

Documentation of Advance Care Planning for Community-Dwelling Elders

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Abstract

Background: Advance planning for end-of-life care has gained acceptance, but actual end-of-life care is often incongruent with patients' previously stated goals. We assessed the flow of advance care planning information from patients to medical records in a community sample of older adults to better understand why advance care planning is not more successful.

Methods: Our study used structured interview and medical record data from community-dwelling older patients in two previous studies: Assessing Care of Vulnerable Elders (ACOVE)-1 (245 patients age ≥ 65 years and screened for high risk of death/functional decline in 1998–1999) and ACOVE-2 (566 patients age ≥ 75 who screened positive for falls/mobility disorders, incontinence, and/or dementia in 2002–2003). We compared interview data on patients' preferences, advance directives, and surrogate decision-makers with findings from the medical record.

Results: In ACOVE-1, 38% of surveyed patients had thought about limiting the aggressiveness of medical care; 24% of surveyed patients stated that they had spoken to their doctor about this. The vast majority of patients (88%–93%) preferred to die rather than remain permanently in a coma, on a ventilator, or tube fed. Regardless of patients' specific preferences, 15%–22% of patients had preference information in their medical record. Among patients who reported that they had completed an advance directive and had given it to their health-care provider, 15% (ACOVE-1) and 47% (ACOVE-2) had advance directive information in the medical record. Among patients who had not completed an advance directive but had given surrogate decision-maker information to their provider, 0% (ACOVE-1) and 16% (ACOVE-2) had documentation of a surrogate decision-maker in the medical record.

Conclusions: Community-dwelling elders' preferences for end-of-life care are not consistent with documentation in their medical records. Electronic health records and standardized data collection for end-of-life care could begin to ameliorate this problem.

Introduction

ADVANCE CARE PLANNING critically informs medical decision-making for seriously ill patients and particularly older patients, who may prioritize quality of life and decreased burden of care over longevity. Multiple professional societies^{1–3} recommend advance care planning, which includes documentation of patient preferences for care, designation of a surrogate decision-maker to enact those

preferences,⁴ and the completion of an advance directive. These activities clarify patients' goals and preferences and facilitate subsequent communication between clinicians and patients regarding the patient's clinical condition, prognosis, and treatment options.

Despite acceptance of advance care planning and advance directives in the care of older patients, less than 30% of Americans have advance directives, and those with chronic disease have similarly low completion rates.⁵ Even when

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advance directives are completed, they often do not result in care consistent with patients' previously stated goals.⁶⁻⁹ Interventions to improve advance care planning have been at best modestly successful,^{8,10,11} although multicomponent interventions that affect multiple aspects of the health-care system have demonstrated a greater effect of advance care planning on care and patient outcomes.^{12,13} Ineffective transfer of patients' advance care planning information to medical records in the various settings where end-of-life care decisions are made could partly explain advance care planning interventions' limited benefit. Previous work has shown that resuscitation orders are not carried over between hospitals and nursing homes¹⁴ or even between admissions at the same hospital.¹⁵ To date, no study has comprehensively evaluated continuity of advance care planning information from the patient through the many health-care settings that patients visit during advanced illness.

In this analysis, we use data from the Assessing Care of Vulnerable Elders (ACOVE) studies to determine how often advance care planning information among community-dwelling patients may be found in the medical record.¹⁶⁻¹⁸ The ACOVE studies evaluate the quality of care provided for vulnerable older patients, using both structured patient interviews and medical record reviews. Unlike other evaluations of advance care planning among acutely ill hospitalized patients¹⁹ or patients in academic settings, ACOVE-1 and ACOVE-2 focused on people age ≥ 65 years in community medical practices. Assessing the concordance of patient reports with medical records in a community sample may provide insight into both the limitations of advance care planning and approaches for making it more successful.

Methods

We analyzed data collected as part of two quality of care evaluations (ACOVE-1 and ACOVE-2) in which medical records and patient interviews were both collected to provide a broad picture of medical care. The RAND institutional review board approved ACOVE-1 and ACOVE-2.

