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Quality of Life and Cost of Care at the End of Life: The Role of Advance Directives

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Abstract

Context—Advance directives (ADs) are expected to improve patients' end-of-life outcomes, but retrospective analyses, surrogate recall of patients' preferences, and selection bias have hampered efforts to determine ADs' effects on patient outcomes.

Objectives—To examine associations among ADs, quality of life, and estimated costs of care in the week before death.

Methods—We used prospective data from interviews of 336 patients with advanced cancer and their caregivers, and analyzed patient baseline interview and caregiver and provider post-mortem evaluation data from the Coping with Cancer study. Cost estimates were from the Healthcare Cost and Utilization Project Nationwide Inpatient Sample and published Medicare payment rates and cost estimates. Outcomes were quality of life (range 0-10) and estimated costs of care received in the week before death. Because patient end-of-life care preferences influence both AD completion and care use, analyses were stratified by preferences regarding heroic end-of-life measures (everything possible to remain alive).

Results—Most patients did not want heroic measures (76%). Do-not-resuscitate (DNR) orders were associated with higher quality of life ($\beta=0.75$, standard error=0.30, $P=0.01$) across the entire sample. There were no statistically significant relationships between DNR orders and outcomes among patients when we stratified by patient preference, or between living wills/durable powers of attorney and outcomes in any of the patient groups.

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Conclusion—The associations between DNR orders and better quality of life in the week before death indicate that documenting preferences against resuscitation in medical orders may be beneficial to many patients.

Keywords

quality of life; end-of-life care; advance directives; costs of care; DNR

Introduction

First formalized by the Patient Self-Determination Act of 1990 and reappearing in recent proposals by Congress (Personalize Your Care Act of 2013 [HR1173], Care Planning Act of 2013 [S1439], Medicare Choices Empowerment and Protection Act [S2240]), health care policies encourage patients to engage in advance care planning (ACP) and complete advance directives (ADs). In its ideal form, ACP begins with conversations between patients, family members, and health care providers about health care preferences and goals.¹ Preferences are documented, but documents are revisited and updated as patients' circumstances change.² These preferences can be documented in ADs through a living will (LW) or designation of a durable power of attorney (DPA), or through medical orders such as do-not-resuscitate (DNR) orders. The goals of ACP and ADs are to provide patients more control over their final months, so that they receive care concordant with their goals and values.³ Given the high cost of care at the end of life (EoL), including care that is potentially inappropriate,⁴⁻⁶ there is a secondary interest in the potential of ACP and ADs to save costs. If documenting preferences in ADs or medical orders leads to less undesired aggressive or futile care at the EoL, it should reduce costs as well as improve quality of life.⁷

The hypothesized effects of ADs on quality of life and EoL care costs, however, have not been clearly demonstrated. Living wills and DPAs are positively associated with quality of life, use of hospice care, and death outside of an inpatient hospice unit in retrospective analyses, but beneficial associations have not been consistently demonstrated between LWs, DPAs, and other prospective measures of patient function and health care use.⁸⁻¹¹ In addition, LWs and DPAs are only related to health care costs in limited circumstances, such as among patients desiring limited treatment who reside in high health care cost areas.^{4,12-13}

Less is known about relationships among DNR orders, quality of EoL care, and costs associated with aggressive care use near the EoL. DNR orders are more specific than LWs/DPAs and provide a way to specify a preference against what is simultaneously the default treatment option when preferences are unknown and a typical example of futile care among patients with advanced cancer.³ Hospitalization costs appear to be lower when patients have pre-existing DNR orders¹⁴ or when both patients and physicians agree that a patient should have a DNR order.¹⁵

Potential relationships between ADs and patient outcomes, however, may have been obscured by several factors. Most existing studies of relationships between ADs and patient outcomes rely on caregivers or other proxy respondents to recall patients' engagement in ACP and use of ADs after the patient's death or focus only on costs incurred while hospitalized.¹⁶ Moreover, most are unable to account for differences in patients that would

be simultaneously associated with both ADs and costs and quality of life at the EoL. For instance, patients who prefer more heroic EoL measures (i.e., doing everything possible to remain alive) should be both less likely to complete ADs⁸ and more likely to receive aggressive life-prolonging measures (which are associated with higher costs and lower quality of life^{7,17-18}) than someone who does not want these measures. In order to isolate the potential impact of ADs on patient outcomes from the influence of patient preferences, it is important to stratify the analysis by patient preferences for EoL care.

