

12-21-2021

Goals of Care Documentation: Insights from A Pilot Implementation Study

Marie C. Haverfield
San Jose State University, marie.haverfield@sjsu.edu

Ariadna Garcia
Stanford University

Karleen F. Giannitrapani
Stanford University

Anne Walling
University of California, Los Angeles

Joseph Rigdon
Wake Forest School of Medicine

See next page for additional authors

Follow this and additional works at: https://scholarworks.sjsu.edu/faculty_rsca



Part of the [Health Communication Commons](#)

Recommended Citation

Marie C. Haverfield, Ariadna Garcia, Karleen F. Giannitrapani, Anne Walling, Joseph Rigdon, David B. Bekelman, Natalie Lo, Lisa S. Lehmann, Josephine Jacobs, Natalia Festa, and Karl A. Lorenz. "Goals of Care Documentation: Insights from A Pilot Implementation Study" *Journal of Pain and Symptom Management* (2021): 485-494. <https://doi.org/10.1016/j.jpainsymman.2021.12.023>

This Article is brought to you for free and open access by SJSU ScholarWorks. It has been accepted for inclusion in Faculty Research, Scholarly, and Creative Activity by an authorized administrator of SJSU ScholarWorks. For more information, please contact scholarworks@sjsu.edu.

Authors

Marie C. Haverfield, Ariadna Garcia, Karleen F. Giannitrapani, Anne Walling, Joseph Rigdon, David B. Bekelman, Natalie Lo, Lisa S. Lehmann, Josephine Jacobs, Natalia Festa, and Karl A. Lorenz

Original Article

Goals of Care Documentation: Insights from A Pilot Implementation Study



Marie C. Haverfield, PhD, Ariadna Garcia, MS, Karleen F. Giannitrapani, PhD, Anne Walling, MD, Joseph Rigdon, PhD, David B. Bekelman, MD, MPH, Natalie Lo, Lisa S. Lehmann, MD, Josephine Jacobs, PhD, Natalia Festa, MD MBA, and Karl A. Lorenz, MD MS

VA Palo Alto, Center for Innovation to Implementation (Ci2i), Menlo Park, California, USA; Department of Communication Studies, San José State University, San Jose, California, USA; School of Medicine, Stanford University, Stanford, California, USA; Division of General Internal Medicine and Health Services Research, University of California, Los Angeles (UCLA), Los Angeles, California, USA; Wake Forest School of Medicine, Department of Biostatistics and Data Science, Medical Center Boulevard, Winston-Salem, North Carolina, USA; Department of Medicine, Department of Veterans Affairs, Eastern Colorado Health Care System, Aurora, Colorado, USA; Division of General Internal Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora, Colorado, USA; Veterans Affairs New England Healthcare System, Bedford, Massachusetts, USA; Yale New Haven Hospital, Department of Internal Medicine, Section of Geriatrics, New Haven, Connecticut, USA

Abstract

Context. The Life Sustaining Treatment Decision Initiative is a national effort by the Veterans Health Administration to ensure goals of care documentation occurs among all patients at high risk of life-threatening events.

Objectives. Examine likelihood to receive goals of care documentation and explore associations between documentation and perceived patient care experience at the individual and site level.

Methods. Retrospective, quality improvement analysis of initiative pilot data from four geographically diverse Veterans Affairs (VA) sites (Fall 2014-Winter 2016) before national roll-out. Goals of care documentation according to gender, marital status, urban/rural status, race/ethnicity, age, serious health condition, and Care Assessment Needs scores. Association between goals of care documentation and perceived patient care experience analyzed based on Bereaved Family Survey outcomes of overall care, communication, and support.

Results. Veterans were more likely to have goals of care documentation if widowed, urban residents, and of white race. Patients older than 65-years and those with a higher Care Assessment Needs score were twice as likely as a frail patient to have goals of care documented. One pilot site demonstrated a positive association between documentation and perceived support. Pilot site was a statistically significant predictor of the occurrence of goals of care documentation and Bereaved Family Survey scores.

Conclusion. Older and seriously ill patients were most likely to have goals of care documented. Association between a documented goals of care conversation and perceived patient care experience were largely unsupported. Site-level largely contributed to understanding the likelihood of documentation and care experience. *J Pain Symptom Manage* 2022;63:485–494. © 2021 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Implementation, advance care planning, quality improvement

Address correspondence to: Department of Communication Studies, Hugh Gillis Hall (HGH), 220 E. San Fernando Street, California, USA. E-mail: marie.haverfield@sjsu.edu

Accepted for publication: 16 December 2021.

Key Message

Results suggest importance of site-level effects in understanding clinical benefits, reproducibility, and feasibility of advance care planning interventions. Findings present pragmatic considerations for future advance care planning standardization efforts and the need for consistency in the chain of communication—from interpersonal to organizational—to ensure goals of care are met.

Introduction

Advance care planning refers to the process of gathering and confirming a patient's values, goals, and preferences for medical care in the event that they lose decisional capacity.¹ This process often unfolds in a goals of care conversation where patient (or surrogate) and provider discuss patient wishes for medical treatment and/or end-of-life care,^{2–4} which is associated with downstream benefits to patients, caregivers, providers, and health care systems including improved quality of care at the end of life, fewer hospital deaths and an increase in utilization of hospice services.^{5,6} However, the process of routinely eliciting, understanding, and documenting patients' preferences for goals of care remains a challenging aspect of caring for the seriously ill.

