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# Advance Directives and Intensity of Care Delivered to Hospitalized Older Adults at The End-of-Life

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## Abstract

### Background

Older adults prefer comfort over life-sustaining care. Decreased intensity of care is associated with improved quality of life at the end-of-life (EOL).

### Objectives

This study explored the association between advance directives (ADs) and intensity of care in the acute care setting at the EOL for older adults.

### Methods

A retrospective, correlational study of older adult decedents (N = 496) was conducted at an academic medical center. Regression analyses explored the association between ADs and intensity of care.

### Results

Advance directives were not independently predictive of aggressive care but were independently associated with referrals to palliative care and hospice; however, effect sizes were small, and the timing of referrals was late.

### Conclusion

The ineffectiveness of ADs to reduce aggressive care or promote timely referrals to palliative and hospice services, emphasizes persistent inadequacies related to EOL care. Research is needed to understand if this failure is provider-driven or a flaw in the documents themselves.

### Keywords

acute care, advance directives, quality of life, end-of-life

### Abbreviation

ACP Advanced care planning

AD Advance directives

CCI Charlson comorbidity index

HER Electronic health record

EOL End-of-life

LOS Length of stay

LW Living will

POA-HC Power of attorney for healthcare

PC Palliative care

QOL Quality of life

SDM Surrogate decision-maker

The rapid growth of the aging population<sup>1</sup> places increased demands on an already strained healthcare system. Given the significant healthcare expenditures in the final year of life,<sup>2</sup> the costs of providing ongoing care for patients who live longer with chronic, progressive disease will only rise. While advanced care planning (ACP) is effective in reducing unnecessary and unwanted care at the end-of-life (EOL),<sup>3, 4, 5, 6</sup> there is a lack of consistent similar evidence for advance directives (AD).

Advanced care planning is a process whereby patients receive personalized education about their health conditions and are engaged in discussions of EOL preferences,<sup>7</sup> while ADs are formal documents expressing personal preferences and a designated surrogate decision-maker (SDM).<sup>5</sup> Advanced care planning is consistently associated with reduced aggressive care,<sup>3, 4, 6</sup> increased hospice utilization,<sup>4, 6</sup> and improved QOL at the EOL.<sup>6</sup> However, there is no consistent association between the presence of ADs and type of care received, and much of the research on the impact of ADs narrowly focus on oncology,<sup>4, 6, 8, 9</sup> heart failure,<sup>10</sup> or critically ill patients<sup>9, 11, 12, 13</sup> making it unclear if findings generalize to other populations. Additionally, most AD and ACP research includes all adults, neglecting the unique needs of the vulnerable older adult population. Many studies rely on SDMs for information on the presence or absence of an AD prior to death.<sup>5, 14, 15, 16</sup> While proxy studies often report an association between ADs and limited aggressive care at the EOL, studies in which an AD is confirmed within the electronic health record (EHR) do not consistently find this association.<sup>9, 11, 12, 17</sup>

Older adults prefer comfort over treatments that prolong life<sup>18, 19</sup>; however, 30% of Medicare expenditures are incurred in the final year of life,<sup>20</sup> with half resulting from acute hospitalizations.<sup>21</sup> This inconsistency between patient preferences and delivery of high-technology, high-cost care suggests that care delivered near death may not promote quality of life (QOL) at the EOL. ACP and ADs have been proposed as means to improve congruence of care with patients' preferences.

The landmark SUPPORT study identified inadequacies of AD documentation<sup>22, 23</sup> that persist today.<sup>19</sup> Inadequate documentation of ADs, both through low rates of completion and poor articulation of actual preferences, remains a persistent challenge for EOL care delivery<sup>8, 12, 19</sup>. Since the impact of ADs on the intensity of care delivered to hospitalized older adults at the EOL is not clearly established, further objective investigation of the influence ADs exert on care delivery is necessary before devoting additional resources toward increasing completion rates of these documents. The purpose of this study was to evaluate the relationship between the presence of a documented AD within the EHR and the intensity of care received by older adults in the acute care setting at the EOL.

## Theoretical framework

This study was guided by the Quality Health Outcomes Model (QHOM),<sup>24, 25, 26</sup> which posits that patient outcomes are influenced by patient characteristics, system characteristics, and interventions. The model considers the impact of interventions directly on patient outcomes and integrates both patient state and trait characteristics. [Fig. 1](#) illustrates the concepts of the QHOM with the associated variables examined in this study.