In this study, we use prospective data and account for observable differences in patients' EoL care preferences to examine associations among ADs, quality of life, and estimated costs associated with care use in the week before death among patients with advanced cancer. We hypothesized that both DNRs and LWs/DPAs would be associated with better quality of life before death by allowing a patient to communicate and document care preferences, especially among patients who preferred fewer heroic EoL care measures.¹⁷⁻¹⁸ We hypothesized that DNR orders would have a stronger relationship with lower EoL care costs, because LW/DPAs can include specifications for more or less aggressive life-prolonging treatment. ADs and medical orders should only lead to reduced costs for individuals who desire limiting expensive, aggressive treatment at the EoL, because providers may err on the side of providing more life-prolonging care when patients' preferences are unknown.¹³

Methods

Data Sources

Data on patient characteristics and quality of life in the week before death come from the Coping with Cancer (CwC) cohort of patients with advanced cancer (disease refractory to first-line chemotherapy or distant metastases) and caregivers who were recruited from outpatient clinics in Connecticut, Massachusetts, New Hampshire, New York, and Texas between 2002-2008. Institutional review board approval was obtained from each recruitment site. English- and Spanish-speaking patients without dementia (scored <6 on the Short Portable Mental Status Questionnaire¹⁹) or delirium identified a caregiver (unpaid family member or friend) who provided the majority of their care. Written informed consent was obtained from participants.

Data from patient baseline interviews (median of 3.5 months before death) and from postmortem caregiver interviews (median two weeks after death) were used for this study. Using methods similar to those used previously by our team,^{7,20} EoL care costs were estimated based on care utilization in the last week of life reported in the post-mortem interviews. Unit costs were estimated from the 2008 Healthcare Cost and Utilization Project's Nationwide Inpatient Sample (HCUP NIS),²¹ Centers for Medicare & Medicaid (CMS) reimbursement rates,²²⁻²³ and published estimates in the literature.²⁴⁻²⁸

Measures

Advance Directives and Medical Orders—At baseline, patients were asked whether they had completed a DNR order (“Have you completed a Do Not Resuscitate (DNR)

order?” [1=yes, 0=no]). They also were asked whether they had a signed LW and/or DPA (“Do you have a signed Living Will, or Health Care Proxy, Durable Power of Attorney for health care, all or none?” [1 = LW, Health Care Proxy, and/or DPA, 0 = none of these]).

Preferences for Heroic EoL Care—At baseline, patients were asked whether they would want “...everything possible to keep you alive even if you were going to die in a few days anyway?” (1=yes, 0=no). To be concise, we refer to “everything possible to keep you alive” as heroic measures.

Quality of Life in the Week Before Death—We used caregiver reports of quality of life in the week before death rather than patient reports because it is not possible to prospectively identify a patient's last week of life. Quality of life in the week before death was measured as the average of caregivers' answers to three questions during the post-mortem interview: 1) “In your opinion, how would you rate the overall quality of the patient's death/last week of life?” (0=worst possible, 10=best possible); 2) “In your opinion, just prior to the death of the patient [his/her last week, or when you last saw the patient], how would you rate his/her level of psychological distress?” (0=none, 10=extremely upset) and 3) “...physical distress?” (0=none, 10=extremely distressed).^{17,29} Distress scores were reverse-scored so that higher numbers indicate better quality of life. Scores were averaged²⁹ rather than summed¹⁷ to account for two individuals missing answers to one of the three questions. When caregivers were unavailable or not knowledgeable about the patient's death (45% of ratings [$n=153$] were completed by caregivers), the health care provider (often a nurse) who last cared for the patient answered the questions. We controlled for rater identity in regression analyses of quality of life, although caregivers and non-caregivers did not differ significantly in average ratings of quality of life in the week before death (caregivers: mean = 6.0, standard deviation [SD] = 2.8; non-caregivers: mean = 6.5, SD = 2.6; $P=0.11$).