In 2017, the VHA initiated the Life-Sustaining Treatment Decision Initiative (LSTDI) through the VA National Center for Ethics in Health Care with the aim of enhancing the quality and frequency of goals of care documentation among all seriously ill Veterans.⁷ A main feature of the LSTDI is to increase documentation of the patient's goals, values, and preferences regarding life-sustaining treatments. The LSTDI goals of care documentation involves a standardized note template and order set for the VA's electronic health record system to document and track patient, or when appropriate their surrogates, decisions to limit life-sustaining treatments (e.g., do not resuscitate, no mechanical ventilation).⁴

VHA's efforts to implement routine goals of care documentation has the potential to improve patient-provider communication and perceived quality of care on a national basis. Some randomized controlled trials, primarily in academic centers, using elements similar to the LSTDI have demonstrated benefits including communication quality, frequency, and timeliness of serious illness conversations as well as a reduction in anxiety and depression.^{8,9} However, trials implementing routine goals of care documentation reflect atypical settings. Insufficient attention to context makes generalizing results to other health systems difficult. Unobserved factors foster effectiveness, but hinder scalability.¹⁰

As such, more research is needed for a better understanding of implementation in more diverse settings such as the VA, given its large size and distinct sites. This study examines the likelihood of having a documented goals of care conversation and the impact of documentation on perceived patient care experience at the patient and site-level.

Methods

We evaluated the VA pilot of the LSTDI in four diverse practice settings. Our evaluation was conducted by the VA Geriatrics and Extended Care national Quality Improvement Resource Center in collaboration with the National Center for Ethics in Health Care and the VA's Geriatrics and Extended Care national program office for hospice and palliative care. The Stanford/VA Palo Alto Institutional Review Board reviewed and exempted this work from ethics approval as quality improvement. See Giannitrapani et al. (2020) for a description of the full LSTDI pilot program.¹¹

Sample and Procedures

Our cohort included 228,047 eligible patients 18 years old and older with inpatient and/or outpatient encounters at the pilot sites between January 1, 2014 and December 31, 2016 (intervention period). We limited the dataset to inpatient and outpatient visits where a goals of care documentation may be applicable (i.e., inpatient hospitalization, primary care clinics, subspecialty clinics) according to VHA stop codes. Stop codes, specific to VHA, are numerical identifiers entered by a provider into the patient's electronic medical record based on patient health status, illness, or treatment.¹² The VA LSTDI pilot involved four geographically diverse VA healthcare systems providing comprehensive care and networks of services: Captain James A. Lovell Federal Health Center, North Chicago, IL; VA Black Hills Health System, Fort Meade, SD; William S. Middleton Memorial Veterans Hospital, Madison, WI; and VA Salt Lake Health Care System, Salt Lake City, UT. Pilot locations were selected based on their commitment to test and implement the routine goals of care documentation. Each pilot site provides inpatient, outpatient, and home care services, with outpatient primary care clinics at locations separate from the primary medical center(s).¹¹ On-site extended care facilities and hospice beds are available at three of the four sites.

We first evaluated reach of the initiative, accounting for patient characteristics and site. We also evaluated the effect of documentation on perceived patient care experience using the validated national palliative and end-of-life outcomes measure, the Bereaved Family Survey.¹³

Measures

Demographics and Patient Health Status. Patient demographic characteristics included gender, marital status, urban/rural status, race, ethnicity (Hispanic and Non-Hispanic only), and vital status. Veterans were categorized as deceased if they died during the intervention period. Rural-Urban Commuting Area codes were used if available to identify urban/rural status of Veterans that were missing the urban/rural status in the original data source.¹⁴ The Care Assessment Needs score (range 0–99) is a validated measure of the likelihood of hospitalization or death within one year, higher scores indicate higher risk of hospitalization and/or mortality compared to Veterans with lower scores.¹⁵ We operationalized the Care Assessment Needs score utilizing indicator variables to represent four groups with differing hospitalization and mortality risk: < 80, 80–89, 90–94, > = 95. The most recent score for each Veteran prior to either the documented goals of care conversation or the Veteran's first visit during the pilot period was used, if available. Otherwise, we utilized the first available Care Assessment Needs score, limiting scores abstraction to one year prior to the intervention period and two years after, due to reporting delays.

Serious health conditions were characterized according to a taxonomy previously utilized to describe patterns of serious illness and outcomes: 1) End Stage Liver Disease (ESLD), 2) End Stage Renal Disease (ESRD), 3) Cancer, 4) Cardio pulmonary failure (congestive heart failure or chronic obstructive pulmonary disease), 5) Dementia, 6) Frailty, or 7) Other.¹⁶ See Ruiz et al., 2018 for a description of each indexed criteria. Both International Classification of Diseases codes, ICD-9 and ICD-10, were used to ascertain clinical diagnoses assigned to the patients up to 1 year prior to the visit where goals of care were documented. Health conditions were categorized as mutually exclusive and hierarchical, as listed above, in terms of likely impact on end-of-life care.¹⁷

VA Bereaved Family Survey. The Bereaved Family Survey is a validated, reliable, National Quality Forum endorsed quality measure that is distributed as a survey to designated friends or family of decedents.¹⁶ To be eligible to complete a survey, decedents must have received inpatient care in a VA facility within 30-days before death. The full survey includes 17 items with an Overall Care score as a single item global rating of end-of-life care by the family of the decedent on a 5-point Likert scale. We dichotomized the variable as "excellent" versus all other categories, in accordance with VA's national "top box" scoring. We also examined validated survey subscales for a) quality of end-of-life communication and b) support. Both subscales were dichotomized using validated cut-offs based on the associations with the survey's Overall Care score.¹⁸ We

dichotomized scores as excellent versus not excellent. Excellence was determined as follows: Overall Score ≥ 4 , Communication ≥ 13 , and Support ≥ 7 . Response rates to the survey averaged 38%. Higher survey scores reflect satisfaction with the patient care experience and have previously been associated with palliative care consultation, avoidance of inappropriately aggressive care, and important staffing and patient differences including minority status.^{19–21}

