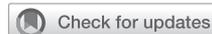


Original Article

Examining Age Inequalities in Operationalized Components of Advance Care Planning: Truncation of the ACP Process With Age



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Abstract

Context. Opportunities for patients to receive unnecessary, costly, and potentially harmful care near the end of life abound. Advance care planning (ACP) can help to make this vulnerable period better for patients, caregivers, and providers.

Objective. The objective of this study was to determine whether older age predicted the presence of certain forms of retrievable ACP documentation in the electronic health record (EHR) in a large sample of hospice-referred patients.

Methods. This was a retrospective analysis of medical-record data on 3595 patients referred to hospice between January 1, 2013 and December 31, 2015. EHR documentation of an ACP note in the problem list, presence of a scanned advance directive, and the presence of a verified do-not-resuscitate order were the outcome measures. Logistic regression was used to assess the effect of age, education, race, gender, cancer diagnosis, dementia diagnosis, palliative encounter, and death on the outcome variables.

Results. Our results suggest that when we control for prognosis, patients over age 70 years may experience gaps in ACP communication. We found that as patients age, the odds of having documentation of a conversation (odds ratio [OR] = 0.56; $P < 0.001$) or scanned advance directive decreased (OR = 0.63; $P < 0.001$), while the odds of having a verified do-not-resuscitate order increased (OR = 1.42; $P < 0.001$).

Conclusion. The results of this study may imply some degree of unilateral and physician-driven decision making for end-of-life care among older adults. Collaborative efforts between an interdisciplinary medical team should focus on developing policies to address this potential disparity between younger and older adults at the end of life. *J Pain Symptom Manage* 2019;57:731–737. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Advance care planning, end of life, electronic health records, hospice, advance directives, physician communication

Introduction

Advance care planning (ACP) refers to the research and communication parts of making decisions regarding a person's future care.¹ ACP ideally includes comprehensive communication with a patient, taking into account disease severity, prognosis, and patient preferences for medical care, to 1) define and document the patient's preferences for future care and 2) to identify and prepare proxy decision makers to express preferences on behalf of the patient in the

case of incapacitation. ACP can also include completion of documentation, such as written advance directives (ADs), physician orders for life-sustaining treatment,² and completion of code status orders, such as EHR-based or portable do-not-resuscitate (DNR) orders.

Having clear, easily accessible documentation of patients' end-of-life care goals is critical for patients who are facing the burden of a serious illness. Although there is variation across societies about appropriate

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timing for ACP conversations, numerous guidelines emphasize the urgency of ACP early and often, especially if the patient is expected to die within a year.^{3,4} This urgency extends to patients referred to hospice with an estimated life expectancy of six months or less, for which ACP conversations should universally occur as part of patient and family preparation for hospice care.⁵ Studies have shown that hospice patients with completed ACP are more likely to die in a preferred setting and have longer hospice enrollment.⁶ Ideally, ACP is delivered systematically to patients early in the course of chronic or progressive illness in anticipation of clinical deterioration and loss of decision-making capacity.⁷

When approaching the end of life, patients with ACP are found to have better acceptance of terminal conditions, acceptance of palliative care, and better quality of life.⁸ In addition, those with documented ACP receive end-of-life medical care that is more consistent with their wishes.^{8,9} Despite the importance of ACP, only one-fourth to one-third of all patients have ACP in the form of an AD and end-of-life conversation.^{10,11} Lack of ACP can lead to medical care that is not concordant with patients' wishes at the end of life, as well as increased distress for the patient and caregiver.^{12,13} There is consensus in existing literature that the geriatric population is more likely to have ACP.^{10,14–16}

Although older age is a predictor of having a completed AD and a verified DNR, existing research does not expound on age-related differences in the delivery of comprehensive ACP in the form of communication and documentation. Results from the landmark SUPPORT trial showed that DNR orders were written with greater frequency and more quickly for older patients, regardless of prognosis.¹⁷ There is a gap in existing research concerning the specific ACP practices that contribute to the greater frequency of DNR orders among older adults. Specifically, it is not clear if older adults are also more likely to have consultations with clinicians or a review of legal documents leading up to the invocation of the DNR. The higher burden of chronic disease, frailty, and decreased functional status among geriatric patients compared to nongeriatric patients has created challenges in conducting a comparative analysis of ACP practices that adjusts for comorbidity and expected life expectancy.¹⁸ This study describes a comparative analysis of ACP practices between geriatric and nongeriatric patients by focusing on those referred to hospice with a life expectancy of six months or less.