Estimated Costs of Care Received in the Week Before Death—To calculate costs, we considered both the location of the patient's death (intensive care unit [ICU], hospital outside of ICU, nursing home, inpatient hospice, and home) and services (ICU length of stay, number of days receiving mechanical ventilation, feeding tube, chemotherapy [yes/no], resuscitation [yes/no], and inpatient or outpatient hospice [none, <one week, one week]) reported in the week before death. Costs were adjusted by the medical Consumer Price Index to 2013 dollars.³⁰ Estimates reflect all-payer costs,⁷ except for chemotherapy and nursing home estimates, which reflect Medicare costs.^{22,26} For individuals who died in the ICU, we used published estimates of daily care costs for ICU patients who did and did not receive mechanical ventilation.²⁵ For those who died in the ICU, reported ventilation or resuscitation was assumed to be included in ICU costs, and days not in the ICU were assumed to be within the hospital.^{20,25} Average non-ICU daily hospitalization costs were calculated from the HCUP NIS, using non-neonatal and non-maternal discharges for individuals with any cancer diagnosis anywhere in the discharge record but without any International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) procedure codes for invasive ventilation, resuscitation, or chemotherapy.

For individuals who died in the hospital outside of the ICU, we assumed they had been in the hospital for the entire week prior to death based on HCUP NIS average lengths of stay

for patients with in-hospital deaths (mean=8.8 days). We added daily costs for reported ICU stays, average hospitalization costs for days with no specific services reported, and HCUP NIS daily cost estimates for hospital stays with primary codes for resuscitation and non-invasive ventilation received outside the ICU.

We assumed individuals who died in inpatient hospice within one week of hospice admission and who had no outpatient hospice care were in the hospital prior to hospice. Home hospice and inpatient hospice costs were taken from 2013 Medicaid daily reimbursement rates.^{7,23}

We assumed that individuals who died in nursing homes had lived in a nursing home for at least seven days and used Medicare's average daily reimbursement rates for cost estimates.^{22,31} For patients who died at home, we added hospitalization costs recorded in the week before death to hospice²³ and other outpatient care costs. Outpatient care daily costs were averaged from published estimates of costs of outpatient care other than hospice or chemotherapy for patients with cancer.^{24,27-28}

For all patients who received chemotherapy in the last week of life (regardless of site of death), chemotherapy costs were added to estimates of other care use and were taken from published Medicare cost estimates.²⁶

Control Variables—We controlled for several sociodemographic and clinical variables: age, gender, self-reported race/ethnicity (White vs. Black, Hispanic, or other race/ethnicity), health insurance possession, Northeast versus Southwest recruitment site, quality of life rater identity, and Charlson Comorbidity Index.^{4,32}

Statistical Analysis

Any analysis of the relationship between ADs and patient outcomes is subject to confounding because of selection bias. That is, a common factor (patient EoL preferences) is thought to be associated both with likelihood of completing ADs and with patient outcomes associated with care choices. Because our sample was relatively small, we used stratification³³ rather than methods such as propensity scores or instrumental variables to account for confounding because of selection bias. We stratified the sample into individuals who did and did not prefer heroic EoL measures to account for the potential influence of baseline care preferences on both AD and EoL outcomes. We did not use an interaction term between AD and preferences because it would not account for simultaneous relationships among preferences and AD likelihood and among preferences and patient outcomes. Because ADs are intended to be consulted when quick care decisions for unresponsive patients are needed,¹⁰ we focused on preferences for or against heroic EoL care. For the entire sample and within each stratum, the association between ADs and quality of life was evaluated with ordinary least squares regression, and the association between ADs and costs was evaluated with a generalized linear model with a gamma distribution and log link function. We ran models with and without adjustment for patient sociodemographic and clinical characteristics. For cost analyses, mean incremental effects (changes in outcomes when an individual changes from no AD to AD, holding all other covariates at their original values) were calculated.