Statistical Analyses

Our first analysis evaluated the associations of patient characteristics and site as predictors of a documented goals of care conversation. Occurrence of a goals of care documentation was determined using data fields automatically recorded in the VA's electronic health record when the LSTDI template for documenting a goals of care conversation is used. The template includes four required fields to qualify as a goals of care conversation, and 9 additional data elements that are not required, but can be completed to document additional patient preferences. Required data elements include Informed Consent, Decision Making Capacity, Goals of Care and Resuscitation preferences. Veterans with documentation of these four required fields were included in the goals of care documentation group and those who may have been eligible for a documented goals of care conversation but whose records did not show documentation comprised the non-goals of care group. Although a minority of the documented group had two or more goals of care conversations documented,¹¹ we used data recorded during the initial goals of care conversation for this analysis and we used data from the first qualifying encounter for comparison in the non-goals of care group. We summarized demographic characteristics using means/frequencies and standardized mean differences. The standardized difference (referred to as the "effect size" by Cohen, 1988) describes the difference in means in units of standard deviation.²² A widely accepted criteria for effect sizes suggests that a standardized mean difference of 0.2 or less is considered small, 0.5 medium and 0.8 large.²³

In our second analysis, we sought to examine the association between a documented goals of care conversation and the perceived patient care experience according to available Bereaved Family Survey data. Utilizing logistic regression with site-level fixed effects, we regressed our primary outcome, document of a goals of care conversation, based on applicable population characteristics using the following covariates: gender, marital status, urban/rural status, race, ethnicity, age, health condition, Care Assessment Needs Score, and site. Among decedents with available Bereaved Family Survey data, we calculated the propensity score for each subject eligible to receive a documented goals

of care conversation via logistic regression using the variables age, gender, marital status, race, ethnicity, health condition, Care Assessment Needs score, and facility. Veterans were matched 1:1 on the propensity score exactly by facility.²⁴ We evaluated the quality of matching by comparing standardized mean differences. We performed a complete case analysis since no data was missing in the reduced sample of patients with a documented goals of care conversation and Bereaved Family Survey data. To test associations between documentation and each survey outcome, we performed a mixed effect analysis on the matched cohort adjusting for age, marital status, gender, race, ethnicity, urban/rural status, Care Assessment Needs score, and health condition, with site as a random effect. To further understand whether perceived patient care associated with documentation differed by site we included an interaction term between site and goals of care documentation for each of the three Bereaved Family Survey outcomes. Additionally, likelihood ratio test between models with and without the interaction term was performed to determine whether site variation was significant for each of the survey outcomes. All tests were two-sided and p-values less than 0.05 were considered to be statistically significant. Analysis were performed on MS SQL Server and R (version 3.5.1).

Results

A total of 228,047 Veterans received care at the four sites during the intervention period and were eligible to have a documented goals of care conversation. Among eligible Veterans, 6664 (2.9%) of those had a documented goals of care conversation (Table 1), of which 1288 (19.3%) had more than one conversation documented. Veterans in the documented goals of care and non-goals of care groups were predominantly white (87.1% vs 77.4%) non-Hispanic (95.2% vs 84.8%), and male (93.2% vs 85.4%), respectively. Both groups had notable differences in marital status proportions; married Veterans accounted for 45.9% vs 51.4%, widowers for 15.7% vs 5.3% and divorced Veterans for 25.2% vs 19.2% in the respective documented goals of care and non-goals of care groups. Most Veterans in the documented goals of care group lived in an urban area (64.7%), as compared to the non-goals of care group (59.8%). Veteran with documented goals of care compared to those without goals of care documentation had higher mortality (27.3% vs 6%); were likelier to be older than 65-years of age (74.4% vs 45.8%), and to have Care Assessment Needs scores ≥ 95 (25.8% vs 4.7%). Veterans with a documented goals of care conversation were more likely to have a serious health condition than those in the non-goals of care group. For example, 32.5% vs 1.8% received a diagnosis of cardio pulmonary failure during the pilot period.

Table 1
Patient Level Characteristics Based on Goals of Care Documentation

n	Goals of Care 6664	No-Goals of Care 221383	SMD*
Gender (%)			
Female	456 (6.8)	32224 (14.6)	0.25
Male	6208 (93.2)	189152 (85.4)	
Missing	0 (0.0)	7 (0.0)	
Marital Status (%)			
Married	3056 (45.9)	113840 (51.4)	0.53
Never married	780 (11.7)	34250 (15.5)	
Divorced	1677 (25.2)	42546 (19.2)	
Widowed	1046 (15.7)	11773 (5.3)	
Separated	100 (1.5)	4203 (1.9)	
Unknown	5 (0.1)	14771 (6.7)	
Deceased (%)			
No	4845 (72.7)	208025 (94.0)	0.59
Yes	1819 (27.3)	13358 (6.0)	
Urban Rural Status (%)			
Urban	4314 (64.7)	132425 (59.8)	0.17
Rural	1952 (29.3)	72119 (32.6)	
Highly rural	360 (5.4)	11423 (5.2)	
Continental USA	0 (0.0)	9 (0.0)	
Missing	38 (0.6)	5407 (2.4)	
Race (%)			
White	5806 (87.1)	171413 (77.4)	0.43
Black or African American	527 (7.9)	14991 (6.8)	
Asian	33 (0.5)	1479 (0.7)	
Native Hawaiian or other pacific islander	46 (0.7)	1822 (0.8)	
American Indian or Alaska native	64 (1.0)	3217 (1.5)	
Multirace	103 (1.5)	3082 (1.4)	
Unknown	85 (1.3)	25379 (11.4)	
Ethnicity (%)			
Not Hispanic or Latino	6345 (95.2)	187810 (84.8)	0.39
Hispanic or Latino	198 (3.0)	9248 (4.2)	
Unknown	121 (1.8)	24325 (11.0)	
Age (%)			
<65	1703 (25.6)	119881 (54.2)	0.61
≥ 65	4961 (74.4)	101502 (45.8)	
Disease (%)			
End Stage Liver Disease	401 (6.0)	530 (0.2)	3.08
End Stage Renal Disease	161 (2.4)	186 (0.1)	
Cardio	2168 (32.5)	3933 (1.8)	
Cancer	894 (13.4)	1167 (0.5)	
Dementia	407 (6.1)	467 (0.2)	
Frailty	502 (7.5)	1444 (0.7)	
Other	1601 (24.0)	11188 (5.1)	
None	530 (8.0)	202468 (91.5)	
Care Assessment Needs Score (%)			
<80	2441 (36.6)	141250 (63.8)	0.91
80-89	1038 (15.6)	16875 (7.6)	
90-94	910 (13.7)	9160 (4.1)	
≥ 95	1716 (25.8)	10335 (4.7)	
Not available	559 (8.4)	43763 (19.8)	

*SMD = Standardized Mean Differences. Difference of 0.2 or less is considered small, 0.5 medium and 0.8 large.