Study sample

ACOVE-1. ACOVE-1 collected data on the quality of medical care provided to 372 seniors in two managed care organizations.¹⁶ These patients were identified as being at increased risk for death or functional decline using the VES-13 survey²⁰ and had medical records available. Participants' medical records from July 1, 1998, to July 31, 1999, were collected from five different sources of care: providers' offices (both primary care and specialty), acute care hospitals, emergency departments, skilled nursing facilities, and outpatient care (e.g., home health agencies and outpatient services, such as physical therapy). Based on utilization data, 95% of all medical records were retrieved. Patients receiving active treatment for malignant conditions (other than non-melanoma skin cancer) were excluded from the study.¹⁶

Of the 372 participants, 341 were alive during the interview period (August through October 2000), and 245 completed a detailed telephone interview including questions on preferences for end-of-life care. The main reasons for not being interviewed included respondent unwillingness ($n = 64$) and inability to contact the patient ($n = 30$).

ACOVE-2. ACOVE-2 was developed as an intervention to improve the quality of care for patients age ≥ 75 years who screened positive for at least one of three target conditions: falls/gait impairment, incontinence, or cognitive impairment.^{17,18} In ACOVE-2, 644 patients met inclusion criteria and had medical records available. Of these 644 patients, 606 were alive during the interview period at the end of study, and 566 participated in the interview (40 patients refused to participate in the interview, were too ill, or could not be contacted). Participants received care from two large medical groups in California. Medical record data covered outpatient clinician (primary care and some specialty care) visits over 13 months: April 2002 to May 2003 for one medical group and July 2002 to August 2003 for the other.

Data

Interview data collection. ACOVE-1 collected information regarding patients' end-of-life care preferences in a computer-assisted telephone interview (Appendix), which was pilot tested using cognitive interviewing techniques. The computer-assisted telephone interview covered specific wishes for end-of-life care and whether these had been discussed with the patient's doctor. The interviewer also inquired whether patients had signed an advance directive (durable power of attorney for health care or living will). If they said "yes," patients were asked whether they had given a copy of this document to a health-care provider or hospital. Patients were also asked if they had informed a health provider of a person who could make decisions regarding medical treatment for them if they could not speak for themselves.

ACOVE-2 also surveyed patients using a computer-assisted telephone interview. However, questions were limited to advance care planning (Appendix; available online at www.liebertpub.com). Patients were asked whether they had an advance directive, and if they said "yes," whether they had given this document to their provider. Patients were also asked whether they had informed their provider of a surrogate decision-maker.

Medical record abstraction. Trained nurse abstractors reviewed medical records from ACOVE-1 and ACOVE-2 using structured abstraction forms. Ten percent of records were reabstracted for interrater reliability in both studies, demonstrating greater than 90% reliability.^{16,18}

In ACOVE-1, medical record abstraction was performed separately for each of the five settings of care from which medical records were collected. For each source of medical records, the abstractor used a structured abstraction form to collect detailed information about any documentation in the record that addressed a) patients' preferences for end-of-life care and b) documentation that a surrogate had been designated. For preference and surrogate documentation, abstractors searched for information in a hierarchical manner, with a formal advance directive document at the top of the hierarchy and "no data found" at the bottom (Appendix Tables 1 and 2).

Analysis

Patient reports. When examining patients' reports of their end-of-life care preferences, we used patient interview data from ACOVE-1 only, since ACOVE-2 did not collect end-of-life preference data. For advance directives and surrogate decision-makers, we present patients' reports from both

ACOVE-1 and ACOVE-2. Patient reports are taken directly from responses to the interview questions (Appendix), except that in ACOVE-1, patients were asked two separate questions about having given a) an "advance directive or durable power of attorney" or b) a "living will" to their provider. We considered patients to have given an advance directive to their provider if either question was answered affirmatively.