To test the sensitivity of our results to our chosen cost estimates, we repeated the cost analyses but assumed that patients were hospitalized for five days (the median length of stay for decedents from the HCUP NIS) and assumed that patients who received inpatient hospice care had been admitted directly from home. We also explored the impact of various estimated hospital lengths of stay for patients who died in an ICU. Analyses were conducted with Stata 13.1.³⁴

Results

Of the 413 patients who died, 365 (88%) provided information at baseline on ADs and EoL care preferences. Patients who did and did not provide information on ADs and EoL preferences did not have significantly different quality of life or estimated care costs in the last week of life (data not shown). Analyses were restricted to those who had non-missing data on all control and outcome variables for DNR orders ($n=331$) and LW/DPA ($n=336$). Neither costs nor quality of life were significantly different among those with and without missing observations on control variables (data not shown).

Of the sample, 136 (41.1%) had a DNR order and 178 (53.0%) had a LW/DPA, and 111 (33.0%) had both a DNR order and LW/DPA. The average quality of life in the week before death was 6.3 (SD=2.7, range 0-10), and the mean estimated cost of care in the last week of life was \$8,110 (SD=\$9,957; range \$1,022-\$38,819) (Table 1). Most patients ($n=256$ [76.2%]) did not want heroic EoL measures. Patients who preferred heroic EoL measures were younger, more likely to be non-White and from a Southwest clinic site, and less likely to have health insurance, a DNR order, or a LW/DPA than those who did not prefer heroic EoL measures (Table 1).

For the entire sample, the presence of a DNR order was significantly associated with better quality of life in the week before death (with DNR: mean = 6.7, SD = 2.5; without DNR: mean = 6.0, SD=2.8, $P=0.01$). This relationship did not remain significant when we examined bivariate relationships and stratified by preferences for heroic measures (Table 2). In the adjusted regression model, DNR orders remained associated with better quality of life in the week before death when the sample was not stratified by preference (adjusted $\beta = 0.75$, standard error [SE]=0.30, $P=0.01$) (Table 3). By contrast, we did not find any evidence of a significant relationship between LWs/DPAs and quality of life in the week before death among the entire sample or when the sample was stratified by preference for heroic care.

With the cost estimates outlined above, we found that the presence of a DNR order was associated with lower estimated costs in the last week of life in unadjusted generalized linear models of the entire sample (mean incremental effect= -\$3,004, SE = \$1,071, $P=0.005$) and in unadjusted and adjusted models among patients who preferred no heroic measures (adjusted mean incremental effect = -\$3,082, SE = \$1,395, $P=0.03$). However, these results were not robust to choice of estimate; relationships between DNR orders and costs did not remain statistically significant when we ran sensitivity analyses with shorter estimated hospital lengths of stay (data not shown). No matter the cost estimate chosen, we did not find any evidence of a relationship between LW/DPAs and costs for any patient group.

Discussion

In this study, we examined associations among different types of ADs and medical orders, quality of life, and estimated costs of care in the last week of life of patients with advanced cancer. Contrary to our expectations, we did not find evidence of different relationships between ADs and patient outcomes when we stratified by patient preferences for heroic EoL measures. We did, however, demonstrate an association between DNR orders and better quality of life in the week before death among all patients. These results highlight the potential importance of completing a DNR order for patients who do not want to be resuscitated.

To our knowledge, this is the first study that explores the relationship between DNR orders and quality of life and estimated costs of care in the week before death in an analysis that adjusts for patient EoL care preferences. Although other studies have reported an association between DNR orders and lower EoL care costs,¹⁴ those analyses were not stratified by patient preferences. In addition, our study confirms the results of others in that we did not find a significant relationship between LW/DPAs and costs associated with EoL care.^{4,12} Although we hypothesized that LW/DPAs would be associated with better quality of life at the EoL, we found no evidence of this in the entire sample or when we stratified by preference for heroic measures. Problems with making LWs and DPA plans accessible to health care providers and upholding preferences stated in LWs are well-known.^{1,35-36} Unlike LWs or DPAs, DNR orders reflect a specific care plan and are readily documented in medical charts. This accessibility may allow DNRs to be more strongly associated with care received and quality of life near the EoL. Similarly, EoL care discussions with providers (who may be the ones making care decisions at the EoL) are associated with lower care costs and better quality of life in the week before death.⁷