This study aims to compare the presence of retrievable ACP documentation in the EHR for patients over 70 and under 70 with a predicted survival of six months or less implied by hospice referral. We hypothesized that patients over 70 years would be more likely

to have ACP in the EHR, based on prior research showing a greater likelihood of ADs and DNR among the elderly. Results of this study will provide understanding about unique ACP experiences of older patients at the end of life to help inform tailored interventions, clinical guidelines, and best practices to address potential communication disparities.

Methods

This was a cross-sectional analysis of patient data in the EHR of a large Midwestern academic medical center. The data source was information maintained in the EHR of patients ($n = 3595$) treated between January 2013 and December 2015. Data for this study were deidentified and obtained through an Honest Broker Protocol. The study was submitted for IRB review and was determined to be exempt.

This study analyzed three dependent variables: an ACP note in the problem list, a scanned ACP document such as a living will or health care power-of-attorney form approved by the state in which the study took place, and a verified DNR order. These measures were chosen because they were incorporated into clinical workflows and determined to be institutional best practices for the delivery of ACP. Although physician orders for life-sustaining treatment forms are also commonly used in some states to operationalize end-of-life wishes, not all states and institutions (including this study site) have incorporated them into routine clinical care.² ACP note in the problem list is a dichotomous variable indicating if a note was present in each patient's medical record. These notes designate whether ACP was addressed (e.g., "advance directive discussed with patient") by a member of the patient care team. Scanned ACP document in the EHR is a dichotomous variable indicating if a scanned document, such as a state-approved living will or health care power-of-attorney form, was scanned into the patient's chart. Verified DNR order, the final dependent variable, is a measure of whether the code status was verified with the patient by the clinician and determined to be "do not resuscitate" during the most recent hospital admission, before death, or the end of the study period. DNR order is commonly used to operationalize the desire to forego life-sustaining treatment such as cardiopulmonary resuscitation and more broad measures of life-sustaining intervention.^{19,20} All these dependent variables are considered "retrievable" ACP meaning they can be accessed and retrieved from an individual patient's EHR.

Consistent with the literature on ACP predictors for general populations, we included the following variables in our analysis: age,^{10,14} education,¹⁰ race,²⁰ sex, palliative medicine encounter,²⁰ cancer diagnosis,^{21,22} dementia diagnosis,^{23,24} and death.¹⁰ Race

was included as a vector of dummy variables indicating “white,” “black,” or “other.” Palliative medicine encounter is a dichotomous variable indicating if the patient had a palliative encounter during the study period. Diagnosis measures the presence of a cancer diagnosis (coded 1) versus all other diagnoses (coded 0). Death is a dichotomous variable indicating if the individual died during the study period. We included age as a dichotomous predictor indicating 70 years old or greater (coded 1) versus 69 or younger (coded 0).

Patient zip code was ascertained from the medical record. We linked patient zip code to Zip Code Tabulation Area (ZCTA), which are areal representations of United State Postal Service Zip Codes.²⁵ ZCTA-level estimates of education were available in the American Community Survey five-year estimates that are conducted by the U.S. Census Bureau and available at American FactFinder.²⁶ Education was calculated to indicate a proportion of the ZCTA having some college education or greater. The proportion was then recoded into quartiles, resulting in a four-level ranking of education status.

Stata IC/Version 14.2 was used for the analysis.²⁷ Bivariate analyses of the three outcome variables were done on each of the independent variables. We used ACP note in the problem list, scanned AD, and verified DNR order as outcome variables for the multivariate logistic regression models. Multivariate logistic regression models were used to estimate adjusted odds ratios.

