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Community-Based Palliative Care and Advance Care Planning Documentation: Evidence from a Multispecialty Group

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Abstract

Background/Objectives—with the growing public demand for access to critical health data across care settings it is essential that Advance Care Planning (ACP) information be included in the Electronic Health Record (EHR) so that multiple clinicians can access them and understand patients' preferences for end-of-life care. Community-based palliative care programs often incorporate ACP services. This study examines whether a community-based palliative care program is associated with digitally extractable ACP documentations in the EHR.

Design—an observational study using propensity score weighted Generalized Estimation Equations to examine patterns of digitally extractable ACP documentation.

Setting—the Palo Alto Medical Foundation (PAMF), a multispecialty ambulatory healthcare system in Northern California.

Participants—EHR records of 3,444 patients 65, with serious illnesses, between January 1, 2013 and December 31, 2014.

Intervention—community-based palliative care program in PAMF.

Measurements—digitally extractable ACP in EHR.

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Author Contributions: Dr. Tai-Seale had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Study Design: Dr. Tai-Seale, Dr. Dillon, Dr. Ritchie, Dr. Yang, Dr. Tapper, Dr. Lai, and Dr. Yu. Analysis and interpretation: Dr. Yang, Dr. Allore, Dr. Tai-Seale, Dr. Dillon, Dr. Ritchie, Dr. Tapper, Dr. Lai, and Dr. Yu. Manuscript preparation: Dr. Tai-Seale, Dr. Dillon, Dr. Ritchie, Dr. Tapper, Dr. Yu, and Dr. Yang. All of the authors read and approved the manuscript for publication.

Results—We found that only 14% (483 of 3,444) of patients with serious illnesses had digitally extractable ACP in electronic health records. Of the 6% of patients receiving palliative care, 65% had ACP versus 11% of patients without palliative care. Study results showed a strong positive association between palliative care and ACP.

Conclusion—Only a small percentage of patients with serious illnesses had ACP documentations in the EHR. Palliative care delivered by board-certified palliative care specialists was used infrequently by patients with serious illnesses. Palliative care service use was associated with higher rates of ACP, after controlling for organizational and patient characteristics using propensity score weighting method. Scalable interventions targeted at non-palliative care clinicians for universal access to ACP are needed.

Keywords

palliative care; advance care planning; electronic health records

INTRODUCTION

Professional and public support for advance care planning (ACP) has risen as the specialty of palliative care experiences exponential growth and plays an increasingly important role in community-based healthcare practices.¹ Aimed at alleviating pain and suffering, ACP involves enhancing patients understanding of treatment options, and encouraging patients to communicate and document their preferences for end of life care. ACP is a central function of palliative care.

A common aspect of ACP includes the completion of forms such as advance directives, living wills and powers of attorney for healthcare, collectively known as Advance Health Care Directives (AHCD), and Physician Orders for Life-Sustaining Treatment (POLST). AHCD are legal documents that need to be signed by two qualified adult witnesses in California. POLST is used to translate patient preferences into specific medical orders to be honored by all healthcare professionals. It is recommended for patients with a life expectancy of 1–2 years.² POLST forms must be signed by the patient or surrogate (in most states) and the physician making the order. It was hoped that the electronic health record (EHR) would facilitate the documentation and retrieval of patients' wishes captured in AHCD and POLST forms. Previous research has demonstrated, however, that ACP documentation was infrequent and inconsistent in the EHR of a large healthcare delivery organization.³ With the growing public demand for access of critical health data across care settings, such as the investment in building Health Information Exchanges⁴ it is essential that important ACP information be included in the EHR so that multiple clinicians, even from different healthcare organizations, can retrieve them, understand what is most important to patients and clarify their preferences for end-of-life care. This can be particularly important for patients with serious illnesses and multiple chronic conditions (MCC) because they face a number of challenging and preference-sensitive decisions, e.g., whether or not to have cardiopulmonary resuscitation (CPR), artificial feeding, and who will speak for them if they are unable or unwilling to speak for themselves. Furthermore, clinicians have been encouraged to discuss with patients or their surrogates about life values, goals, and treatment preferences, and use this knowledge, gained in periodic revisiting of

perceptions over time, as a guide for matching subsequent care decisions with the patient's wishes.¹ Yet, such discussions may be wasted if clinicians cannot readily access those preferences when necessary,^{4,5} regardless of how sophisticated Health Information Exchanges are.

