

ORIGINAL RESEARCH

“They’re Going to Unplug Grandma”: Advance Directive Discussions and Documentation Do Not Decrease Survival in Patients at Baseline Lower Risk of Death

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OBJECTIVE: To determine the effect of having advance directive (AD) discussions or having an AD in the medical record on patient survival.

DESIGN: Prospective observational cohort study.

SETTING: Three Colorado area hospitals: a large academic tertiary referral center, a Veteran’s Affairs medical center, and an urban safety net hospital.

PARTICIPANTS: Four hundred fifty-eight adults admitted to the general internal medicine service interviewed about AD discussions. A concurrent chart review documented the presence of an AD in the medical record. Participants were stratified into low, medium, and high risk of death within 1 year based on validated prognostic criteria.

MEASURES: Kaplan-Meier survival plots were estimated for those at low and medium risk of death.

RESULTS: No significant differences in survival for participants at low and medium risk of death who reported having had an AD discussion and those who had not (Wilcoxon low risk, $P = 0.97$; medium risk, $P = 0.28$; and log-rank low risk, $P = 0.82$; medium risk, $P = 0.45$), and for those who had an AD in the medical record vs those who did not (Wilcoxon low risk, $P = 0.84$; medium risk, $P = 0.78$; and log-rank low risk, $P = 0.86$; medium risk, $P = 0.69$).

CONCLUSIONS: There is no evidence that AD discussions or documentation result in increased mortality. In regards to the current national debate about the merits of advance care planning, this study suggests that honoring patients’ wishes to engage in AD discussions and documentation does not lead to harm. *Journal of Hospital Medicine* 2012;7:3–7. © 2011 Society of Hospital Medicine

All new legislation concerning advance care planning was removed from the Affordable Care Act, signed into law in March 2010. However, through a Medicare payment regulation, Centers for Medicare and Medicaid Services (CMS) was able to add a provision allowing compensation to physicians for advance directive (AD) discussions as part of the annual Medicare wellness exam. Previously, under President George W. Bush, funding for AD discussions was already part of the Welcome to Medicare visit. Once again, the provision was misrepresented and distorted in the media, talk radio shows, and social networking sites. Within days of the announcement, the White House removed the regulation stating that the controversy surrounding the provision was distracting from

the overall debate about healthcare. The term “death panels” has now entered our national lexicon and serves to undermine the efforts of the palliative care field which, through discussions with patients and families, attempts to provide care consistent with patients’ goals.

In fact, ADs have been a cornerstone of ethical decision making, by supporting patient autonomy and allowing patient wishes to be respected when decisional capacity is lacking. Advance directives may include a living will, a Medical Durable Power of Attorney, or may be a broader more comprehensive document outlining goals, values, and preferences for care in the event of decisional incapacity. ADs allow patients to express preferences that incorporate both *quantity* and *quality* of life, as there are times when interventions at the end of life may increase length of life to the detriment of quality of life. In this context, patients may choose to value quality of life and request the interventions be withdrawn that focus on maintaining life without hope for quality of life. ADs also permit patients who prefer quantity over quality of life to communicate these wishes. These conversations are complex and time-consuming. Patients may have profound misperceptions about the benefits offered by interventions at the end of life. Having detailed

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conversations with healthcare providers about actual benefits, risks, and alternatives has been shown to impact that decision-making process.¹ In our current payment system, these time-consuming conversations are not compensated by private or public insurers, and are incompatible with 20-minute appointments, so they rarely occur.²⁻⁴ While Nancy Cruzan and Terri Schiavo brought national attention to the issue for a brief time, recent data suggest that only ~30% of adults have completed an AD,⁵⁻⁷ however, 93% of adults would like to discuss ADs with their physician.⁸ Furthermore, Silveira et al. showed that older adults with ADs are more likely than those without ADs to receive care that is consistent with their preferences at the end of life.⁹ ADs were the sole predictor of concordance between preferred and actual site of death in a cohort of seriously ill, hospitalized patients.¹⁰ Patients with advanced cancer who discussed their end of life wishes with their physician were more likely to receive care consistent with their preferences.¹¹