Results

The primary finding emerging from our study, discussed in more detail later, was that adults over 70 years nearing the end of life were significantly ($P < .001$) less likely to have ACP in the form of a note in the problem list or a scanned AD and significantly more likely to have ACP in the form of a verified DNR order ($P < 0.001$).

Patient characteristics are outlined in [Table 1](#). Mean age was 64.6 years; approximately 84.1% identified as white, with 13.0% identifying as black. The most common diagnosis was cancer (68.8%); a small percentage of patients (2.1%) had dementia. Approximately 40.9% of the patients had a palliative encounter and 66.5% of patients died during the study period.

The bivariate analysis for ACP note in the problem list, scanned document in the EHR, and verified DNR order is detailed in [Table 2](#). Bivariate analysis for note in the problem list indicated statistically significant ($P < 0.05$) relationships for age, race, palliative encounter, cancer diagnosis, and death. Younger patients under 70 years had a note in the problem list 9.0% of the time while older patients had one 4.1% of the time. Black patients had a note 4.9% of

Table 1
Patient Characteristics

Patients	3595 (100%)
Mean age	64.56
Average education ^a	54.34%
Race	
White	3022 (84.06%)
Black	466 (12.96%)
Other	107 (2.98%)
Hispanic	86 (2.39%)
Palliative encounter	1470 (40.89%)
Female	1757 (48.87%)
Cancer diagnosis	2474 (68.82%)
Dementia diagnosis	75 (2.09%)
Died during study period	2391 (66.51%)

^aPercent with some college or greater.

the time while white patients had a note 7.7% of the time. Those with a palliative encounter, who had a cancer diagnosis, and those who died were all significantly more likely to have a note in the problem list.

Bivariate analysis for scanned AD in the EHR indicated significant relationships for older age, palliative encounter, cancer diagnosis, and death. The key study variable, patient age, showed a similar relationship to having a document, as discussed previously, for having an ACP note. Other variables, including palliative encounter, cancer diagnosis, and death showed similar relationships to having a note in the problem list.

Bivariate analysis for verified DNR order indicated statistically significant relationships for age, education, race, palliative encounter, cancer, and death. Patients under 70 years had a verified DNR order 56.1% of the time while older adults had it 65.2% of the time. Verified DNR order tended to decrease for each increasing quartile of education: from 63.8% in the lowest quartile to 55.5% in the highest quartile. African Americans were less likely to have a DNR order than were whites. Those who had a palliative encounter, those who had a diagnosis other than cancer, and those who did not die during the study period were all more likely to have a verified DNR order.

Multivariate analysis models using logistic regression to estimate odds ratios for the outcome variables are outlined in [Table 3](#). Having an ACP note in the problem list was significantly associated with age, education, palliative encounter, cancer diagnosis, and death. Those aged 70 years or older were 44% less likely than those aged 69 years or younger to have a note in the problem list. Those in the highest quartile of education were 54% more likely to have an ACP note in the problem list than were those in the lowest quartile of education. Those with a palliative encounter were 56% more likely to have an ACP note in the problem list. Those with a cancer diagnosis were over 600% more likely to have a note in the problem list than were those with other diagnoses, and those who died during the study period were 53%