Community-based palliative care aims to meet the needs of community-dwelling patients living with serious chronic illnesses, allow time for deeper patient and family understanding of illness and care goals, and offer new opportunities to avoid health related crises and provide continuing patient- and family-centered support.⁶ Referrals by another physician is usually required, however, before a patient can receive palliative care services. Physician factors, such as length of practice, knowledge and personal experience with palliative care are significantly associated with palliative care referral decisions.^{7,8} Furthermore, some physicians conflate hospice and palliative care, and have difficulties identifying the appropriate time to refer patients with an unpredictable prognosis trajectory.⁹

We examine the association between use of community-based palliative care services and changes in ACP documentation in the EHR by analyzing ACP documentation patterns over a two-year period as a healthcare system implemented a community-based palliative care program.

METHODS

Setting

The Palo Alto Medical Foundation (PAMF) is a large, multispecialty healthcare system with approximately 1,400 physicians serving about one million patients in Northern California. Established in February 2011, PAMF's Palliative Care Program uses an interdisciplinary approach to serve patients with serious illnesses by providing direct patient care, consultation, and in-service training of other clinicians. In October 2011, the Palliative Care Program implemented a system-wide change in workflow by standardizing the location in the EpicCare EHR for a designated "Advance Directive/Code Status" button. Located in the default screen, when selected this button displays all of the scanned ACP documents. The Palliative Care Program was implemented in June 2012 in the Palo Alto Division, January 2013 in the Camino Division, and October 2014 in the Alameda Division.

In addition to the Palliative Care Program, PAMF has a universal "health maintenance reminder" to have an "Advance Directive discussion," which is triggered in the EHR for all patients when they turn 65. The reminder will keep on "firing" until it has been satisfied by a clinician. Furthermore, the advance directive is a part of the Health Questionnaire in the Welcome to Medicare and Medicare Annual Wellness Visit EpicCare EHR SmartSet, which is a standardized ordering and documentation tool requiring the clinician to document the existence of an advance directive. Beginning in 2013, information on the date when individual ACP documentation was made became available in the EHR, after a change in PAMF's EHR workflow took place at the end of 2012. The identity of the clinician who documented ACP had also been recorded in the EHR since then. Beyond these system-wide workflows, it is up to individual clinicians regarding when and how to have ACP discussions with patients and where to document ACP decisions in the EHR. While some clinicians

notes ACP in the problem list in the EHR, which makes them digitally extractable, others describe them in free text in the encounter notes.¹⁰

We examined changes in ACP documentation practices in 2013–2014. We then investigated the association between the use of palliative care services and ACP documentation practices for older patients with serious illness and multiple chronic conditions (MCC). We hypothesized that the rate of digitally extractable ACP documentation would be associated with receiving palliative care services. We applied propensity score weighting¹¹ to address the potential selection bias of palliative care service use.

Data Source

We considered a patient's ACP documentation to be "digitally extractable" if it was found in the problem list of EpicCare EHR, because it is the first place in the EHR where clinicians look for ACP decisions.

Participants

The inclusion criteria for patients were: (1) active patients in 2013–2014, i.e., having had at least one in-person encounter with a PAMF clinician in 2013–2014; (2) age 65 years or older; (3) at least one condition from the list of serious illness diagnosis codes used by the National Committee for Quality Assurance (NCQA)¹² in their problem list; (4) not having any ACP before 2013; and (5) no record of using palliative care before 2013. Criteria (4) and (5) enabled us to construct a "clean window" to examine the association between receiving palliative care services and ACP documentation in the problem list in an observational study.¹³ The study cohort included 3,444 unique patients meeting these inclusion criteria. We constructed a panel data set with patient-month as the unit of analysis.