Advance directives are based on the ethical principle of autonomy and, with the growing evidence that ADs may improve care at the end of life, public understanding of the issue is critical. We had presented early preliminary data in a letter to the editor showing that having had an advance directive discussion or an AD in the medical record was not associated with an increased risk of death.¹² This research, along with the work of Silveira and colleagues,⁹ was cited by the Obama administration when they decided to add the regulation for including advance care planning as part of the annual Medicare wellness exams. This brief report presents a more comprehensive examination of the relationship of AD discussions and AD documentation with survival in a group of hospitalized patients.

METHODS

Study Sites and Participant Recruitment

This was a multisite, prospective study of patients admitted to the hospital for medical illness. The Colorado Multi-Institutional Review Board approved this study.

Over a 17-month period starting in February 2004, participants were recruited from 3 hospitals affiliated with the University of Colorado—Denver Internal Medicine Residency program: the Denver Veterans' Administration Center (DVAMC); Denver Health Medical Center (DHMC), the city's safety net hospital; and University of Colorado Hospital (UCH), an academic tertiary, specialty care and referral center. Exclusion criteria included: admission <24 hours, pregnancy, age <18 years, incarceration, spoke neither English nor Spanish, lack of decisional capacity. Recruitment was done on the day following admission to the hospital throughout the year, to reduce potential bias due to seasonal trends. A trained assistant

recruited on variable weekdays (to allow inclusion of weekend admissions). Of 842 admissions occurring during the recruitment, 331 (39%) were ineligible (175 discharged and 2 died within 24 hours postadmission; 76 lacked decisional capacity; and 78 met other exclusion criteria listed above). All other patients (n = 511) were invited to participate and 458 patients consented.

Participant Interview and Measures

Fifty-three (10%) refused; 458 gave informed consent and participated in a bedside interview, including questions related to advance care planning. In this interview, participants were first asked to define an AD. Their response was either confirmed or corrected using a standard simple explanation that defined and described ADs:

An advance directive is a document that lets your healthcare providers know who you would want to make decisions for you if you were unable to make them for yourself. It can also tell your healthcare providers what types of medical treatments you would and would not want if you were unable to speak for yourself.

They were then asked if any healthcare provider had ever discussed ADs with them (AD discussion is a primary variable of interest).

Chart Review and Vital Records Data Collection

We reviewed each medical record to determine admitting diagnoses, CARING criteria (a set of simple criteria developed by our group to score the need for palliative care, which has been shown to predict death at 1 year),¹³ socioeconomic and demographic information, and the presence of ADs in the medical record (documentation of AD is a primary variable of interest). We defined ADs broadly, including: living will, durable power of attorney for healthcare, or a comprehensive advance care planning document (eg, Five Wishes). The CARING criteria are validated criteria that accurately predict death at 1 year, and were developed to identify patients who would be appropriate for a palliative care intervention. It is based on the following variables: Cancer as a primary admitting diagnosis, Admitted ≥ 2 times to the hospital in the past year for a chronic medical illness, Resident of a nursing home, ICU admission with >2 organ systems in failure, and ≥ 2 Non-Cancer hospice Guidelines as well as age. Scores range from ≤ 4 = low risk of death, 5-12 = medium risk of death, and ≥ 13 = high risk of death at 1 year. We accessed hospital records and state Vital Records from 2003 to 2009 to determine which patients died within a 12-month follow-up period, and their date of death (primary outcome).

Cohort Risk Stratification

Based on their CARING score, participants were classified as being at low, medium, or high risk of death at 1 year.¹³ The probability of imminent death in the

group of high-risk patients is the main indication for an advance directive, and therefore the analysis of this high-risk group would be confounded. Therefore, those at high (and unclassified) risk of death (89 [and 13] out of 458 interviewed patients) were excluded from the survival analysis. Including persons at high risk of death in this analysis would lead to confounding by indication—that physicians are most likely to address ADs with patients that they perceive are likely to die in the near future. An example of this in the literature is the timing of do-not-attempt-resuscitation orders (DNAR). It is well documented that most DNAR orders are written within 1 to 2 days of death.^{14–16} The DNAR orders do not cause or lead to death, they are simply finally written for patients that are actively dying.

