
1 Visits	75	92.6	239	92		
2 Visits	4	4.9	7	2.7		
3 - 4 Visits	0	0.0	9	3.5		
5 or More Visits	2	2.5	6	2.3		
Annual Number of Hospital Admissions	81		261			0.02
1 Admissions	61	75.3	207	79.3		
2 Admissions	11	13.6	29	11.1		
3 Admissions	3	3.7	21	8.1		
4 + Admissions	6	7.4	4	1.5		
Annual Number of ICU Admissions	15		36			0.09
1 Admission	12	80.0	35	97.2		
2 Admissions	2	13.3	1	2.8		
3 Admissions	1	6.7	0	0.0		
Annual Number of Inpatient Hospital Days	81		261			<0.01
0 - 2 Days	21	25.9	90	34.5		
3 - 5 Days	27	33.3	94	36		
6 - 13 Days	17	21.0	63	24.1		
14 + Days	16	19.8	14	5.4		
Annual Number of ICU Days	81		261			<0.01
0 - 2 Days	71	87.7	253	96.9		
3 - 5 Days	6	7.4	7	2.7		
6 - 13 Days	3	3.7	1	0.4		
14 + Days	1	1.2	0	0		
Total Charges	81		261			0.02
< \$50,000	18	22.2	71	27.2		
\$50,000 - \$69,999	19	23.5	68	26.1		
\$70,000 - \$134,999	14	17.3	68	26.1		
> \$135,000	30	37.0	54	20.7		

Table 3: Logistic Regression of Not Having an Advanced Directive on File among COPD Patients (N=342)

	OR	95% CI	P value
Age			
Age less than 65 years	-----	-----	-----
Age 65 or above	0.27	[0.15, 0.49]	<0.01
Sex			
Male			
Female	0.73	[0.42, 1.28]	0.27
Race/Ethnicity			
White, Causaian, non-Hispanic			
Black, African American, non-Hispanic	2.67	[1.23, 5.76]	0.01
Asian, Pacific Islander	4.15	[1.31, 13.12]	0.02
Hispanic, Native American, Unknown, Missing, Declined to state	4.17	[1.94, 8.94]	<0.01
Health Insurance Type			
Public, None, Self pay, Other			
Private	1.30	[0.54, 3.15]	0.55
Marital Status			
Married	1.34	[0.72, 2.48]	0.35
Divorced, Widowed, Separated, Single, Unknown, Missing, or Declined to state	-----	-----	-----