Medical record data. We considered an advance directive as present in the medical record if a) abstractors found an advance directive in the chart, or b) an advance directive could not be found, but abstractors found an advance directive mentioned somewhere in the chart. For information about patient end-of-life care preferences or designation of a surrogate decision-maker to be considered as present in the medical record, we tested two definitions, one stringent and one lenient. The stringent definition required finding either a) an advance directive or b) a physician note specifying the information. The more lenient definition additionally conferred credit for notations of attempts to identify preferences or a surrogate, patient refusal to specify preferences or a surrogate, documentation that preferences or surrogates were unknown, or any mention of an advance directive (for preferences) in the chart when the actual document was not found. Since the number of patients having preferences or surrogates documented in the medical record did not change meaningfully using the lenient and stringent definitions, we present findings based on the lenient definition.

For ACOVE-1, we paired medical record data from clinicians' offices with hospital data, and data from clinicians' offices with emergency department data, to examine to what extent advance care planning information from one site was available at the other. If patients presented with multiple recorded episodes of care for a particular type of care (e.g., hospitalizations from two different hospitals), then the medical record with the highest-quality information with regard to advance care planning was used for analysis. The kappa statistic was used to characterize concordance on level of documentation across settings.

Linking patient reports with medical record data. We compared patients' interview data with medical record data to ascertain whether the medical record contained patient-reported information. Because patient preferences are highly individualized and often vary over time, we did not specifically match the content of patients' preferences in the interview with medical record content. Rather, we focused on determining whether any kind of preference information was present in the record for patients who noted specific preferences in the interview.

Statistical analysis. Intercooled Stata 9.2 (StataCorp, College Station, TX) was used for data analysis. Categorical data are presented as frequencies, and continuous data as means. Two-sample *t*-tests and *z*-tests were used for continuous and categorical data, respectively.

Results

Demographics (Table 1)

Both studies had samples (ACOVE-1, $N = 372$; ACOVE-2, $N = 644$) with a similar mean age (81 years, $p = 0.10$) and

TABLE 1. PATIENT CHARACTERISTICS IN ACOVE-1 AND ACOVE-2

Characteristics	ACOVE-1 (n = 372)	ACOVE-2 (n = 644)
Demographics		
Mean age (standard deviation)	81 (7)	81 (5)
Women (%)	64	66
White (%)	97	95
High school graduate (%)	59	88
Mean vulnerability score ^a	5.3 (2.3)	4.6 (2.9)
Mean self-reported health (5 point) ^b	2.6 (1.1)	2.9 (1.0)
Clinical conditions (%)		
Atrial fibrillation	13	12
Chronic obstructive pulmonary disease	25	20
Chronic renal insufficiency	6	11
Coronary artery disease	31	36
Dementia	8	17
Depression	16	27
Diabetes mellitus	24	22
Heart failure	15	21
Hypertension	61	73
Incontinence	9	44
Osteoporosis	12	30
Stroke	1	30

Parts of this table were compiled from previous work.^{16,18,23} ACOVE-1 was an observational study of patients age ≥ 65 years at increased risk of death or functional decline (defined as vulnerability score ≥ 3),²⁰ whereas ACOVE-2 was a quality improvement intervention that enrolled patients age ≥ 75 years who screened positive for falls, incontinence, and/or cognitive impairment. Definitions of clinical conditions varied slightly between the two studies and were based on different sources of medical records (for ACOVE-1, all medical records; for ACOVE-2, medical records from provider offices).

For ACOVE-1, $N = 245$ for ethnicity and education. For ACOVE-2, $N = 592$ for ethnicity and education, and $N = 642$ for self-reported health.

^aBased on the Vulnerable Elders-13 Survey, which has a range of 0–10. A higher score indicates a greater risk of functional death or decline over the next 2 years.

^bBased on the excellent to poor 5-point scale with a range of 1–5. A higher score indicates a better self-reported health.

percent women (about two thirds, $p = 0.40$); both samples were mostly white. ACOVE-2 patients had completed high school at higher rates than ACOVE-1 patients (88% vs. 59%), were less vulnerable to death or functional decline (VES-13 score 4.6 vs. 5.3), and had slightly better self-reported health (2.9 vs. 2.6 on a 5-point scale on which higher is better). ACOVE-2 had more patients with dementia or incontinence due to ACOVE-2 selection criteria for these conditions.