Preferences and ADs were not always congruent among patients in our sample. For instance, 29% of those who wanted heroic EoL measures reported having a DNR order at baseline. Possible reasons for this include inaccurate recall of DNR orders by patients or a misunderstanding of what a DNR order entails. Both of these possibilities highlight the need to ensure that patients and families are well-educated about care options at the end of life.³⁷⁻³⁸

Our analysis is limited in that it evaluates associations between AD completion and patient outcomes, rather than causal relationships. We prospectively measured patient-reported EoL care preferences, but we could not account for unobserved factors, such as physician or family preferences, the extent to which patients discussed preferences with physicians, other patient values, or health literacy, that may influence both AD completion and patient outcomes. By stratifying the sample by a hypothesized confounding factor, our sample size was reduced; therefore, our results should be replicated in larger samples. Our measures of ADs relied on patient self-report at baseline, and we could not account for LW content or details of the conversations surrounding AD completion.¹³ It is possible that patients thought they had completed ADs and medical orders when they had not. DNR status may have changed between the baseline interview and time of death. In addition, although caregivers and patients had correlated measures of patient quality of life at baseline,¹⁷ their

perceptions of quality of life in the week before death may have differed. Our cost data were estimated from national data,⁷ and our results were sensitive to choice of estimate used. Future studies should include actual costs incurred by patients from medical claims data.

A strength of our study is that patients were recruited before a terminal hospitalization and died in a variety of settings.⁷ This enabled us to examine ADs and medical orders that were more likely to have been a result of careful thought rather than last minute orders during a health crisis.³⁹ LW/DPA and DNR rates in our sample were similar to those reported elsewhere,^{8,40-43} although our DNR rates are high for the time period in which they were completed (median time between interview and death was 3.5 months, interquartile range 2-7 months).⁴¹ In addition, our sample reflects the racial diversity of the U.S. (62% white, 20% black, 17% Hispanic; in the 2010 U.S. Census: 72% white, 13% black, and 16% Hispanic).⁴⁴

Future research should explore whether ADs are associated with quality of life and cost differences over longer periods of time for patients with advanced cancer. However, by studying the last week of life, in which mental and physical symptoms change rapidly, we can better understand how ADs are associated with the circumstances in which patients die. This time period is also important to caregivers; better quality of life in the week before death predicts improved bereavement adjustment among caregivers of patients with advanced cancer.²⁹

Conclusions

Medical orders are associated with better patient quality of life when patient goals of treatment are readily available to medical providers and reflect clearly defined acts, as is the case when patients who do not desire resuscitation complete a DNR order. This study demonstrates the potential benefit of completing DNR orders for patients who do not desire resuscitation, and it supports the need for continued patient education about benefits and risks of EoL treatment options.

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Table 1

Characteristics of Sample

Variable	Mean (SD) or Frequency (%)			P-value ^b
	Entire Sample (n=336) ^a	Prefers No Heroic Measures (n=256)	Prefers Heroic Measures (n=80)	
Outcomes				
Quality of life in week before death ^c	6.3 (2.7)	6.4 (2.6)	6.0 (2.7)	0.21
Estimated costs of care in week before death	\$8110 (\$9957)	\$7880 (\$9827)	\$8847 (\$10,391)	0.59 ^d
Advance directives				
DNR ^e	136 (41.1%)	113 (44.8%)	23 (29.1%)	0.01
LW/DPA	178(53.0%)	151 (59.0%)	27 (33.7%)	<0.001
Sociodemographic and clinical characteristics				
Age	58.3 (12.7)	59.7 (11.9)	53.6 (13.9)	<0.001
Male	183 (54.5%)	136 (53.1%)	47 (58.7%)	0.38
Race/Ethnicity				<0.001
White	209 (62.2%)	180 (70.3%)	29 (36.3%)	
Black	66 (19.6%)	37 (14.5%)	29 (36.2%)	
Hispanic	56 (16.7%)	36 (14.1%)	20 (25.0%)	
Other	5 (1.5%)	3 (1.2%)	2 (2.5%)	
Northeast recruitment site (vs. Southwest)	149 (44.3%)	127 (49.6%)	22 (27.5%)	0.001
Health Insurance	192 (57.1%)	159 (62.1%)	33 (41.2%)	0.001
Charlson Comorbidity Index	8.3 (2.7)	8.4 (2.8)	8.0 (2.5)	0.35

SD = standard deviation; DNR = do not resuscitate; DPA = durable power of attorney; LW = living will.