Measurement

Outcome variables included (1) an indicator for having AHCD, and (2) an indicator for having POLST documented in the problem list area of EHR. The main explanatory variable was an indicator for receiving palliative care. Covariates included patient's characteristics (age, sex, race/ethnicity, an indicator variable for MCC based on Charlson Comorbidity Index score,¹⁴ type of serious illness, number of distinct clinicians encountered); characteristics of the patient's most frequently encountered clinician in a particular month, and that clinician's sex, specialty, and geographic division in which he/she practiced. Secular trend was accounted for by the number of months since Jan 1, 2013, the beginning of the observation period.

We used Generalized Estimation Equations (GEE) to examine the association between having ACP documentation, receiving palliative care, and explanatory variables mentioned above. Because patients were not randomly assigned to receiving palliative care services (treatment) or not (comparison), we controlled for differences between those two groups of patients using propensity score weights.¹² A propensity score model was estimated using logistic regression, with covariates evaluated at the beginning of 2013, including patients' and clinicians' characteristics and interaction terms of some covariates. Mean comparison test results show that the two groups of patients were not statistically significantly different

from each other in these covariates after applying the propensity score weights (detailed results are available upon request). For sensitivity analyses, we employed one-to-one nearest neighbor propensity score matching with replacement. The results were similar. This research was approved by the institutional review board.

RESULTS

ACP and Use Of Palliative Care Services

Table 1 displays the ACP documentation rates among patients with serious illnesses categorized into patients with palliative care and without palliative care groups in the two-year period. Of the six percent of seriously ill patients (N=199) who had received palliative care services, 3.5 percent of them had AHCD only, 30.2 percent had POLST only, 31.2 percent had both AHCD and POLST, and 35.2 percent had neither during the two-year observation period. The rates of ACP among those who did not use any palliative care (N=3,245) were much lower, despite having serious illnesses, 89.1 percent of them had neither AHCD nor POLST.

The Figure shows the trends of ACP documentation rates over time from January 2013 to December 2014, comparing patients with versus without palliative care. While the rates of POLST hover below two percent among those without palliative care, the rates nearly doubled from 37.5 percent in Jan 2013 to 72.0 percent in December 2014 among those with palliative care services.

Association between Palliative Care Services and ACP Documentation

Receipt of community-based palliative care was strongly and significantly associated with increased odds of having accessible AHCD (OR=14.17, 95%CI=5.07, 39.58) and POLST (OR=175.79, 95%CI=24.86, 1243.21) (Table 2). Furthermore, patients served by clinicians in the Santa Cruz division, historically the first division to implement palliative care, were far more likely to have an accessible POLST (OR=4.98, 95%CI=1.43, 17.39) than patients in the Camino division.

DISCUSSION

Digitally extractable documentation of ACP is a necessary step in ensuring health care providers are able to view and act upon a patient's identified preferences. We used the problem list in EHR as a surrogate measure of presence of ACP discussions and found the majority of patients with serious illnesses without digitally extractable ACP. Rates of ACP documentation in our sample are similar to those found by others.¹⁵ Systematic reviews indicate that ACP and early discussions about goals of care enhance quality of life, decrease non-beneficial care, improve family outcomes, and may reduce costs.¹⁵ While palliative care is still predominately provided in hospice and hospital settings in the U.S.,^{16–18} outpatient palliative care is experiencing growth.¹⁹ PAMF's community-based interdisciplinary palliative care program has significantly improved ACP practices for patients at PAMF. Its reach, however, is still limited as only six percent of seriously ill patients received palliative care between 2013 and 2014, among those who had not received palliative care before 2013. Interestingly, patients with cancer were far more likely to receive palliative care, and in turn

were more likely to have ACP. About 90 percent of PAMF's seriously ill patients did not have cancer (Table 1). Of these patients without cancer the majority had neither received palliative care, nor had digitally extractable ACP in their EHR, even though they had life-limiting serious illnesses such as severe heart failure or oxygen dependent chronic obstructive pulmonary diseases.