Documentation of patient preferences (Table 2)

Among the 245 interviewed patients in ACOVE-1, 92 (38%) reported having thought about limiting the aggressiveness of medical care they wished to receive and 59 (24%) reported having spoken to their doctor about this. Among these 59 patients, 56 responded to interview items about which decisions they had made with their physicians: 6 (11%) decided not to be hospitalized; 15 (27%), not to have major surgery; 10 (18%), not to receive cardiopulmonary resuscitation; 16 (29%), not to have a feeding tube; and 17 (30%), not to be attached to a ventilator. Five of the 56 participants did not make any care limitation decisions after discussing the issue with their

TABLE 2. PATIENT REPORT/MEDICAL RECORD COMPARISON FOR PREFERENCE DOCUMENTATION, ADVANCE DIRECTIVE, AND SURROGATE DECISION-MAKER

	ACOVE-1 (N = 245)		ACOVE-2 (N = 566)	
	N (%)	Information present in chart, %	N(%)	Information present in chart, %
Preferences				
Has thought about limiting aggressiveness of medical care	92 (38)	15	NA	NA
Spoke to doctor about limiting aggressiveness of medical care	59 (24)	22	NA	NA
Prefers not to receive resuscitation	81 (34) ^b	17	NA	NA
Prefers to die rather than remain permanently in coma	228 (93)	16	NA	NA
Prefers to die rather than remain permanently ventilated	207 (90) ^c	16	NA	NA
Prefers to die rather than remain permanently tube fed	203 (88) ^d	15	NA	NA
Written advance directives (AD)^a				
Patient completed AD and gave to health-care provider	109 (44)	15	221 (39)	47
Patient completed AD and did not give to health-care provider	48 (20)	8	159 (28)	17
Patient completed AD and does not know/data missing	7 (3)	14	33 (6)	33
Patient stated that AD never completed	80 (33)	0	146 (26)	11
ACOVE-1 (N = 80) ACOVE-2 (N = 146)				
Surrogate decision-maker information if no AD completed per interview				
	N (%)	Information present in chart, %	N (%)	Information present in chart, %
Patient stated gave surrogate information to health-care provider	24 (30)	0	43 (29)	16
Patient stated did NOT give surrogate information to health-care provider	54 (68)	0	101 (69)	5
Patient does not know if gave surrogate information to health-care provider	2 (3)	0	2 (1)	0

For both ACOVE-1 and ACOVE-2, the left column represents the number and percentage of patients as a proportion of the denominator listed in the header. The right column represents the percentage of patients in the left column for whom any kind of preference, advance directive, or surrogate information was present in the medical record. NA = not applicable.

^aOne additional patient (ACOVE-1) and seven additional patients (ACOVE-2) not represented in the column did not know whether they had completed an AD.

^bn = 238.

^cn = 229.

^dn = 230.

physician. Among the 59 patients who reported speaking with their physicians about limiting medical care, only 13 (22%) had any medical record documentation about patient preferences.

When ACOVE-1 participants were asked about their willingness to be kept alive in future adverse health states, 34% indicated that they would not want to be resuscitated if their heart stopped beating. When patients were presented with hypothetical questions about living in an adverse health state, 93% preferred to die rather than be permanently unconscious, 90% preferred to die rather than be permanently attached to a ventilator, and 88% preferred to die rather than be permanently fed through a tube. For each of the different clinical scenarios, only 15%–17% of patients had any preference documentation in their medical records.