Veterans demographics also varied by site (Table 2). Captain James had more females in the documented goals of care group (14.8%) and non-goals of care group (22.4%) compared to other sites. Also in comparison to other sites, Captain James had lower mortality (goals of care group: 9.9% vs non-goals of care group: 3.2%); and a higher number of black or African

Table 2
Site-Level Patient Characteristics Based on Goals of Care Documentation

	Captain James		Black Hills		Madison		Salt Lake City		SMD ^b
	GoC ^a	No-GoC	GoC	No-GoC	GoC	No-GoC	GoC	No-GoC	
n	2080	48075	704	26251	1811	56443	2069	90614	
Gender (%)									
Female	308 (14.8)	10761 (22.4)	29 (4.1)	3349 (12.8)	60 (3.3)	5802 (10.3)	59 (2.9)	12312 (13.6)	0.27
Male	1772 (85.2)	37307 (77.6)	675 (95.9)	22902 (87.2)	1751 (96.7)	50641 (89.7)	2010 (97.1)	78302 (86.4)	
Missing	0 (0.0)	7 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Marital Status (%)									
Married	872 (41.9)	21070 (43.8)	328 (46.6)	14030 (53.4)	852 (47.0)	29467 (52.2)	1004 (48.5)	49273 (54.4)	0.47
Never married	450 (21.6)	13857 (28.8)	54 (7.7)	2988 (11.4)	164 (9.1)	7494 (13.3)	112 (5.4)	9911 (10.9)	
Divorced	475 (22.8)	5807 (12.1)	178 (25.3)	5480 (20.9)	489 (27.0)	11887 (21.1)	535 (25.9)	19372 (21.4)	
Widowed	242 (11.6)	2350 (4.9)	133 (18.9)	1654 (6.3)	283 (15.6)	3063 (5.4)	388 (18.8)	4706 (5.2)	
Separated	38 (1.8)	700 (1.5)	10 (1.4)	489 (1.9)	22 (1.2)	1048 (1.9)	30 (1.4)	1966 (2.2)	
Unknown	3 (0.1)	4291 (8.9)	1 (0.1)	1610 (6.1)	1 (0.1)	3484 (6.2)	0 (0.0)	5386 (5.9)	
Deceased (%)									
No	1874 (90.1)	46550 (96.8)	432 (61.4)	23126 (88.1)	1128 (62.3)	52647 (93.3)	1411 (68.2)	85702 (94.6)	0.47
Yes	206 (9.9)	1525 (3.2)	272 (38.6)	3125 (11.9)	683 (37.7)	3796 (6.7)	658 (31.8)	4912 (5.4)	
Urban Rural Status (%)									
Urban	1814 (87.2)	39385 (81.9)	196 (27.8)	7999 (30.5)	671 (37.1)	24849 (44.0)	1633 (78.9)	60221 (66.5)	0.87
Rural	232 (11.2)	6154 (12.8)	282 (40.1)	11764 (44.8)	1120 (61.8)	29571 (52.4)	318 (15.4)	24674 (27.2)	
Highly rural	2 (0.1)	68 (0.1)	222 (31.5)	5826 (22.2)	19 (1.0)	767 (1.4)	117 (5.7)	4762 (5.3)	
Continental USA	0 (0.0)	1 (0.0)	0 (0.0)	1 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	7 (0.0)	
Missing	32 (1.5)	2467 (5.1)	4 (0.6)	661 (2.5)	1 (0.1)	1256 (2.2)	1 (0.0)	950 (1.0)	
Race (%)									
White	1565 (75.2)	32794 (68.2)	633 (89.9)	19990 (76.1)	1628 (89.9)	45523 (80.7)	1980 (95.7)	73106 (80.7)	0.55
Black or African American	437 (21.0)	7176 (14.9)	5 (0.7)	471 (1.8)	47 (2.6)	2420 (4.3)	38 (1.8)	4924 (5.4)	
Asian	23 (1.1)	723 (1.5)	0 (0.0)	68 (0.3)	2 (0.1)	162 (0.3)	8 (0.4)	526 (0.6)	
Native Hawaiian or other pacific islander	23 (1.1)	780 (1.6)	2 (0.3)	135 (0.5)	16 (0.9)	312 (0.6)	5 (0.2)	595 (0.7)	
American Indian or Alaska native	5 (0.2)	226 (0.5)	40 (5.7)	1611 (6.1)	7 (0.4)	284 (0.5)	12 (0.6)	1096 (1.2)	
Multirace	14 (0.7)	578 (1.2)	5 (0.7)	330 (1.3)	67 (3.7)	683 (1.2)	17 (0.8)	1491 (1.6)	
Unknown	13 (0.6)	5798 (12.1)	19 (2.7)	3646 (13.9)	44 (2.4)	7059 (12.5)	9 (0.4)	8876 (9.8)	
Ethnicity (%)									
Not Hispanic or Latino	1967 (94.6)	37631 (78.3)	684 (97.2)	22664 (86.3)	1722 (95.1)	49719 (88.1)	1972 (95.3)	77796 (85.9)	0.39
Hispanic or Latino	93 (4.5)	2814 (5.9)	15 (2.1)	547 (2.1)	7 (0.4)	731 (1.3)	83 (4.0)	5156 (5.7)	
Unknown	20 (0.9)	7630 (15.9)	5 (0.7)	3040 (11.6)	82 (4.5)	5993 (10.6)	14 (0.7)	7662 (8.5)	
Age (%)									
<65	959 (46.1)	31464 (65.4)	93 (13.2)	13336 (50.8)	308 (17.0)	26616 (47.2)	343 (16.6)	48464 (53.5)	0.53
>=65	1121 (53.9)	16611 (34.6)	611 (86.8)	12915 (49.2)	1503 (83.0)	29826 (52.8)	1726 (83.4)	42150 (46.5)	
Disease (%)									
End Stage Liver Disease	87 (4.2)	43 (0.1)	47 (6.7)	87 (0.3)	159 (8.8)	201 (0.4)	108 (5.2)	199 (0.2)	1.92
End Stage Renal Disease	43 (2.1)	20 (0.0)	14 (2.0)	38 (0.1)	48 (2.7)	53 (0.1)	56 (2.7)	75 (0.1)	
Cardio	572 (27.5)	390 (0.8)	250 (35.5)	682 (2.6)	650 (35.9)	1389 (2.5)	696 (33.6)	1472 (1.6)	
Cancer	165 (7.9)	117 (0.2)	133 (18.9)	211 (0.8)	341 (18.8)	446 (0.8)	255 (12.3)	393 (0.4)	
Dementia	85 (4.1)	50 (0.1)	66 (9.4)	70 (0.3)	106 (5.9)	123 (0.2)	150 (7.2)	224 (0.2)	
Frailty	200 (9.6)	215 (0.4)	31 (4.4)	229 (0.9)	109 (6.0)	418 (0.7)	162 (7.8)	582 (0.6)	
Other	870 (41.8)	2245 (4.7)	88 (12.5)	1801 (6.9)	268 (14.8)	2896 (5.1)	375 (18.1)	4246 (4.7)	
None	58 (2.8)	44995 (93.6)	75 (10.7)	23133 (88.1)	130 (7.2)	50916 (90.2)	267 (12.9)	83423 (92.1)	
CAN^c Score (%)									
<80	780 (37.5)	23389 (48.7)	239 (33.9)	16657 (63.5)	651 (35.9)	40509 (71.8)	771 (37.3)	60695 (67.0)	0.81
80-89	266 (12.8)	1951 (4.1)	106 (15.1)	2044 (7.8)	311 (17.2)	4740 (8.4)	355 (17.2)	8140 (9.0)	
90-94	211 (10.1)	993 (2.1)	107 (15.2)	1112 (4.2)	277 (15.3)	2617 (4.6)	315 (15.2)	4438 (4.9)	
>=95	338 (16.2)	1187 (2.5)	215 (30.5)	1334 (5.1)	554 (30.6)	3178 (5.6)	609 (29.4)	4636 (5.1)	
Not available	485 (23.3)	20555 (42.8)	37 (5.3)	5104 (19.4)	18 (1.0)	5399 (9.6)	19 (0.9)	12705 (14.0)	