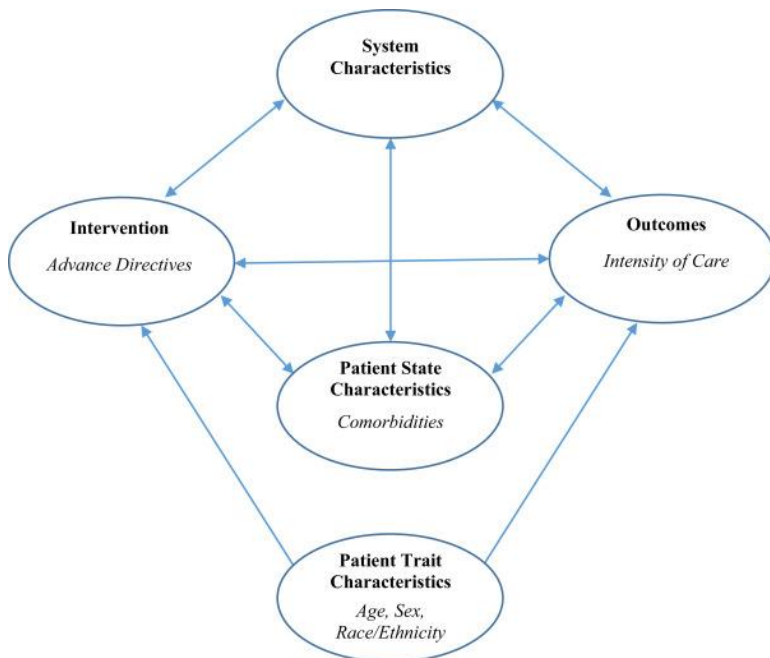


Fig. 1. Study variables in the context of the QHOM.

## Methods

### Study design

A retrospective, correlational study was conducted to explore the relationship between ADs and intensity of care at the EOL using the EHRs of older adult decedents from a large, tertiary access, level one trauma center in the Midwest United States. The sample included patients aged 65 and older, who died during a hospital admission between January 2014 and December 2016. Patients were excluded if they were discharged to the inpatient hospice service where care was managed within the same hospital building by an outside hospice agency.

### Sample

An a priori G-power analysis<sup>27</sup> conducted for a medium effect<sup>28</sup> indicated that a total sample of 485 people was necessary to detect a moderate effect with 80% power. An institutional self-service cohort discovery tool (i.e. an electronic data warehouse) was used to identify potential patients guided by the following inclusion criteria: age  $\geq$  65, deceased, inpatients, and admission to the same hospital. Date of death was matched with the date of discharge to verify that death occurred during the terminal admission. All subjects that did not die during hospital admission were excluded.

### Study variables

#### Predictor variable

The presence or absence of an AD signed before the terminal hospital admission, either present in the medical record prior to admission or added to the EHR within 24 h of admission, and retrievable from the EHR, served as the binary predictor variable (e.g., yes/no). An AD signed after hospital admission was coded as no.

## Outcome variables

Variables for intensity of care were selected following an extensive literature review with the most common variables included in this study.<sup>4, 5, 6, 9, 10, 11, 12, 14, 16, 17</sup> Outcome variables were categorized into indicators of either aggressive or conservative care. Aggressive care measures were mechanical ventilation (MV), new initiation of artificial enteral nutrition, admission or transfer to the intensive care unit (ICU) and ICU length of stay, cardiopulmonary resuscitation (CPR), new dialysis including hemodialysis and continuous renal replacement therapy (CRRT), invasive procedures such as bronchoscopy, surgical procedures or tube placement (e.g., chest tube, external ventricular drain, permanent feeding tube), and the use of cardiovascular supports (e.g., vasopressors, intra-aortic balloon pump, extracorporeal membranous oxygenation, or new placement of a ventricular access device). Measures of conservative care were palliative care (PC) consultation, hospice referral, a do-not-resuscitate code status at death, and utilization of comfort care order sets. Palliative and hospice referrals were considered present if a consult note was present in the EHR. Date of consultation was noted with respect to the number of days consultation occurred prior to death.

