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Documentation and Discussion of Preferences for Care Among Patients With Advanced Cancer

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Abstract

Purpose: We sought to describe the documentation, frequency, and timing of discussions about patient preferences for care and to examine patterns of palliative care and hospice use among patients with advanced cancer.

Methods: We prospectively abstracted the medical records of 118 patients receiving care at a Veterans Administration (VA) facility from diagnosis of stage IV disease to 12 months postdiagnosis or death. We used univariate statistics to describe the type and frequency of documentation of patient preferences and palliative care/hospice referral. We calculated the time from diagnosis to the first documentation of preferences and the time from first documentation to death. We compared documentation of patient preferences between decedents and nondecedents using χ^2 tests.

Results: The majority of patients (81%) had some documentation of their care preferences recorded, although decedents were significantly more likely to have had their preferences documented than nondecedents (96% v 60%; $P < .000$). Most (53%) patients did not have a formal advance directive documented in the medical record. The mean time from diagnosis to the first documentation of preferences was approximately 2 months. More than half of all patients (53%) and almost three-quarters of decedents (73%) had a palliative care consultation.

Conclusion: Despite high rates of preference documentation, there remains room for improvement. Providers may need to be helped to identify patients earlier in their trajectory for appropriate palliative care services, and future work should focus on developing useful alternatives to advance directives for adequately documenting patient preferences.

Introduction

High-quality, patient-centered cancer care requires effective communication and coordination regarding preferences and goals of care, across settings and between patient, family members, and the multidisciplinary care team. A critical tool to achieving this is adequate documentation of patient preferences within the medical record, which helps to ensure that patient wishes are communicated and acted on across care settings and providers, and has been shown to increase patient autonomy in decision making and to decrease resource use.¹ Unfortunately, evidence suggests that documentation of preferences among patients with cancer is suboptimal,²⁻⁴ and as a result, providers are often unaware of their patients' preferences regarding treatment.⁵⁻⁸

In addition to adequate documentation of preferences, a growing body of literature has highlighted the relevance of having early and regular discussions about patient preferences to improving the quality of cancer care.^{9,10} Earlier discussions are associated with more preference-concordant care at the end of

life¹¹ and may lead to longer integration of hospice care^{12,13} and fewer aggressive interventions near death.¹² Early discussions about patient preferences may also lead to earlier palliative care use,¹¹ which has been shown to result in significant improvements in quality of life and mood among patients with metastatic cancer, as well as less aggressive care at the end of life compared with standard oncologic care.¹⁴ Such findings have led multiple consensus organizations to formally encourage early and regular communication regarding preferences and goals of care for patients with advanced cancer.^{15,16} To date, little is known about when or how often patients with advanced cancer have these discussions with their providers.

The purpose of the current study was to describe the documentation, frequency, and timing of discussions about patient preferences and goals of care, and to examine patterns of palliative care and hospice use in a prospective, longitudinal cohort of patients with advanced cancer at a large Veterans Administration (VA) medical center.

Methods

Study Sample

The Cancer Quality-ASSIST (Assessing Symptoms Side Effects and Indicators of Supportive Treatment) study included patients diagnosed in 2006 with stage IV breast, colorectal, esophagus/stomach, genitourinary, head and neck (H&N), liver/biliary, lung, pancreas, or prostate cancer, identified from the VA Greater Los Angeles Health Care System (VA GLAHS) cancer registry (N = 146). Additional inclusion criteria included being alive 30 days postdiagnosis and having at least one postdiagnosis outpatient visit at the VA GLAHS, resulting in a final study sample of 118 patients. The study population included both decedents (n = 71)—all patients who died during the study period (January 2006 through June 2008)—and nondecedents (n = 47).

Data Collection

Patient data were abstracted from the VA electronic medical record (EMR) from diagnosis of stage IV cancer to 12 months postdiagnosis or death, whichever came first. The VA EMR is used exclusively to document all patient care provided within the VA system and includes both inpatient and outpatient notes. Referral to hospice, date of death, and place of death are also recorded within the EMR. We developed a clinically detailed medical record abstraction tool in Microsoft Access as well as abstraction guidelines to collect data elements in the domain of information and care planning. After a week-long training, three experienced nurse abstractors used the tool to abstract data from patients' records between June and September 2008. To ensure reliability of abstraction, they abstracted the charts of 5% of the study sample for the primary variables of interest: documentation of an advance directive, a surrogate decision maker, a clinician note describing patient preferences, and a palliative care referral. Percent agreement across all three nurse abstractors ranged from 75% to 92%.