Statistical Analysis

SAS 9.1© (SAS Institute, Cary, NC) was used for all analyses. Survival analysis was conducted to examine time to death. Interaction effects of the variable of interest with patient risk were assessed by estimating Kaplan-Meier survival curves for low and medium risk groups separately. The Wilcoxon and log-rank tests were employed to compare those with and without AD discussions (and accounting for clustering within hospitals) and documentation. Since the stratification into risk groups involves the use of the CARING criteria, which were the main confounders, additional risk adjustment in each risk group was not performed. Post hoc power analysis showed an ability to detect a 13 percentage points difference in mortality rate, with 80% power for a 2-sided test and $\alpha = 0.05$, assuming a 20% death rate for the group without AD discussion (adjusting for the covariate distribution difference between those with and without AD discussion).

RESULTS

Characteristics of the 356 study subjects are listed in Table 1. Overall, the sample population was ethnically diverse, slightly above middle-aged, mostly male, and of lower socioeconomic status, reflecting the hospitals' populations. Using the CARING criteria, 297 subjects were found to be at low risk, and 59 subjects at medium risk, of death at 1 year.

Overall, 206 (45%) reported a discussion about ADs with a healthcare provider. However, we found that only 56 (10%) had an AD document on their chart. Twenty-eight (6%) had a living will, 43 (9%) had a durable power of attorney, and 30 (7%) had a broader AD document. Between 2003 and 2009, 121 (26%) patients died. Unadjusted mortality rates for those with and without documentation and discussions of ADs are displayed in Figure 1.

Kaplan-Meier survival curves showed that, for subjects with a low or medium risk of death at 1 year, having had an AD discussion or having an AD in the

TABLE 1. Participant Characteristics (n = 356)

| | Percent (n) or Mean \pm SD |
|---|------------------------------|
| Ethnicity | |
| African American | 19% (69) |
| Caucasian | 55% (194) |
| Latino | 19% (66) |
| Other | 8% (27) |
| Age (years) | 57.2 \pm 15 |
| Female gender | 34% (122) |
| Admitted to | |
| DVAMC | 41% (147) |
| DHMC | 34% (122) |
| UCH | 24% (87) |
| CARING criteria | |
| Cancer diagnosis | 4% (15) |
| Admitted to hospital \geq 2 times in the past year for chronic illness | 31% (109) |
| Resident in a nursing home | 2% (7) |
| Non-cancer hospice guidelines (meeting \geq 2) | 1% (4) |
| Income less than \$30,000/yr | 81% (284) |
| No greater than high school education | 53% (188) |
| Living situation | |
| Home owner | 36% (125) |
| Rents home | 38% (132) |
| Unstable living situation | 27% (94) |
| Low social support | 37% (169) |
| Uninsured | 14% (51) |
| Regular primary care provider | 72% (254) |

Abbreviations: CARING criteria, a set of simple criteria developed by our group to score the need for palliative care, which has been shown to predict death at 1 year; DHMC, Denver Health Medical Center; DVAMC, Denver Veterans Affairs Medical Center; SD, standard deviation; UCH, University of Colorado Hospital.

medical record did not affect survival in subjects (Figures 2 and 3). Cox proportional hazards models adjusting for other covariates confirmed the results of the survival analysis (data not shown). Minimal intra-class correlation coefficients (0.005) were observed for the outcomes. Therefore, no models accounting for clustering within hospitals were developed.