^aGoC = Goals of Care.

^bSMD = Standardized Mean Differences. Difference of 0.2 or less is considered small, 0.5 medium and 0.8 large.

^cCAN = Care Assessment Needs.

American Veterans in both the documented goals of care and non-goals of care groups (21% vs 14.9%). Most Captain James (documented goals of care group: 87.2% vs non-goals of care group 81.9%) and Salt Lake City (documented goals of care group: 78.9% vs non-goals of care 66.5%) Veterans resided in urban areas, as compared to Black Hills and Madison. Veterans at Captain James were also younger in the documented

goals of care group (53.9%; aged 65 and older) as compared to other sites. A similar pattern was observed in the non-goals of care group (34.6%). The proportion of patients in the documented goals of care group with a Care Assessment Needs score >= 95 was lower at Captain James than at the other sites (16.2%), the same trend was observed for the non-goals of care group (2.5%).

Associations of Patient Characteristics and Site with Documented Goals of Care

Several patient characteristics were associated with a patient's likelihood to have a goals of care conversation documented: marital status, race, ethnicity, region, age, health condition, Care Assessment Needs score, and site of care (Table 3). With respect to marital status, widowed Veterans were significantly more likely to have goals of care documented when compared to their married counterparts (OR 1.68; 95% CI, 1.52, 1.85). Veteran's who identified themselves as never married (OR 0.85; CI, 0.77, 0.95), divorced (OR 0.91; CI, 0.85, 0.98), or separated (OR 0.64; CI, 0.5, 0.8) were significantly less likely to have goals of care documented, as compared to married Veterans. With respect to geography (i.e., urban, rural, or highly rural), Veterans in urban areas (OR 1.31; CI, 1.22, 1.41) were significantly more likely to have goals of care documented when compared to those receiving care in rural areas. For age, Veterans aged 65-years or older were more likely have a goals of care conversation documented (OR 2.63; CI 2.44, 2.84) as compared to their younger counterparts. Veterans with cancer were more likely to have goals of care documented compared to all of the other health conditions. Despite disease-specific disparities, the likelihood of a documented goals of care conversation increased with the Care Need Assessments score for groups with scores ≥ 80 (OR 1.44; CI, 1.31, 1.57), ≥ 90 (OR 1.63; CI, 1.48, 1.8), and ≥ 95 (OR 1.97; CI, 1.81, 2.14). Gender was not associated with the likelihood of a documented goals of care conversation and further analysis confirmed no interaction between Care Assessment Needs score and serious health condition.

We also examined whether there were site level differences in the likelihood of having goals of care documented. Veterans at Black Hills (OR 0.21; CI, 0.18, 0.24), Madison (OR 0.31; CI, 0.28, 0.34), and Salt Lake City (OR 0.26; CI, 0.24, 0.29) were significantly less likely to have goals of care documented when compared to the Captain James site.