^a Means and frequencies for sample with no missing data on control or outcome variables

^b P-values for bivariate tests between patients who did and did not prefer heroic measures.

^c Range 0-10, with higher numbers indicating better quality.

^d Wilcoxon rank-sum test.

^e DNR order data from 331 patients

Table 2

Estimated Costs and Quality of Life in Week Before Death Associated with Completion of Advance Directives and Medical Orders, Stratified by Patient Preferences

	Quality of Life ^a		Estimated Costs	
	Mean (SD)	P-value ^b	Mean (SD)	P-value ^c
Entire sample				
No DNR (<i>n</i> =195) ^d	6.0 (2.8)	0.01	\$9,330 (\$10,607)	0.12
DNR (<i>n</i> =136)	6.7 (2.5)		\$6,326 (\$8,733)	
No LW/DPA (<i>n</i> =158)	6.2 (2.8)	0.49	\$9,146 (\$10,787)	0.31
LW/DPA (<i>n</i> =178)	6.4 (2.5)		\$7,190 (\$9,089)	
Prefers no heroic measures				
No DNR (<i>n</i> =139)	6.1 (2.8)	0.07	\$9,300 (\$10,550)	0.07
DNR (<i>n</i> =113)	6.7 (2.5)		\$6,032 (\$8,586)	
No LW/DPA (<i>n</i> =105)	6.3 (2.8)	0.82	\$9,061 (\$10,775)	0.27
LW/DPA (<i>n</i> =151)	6.4 (2.5)		\$7,059 (\$9,056)	
Prefers heroic measures				
No DNR (<i>n</i> =56)	5.7 (2.8)	0.11	\$9,402 (\$10,842)	0.80
DNR (<i>n</i> =23)	6.8 (2.5)		\$7,766 (\$9,492)	
No LW/DPA (<i>n</i> =53)	5.9 (2.7)	0.64	\$9,317 (\$10,914)	0.89
LW/DPA (<i>n</i> =27)	6.2 (2.7)		\$7,925 (\$9,410)	

SD = standard deviation; DNR = do not resuscitate; DPA = durable power of attorney; LW = living will.

^aRange 0-10; higher numbers indicate better quality.

^b*t*-test for difference in quality of life between patients with no advance directive/medical order and those with an advance directive/medical order.

^cWilcoxon rank-sum test for difference in costs of care between patients with no advance directive/medical order and those with an advance directive/medical order.

^dDNR order data from 331 patients; LW/DPA data from 336 patients.

Table 3

Associations Among Advance Directives, Medical Orders, and Quality of Life in the Week Before Death

DNR Orders (n=331)						
	Unadjusted Beta^a	SE	P-value	Adjusted Beta^b	SE	P-value
Entire sample	0.73	0.29	0.01	0.75	0.30	0.01
Prefers no heroic measures (n=252)	0.60	0.33	0.07	0.65	0.34	0.06
Prefers heroic measures (n=79)	1.06	0.66	0.11	0.98	0.68	0.15
Living Wills/Durable Powers of Attorney (n=336)						
	Unadjusted Beta	SE	P-value	Adjusted^b Beta	SE	P-value
Entire sample	0.20	0.29	0.49	0.42	0.34	0.21
Prefers no heroic measures (n=256)	0.08	0.34	0.82	0.30	0.39	0.44
Prefers heroic measures (n=80)	0.31	0.65	0.64	0.34	0.74	0.64

DNR = do not resuscitate; SE = standard error.

^aRepresents change in quality of life associated with presence of an advance directive or medical order.^bAdjusted for sociodemographics, illness characteristics, and rater identity.