DISCUSSION

We found no decrease in survival for patients at low and medium 1-year risk of death who reported having discussed ADs or who had an AD in their medical record, providing important evidence that having advance care planning discussions do not hasten death in this group of adults. However, it is possible that ADs, when implemented properly, may dictate withdrawal or withholding of interventions that may extend quantity of life at a quality unacceptable for the person executing the directive. For example, a feeding tube delivering artificial nutrition and hydration may grant years to someone in a persistent vegetative state, but those years, without the ability to be aware or interact with surroundings and loved ones, may not be a life worth living for some individuals. One explanation for our negative findings may be that the circumstances in which an AD may have an effect on outcomes may not yet have occurred among this lower risk population.

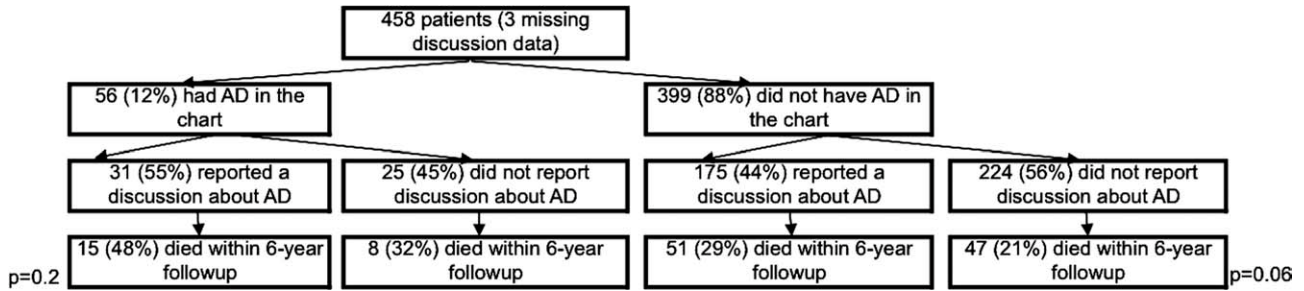


FIG. 1. Unadjusted rates of advance directive (AD) documentation, discussion, and mortality.

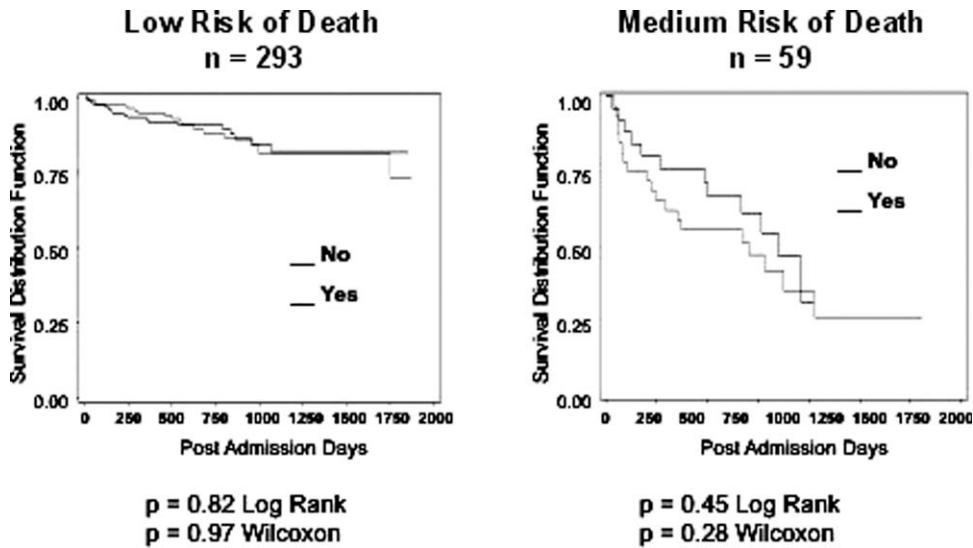


FIG. 2. Kaplan-Meier survival plots for persons reporting having had an advance directive discussion vs not.