Table 2
Bivariate Analysis

	ACP Note in the Problem List		Scanned ACP Document in the EHR		Verified DNR Order	
	Yes, n (%)	No, n (%)	Yes, n (%)	No, n (%)	Yes, n (%)	No, n (%)
Patients	260 (7.2%)	3335 (92.8%)	960 (26.7%)	2635 (73.3%)	1954 (59.18%)	1348 (40.82%)
0–69 yrs	209 (9.0%)	2127 (91.0%)	710 (30.4%)	1626 (69.6%)	1228 (56.10%)	961 (43.90%)
70 yrs or older	51 (4.1%)	1208 (95.9%) ^a	250 (19.9%)	1009 (80.1%) ^a	726 (65.23%)	387 (34.77%) ^a
Education						
Quartile 1	51 (5.8%)	831 (94.2%)	228 (25.9%)	654 (74.1%)	517 (63.75%)	294 (36.25%)
Quartile 2	66 (7.2%)	847 (92.8%)	230 (25.2%)	683 (74.8%)	525 (61.62%)	327 (38.38%)
Quartile 3	63 (7.5%)	777 (92.5%)	221 (26.3%)	619 (73.7%)	428 (55.80%)	339 (44.20%)
Quartile 4	80 (8.3%)	880 (91.7%)	281 (29.3%)	679 (70.7%)	484 (55.50%)	388 (44.50%) ^a
Race						
White	233 (7.7%)	2789 (92.3%)	817 (27.0%)	2205 (73.0%)	1647 (59.50%)	1121 (40.5%)
Black	23 (4.9%)	443 (95.1%)	120 (25.8%)	346 (74.2%)	238 (54.46%)	199 (45.54%)
Other	4 (3.7%)	103 (96.3%) ^b	23 (21.5%)	84 (78.5%)	69 (71.13%)	28 (28.87%) ^b
Palliative encounter						
No	132 (6.2%)	1993 (93.8%)	519 (24.4%)	1606 (75.6%)	963 (52.25%)	880 (47.75%)
Yes	128 (8.7%)	1342 (91.3%) ^b	441 (30.0%)	1029 (70.0%) ^a	991 (67.92%)	468 (32.08%) ^a
Sex						
Male	132 (7.2%)	1706 (92.8%)	492 (26.8%)	1346 (73.2%)	999 (59.18%)	689 (40.82%)
Female	128 (7.3%)	1629 (92.7%)	468 (26.6%)	1289 (73.4%)	955 (59.17%)	659 (40.83%)
Cancer						
Cancer	246 (9.9%)	2228 (90.1%)	755 (30.5%)	1719 (69.5%)	1185 (52.50%)	1072 (47.50%)
Other diagnosis	14 (1.3%)	1107 (98.8%) ^a	205 (18.3%)	916 (81.7%) ^a	769 (73.59%)	276 (26.41%) ^a
Dementia						
Dementia	4 (5.3%)	71 (94.7%)	20 (26.7%)	55 (73.3%)	27 (49.10%)	28 (50.90%)
No dementia	256 (7.3%)	3264 (92.7%)	940 (26.7%)	2580 (73.3%)	1927 (59.35%)	1320 (40.65%)
Death						
Yes	206 (8.6%)	2185 (91.4%)	692 (28.9%)	1699 (71.1%)	1241 (56.10%)	971 (43.90%)
No	54 (4.5%)	1150 (95.5%) ^a	268 (22.3%)	936 (77.7%) ^a	713 (65.41%)	377 (34.59%) ^a

ACP = advance care planning; EHR = electronic health record; DNR = do-not-resuscitate.

^a*P* < 0.001 across categories.

^b*P* < 0.05 across categories.

more likely to have an ACP note in the problem list than those who did not die during the study period.

Having a state-approved ACP document scanned into the EHR was significantly associated with age, education (borderline significance), palliative encounter, cancer diagnosis, and death. Those aged 70 years or older were 37% less likely than those aged 69 years or younger to have a scanned document in the EHR. Those in the highest quartile of education were 22% more likely to have a scanned document in the EHR than were those in the lowest quartile of education. Those with a palliative encounter were 36% more likely to have a scanned document in the medical record. Those with a cancer diagnosis were 82% more likely to have a scanned document than were those with other diagnoses, and those who died during the study period were 24% more likely to have a scanned document in the medical record.