Association of Patient Characteristics and Site with Bereaved Family Survey Outcomes

Out of 228,047 Veterans, 15,177 (6.7%) died during the pilot period (Fig. 1). For those with goals of care documented (n = 1,819), 851 (46.8%) were inpatient deaths. For those with no documented goals of care (n = 13,358), 1,226 (9.2%) were inpatient deaths. Of the Bereaved Family Survey eligible inpatient decedents (n = 2,077), 771 (37.1%) had a complete survey available (Fig. 1). Propensity score matching yielded 353 matched goals of care documented-control pairs

Table 3
Demographic Characteristics Associated with Goals of Care Documentation

	Odds Ratio ^a	Pvalue
(Intercept)	0.57 (0.48, 0.68)	
Gender (ref = Male)		0.1281
Female	1.1 (0.97, 1.24)	
Marital Status (ref = Married)		<0.001
Never Married	0.85 (0.77, 0.95)	
Divorced	0.91 (0.85, 0.98)	
Widowed	1.68 (1.52, 1.85)	
Separated	0.64 (0.5, 0.8)	
Unknown	0.11 (0.03, 0.34)	
Race (ref = Black or African American)		<0.001
White	1.1 (0.98, 1.25)	
Native Hawaiian or other pacific islander	0.84 (0.58, 1.22)	
American Indian or Alaska native	0.65 (0.48, 0.88)	
Asian	1.07 (0.69, 1.66)	
Multirace	1.14 (0.87, 1.49)	
Declined	0.4 (0.26, 0.74)	
Unknown	0.92 (0.65, 1.28)	
Ethnicity (ref = Not Hispanic or Latino)		<0.001
Hispanic or Latino	0.91 (0.76, 1.07)	
Declined	1.34 (1, 1.79)	
Unknown	0.49 (0.33, 0.73)	
Age (ref = < 65)		<0.001
> = 65	2.63 (2.44, 2.84)	
Urban Rural Status (ref= Rural)		<0.001
Urban	1.31 (1.22, 1.41)	
Highly rural	0.95 (0.82, 1.1)	
Health condition (ref= Cancer)		<0.001
End Stage Liver Disease	1.18 (0.99, 1.39)	
End Stage Renal Disease	0.9 (0.71, 1.16)	
Cardio pulmonary failure	0.65 (0.58, 0.73)	
Dementia	0.89 (0.75, 1.05)	
Frailty	0.46 (0.4, 0.54)	
Other	0.23 (0.21, 0.26)	
Care Assessment Needs Score (ref = < 80)		<0.001
80-89	1.44 (1.31, 1.57)	
90-94	1.63 (1.48, 1.8)	
> = 95	1.97 (1.81, 2.14)	
Not available	1.87 (1.64, 2.12)	
Site (ref = Captain James)		<0.001
Black Hills	0.27 (0.24, 0.3)	
Madison	0.35 (0.31, 0.38)	
Salt Lake City	0.31 (0.28, 0.34)	

^aModel on the full cohort adjusted by: Gender = Marital Status, Race, Ethnicity, Age, Serious Health Condition, Care Assessment Needs Score and Site as a fixed effect.

(n = 706). Gender, marital status, urban/rural status, race, ethnicity, and age had standardized mean differences < 0.2, therefore, both groups were considered well-balanced. For health conditions and Care Assessment Needs score, standardized mean differences was 1.58, 0.42 respectively.

The occurrence of a documented goals of care conversation was not significantly associated with any of the Bereaved Family Survey outcome measures across the combined, four-site cohort (Table 4). For the overall and support scores, there was variation by site. However, there was no variation by site for the survey's communication score.

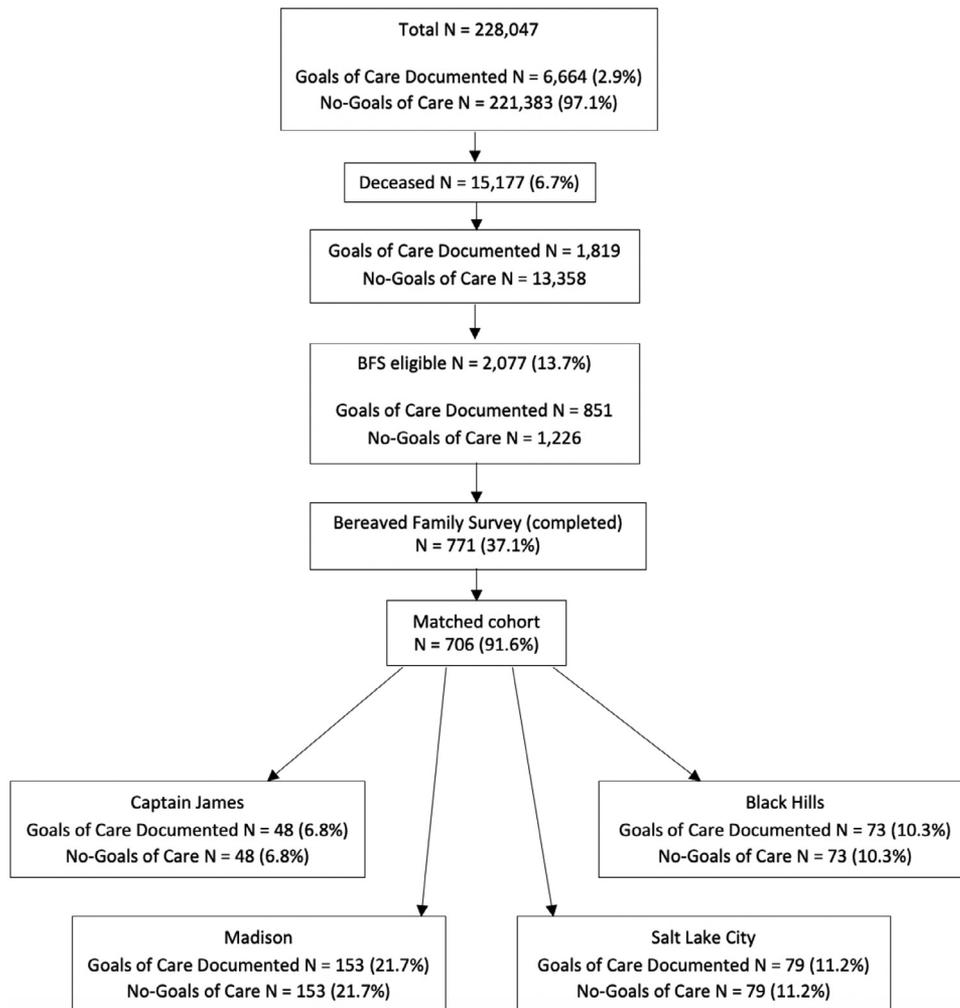


Fig. 1. CONSORT diagram.