There are some caveats to keep in mind when interpreting our results. First, it was an observational study of ACP documentation in a digitally extractable location in the EpicCare EHR, without randomization of patients to palliative care or not. While propensity score weighting allowed us to mimic randomization based on observable factors, it could not rule out potential effects of unobservable confounders. Therefore, the findings show association rather than causal relationship. Second, our measure ACP documentation relied on EHR problem list entry. It did not include ACP documented in other locations in the EHR.⁷ For patients without ACP documentation in the problem list it is unknown whether they had not had ACP conversations, or if they had had them without subsequent documentation in the problem list. While relying on problem lists could potentially underestimate the true rates of ACP conversation and its documentation in the EHR,^{3,20} it did provide a surrogate measure for whether ACP documentations were accessible or digitally extractable, which is an essential prerequisite for ensuring that patients' wishes can be honored. We also acknowledge that the problem list may not provide the most accurate information about ACP documentation. For example, some ACP in the problem list may not be accompanied by signed, legally acceptable ACP documentation. However, the PAMF Palliative Care Team examines the accuracy of the ACP documentation in the problem list at intake of new patients. They found that only a small percent (5–10%) of the ACP in problem list was not accompanied by signed and scanned ACP documents. Since only records of patients referred to palliative care are being reviewed this way, this low error rate may not be applicable to other patients, however.

Implications for Policy or Practice

While there may be increasing documentation of ACP in the EHR over time, we must be mindful about the quality of these ACP conversations. Completion rates of POLST and AHCD by themselves do not mean success, if they do not stem from ongoing in-depth dialogue about patients' fears, hopes, and goals and result in treatment aligned with patients' wishes.²¹ Ultimately, the hope would be that earlier ACP conversations would lead to enhanced goal-concordant care.

Palliative care is a high value but limited resource.²² Ideally palliative care should be integrated into medical care for seriously ill patients. There is a shortage of palliative care clinicians both locally and nationally, however. There are eight palliative care physicians out of over 1,400 physicians at PAMF. Between 2013 and 2014, only six percent of PAMF's seriously ill patients were seen by PAMF's palliative care program. Substantial barriers to access to community-based palliative care means that palliative care delivered by board-certified palliative care specialists will only be available for a minority of patients. We need to meet the needs of the majority of patients who will never be seen by those specialists. Similar to collaborative care for patients with depression to address the shortage of

psychiatrists,²³ team-based care for patients with serious illness could include palliative care specialists as consultants and trainers, who would provide specialized support in challenging situations, and as suggested by the Institute of Medicine, train other clinicians to provide “primary palliative care.”²⁴

In conclusion, digitally extractable ACP could increase the likelihood that patients’ wishes are accessible to clinicians within a health system, and across shared, interoperable EHRs to enable clinicians outside of individual delivery systems to access them.. We found that palliative care service use was associated with higher rates of ACP, after controlling for organizational and patient characteristics using propensity score weighting method. Scalable interventions targeted at non-palliative care clinicians for universal access to ACP are needed to ensure that patients’ wishes can be honored wherever and whenever they cannot speak for themselves.

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Figure 1.
ACP Documentation Rate Among Patients with Serious Illnesses With and Without Palliative Care Over Time

Table 1

ACP Documentation Rates Among Seriously Ill Patients With and Without Palliative Care in 2013 to 2014