## Confounding variables

With existing literature focused on specific diagnoses, this study specifically included multiple comorbidities and stratified based on overall disease burden. Data were collected for age, sex, race, ethnicity, and preexisting comorbidities guided by the QHOM framework. The Charlson Comorbidity Index (CCI)<sup>29, 30</sup> was used to measure comorbid conditions. The CCI has been validated in acute care populations<sup>31, 32, 33, 34</sup> and predicts one-year mortality based on chronic disease and age, with a higher CCI score predicting a higher risk of death.<sup>31, 32, 33, 34</sup> Its predictive ability has remained consistent from International Classification of Diseases, version 9 (ICD-9)<sup>35</sup> to ICD-10.<sup>36, 37, 38</sup>

## Data collection

Data were abstracted from the EHR. Every medical record was searched by the author M.T. for each variable of interest and logged onto a data collection form, identified only by a unique study identifier. Ten percent of data forms were audited by author J.G for accuracy.

## Statistical analysis

Logistic regression was performed to evaluate the association of predictors with care received in the acute care setting at the EOL,  $\alpha$  set to  $< .01$ . Rejection of the null hypothesis indicated that the model was able to differentiate between those who did and did not receive the outcome of interest. All analyses were conducted using SPSS, v24.<sup>39</sup> Modeling began with all predictor variables (AD, age, CCI, and sex). In an intentional, step-down fashion, predictors for subsequent models were individually removed, based on the statistical significance of their unique contribution to a given model, and the model was re-run with remaining predictors. At each step, models were compared with a Likelihood Ratio Test (LRT). A non-significant difference between the two models resulted in retention of the more parsimonious model. This process was repeated until the most parsimonious model was identified. Outcome variables for which ADs were significantly associated were further analyzed utilizing *t*-tests, equal variances assumed, to evaluate mean differences between those with and without an AD.

Multiple regression was performed to evaluate the impact of predictor variables on the continuous outcome variable, total ICU LOS, for the subgroup of patients who received ICU care ( $n = 426$ ). Utilizing a step-down approach, predictors were removed based on the statistical significance of their unique contribution to a given model.  $F$  ratio tests were used to compare models, and the most parsimonious model, without a significant  $F$  ratio change, was retained. For both logistic and multiple regression analyses, the AD predictor (variable of interest) was never removed from any model, regardless of statistical significance.

Race and ethnicity were excluded as predictors due to an overrepresentation of Caucasians (78.8%) and underrepresentation of all other groups in the sample population relative to the local demographics of the general population.<sup>40</sup> Additionally, 3.6% of subjects were identified as “unknown” for race and ethnicity. The standardized residuals of CCI, removing the effect of age, served as the CCI variable in all analyses thus eliminating the correlation between age and CCI that was present in preliminary analyses. Finally, descriptive analyses indicated that patients who received extracorporeal membranous oxygenation, intra-aortic balloon pump, or new placement of a ventricular access device therapies were captured within the variable, vasopressors. Analyses of those therapies were subsequently excluded. Probabilities for differences in outcomes associated with ADs are reported regardless of the statistical significance of the AD predictor in the model to report all associations identified between ADs and care delivered.

## Ethical considerations

This study was approved by all required institutional review boards and compliance offices.

## Results

Nine hundred fifty-nine patients met inclusion criteria of which 496 cases were selected, using computerized randomization, for data collection and analysis. Demographic characteristics, descriptive statistics of comorbidities, and outcome variables are presented in [Tables 1](#) and [2](#). The variance explained by each overall model is reported ([Fig. 2](#)) using Nagelkerke's pseudo- $R^2$  ( $R_{pseudo}^2$ ). [Table 3](#), [Table 4](#), [Table 5](#), [Table 6](#) summarize all regression models and model comparisons, including  $\chi^2$ ,  $OR$ , and  $R_{pseudo}^2$ .

Table 1. Demographic characteristics

Characteristic	Value
Subjects, $N$ (%)	496 (100)
Women	252 (48.8)
Men	254 (51.2)
Age, $M$ ( $SD$ ) total	78.52 (8.58)
Women	79.59 (8.44)
Men	77.51 (8.61)
Marital status, $n$	
Married	222
Single	69
Widowed	139
Divorced	37

Legally separated	6
Significant other	1
Unknown	22
Race, <i>n</i>	
White or caucasian	391
Black or African American	67
Hispanic	11
Asian	7
American Indian or Alaska Native	1
Other	1
Unknown	18
Ethnicity, <i>n</i>	
Non-hispanic	465
Hispanic	11
Unknown	20
Advance directives on file, <i>n</i> (%)	232 (46.8)
women	110 (43.7)
men	122 (48.0)
Types of advance directives, <i>n</i>	
POA-HC	181
LW	3
POA-HC and LW	42
State DNR	5
SNF form	1

POA-HC, Power of attorney for healthcare; LW, Living will.