Discussion

This study examined how a VA multi-site goals of care initiative program implemented goals of care documentation and the perceived quality of care based on goals of care documentation, at both the patient and site-level. During a two-year intervention implementation phase, goals of care documentation were more likely to occur for older, single, urban, cancer diagnosed, and sicker Veterans. Further, populations reached by the VA LSTDI varied among pilot sites. This shows that variation in a documented goals of care conversation was associated with Veteran's age, marital status, rurality, and health characteristics (i.e., seriously ill), consistent with prior research.²⁵ While LSTDI implementation was associated with better perceived patient care experience as measured by the Bereaved Family survey at one site, in complete models these differences did not achieve statistical significance.

Based on findings, clinicians appear to be making a concerted effort to document wishes for sicker patients however, there are also underlying issues that may

explain why some patients are less likely to have these conversations (e.g., married, non-white, rural). Multiple patient, family, provider, and contextual reasons contribute to these differences and more research is badly needed to foster better understanding of why these differences persist and how to address them.²⁶ Approaches to enhancing routine goals of care documentation for all eligible patients, particularly among ethnic and racial minorities, is an important point of focus for future implementation programming. Relatedly, only a small portion of eligible patients (2.9%) had a goals of care conversation documented during the pilot period. Greater understanding of the uptake at each site, including role readiness of providers, is an important next step in research related to implementation of routine goals of care conversations.

The association between a documented goals of care conversation and perceived patient care experience was largely unsupported. Notably, one site (Captains James) noted a significant association for the support sub-scale, pointing to the potential utility of the

Table 4
Bereaved Family Survey and Goals of Care Documentation Association (Overall and by Site)

	Bereaved Family Survey Overall Score		Bereaved Family Survey Communication Score		Bereaved Family Survey Support Score	
	Odds Ratio	P value	Odds Ratio	P value	Odds Ratio	P value
Goals of Care overall ^b	1.3 (0.84,2.01)	0.23	1.35 (0.82, 2.21)	0.23	1.56 (0.97,2.49)	0.06
Goals of Care by site ^c		<0.001		0.16		<0.01
Captain James	1.09 (0.90, 1.33)		1.11 (0.93, 1.31)		1.31 (1.10, 1.57) ^a	
Black Hills	1.13 (0.97, 1.32)		0.99 (0.86, 1.13)		1.04 (0.91, 1.21)	
Madison	1.02 (0.91, 1.15)		1.10 (0.99, 1.23)		1.05 (0.94, 1.17)	
Salt Lake City	1.00 (0.85, 1.18)		0.97 (0.84, 1.12)		1.01 (0.87, 1.17)	

^aDenotes statistically significant ($P<0.01$)

^bModel adjusted by: Gender, Marital Status, Race, Ethnicity, Age, Health Condition, Care Assessment Needs Score and Site as a random effect

^cLikelihood ratio test between models with and without the interaction term between goals of care documentation and site.

Bereaved Family Survey as well as the impact of a documented goals of care conversation on patient care. Overall, documentation did not result in changes in Bereaved Family Survey score, which underscores the importance of better understanding the quality of the goals of care conversation itself. Recent high quality research raises important questions about the effectiveness of advance care planning, although experience affirms the critical nature of high quality communication.^{27,28} Future research is needed to address challenges of measurement, and our research is intended to highlight the added issue of context.

Variation in site-level LSTDI implementation could partly explain which Veterans received LSTDI. The LSTDI was intended to affect patient-clinician encounters which is where we measured communication processes. Both the patient and site affect the occurrence of a documented goals of care conversation (e.g., readiness to discuss) and known differences seen also in non-VA settings (e.g., fewer documented goals of care among nonwhite race) are reflected both in our pilot and national data on LSTDI use.^{11,25} Components of LSTDI rollout such as the quality of trainings, engagement of leadership, organizational levels and disciplines involved in the initiative were particular to each site and had potential to affect the experience and outcomes of efforts across entire facilities, as has been noted in other implementation contexts.^{29,30}

The influence of site-level effects are crucial to acknowledge in research on goals of care conversations and future communication research. As noted earlier, site effects may be underappreciated because trials implementing goals of care documentation often reflect atypical settings, and insufficient consideration of site differences makes generalizing results to other health systems difficult.¹⁰ Large studies implementing goals of care documentation risk failure unless they are planned with adequate understanding to address and adapt to site level implementation barriers.^{31,32} For example, communication with patients must be supported by consistency, reliability, and integrity of organizations handling that information and ensuring ongoing goal concordant care.

Our study is limited by the number of implementation sites and Veteran recipients of a documented goals of care conversation. However, site diversity illuminates the importance of understanding site effects in communication research. Relatedly, we acknowledge that lack of documentation of a goals of care conversation does not necessarily mean a conversation did not occur, particularly for full code patients. However, this is likely a conservative bias of early pilot implementation. While our study is limited to Veterans, the VA healthcare system is a favorable context within which to examine multisite implementation efforts due to the unique and extensive palliative care infrastructure and

large number of diverse but well characterized hospitals and health systems. Finally, this work does not account for the interpersonal exchange that occurs during the goals of care conversation.

In summary, our analysis demonstrated expected associations with patient characteristics and the likelihood of documented goals of care conversation. Although most differences in outcomes did not reach statistical significance, variability at both Veteran and site levels raises important considerations with respect to future research focused on implementation of routine goals of care documentation. Pragmatic studies of advance care planning are needed that address the association between implementation, site differences, and effectiveness.

Disclosures and Acknowledgements

The authors declare no conflicts of interest, no competing interests, and no contributors or funders to acknowledge. Research was presented at the 2020 Annual Assembly of Hospice and Palliative Care, San Diego, CA.