Documentation of advance directive completion (Table 2)

Of the 245 patients interviewed in ACOVE-1, 164 (67%) reported completing an advance directive. Among these 164 patients, 109 (66%) reported giving the advance directive to their health-care provider, 48 (29%) reported that they did not, and 7 (4%) did not know. Examination of medical records found that only 15% contained an advance directive or any

documentation about the existence of an advance directive among the 109 patients who reported giving a copy to their physician. Among the 80 patients who stated they did not have an advance directive, 24 (30%) reported communicating information about a surrogate decision-maker to their physician. We found that none of these 24 patients had information about a surrogate decision-maker in any medical record.

Of 566 interviewed patients in ACOVE-2, 413 (73%) stated that they had completed an advance directive, and 221 (54%) of these 413 patients reported giving it to their health-care provider. Of these 221 patients, 47% had evidence of an advance directive in their medical record. Among those 146 patients who stated they had not completed an advance directive, 43 patients reported giving their health-care provider surrogate information, of whom 7 (16%) had such information in the medical record.

Advance care planning documentation across settings of care

In ACOVE-1, any kind of advance care planning documentation was present in records of 71 out of 372 patients (19%). This included 39 (11%) of 368 patients' records from provider offices, 37 (52%) of 71 patients' hospital records, 1 (1%) of 72 patients' emergency department records, 9 (81%) of

TABLE 3. CONTINUITY OF ADVANCE CARE PLANNING BETWEEN PROVIDER OFFICES AND HOSPITAL, AND BETWEEN PROVIDER OFFICES AND EMERGENCY DEPARTMENT

	<i>AD or note containing preferences</i>	<i>Note seeking AD or preferences</i>	<i>"Full code"</i>	<i>No AD or preference data</i>	<i>Total</i>
<i>Provider offices</i>					
<i>Hospital</i>					
AD or note containing preferences	4	0	0	2	6
Note seeking AD or preferences	0	4	0	2	6
"Full code"	0	1	0	0	1
No AD or preference data	8	13	4	3	28
Total	12	18	4	7	41
<i>Emergency department</i>					
AD or note containing preferences	0	0	0	7	7
Note seeking AD or preferences	0	1	0	4	5
"Full code"	0	0	0	0	0
No AD or preference data	0	0	0	7	7
Total	0	1	0	18	19

Numbers in the table represent the number of patients with records containing information in the specified row and column header. Using the kappa statistic, concordance between settings on the level of advance care planning documentation was no greater than chance (for the provider office/hospital comparison, kappa = 0.05, $p = 0.22$; for the provider office/emergency department comparison, kappa = 0.09, $p = 0.07$). Abbreviations: AD, advance directive.

11 patients' skilled nursing facility records, and 2 (2%) of 89 patients' ancillary outpatient care records. Thirty (42%) of these 71 patients with some kind of advance care planning documentation also had some kind of surrogate information. An additional two patients without advance care planning documentation had some kind of surrogate information in the chart in at least one health-care setting.

Table 3 compares continuity of advance care planning documentation between the provider office and the hospital: 41 (58%) of 71 patients with any medical record evidence of advance care planning in any setting had both hospital and provider office records. Of the 12 hospital records that contained an advance directive or note about patient preferences, we found only four cases with corresponding documentation in the provider office record. Among the 18 hospital charts in which a note indicated a search of advance directive or preference information, only five provider office records contained any advance care planning documentation. Concerning continuity between provider office and emergency department settings (Table 3), in 12 of 19 cases in which both records were present, there was advance care planning documentation in the provider office chart, but in only 1 of these 12 was any documentation found in the emergency department record. For both the provider office/hospital and provider office/emergency department comparisons, concordance on the level of advance care planning documentation across settings was no greater than chance.

Discussion

Despite substantial deficits in end-of-life care in the U.S. health system, the role of advance care planning in improving end-of-life care has been difficult to discern.⁸ This study demonstrates that translation of patient end-of-life care preferences into documentation of advance care planning is poor. Previous work suggests that clinicians do not systematically document what transpires during the clinical encounter,

particularly for psychosocial information,²¹ so our results likely reflect a mix of not discussing advance care planning in the clinical encounter and failure to document those discussions that are occurring. Lack of documentation of advance care planning could interfere with end-of-life care because clinicians may later use the medical record to identify patients' previously stated wishes. However, given this study's finding that advance care planning information is not reliably available across health-care settings, improving advance care planning documentation would likely help end-of-life care only in tandem with a means to access this information across different health-care venues.