DNR; Do Not Resuscitate; DNR, Do Not Resuscitate; SNF; Skilled Nursing Facility.

Table 2. Comorbidity burden and outcome variable distributions among participants

Characteristic	Value
Outcome variables, <i>n</i> (%)	
Dialysis	90 (18.1)
Invasive procedures	208 (41.9)
Mechanical ventilation	310 (62.5)
Artificial enteral nutrition	156 (31.5)
Cardiovascular support	252 (50.8)
Admission or transfer to ICU	427 (86.1)
Comfort care order set	296 (59.7)
Cardiopulmonary resuscitation	105 (21.2)
Code status at death (DNR)	353 (71.2)
Palliative care consultation	143 (28.8)
Hospice referral	143 (28.8)
Comorbidity burden, <i>n</i> (any history of), <i>n</i>	
Acute MI	56
Cerebrovascular disease	127



Chronic pulmonary disease	137
Connective tissue disease	29
Dementia	71
Heart failure	166
Mild liver disease	22
Any non-metastatic malignancy	115
Diabetes without complications	113
Diabetes with complications	38
Hemi- or paraplegia	26
HIV/AIDS	0
Metastatic solid tumor	57
Moderate or severe liver disease	8
Renal disease	153
Peptic ulcer disease	30
Peripheral vascular disease	101

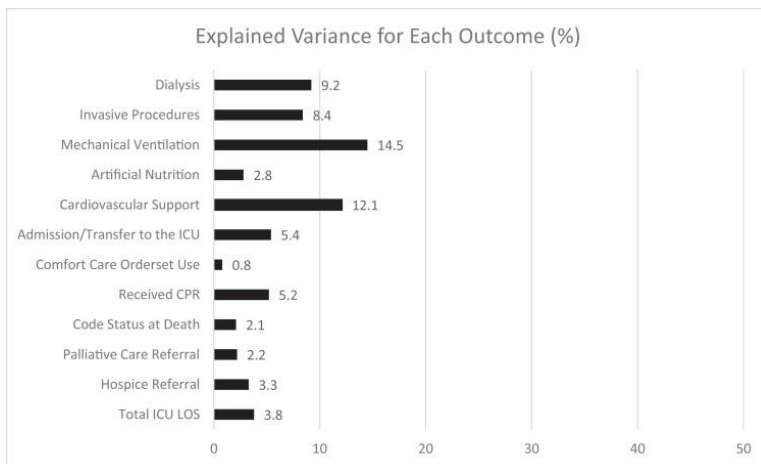


Fig. 2. Percentage of variance explained by each retained model for each outcome variable.



	Advance directive	-0.692	0.309	5.001	1	.025	0.501	[0.273, 0.918]
	(Intercept)	-1.846	0.179	105.929	1	< .001	0.158	
Palliative care consult								
	Advance directive	0.558	0.200	7.783	1	.005	1.748	[1.181, 2.587]
	(Intercept)	-1.181	0.145	66.182	1	< .001	0.307	
Hospice referral								
	Advance directive	0.679	0.201	11.389	1	.001	1.972	[1.329, 2.925]
	(Intercept)	-1.245	0.148	71.067	1	< .001	0.288	

Table 4. Multiple regression model for total ICU length of stay outcome variable

	Predictors	<i>b</i>	<i>SE b</i>	$\beta$	<i>t</i>	<i>p</i>	95% CI
Total ICU LOS	(Intercept)	4.802	0.426		11.283	< .001	[3.965, 5.638]
	Advance directive	0.114	0.626	0.009	0.182	.856	[-1.116, 1.344]
	Age	-0.148	0.036	-0.195	-4.078	< .001	[-0.220, -0.077]

ICU, Intensive Care Unit; LOS, Length of Stay.