References

1. Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage* 2017;53:821–832.
2. Edmonds KP, Ajayi TA. Do we know what we mean? An examination of the use of the phrase “goals of care” in the literature. *J Palliat Med* 2019;22:1546–1552.
3. Stanek S. Goals of care: a concept clarification. *J Adv Nurs* 2017;73:1302–1314.
4. VHA Handbook. Life-sustaining treatment decisions: Eliciting, documenting, and honoring patients’ values, goals and preferences. 1004.03. Washington, DC: Department of Veteran Affairs, Veterans Health Administration; 2017 11 January.
5. Bischoff KE, Sudore R, Miao Y, Boscardin WJ, Smith AK. Advance care planning and the quality of end-of-life care in older adults. *J Am Geriatr Soc* 2013;61:209–214.
6. Institute of Medicine. Dying in America: Improving quality and honoring individual preferences near the end of life. Washington, D.C.: The National Academies Press; 2015.
7. Foglia MB, Lowery J, Sharpe VA, Tompkins P, Fox E. A comprehensive approach to eliciting, documenting, and honoring patient wishes for care near the end of life: the veterans health administrations life-sustaining treatment decisions initiative. *Jt Comm J Qual Patient Saf* 2019;45:47–56.
8. Paladino J, Bernacki R, Neville BA, et al. Evaluating an intervention to improve communication between oncology clinicians and patients with life-limiting cancer: a cluster randomized clinical trial of the serious illness care program. *JAMA oncology* 2019;5:801–809.
9. Bernacki R, Paladino J, Neville BA, et al. Effect of the serious illness care program in outpatient oncology: a cluster randomized clinical trial. *JAMA Int Med* 2019;179:751–759.
10. Dal-Ré R, Janiaud P, Ioannidis JP. Real-world evidence: how pragmatic are randomized controlled trials labeled as pragmatic? *BMC medicine* 2018;16:49.
11. Giannitrapani, K, Walling, A, Garcia, A. et al. Pilot of the life-sustaining treatment decisions initiative among veterans with serious illness. *Am J Hosp Palliat Care*.
12. Veterans Health Administration (VHA). *PC-MHI stop code guidance*. (2014). https://www.mirecc.va.gov/cih-visn2/Documents/Clinical/Stop_codes_for_PCMHI_Clinics_2.pdf
13. Casarett D, Pickard A, Bailey FA, et al. A nationwide VA palliative care quality measure: the family assessment of treatment at the end of life. *J Palliat Med* 2008;11:68–75.
14. RuralHealth Research Center. *Rural-Urban Commuting Area Codes (RUCAs)*. (2019). <http://depts.washington.edu/uwruca/ruca-approx.php>
15. Ruiz JG, Priyadarshni S, Rahaman Z, et al. Validation of an automatically generated screening score for frailty: the care assessment need (CAN) score. *BMC Geriatr* 2018;18:106.
16. Kaltman J, Walling AM, Wenger N. Implementing the bereaved family survey for an advanced cancer population. 2017.
17. Wachterman MW, Pilver C, Smith D, Ersek M, Lipsitz SR, Keating NL. Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Intern. Med.* 2016;176:1095.
18. Smith D, Thorpe JM, Ersek M, Kutney-Lee A. Identifying optimal factor scores on the bereaved family survey: implications for practice and policy. *J Pain Symptom Manage* 2019;58:108–114.
19. Ersek M, Miller SC, Wagner TH, et al. Association between aggressive care and bereaved families’ evaluation of end-of-life care for veterans with non-small cell lung cancer who died in Veterans Affairs facilities. *Cancer* 2017;123:3186–3194.
20. Kutney-Lee A, Smith D, Thorpe J, et al. Race/ethnicity and end-of-life care among veterans. *Medical care* 2017;55:342–351.
21. Roza KA, Lee EJ, Meier DE, Goldstein NE. A survey of bereaved family members to assess quality of care on a palliative care unit. *J Palliat Med* 2015;18:358–365.
22. Cohen J. *Statistical power analysis for the behavioral sciences*. 2nd ed. Hillsdale, NJ: Erlbaum; 1988.
23. Austin PC. Using the standardized difference to compare the prevalence of a binary variable between two groups in observational research. *Commun Stat Simulation Comput* 2009;38:1228–1234.
24. Sekhon JS. Multivariate and propensity score matching software with automated balance optimization: the matching package for R. *J Stat Softw* 2011;42:1–52.
25. Levy C, Ersek M, Scott W, et al. Life-sustaining treatment decisions initiative: early implementation results of a National veterans affairs program to honor veterans’ care preferences. *J Gen Intern Med* 2020;24:1–10.
26. Jones T, Luth EA, Lin SY, Brody AA. Advance care planning, palliative care, and end-of-life care interventions for racial and ethnic underrepresented groups: a systematic review. *J Pain Symptom Manage* 2021;62:e248–e260.

27. Morrison RS, Meier DE, Arnold RM. What's wrong with advance care planning? *JAMA* 2021;326:1575–1576.
28. Curtis JR. Three stories about the value of advance care planning. *JAMA* 2021;326:2133–2134.
29. Shore S, Ho PM, Lambert-Kerzner A, et al. Site-level variation in and practices associated with dabigatran adherence. *JAMA* 2015;313:1443–1450.
30. Rose AJ, Berlowitz DR, Miller DR, et al. INR targets and site-level anticoagulation control: results from the Veterans Affairs Study to Improve Anticoagulation (VARIA). *J Thromb Haemost* 2012;10:590–595.
31. Waltz TJ, Powell BJ, Fernández ME, Abadie B, Damschroder LJ. Choosing implementation strategies to address contextual barriers: diversity in recommendations and future directions. *Implement Sci* 2019;14:1–15.
32. Powell BJ, Waltz TJ, Chinman MJ, et al. A refined compilation of implementation strategies: results from the Expert Recommendations for Implementing Change (ERIC) project. *Implement Sci* 2015;10:21.