Main Measures

We collected detailed information on the following recorded documentation:

1. Advance directive (AD): any formal documentation of patient preferences or surrogate identification, such as the VA advance directive form or a living will.
2. Surrogate decision maker: any patient-identified surrogate decision maker, including that found in an existing AD or a designated power of attorney for health care.
3. Clinician note describing patient preferences, other than that found in an AD.
4. Do-not-resuscitate (DNR) preference: formal DNR order or a clinician note documenting patient preference for DNR.
5. Palliative care consults: formal multidisciplinary team consultation providing specialized support with care planning, symptom management, and/or psychosocial issues.
6. Hospice referrals, including inpatient and home hospice.

Table 1. Patient Characteristics

Characteristic	Full Cohort (N = 118)		Decedents (n = 71)		Nondecedents (n = 47)	
	No.	%	No.	%	No.	%
Age, years						
Mean		65.9		66.6		65.1
SD		9.9		10.2		10.2
Female	2	2	1	1	1	2
Race/ethnicity						
White	73	62	47	66	26	56
Nonwhite	45	40	24	33	21	44
African American	36	31	20	28	16	34
Hispanic	3	3	1	1	2	4
Asian	3	3	2	3	1	2
Other	3	3	1	1	2	4
Cancer type*						
Head and neck	27	23	11	15	16	34
Lung	27	23	23	33	4	9
Prostate	20	17	4	6	16	34
Colorectal	15	13	9	13	6	13
Esophagus/stomach	10	8	8	11	2	4
Genitourinary	8	7	6	8	2	4
Pancreas	6	5	5	7	1	2
Liver/biliary	4	3	4	6	0	0
Breast	1	1	1	1	0	0
Brain metastases	17	14	14	20	3	6

* In order of most to least prevalent in the full cohort.

7. Place of death, including hospital, hospice, home or nursing home, both within and outside the VA.

Data Analysis

We used univariate statistics to describe the distribution of patient characteristics, type/frequency of documentation of patient preferences, and palliative care/hospice referral among the full study cohort. We calculated the time from diagnosis of stage IV cancer to the first documentation of preferences to death. *t* test was used to compare median differences in timing of documentation, and χ^2 test or Fisher's exact test (where appropriate) were used to compare documentation of patient preferences for care between decedents and nondecedents. The institutional review board at the VA GLAHS approved the study.

Results

Patient Characteristics

Patients were primarily male (98%) and white (62%), and the mean age was 66 years (Table 1). The three most common tumor types were H&N (23%), lung (23%), and prostate (17%). Among decedents, lung cancer was the most prevalent (33%), whereas nondecedents had a higher prevalence of H&N and prostate cancer (34%). Sixty percent of our study population (n = 71) died within the 1-year study period.

Table 2. Documentation of Patient Preferences for End-of-Life Care

Documentation	Full Cohort (N = 118)		Decedents (n = 71)		Nondecedents (n = 47)		P
	No.	%	No.	%	No.	%	
Preferences for care							<.001
None	22	19	3	4	19	40	
Any	96	81	68	96	28	60	
Advance directive documentation							.273
None	63	53	35	49	28	59	
Any	55	47	36	51	19	41	
1	46	39	5	7	4	9	
> 2	9	8	3	4	19	40	
Note describing patient preferences							<.001
None	51	43	16	23	35	74	
Any	67	57	55	77	12	26	
1	27	23	20	28	7	15	
> 2	40	34	35	49	5	11	
Time from diagnosis to first documentation of preferences, days							.0547
Median	33.5		32		63		
Interquartile range	72		68		143		
Time from first documentation of preferences to death, days							
Median	NA		8.5		NA		
Interquartile range			155				
Other documentation							.0547
Durable power of attorney for health care or surrogate decision maker	69	58	43	61	26	55	
Discussion regarding prognosis	58	49	51	72	7	15	<.001
Do-not-resuscitate order	51	43	45	63	6	13	<.001

Abbreviation: NA, not applicable.

Documentation of Patient Preferences

The majority of patients (81%) in our study had some documentation of their preferences for care recorded (either an AD or a clinician note describing patient preferences) (Table 2), although decedents were significantly more likely to have had their preferences for care documented than nondecedents (96% *v* 60%; *P* < .001).

More than half of all patients (53%) did not have an AD documented in the medical record; however, 57% of patients did have documentation of a clinician note describing their preferences. Decedents were significantly more likely than nondecedents (77% *v* 26%; *P* < .001) to have had a clinician note describing their preferences documented in the record. More than a third of all patients had their preferences documented in more than one note, and almost half of decedent patients had preferences documented on at least two different occasions. The median time from diagnosis to the first documentation of preferences was approximately 33 days (interquartile range [IQR], 72 days). The median time from the first documentation of preferences for care to death was almost 3 months (IQR, 5.2 months).