Table 5. Logistic regression likelihood ratio test

Model	$\chi^2$ (df)	$p_{\text{model}}$	$\Delta\chi^2$ ( $\Delta df$ )	$p_{\text{difference}}$
Dialysis				
1 (all predictors)	35.206 (4)	< .001		
2 (removed sex)	35.047 (3)	< .001	0.159 (1)	.6901
3*** (removed sex + CCI)	28.855 (2)	< .001	6.192 (1)	.0128
4 (removed sex + CCI + age)	0.919 (1)	.338	27.936 (1)	< .00001
Invasive procedures				
1 (all predictors)	34.939 (4)	< .001		
2 (removed sex)	34.897 (3)	< .001	0.042 (1)	.8376
3*** (removed sex + CCI)	31.912 (2)	< .001	2.985 (1)	.0840
4 (removed sex + CCI + age)	4.252 (1)	.039	27.66 (1)	< .00001
Mechanical ventilation				
1 (all predictors)	56.155 (4)	< .001		
2*** (removed sex)	55.634 (3)	< .001	0.521 (1)	.4704
3 (removed sex + CCI)	48.453 (2)	< .001	7.181 (1)	.0074
4 (removed sex + CCI + age)	12.496 (1)	< .001	43.138 (2)	< .00001
Artificial nutrition				
1 (all predictors)	10.609 (4)	.031		
2 (removed sex)	10.609 (3)	.014	0 (1)	1
3*** (removed sex + CCI)	9.979 (2)	.007	0.63 (1)	.4274
4 (removed sex + CCI + age)	0.035 (1)	.851	9.944 (1)	.0016
CV support				
1 (all predictors)	48.470 (4)	< .001		
2 (removed sex)	48.191 (3)	< .001	0.279 (1)	.5974
3*** (removed sex + CCI)	47.315 (2)	< .001	0.876 (1)	.3493
4 (removed sex + CCI + age)	4.573 (1)	.032	42.742 (1)	< .00001
Admit/Transfer to the ICU				
1 (all predictors)	18.645 (4)	.001		
2 (removed sex)	18.359 (3)	< .001	0.286 (1)	.5928
3*** (removed sex + CCI)	15.197 (2)	.001	3.162 (1)	.0754
4 (removed sex + CCI + age)	4.033 (1)	.045	11.164 (1)	.0008
Comfort care orderset				
1 (all predictors)	5.182 (4)	.269		
2 (removed age)	5.134 (3)	.162	0.048 (1)	.8266

3 (removed age + sex)	4.784 (2)	.091	0.35 (1)	.5541
4*** (removed age + sex + CCI)	3.076 (1)	.079	1.708 (1)	.1912
Received CPR				
1 (all predictors)	17.472 (4)	.002		
2 (removed CCI)	17.470 (3)	.001	0.002 (1)	.9643
3*** (removed CCI + sex)	16.792 (2)	< .001	0.678 (1)	.4103
4 (removed CCI + sex + age)	7.227 (1)	.007	9.565 (1)	.0020
Code status at time of death				
1 (all predictors)	9.484 (4)	.050		
2 (removed sex)	9.455 (3)	.024	0.029 (1)	.8648
3 (removed sex + CCI)	8.936 (2)	.011	0.519 (1)	.4713
4*** (removed sex + CCI + age)	5.281 (1)	.022	3.655 (1)	.0559
Received PC consult				
1 (all predictors)	11.386 (4)	.023		
2 (removed age)	11.381 (3)	.010	0.005 (1)	.9436
3 (removed age + sex)	11.162 (2)	.004	0.219 (1)	.6398
4*** (removed age + sex + CCI)	7.860 (1)	.005	3.302 (1)	.0692
Received hospice consult				
1 (all predictors)	13.039 (4)	.011		
2 (removed sex)	13.020 (3)	.005	0.019 (1)	.8904
3 (removed sex + CCI)	13.002 (2)	.002	0.018 (1)	.8933
4*** (removed sex + CCI + age)	11.572 (1)	.001	1.43 (1)	.2318

$\chi^2$ , chi square;  $df$ , degrees of freedom;  $p_{model}$ , significance of the individual model;  $\Delta\chi^2$ , change in chi square between models;  $\Delta df$ , change in degrees of freedom between models;  $p_{difference}$ , significance of the  $\Delta\chi^2$ .

\*\*\* retained model.

Table 6. Multiple regression model summary

Model summary <sup>e</sup>										
Model	R	R <sup>2</sup>	Adjusted R <sup>2</sup>	SE	Change statistics					Durbin-Watson
					$\Delta R^2$	$\Delta F$	$df_1$	$df_2$	p	
1	.199 <sup>a</sup>	0.040	0.031	6.417	0.040	4.369	4	422	.002	
2	.199 <sup>b</sup>	0.040	0.033	6.411	0.000	0.096	1	422	.757	
3***	.195 <sup>c</sup>	0.038	0.033	6.408	-0.002	0.724	1	423	.395	
4	.013 <sup>d</sup>	0.000	-0.002	6.525	-0.038	16.627	1	424	< .001	2.058

a Predictors: Sex, CCI, Age, Advance Directive.

b Predictors: CCI, Age, Advance Directive.

c Predictors: Age, Advance Directive.

d Predictors: Advance Directive.