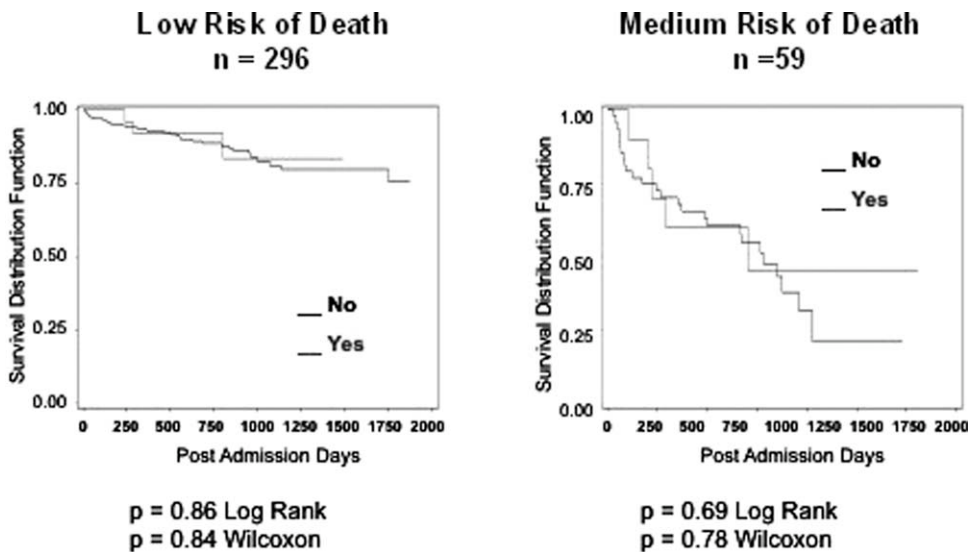


FIG. 3. Kaplan-Meier survival plots for persons who had documented advance directives in their medical record vs not.

Opposition to the process of advance care planning may be considered unethical, by removing the opportunity for individuals to express their desires in the event of decisional incapacity, therefore disregarding patient autonomy. Furthermore, with the growing evidence that AD discussions and documentation help

patients achieve care consistent with their wishes at the end of life,^{9,11,17} preventing advance care planning may worsen end of life outcomes.

Another important finding in our study was that only about 10% of the patients interviewed had completed an AD document, although nearly half reported

they had discussed ADs with a healthcare provider. The patients we interviewed in this study had been admitted to the hospital in the previous 24 hours. As part of the Patient Self-Determination Act, all patients admitted to a healthcare facility should receive information and counseling on AD. Less than half of our cohort reported any discussions about ADs and only 10% had completed an AD, suggesting that huge opportunities exist for improvement in advance care planning. As this study demonstrates, there was no increased mortality from advance care planning among those at low and medium risk of death, and others have shown benefits from the process. AD discussions and documentation should be fostered, especially as the burden of chronic disease increases and the population ages. In targeted studies to improve advance care planning, completion rates of up to 85% have been achieved.¹⁷

Our decision to focus solely on patients at low or medium risk of death, and exclude those at a high risk of death, is based on both clinical and methodological judgment. First, it is important to note that ADs are important even for those at lower risk of death—the 3 critical cases that have shaped AD policy in this country, Karen Ann Quinlan, Nancy Cruzan, and Terry Schiavo, were all otherwise healthy young women.

Our study does have limitations. First, the sample size is small and not powered to detect small differences in survival. In addition, we only examined Vital Records within Colorado, although all participants had either a date of death or recent date of last contact. It is also conceivable that some patients discussed or completed ADs at a later time in their illness trajectory. However, the generalizability of this study is a major strength, by including a population and healthcare settings that are ethnically and socioeconomically diverse. Generalization of results beyond the three types of hospitals should be limited even with the low intraclass correlation. The major limitation of this research is that we do not have data on participant quality of life or whether completing an AD led to increased use of palliative care. During the time the research was conducted, 2 of the 3 hospitals involved had small palliative care services and the third remains without a palliative care service.

In conclusion, our study provides limited data to counteract the misleading claims of those opposed to the advance care planning process. Our results underscore the importance of educating the public on the importance of ADs and cast doubt on the “death” myth surrounding advance care planning. However,

further, preferably longitudinal, study is needed to prospectively understand both the benefits and risks of advance care planning.

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