Having a verified DNR order in the medical record was significantly associated with age, education, race, palliative encounter, cancer diagnosis, dementia diagnosis, and death. Older individuals, 70 years or greater, were 42% more likely to have a verified DNR order. Those with the highest quartile of education were 27% less likely to have a verified DNR order than those in the lowest quartile. Those in quartile 3

were 23% less likely to have a verified DNR order than those in the lowest quartile. Those who had a palliative encounter over the course of the study period were 90% more likely to have a verified DNR order. Those with cancer were 56% less likely to have a verified DNR order and those with dementia were 54% less likely to have a verified DNR order. Finally, those that died over the course of the study period were 23% less likely to have a verified DNR order.

Discussion

In this study, we aimed to compare the presence of retrievable ACP in the EHR between patients over 70 and under 70 who were approaching the end of life. Prior studies have shown age as a significant positive predictor of ACP in the form of an AD and a verified DNR order.^{10,14–16} Existing literature does not explore age-related differences in multiple forms of EHR-retrievable ACP using a sample of patients who have been referred to hospice.

The results showed that older individuals who were referred to hospice were less likely to have ACP documented in the medical record in the form of a scanned document or note in the problem list. Older

Table 3
Multivariate Analysis

	Outcome: ACP Note in the Problem List		Outcome: Scanned Document		Outcome: DNR Order	
	OR (95% CI)	PValue	OR (95% CI)	PValue	OR (95% CI)	PValue
Age						
70+	0.56 (0.40, 0.77)	< 0.001	0.63 (0.53, 0.74)	< 0.001	1.42 (1.21, 1.67)	< 0.001
Education						
Quartile 1	1.00		1.00		1.00	
Quartile 2	1.25 (0.85, 1.84)	0.25	0.95 (0.77, 1.18)	0.67	0.93 (0.76, 1.14)	0.481
Quartile 3	1.43 (0.97, 2.12)	0.07	1.05 (0.84, 1.31)	0.65	0.77 (0.62, 0.95)	0.014
Quartile 4	1.54 (1.06, 2.23)	0.02	1.22 (0.99, 1.50)	0.07	0.73 (0.59, 0.89)	0.002
Race						
White	1.00		1.00		1.00	
Black	0.67 (0.43, 1.05)	0.08	1.00(0.79, 1.26)	0.98	0.78 (0.63, 0.96)	0.021
Other	0.51 (0.18, 1.42)	0.20	0.78 (0.48, 1.25)	0.30	1.61 (1.01, 2.55)	0.044
Palliative encounter						
Yes	1.56 (1.20, 2.03)	0.001	1.36 (1.16, 1.58)	< 0.001	1.90 (1.63, 2.20)	< 0.001
Sex						
Female	1.06 (0.82, 1.37)	0.66	1.02 (0.88, 1.19)	0.77	0.96 (0.83, 1.11)	0.582
Cancer diagnosis						
Cancer	7.70 (4.42, 13.40)	0.001	1.82 (1.51, 2.19)	< 0.001	0.44 (0.37, 0.53)	< 0.001
Dementia						
Dementia	2.09 (0.71, 6.17)	0.18	1.68 (0.98, 2.89)	0.06	0.46 (0.26, 0.81)	0.007
Death						
Yes	1.53 (1.12, 2.10)	0.008	1.24 (1.05, 1.47)	0.01	0.77 (0.66, 0.90)	0.001

ACP = advance care planning; DNR = do-not-resuscitate.

adults were more likely to have a verified DNR order in the EHR. This result is consistent with other studies who have found that DNR orders were written more quickly for older patients.^{16,17,28} Our study confirms that older adults are more likely to have a verified DNR order, while also building on prior research by demonstrating that these older adults are less likely to have intermediary or process-related elements of ACP.