Dependent Variable: Total ICU Length of Stay.

\*\*\* retained model.

## Advance directives

Two hundred and thirty-two decedents (46.8%) had some form of AD present within their medical record within the first 24 h of admission ([Table 1](#)). Various types of ADs were identified. The overwhelming majority of ADs were power of attorney for healthcare (POA-HC) documents,  $n = 181$ , as compared to living wills (LW),  $n = 3$ . An additional  $n = 42$  individuals had both a POA-HC and a LW. POA-HC and LW documents were State of Wisconsin templates. Those with both a POA-HC and a LW had either formal state templates, the Five Wishes document, or a standardized form for Jehovah's Witnesses.

## Indicators of aggressive care

Advance directives were not associated with receiving new dialysis, undergoing invasive procedures, receiving MV, artificial nutrition, CV supports, ICU care, ICU length of stay, or receiving CPR. Models containing AD and age were able to differentiate between those who did and did not receive new dialysis ( $p < .001$ ), invasive procedures ( $p < .001$ ), artificial nutrition ( $p = .007$ ), CV supports ( $p < .001$ ), ICU care ( $p = .001$ ), or CPR ( $p < .001$ ), where only age made a significant contribution to each model ([Table 3](#)). For each one year older, the likelihood of receiving new dialysis, undergoing invasive procedures, receiving artificial nutrition, CV supports, ICU care, or CPR decreased by 7.5%, 5.7%, 3.6%, 7%, 5%, and 4.1%, respectively. The model containing AD, age, and CCI was able to differentiate between those who did and did not receive MV ( $p < .001$ ), where both age ( $p < .001$ ) and CCI ( $p < .001$ ) made significant contributions. With all other variables held constant, both age and comorbidity burden decreased the likelihood of receiving MV, 6.8% and 23.5%, respectively. For the subgroup of individuals who received ICU care ( $n = 426$ ), the predictors age and AD contributed to the most parsimonious model for ICU LOS ( $p < .001$ ); however, only age made a significant contribution ( $p < .001$ ). Total ICU LOS was 0.11 days longer for those patients with an AD ( $p = .856$ ). Older patients had shorter lengths of stay—each year older was associated with a decreased LOS by 0.15 days ( $p < .001$ ).

## Indicators of conservative care

No predictors made meaningful contributions to modeling for either comfort care order sets ( $p = .79$ ) or code status ( $p = .22$ ) ([Table 3](#)). While patients with ADs were half as likely to be a full code, this was not statistically significant ( $p = .025$ ).

Advance directives were associated with referrals to both PC ( $p = .005$ ) and hospice ( $p = .001$ ). An AD was associated with an increased likelihood of referral (74.8% and 97.2%, respectively). Additional analyses were performed to describe the mean difference in the number of days before death of PC and hospice referrals by AD presence. There was no mean difference between the presence ( $n = 80$ ,  $M = 4.39$ ,  $s = 5.328$ ) or absence ( $n = 62$ ,  $M = 3.79$ ,  $s = 6.135$ ) of an AD and the number of days prior to death that palliative care was consulted ( $p = .536$ ). Similarly, there was no mean difference between the presence ( $n = 85$ ,  $M = 3.32$ ,  $s = 3.364$ ) or absence ( $n = 59$ ,  $M = 3.46$ ,  $s = 6.516$ ) of an AD and the number of days prior to death of hospice referral ( $p = .866$ ).

## Discussion

The purpose of this study was to evaluate the relationship between the presence of ADs in the EHR and the intensity of care received by older adults in the acute care setting at the EOL. Indicators of both

aggressive and conservative care were studied. Advance directives were not independently associated with receipt of aggressive care at EOL; however, ADs were associated with increased referrals to palliative care and hospice. Despite increased referrals, ADs were not associated with early initiation of these services.

Echoing other studies,<sup>9, 17, 41</sup> any effect ADs exerted toward aggressive treatment was influenced by age, and in the case of MV, by comorbidity burden. This is not, per se, an indication that ADs are ineffective. While an AD was not an independent predictor in any model, when holding other predictor variables constant, individuals with an AD were less likely to receive ICU care, new dialysis, invasive procedures, MV, CV supports, and CPR. This suggests that ADs have a role in reducing aggressive care, but that more can be done to optimize these benefits to make a meaningful impact on EOL care.