A majority of patients (58%) had a surrogate decision maker documented, almost half (49%) had documentation of a prognosis discussion, and 43% had documentation of a DNR order. Decedents were significantly more likely than

nondecedents to have had a prognosis discussion documented (72% *v* 15%; *P* < .001) and documentation of a DNR order (63% *v* 13%; *P* < .001).

Palliative Care and Hospice Use

More than half of all patients (53%) and almost three-quarters of decedents (73%) had a palliative care consult (Table 3). Most consults were inpatient (37%) rather than outpatient (8%); however, a small subset of patients (8%) received both an inpatient and outpatient consult. More than half of patients who died were referred to hospice (54%), and very few referred patients refused (3%). Of the 41 decedents for whom we had a recorded date of hospice referral, the median length of stay in hospice was 32 days (IQR, 46 days). More than two thirds of patients who died in the hospital (73%), and almost all patients who died in hospice (88%) received a palliative care consult (Appendix Figure 1, online only). The median time between receiving a palliative care consult and death in the hospital was 32 days (IQR, 52.5 days), and median time between the palliative care consult and death in hospice was 61 days (IQR, 62 days).

Discussion

In contrast to prior work among older adults at increased risk for death or functional decline, which demonstrated that pa-

Table 3. Patterns of Palliative Care and Hospice Use

Type of Use	Full Cohort (n = 118)		Decedents (n = 71)	
	No.	%	No.	%
Palliative care				
No consults	56	47	19	27
Total consults	62	53	52	73
Inpatient only	42	37	36	51
Outpatient only	10	8	6	8
Inpatient and outpatient consult	10	8	10	14
Hospice				
Not referred	56	63	62	46
Referred	44	37	38	54
Referred but refused	2	2	2	3
Reason for no referral documented	2	2	1	1
Length of stay, days				
Median	N/A		32	
Interquartile range			46	

Abbreviation: NA, not applicable.

tient preferences for care are often not available within the medical record,¹⁷ we found that most patients with stage IV cancer had had their preferences for care documented, although documentation appeared more often in clinician notes than in a formal AD. Many patients had more than one note describing their preferences documented in the medical record, with the first documentation of preferences appearing on average 2 months after diagnosis of advanced cancer and within 5 months of death. Not surprisingly, decedents were more likely than nondecedents to have had their care preferences documented, over multiple notes in the medical record. Decedents were also more likely than nondecedents to have had a discussion regarding prognosis and to have a DNR order.

Although the majority of patients in our study did not have a formal AD, our documentation rate of 47% is considerably higher than previously reported rates of 20%¹⁸ and 27%⁴ among patients with cancer. There are some possible reasons for the higher rates of AD completion in our study population. First, evidence suggests that severity of illness might be positively associated with completion of ADs,^{4,19,20} and we focused specifically on patients with advanced cancer, who might be more likely to have ADs than patients with earlier stages of cancer. Second, recent organizational initiatives within the VA to increase advance care planning²¹ are likely to have resulted in the higher rates of AD documentation that we found, thus underscoring the relevance of a supportive organizational milieu to facilitating advance care planning processes. Finally, the high rate of documentation of both ADs and clinician notes regarding patient preferences may be due to the universal use of an EMR within the VA healthcare system to document and track all aspects of patient care. Prior work has highlighted the role of an EMR in supporting efficient and standardized documentation of care.^{22,23}

Despite the higher rates of AD completion among our study population than have been previously reported, the finding that more patients had a note describing their preferences than had a formal AD suggests that the limitations of formal documents for adequately capturing patient preferences for care described earlier^{8,24-31} persist. Clinicians may be more likely to document a note in the medical record that allows them greater flexibility in their description of patient preferences. The Physician Orders for Life Sustaining Treatment form may help address this need by ensuring that treatment preferences are robustly characterized and more easily translated into actionable physician orders.³² Future research should explore alternative ways of recording preferences that can be transferred across settings and robustly capture the range of choices available to patients in their end-of-life care.