Operationalized ACP in the absence of process-related ACP may suggest higher paternalistic tendencies in geriatric populations and decreased emphasis on patient autonomy and shared decision-making. Making decisions about resuscitation without having and documenting preliminary ACP conversations and considering ACP documents is troublesome because it indicates a gap in communication with older adults regarding their preferences for end-of-life care. This study builds on the work done by the SUPPORT investigators by exploring the verification of DNR order in the EHR as well as two additional measures of intermediary, EHR-documented ACP in a group of patients with a similar prognosis.¹⁷

DNR orders are limited in scope and have been criticized in practice because often physicians leave out discussions and fail to provide extensive information when writing orders for a DNR order in consultation with patients and family.²⁹ According to the AMA Council on Ethical and Judicial Affairs guidelines for appropriate use of DNR order, physicians should discuss the possibility of arrest with all patients and encourage them to express their wishes.³⁰ While a

DNR order should be in the medical record if elected, prior conversations, especially in the outpatient setting and early in the hospital stay, should also be documented. This is particularly important in the case of the patient who has multiple admissions, for whom, in the studied hospital system, code status could revert to “unverified” (indicating a default “full code status”) in the EHR upon discharge.

There are several potential reasons that older adults might face disparities in communication-based ACP. Older individuals may be more likely to face cognitive impairment, necessitating the assessment of decision-making capacity, related to ACP and the potential involvement of surrogates.^{31,32} Dementia was included in the model but other forms of cognitive impairment may be present. Dementia and other cognitive disturbances may be underdocumented and challenging to retrieve through EHR-based research, allowing the potential for missed cases in our study sample.³³ In addition, older individuals may need accommodations related to sensory impairments such as hearing aids, pocket talkers, and/or glasses.³¹ While more time may be required to care for older adults necessitating communication accommodation, physicians already spend less time on average with geriatric patients.³⁴ Although we controlled for severity of illness by including patients nearing the end of life, geriatric patients might present as more complex cases needing more clinical care and attention while allowing less time for critical ACP conversations. Prior research has demonstrated that physicians are more likely to misinterpret ACP for older individuals than they are

to misinterpret ACP for younger individuals.³⁵ These results might demonstrate a certain level of assumption and miscommunication between the provider and the older patient. Finally, older adults may not wish to have an end-of-life conversation or discussion regarding life expectancy, which presents a patient-level barrier to ACP.³⁶

There are several limitations to this study. The population selected for this study focused on patients who elected hospice, and while relevant for our research question, the results may not be generalizable to seriously ill patients who have not elected hospice. Not all providers document ACP in the problem list. Owing to the lack of professional guidelines on documentation of ACP in the medical record, some might be documenting in other areas that are more difficult and cumbersome for other providers to retrieve. More standards and evidence-based guidelines are necessary to create consensus around the best way to document ACP in the EHR. There is no reason to believe that providers would be documenting in less retrievable areas for older patients; therefore, this likely did not bias our results. Scanned documents such as ADs are also less likely to improve medical care than comprehensive ACP communication, building trust over time, and subsequent documentation of care preferences.^{37,38} We did not adjust for comorbidities, but hospice patients face similar disease burden and comorbidities due to a provider's judgment of a terminal condition with six months or less to live. Finally, because this study was conducted at one large academic medical center, the generalizability of the results may be limited. The prevalence of ACP in the EHR might be even less in community hospitals, which may have a less robust EHR program or less comprehensive palliative care programs. More research is needed on how ACP is documented in the EHR of community hospitals and how it may differ from academic and tertiary care centers. The high rates of ACP in cancer patients may reflect that the ACP documentation policy for the studied health system initially originated in the cancer hospital and was later disseminated to other hospitals within the system.

This work adds novel understanding of the frequency of retrievable ACP documentation in the EHR of terminally ill older patients. This study demonstrates that older individuals entering hospice were far less likely to have conversations documented in the problem list and to have ACP documents scanned into the medical record. Despite these deficiencies, older individuals are more likely to have operationalized ACP such as a verified DNR order documented in the EHR. Efforts to increase ACP documentation such as EHR-based patient portal solutions have proved promising,^{39,40} but future tools

will need to consider elderly adults in their use of technology to avoid further isolation. Collaborative efforts between an interdisciplinary medical team comprising palliative, geriatrics, primary care, and other involved subspecialties should focus on implementing processes informed by specialty-based gold standards. These processes should support accessible EHR-based solutions to address this health disparity in comprehensive ACP communication regarding end-of-life care preferences for the elderly.

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