Preferences may not be documented in ADs with enough detail to guide care at the EOL. Legislation through the Patient Self Determination Act has focused on increasing AD documentation via mandates to acute care facilities.<sup>42</sup> However, if care decisions are more impacted by patient factors than by ADs, perhaps efforts should focus on increasing ACP interventions in conjunction with AD completion as ACP communication has been found to decrease aggressive care<sup>4, 5</sup> in a way that promotes QOL at the EOL.<sup>6</sup> Linking ACP conversations with AD completion may be necessary to improve the effectiveness of ADs to promote congruent care and decrease potentially unwanted aggressive care.

The unique influence of ADs was only present for PC consults and hospice referrals; however, the effect sizes were small, potentially related to the smaller number of patients who received these referrals ( $n = 143$ ). While the benefit of these services has been previously described,<sup>43</sup> the current study emphasizes that simply demonstrating an increased number of consultations and referrals is not enough. Aggressive care was not significantly reduced in the sample overall, and referrals to both PC and hospice were late, regardless of AD status. The benefits of early palliative and hospice referrals<sup>44, 45</sup> are overlooked by providers, who may perceive the initiation of these services as failure.<sup>46, 47</sup> Palliative care is an underutilized service that, when integrated within the acute care setting, reduces costs and more importantly, improves the dying process.<sup>48, 49</sup> Additionally, hospice referral more than three days before death is associated with higher quality of death.<sup>18, 50</sup> Changing the culture within healthcare that tends to avoid these services is a major undertaking but a necessary step toward improving EOL care.<sup>19</sup>

No model explained more than 14.5% of the variance in any outcome variable, and half of the models explained 5% or less. Retrospective studies, by their nature, are incapable of capturing the context in which EOL decision-making occurs in addition to other influences, such as severity of illness, socioeconomic factors, cultural values and beliefs, support systems, and SDM selection. In situations where SDMs must make difficult decisions, known patient preferences and values can often be at odds with SDMs' own needs and desires to avoid perceived responsibility for a loved one's death.<sup>51</sup> The inability of surrogates to separate their own interests from those of patients may play a role in decisions made at the EOL, which suggests while documentation of patient preferences is important, communication of those preferences to SDMs and loved ones is essential. These scenarios further emphasize the need of support from PC teams and medical recommendations of providers in navigating goals of care discussions. Future prospective studies are needed to capture these contextual factors.

The proportion of patients in the current study with an AD (46.8%) is consistent with previous studies utilizing objective data from the EHR as opposed to a proxy report of AD presence.<sup>8, 10</sup> Studies that obtain data from SDMs tend to be more optimistic regarding the effectiveness of ADs to both minimize aggressive care and promote care that is congruent with patient preferences.<sup>5, 15, 16</sup> Poor awareness of these differences may encourage a false sense of security in documents that may not be effective in their current form. The failure to improve rates of AD completion over time provides further support for the need to reassess not only provider encouragement to complete such documents, but overall provider engagement in ACP to optimize patient QOL at the EOL.

Finally, it is important to note that of those patients who completed a single AD document, the overwhelming majority completed only a POA-HC. Of all decedents, fewer than 1 in 5 completed both a POA-HC and LW. Since a POA-HC is the document that identifies a designated SDM, it is plausible that the failure of ADs in this study to have an impact on aggressive care or timely referrals to PC and hospice was, in part, due to a focus on simply identifying a trusted SDM. While patients trust a designated SDM's ability to exercise substituted judgment, designees may not believe they truly know their loved one's preferences.<sup>52</sup> In fact, even for patients with both a LW and POA-HC document, the designated SDM can override the LW document. This discordance lends support for the role of primary care and specialty providers in promoting ACP discussions that integrate both patients and their designated SDMs as well as encouraging AD documentation that provides a window into patients' values and preferences to guide future decision-making. Additionally, providers delivering care to hospitalized patients in the acute care setting should be aware of this potential inconsistency early and focus efforts on identifying patient values and preferences to prepare surrogates for their potential role in substituted judgment decision-making.

## Implications

The Centers for Medicare and Medicaid have recognized that financial incentives might motivate providers to more actively engage their patients in EOL discussions.<sup>43</sup> With the recent changes from the Centers for Medicare and Medicaid, providers should consider an increased focus on ACP with patients. The current healthcare climate is increasingly focused on translational science, interprofessional education and collaboration to improve patient care. All healthcare providers, especially physicians, nurses, advanced practice providers, and social workers can work collaboratively to focus efforts on improving ACP and AD documentation. Future research should use an interdisciplinary focus when developing targeted interventional studies toward improving ACP and increasing the completion of meaningful ADs that are practical and applicable to bedside providers. Studying the impact of new EHR solutions that capture conversations and goals of care discussions in addition to AD documents may have relevance.