		Palliative Care		
	Total	Yes	No	p-value
Number of patients	3,444	199	3,245	< 0.01
AHCD (%)	9.0	3.5	9.3	<0.01
POLST (%)	2.6	30.2	1	<0.01
Both (%)	2.4	31.2	0.6	
Neither (%)	86.0	35.2	89.1	
Male (%)	43.8	43.2	43.8	0.87
White (%)	63.4	69.3	63.0	0.07
Age (in years)	80.5	83.5	80.3	< 0.01
Cancer	10.4	16.6	10.0	< 0.01
Heart Failure	36.1	36.2	36.1	0.99
Dementia	26.3	32.7	25.9	0.04
Parkinson's	14.2	14.1	14.2	0.97
Stroke	13.5	5.5	14.0	<0.01
Other	6.9	5.5	7.0	0.43
MCC ^a (%)	59.1	67.8	58.5	< 0.01
N of Distinct Physicians Encountered	7.4	9.7	7.2	< 0.01
Male provider (%)	56.6	51.8	56.9	0.157
Internal Medicine	41.6	37.2	41.8	<0.01
Family Medicine	20.3	29.6	19.7	
Cardiology	7.0	3.5	7.2	
Pulmonology	0.6	0.5	0.6	
Oncology	3.7	12.1	3.2	
Geriatric/Palliative Care	4.3	4.0	4.3	
Other	22.5	13.1	23.1	
Santa Cruz	18.0	27.6	17.4	<0.01
Palo Alto	27.0	33.7	26.6	
Camino	44.4	37.7	44.8	
Alameda	10.6	1.0	11.2	

Note:

^s: based on t-test for continuous variable, and chi-square test for categorical variables.^a: Multiple chronic conditions, Based on Charlson Comorbidity Index score>1.

Table 2
Patient, Clinician, and Division Factors Associated With Having Accessible AHCD/POLST

	AHCD			POLST		
	OR	S.E.	95%CI	OR	S.E.	95%CI
Used palliative care	14.17	7.43	5.07 39.58	175.79	175.45	24.86 1243.21
Male	1.64	0.69	0.72 3.73	0.88	0.46	0.32 2.44
White	1.09	0.58	0.38 3.12	0.58	0.37	0.17 2.05
Age (in years)	1.05	0.03	1.00 1.11	1.08	0.04	1.00 1.16
Cancer	1.02	0.61	0.31 3.31	1.53	1.45	0.24 9.82
Heart Failure	0.96	0.49	0.35 2.59	1.10	0.72	0.30 3.99
Dementia	0.78	0.45	0.25 2.44	0.98	0.69	0.24 3.91
Stroke	0.12	0.13	0.02 0.97	0.25	0.35	0.02 3.67
Parkinson's	0.43	0.25	0.13 1.37	0.78	0.59	0.18 3.44
Other	0.26	0.25	0.04 1.75	0.61	0.67	0.07 5.26
MCC ^a	1.35	0.58	0.58 3.13	0.64	0.37	0.20 2.01
# of Physicians Encountered	0.97	0.05	0.87 1.08	0.93	0.08	0.79 1.10
Male provider	1.05	0.20	0.71 1.53	0.93	0.31	0.49 1.77
Family Medicine	0.77	0.21	0.45 1.31	0.60	0.31	0.22 1.67
Cardiology	0.71	0.17	0.44 1.14	0.79	0.42	0.28 2.24
Pulmonology	0.94	0.51	0.32 2.71	1.52	1.37	0.26 8.86
Oncology	1.12	0.52	0.45 2.80	0.38	0.32	0.07 2.00
Geriatrics/Palliative Care	0.99	0.35	0.50 1.96	1.12	0.49	0.47 2.65
Other	0.85	0.17	0.57 1.27	0.96	0.37	0.45 2.06
Santa Cruz	1.97	0.89	0.81 4.78	4.98	3.18	1.43 17.39
Palo Alto	1.39	0.57	0.63 3.09	1.31	0.63	0.51 3.36
Alameda	2.60	1.49	0.85 8.01	1.19	2.31	0.03 53.46
# Months Since Jan 1, 2013	1.13	0.02	1.09 1.17	1.10	0.03	1.04 1.16
N	45741			45741		

Note: Bold font highlights statistically significant odds ratios. Control groups: Internal medicine, Camino division.

p : Multiple chronic conditions.

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