The VA has established a strong palliative care presence and maintains an open access policy to hospice that is not contingent on relinquishing disease-modifying treatment. Our study population had considerable access to palliative care consultation; more than half of all patients and almost three-quarters of decedents had a palliative care consult, which is unusual in comparison to the availability of palliative consultation outside the VA.³³⁻³⁵ However, much of this was inpatient consultation, indicating the potential for improvement even within the VA for expanding access to palliative care for terminally ill patients. Outpatient palliative care, particularly when provided in collaboration with oncologic care, has been shown to have benefits such as improved quality of life.^{36,37} More than half (54%) of all decedents in our sample were referred to hospice, which is higher than the 48% referral rate previously reported in a sample of Medicare beneficiaries with cancer.³⁸ Our data also demonstrate that very few patients refused hospice care. Physicians often cite patient reluctance to consider hospice as a major barrier to hospice referral³⁹⁻⁴²; however, our data suggest this may not need to be a concern.

Most patients who died in hospice had a palliative care consult, suggesting that palliative care may serve as a conduit for hospice care. Indeed, a recent observational cohort study of patients with cancer who received palliative care consults found that comprehensive consults (involving a plan of care discussion as well as symptom management) were associated with an increased likelihood of hospice referral.⁴³ Ensuring access to palliative care, particularly when a patient has not yet met the eligibility requirements for hospice, may help to increase hospice use in this population.

Data for our study were collected at a single, large VA medical center with a predominantly male population, limiting its applicability to other settings. In addition, the well-established and strong palliative care presence at the study site may have resulted in higher rates of discussion and documentation of preferences than would likely be found outside the VA. Similarly, the ability within the VA to enroll in hospice while still receiving treatment with curative intent may have resulted in higher rates of hospice referral than would be found outside the VA, where hospice use is contingent on discontinuing curative care. However, this would only strengthen our conclusion that,

particularly in non-VA settings, there remains considerable room for improvement in documentation and discussion of preferences and goals of care, as well as hospice use, among patients with stage IV cancer. We were unable to assess mortality risk or morbidity (eg, functional status, symptom burden) at the time of diagnosis of stage IV disease, and it is possible that observed differences in the timing and prevalence of documented patient preferences may be due to differences in patients' expected risk of mortality and overall morbidity. However, we believe that patients with stage IV cancer, regardless of type, are appropriate candidates for discussion and documentation of their care preferences. Finally, although we examined documentation to understand the frequency and timing of goals of care discussions, documentation may not reflect what truly occurred. Similarly, the absence of documentation does not indicate that these discussions did not occur; however, documentation in and of itself is critical to ensuring that patient preferences are consistently and appropriately addressed.

Early and regular patient-provider discussions about preferences and goals of care, and the adequate documentation of these preferences in the medical record, can facilitate high-quality, patient-centered cancer care. Within our VA medical center, most patients with cancer appeared to have their preferences documented, but there remains room for improvement. Providers may need prompts to help them target appropriate patients for palliative care earlier in their trajectory. Future work should focus on developing and implementing useful alternatives to advance directives for robustly documenting patient preferences.

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Palliative Care in the Outpatient Oncology Setting: Evaluation of a Practical Set of Referral Criteria

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Abstract

Background: The National Comprehensive Cancer Network's (NCCN) palliative care (PC) guidelines recommend screening all patients for PC issues at the first visit with their oncologist and at subsequent, clinically relevant times. Criteria for referral to a PC specialist are also part of the guideline. We evaluated the feasibility of screening for PC needs in outpatients attending one GI oncology practice specializing in colorectal cancer and neuroendocrine tumors.

Methods: All patients attending clinic during a 3-week period were screened by the office practice nurse (OPN). A one-page screening tool based on the NCCN guidelines was developed, giving a score from 0 to 13. The OPN also evaluated the NCCN referral criteria.

Results: There were 152 clinic visits by 125 patients during the surveillance period; 119 were screened. Median age was 61 years; half were male. Eighty percent had colorectal cancer, and two thirds had advanced disease. Screening took approximately 3 to 5 minutes per patient. Depending on the PC definition used, between 7% and 17% of patients screened positive; all met the NCCN referral criteria. Psychosocial distress was commoner than physical symptoms. The maximum screening score was 8. A cut point of 5 had the best predictive value for specialist referral, and would result in 13% patients having PC consultations.

Conclusion: Screening identified 7% to 17% of patients in this busy clinic as having PC issues and 13% who might benefit from specialist referral. But even this simple method adds considerably to the clinic workload, so the benefits of implementing routine screening need to be carefully evaluated.

Introduction

Palliative care aims to relieve suffering and improve the quality of life for patients with advanced cancer and their families.

Unlike hospice, palliative care is provided as part of acute care, simultaneous with all other treatments. Which cancer patients would benefit from referral to a palliative care specialist? In the