In addition to focusing on the process of AD completion, understanding better how providers utilize these documents requires further study. Are ADs routinely reviewed by physicians and advanced practice providers? Are documents reviewed only when a patient is incapacitated, or are they interwoven into the fabric of routine decision-making with decisional patients? Do providers encourage family members and SDMs to adhere to documented preferences or are they fearful of litigation if they fail to appease SDMs? And what of patient autonomy? Are these documents not the patient's autonomous wishes in the event they are not able to express their own preferences? The



SUPPORT study raised concerns regarding the specificity of AD documents as a barrier to their utility.<sup>54</sup> Further research should ascertain if this remains the case – Are ADs crafted in a way that provides sufficient detail to truly direct care?

In demonstrating persistently low rates of AD documentation, this study provides additional evidence for the need to increase documentation of patient preferences. Lack of documentation leads to inadequately communicated preferences between patients and their families and increased decisional conflict.<sup>53</sup> Providers have a responsibility to engage with patients and their families, who want to have EOL discussions.<sup>54</sup> The trust that patients place in their providers<sup>55, 56</sup> creates opportunities for ACP conversations. Yet all too often, these do not occur<sup>57, 58</sup> and when they do, patient preferences are not documented. If, as may have been in this study, the majority of people are simply identifying a designated SDM at the exclusion of documenting their values and preferences, efforts must focus on educating patients on the importance of detailing information to guide future decisions. Whether patients' ADs request limits in treatment or all interventions possible, providers are influenced by written preferences.<sup>59</sup> More must be done in medical and nursing schools to prepare providers to engage in these difficult conversations with a sense of comfort and confidence.<sup>60, 61</sup>

## Limitations

The exclusion of those who died in hospice may have limited the breadth of data retrieved for assessing the influences of ADs on EOL care decisions. This applies, as well, to the exclusion of those patients who died outside of the hospital, where extraneous variables that contributed to decision-making within the acute care setting may not have been captured.

Despite literature suggesting that older adults prefer comfort over life-sustaining treatment, decedents in this study may have preferred aggressive care. Surrogate decision-makers may have had this knowledge, which could explain the lack of association between the presence of an AD and decreased aggressive care. This study did not address the question of whether patients received the care that they preferred, but rather if simply having an AD, as encouraged through federal mandates, had any relationship with intensity of care received at the EOL. A prospective study would better ascertain this relationship. If more aggressive care is desired, these preferences should be documented within an AD, especially given that this study did confirm an association between increasing age and decreased aggressive care.

Patients who signed an AD document after admission were excluded under the assumption that care discussions did not occur until after admission. However, discussions, without formal documentation of preferences, may have occurred well in advance of hospitalization. Likewise, patients without an AD in the EHR were coded as not having an AD. The absence of an AD in the EHR does not in and of itself indicate that there is no AD document or that no ACP discussions have occurred. A prospective study to elicit the timing of discussions and preferences from patients and families could overcome these limitations and should be considered in future studies.

This study had no access to EHRs that were held by outside organizations. Patients categorized as having no AD may have had one filed within another healthcare system, and providers, at the time of the patient's care, may have had access to outside records that included an AD. Our retrospective study could not track if ADs were accessed in this manner.

Finally, as a large, urban, tertiary medical center, it was anticipated that the population would represent the larger urban community; however, the racial composition of this convenience sample was not found to be representative of the surrounding area.<sup>40</sup> Caucasian patients were overrepresented with minority underrepresentation most significant among Hispanic patients; therefore, no conclusions could be drawn related to the influence of race and ethnicity relative to ADs and intensity of care received.

## Conclusion

Our healthcare and legal systems have placed a high value on creating a formal AD; however, this value may be misplaced. This study's findings mirror others who have failed to consistently confirm the effectiveness of ADs to reduce aggressive care. The time has come for the focus to shift from document completion for the sake of fulfilling a legislative mandate to increasing efforts to build systems that promote meaningful and timely discussion of treatment preferences through robust ACP processes. Efforts to improve the quality of EOL care must begin with the acknowledgment that the current system is ineffective to achieve our stated goals to open the door for multidisciplinary discussions aimed to improve QOL at the EOL.

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