In ACOVE-1 and ACOVE-2, 67% and 73% of patients reported having an advance directive, compared to 30% (at most) in the general American population.⁵ This difference may result from an older patient population (mean age 81) in the ACOVE studies; also, most patients were at increased risk for death or functional decline based on study selection criteria. In addition, in ACOVE-2, patients were well-educated; higher socioeconomic status has been found to be related to increased rates of advance directive completion in previous work.⁵

Among patients interviewed in ACOVE-1, 24% reported having discussed limiting the aggressiveness of care with a health-care provider. These patients claimed to have covered important topics with the physician: whether or not to stay in the hospital; be attached to a ventilator; or have major surgery, cardiopulmonary resuscitation, or a feeding tube, with a variety of different preferences expressed. The uniqueness of patients' preferences, coupled with the frequent desire to avoid certain medical interventions, reinforce the need to assess older adults' preferences regularly and to document them.

Our study may be the first to explore in detail how patients' personal accounts of advance care planning correlate with actual medical record documentation. We explicitly asked patients whether they had discussed end-of-life preferences with their provider, given their provider an advance directive, or informed their provider of a surrogate decision-maker; we

also performed a comprehensive medical record collection and structured review. One published report reviewing medical records of decedents in a midwestern community examined whether patients had advance directives in place prior to death.¹³ That study demonstrated an 81% presence of written advance directives in the medical record, but these results are not directly comparable to ours, since only decedents' medical records were reviewed and a community-wide advance directive education program was in place. By contrast, we provide data from community-dwelling elders at increased risk for death and functional decline whose health status would be more compromised than a general older population, but likely better off than a sample of decedents.

This study is limited by several competing explanations for the discrepancies we found between what patients reported and what was documented in their medical record. First, patients may have misreported whether they had discussed with, or given documentation to their provider about end-of-life care preferences or a surrogate decision-maker. Over-reporting might reflect a socially desirable response bias,²² while under-reporting might reflect problems with recall. Second, medical records data were abstracted from patient charts, so documents with advance care planning information given by patients to clinicians may have been lost or not filed appropriately. This reflects usual care, however, and points to the need for better systems for capturing patient information. Third, providers might have remembered, but failed to document the advance care planning topics that were verbally discussed during the office visit. While this possibility means we may have underrepresented providers' knowledge of patients' preferences, documentation is nonetheless critical in a health-care system that relies on teams of providers in different settings. Last, this analysis is dependent on patient report, and the complexity of end-of-life care may not lend itself well to a structured telephone interview. Nonetheless, we obtained a variety of responses from patients using the telephone interview format, suggesting, at a minimum, significant variation in preferences that would affect end-of-life care.

The ACOVE-2 cohort showed higher rates of correlation between patient report and medical records and are more recent than ACOVE 1 (2002–2003 vs. 1998–1999). This may be because the two samples are different, particularly in regards to education, geographic location, and rates of dementia and urinary incontinence. Alternatively, this difference may represent an improvement over time regarding communication related to advance care planning among community-dwelling older patients. An updated evaluation of continuity of advance care planning from patient to care settings, including patients cared for by providers using electronic health record systems, would help in determining whether the problems with advance care planning documented here persist.

Conclusions

Preferences for end-of-life care among community-dwelling elders are often not available in medical record documentation. In addition, patients do not consistently discuss end-of-life issues with their providers, even if they have thought about such issues. Future research should address whether electronic health records and/or a structured approach to documenting patients' preferences, such as the Physician Orders for Life-Sustaining Treatment (POLST),

could reduce these problems in a supportive organizational milieu.

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Author Disclosure Statement

All of the authors declare that they have no financial conflicts of interest with respect to the content of this manuscript.

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