

UCSF

UC San Francisco Previously Published Works

Title

Capturing what matters: A retrospective observational study of advance care planning documentation at an academic medical center during the COVID-19 pandemic

Permalink

<https://escholarship.org/uc/item/6k7833cj>

Journal

Palliative Medicine, 36(2)

ISSN

0269-2163

Authors

Sun, Fangdi
DeGette, Raphaela Lipinsky
Cummings, Elizabeth C
et al.

Publication Date

2022-02-01

DOI

10.1177/02692163211065928

Peer reviewed

Capturing what matters: A retrospective observational study of advance care planning documentation at an academic medical center during the COVID-19 pandemic

Palliative Medicine
2022, Vol. 36(2) 342–347
© The Author(s) 2021
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/02692163211065928
journals.sagepub.com/home/pmj



Fangdi Sun*, Raphaela Lipinsky DeGette*^{}, Elizabeth C Cummings,
Lisa X Deng, Karen A Hauser, Zoë Kopp, John C Penner, Brandon S Scott,
Katie E Raffel and Molly A. Kantor

Abstract

Background: Advance care planning allows patients to share their preferences for medical care with the aim of ensuring goal-concordant care in times of serious illness. The morbidity and mortality of the COVID-19 pandemic has increased the importance and public visibility of advance care planning. However, little is known about the frequency and quality of advance care planning documentation during the pandemic.

Aim: This study examined the frequency, quality, and predictors of advance care planning documentation among hospitalized medical patients with and without COVID-19.

Design: This retrospective cohort analysis used multivariate logistic regression to identify factors associated with advance care planning documentation.

Setting/participants: This study included all adult patients tested for COVID-19 and admitted to a tertiary medical center in San Francisco, CA during March 2020.

Results: Among 262 patients, 31 (11.8%) tested positive and 231 (88.2%) tested negative for SARS-CoV-2. The rate of advance care planning documentation was 38.7% in patients with COVID-19 and 46.8% in patients without COVID-19 ($p = 0.45$). Documentation consistently addressed code status (100% and 94.4% for COVID-positive and COVID-negative, respectively), but less often named a surrogate decision maker, discussed prognosis, or elaborated on other wishes for care. Palliative care consultation was associated with increased advance care planning documentation (OR: 6.93, $p = 0.004$).

Conclusion: This study found low rates of advance care planning documentation for patients both with and without COVID-19 during an evolving global pandemic. Advance care planning documentation was associated with palliative care consultation, highlighting the importance of such consultation to ensure timely, patient-centered advance care planning.

Keywords

Advance care planning, ACP, COVID-19, coronavirus, goals of care, palliative care

What is already known about the topic?

- Advance care planning allows patients to receive goal-concordant care and has many established benefits, including increased patient well-being and healthcare savings
- Patients hospitalized with COVID-19 are at risk of clinical decompensation, so goals should be established early in their care.

Department of Medicine, University of California, San Francisco, CA, USA

*These authors contributed equally to this work.

Corresponding author:

Raphaela Lipinsky DeGette, Department of Medicine, University of California, 505 Parnassus Avenue, Room M1480, San Francisco, CA 94143, USA.

Email: Raphaela.lipinskydegette@ucsf.edu

What this paper adds?

- This study shows that advance care planning documentation was low among patients with and without COVID-19 at the beginning of the pandemic.
- Palliative care consult, a code status other than full code, older age, stable housing, and a longer length of stay were associated with increased advance care planning documentation.

Implications on practice, theory, or policy?

- This study describes an unmet need for advance care planning with patients with COVID-19.
- Reinforces the importance of early palliative care involvement in hospitalized patients with COVID-19.

Introduction

Advance care planning supports patients in understanding and expressing their values for medical care during serious illness and is integral to patient-centered care.¹ Advance care planning conversations should ideally occur before the loss of decision-making capacity. The content of these discussions may include, but is not limited to, preferences for life-sustaining treatment, choice of surrogate decision-maker, and other decisions about acceptable medical interventions. Despite established benefits of advance care planning ranging from increased patient and family well-being² to healthcare savings,³ general uptake of advance care planning remains low.⁴

The coronavirus disease of 2019 (COVID-19) pandemic has magnified the urgency of advance care planning conversations. Discussing treatment wishes in advance is especially important for patients with older age or medical comorbidities that put them at high risk for COVID-19 complications such as ICU admission, mechanical ventilation, or death.^{5,6} However, the pandemic has also increased barriers to timely advance care planning discussions. First, many in-person primary care visits have been deferred or cancelled. Patients and providers may also be reluctant to conduct advance care planning discussions by telehealth methods, and certain populations may not have access to needed technology, exacerbating existing socioeconomic disparities. Finally, outpatient staff may be pulled to other clinical responsibilities during periods of surging disease.

Despite its well-accepted importance, little is known regarding patterns of inpatient advance care planning discussion and documentation during the COVID-19 pandemic. The objective of this study was to describe the frequency, quality, and predictors of advance care planning documentation among patients with and without COVID-19 hospitalized at an academic medical center in March 2020. For the purposes of this study, “advance care planning” refers to conversations about treatment preferences that occur in advance of the clinical need for a specific medical decision, such as intubation or CPR. We include in-hospital conversations about wishes for medical care in “advance care planning,” even though

hospitalized patients may be more proximal to these escalations in treatment.

Methods

This retrospective observational study included all patients age 18 or older tested for COVID-19 in a large academic hospital in San Francisco, California between March 1, 2020 and March 31, 2020. During this period, polymerase-chain-reaction assay for SARS-CoV-2, the virus that causes COVID-19, was performed based upon the treating physician’s clinical suspicion for infection; universal or pre-procedural testing had not yet been implemented. Patients with suspected or confirmed COVID-19 were preferentially admitted to a COVID unit. The hospital uses an open ICU model, with ICU patients cared for by both a primary team and consulting ICU team, though patients with COVID were cared for only by a primary ICU team. Palliative care consultation was available per usual clinical care, but the hospital did not have a dedicated palliative care unit. As part of a year-long health system-wide initiative preceding the pandemic, providers were encouraged to document advance care planning conversations within an advance care planning navigator, an easily accessible section within the electronic medical record (EMR) that centralizes advance care planning documentation, code status (i.e. the preferences around CPR and intubation), and advance directives.⁷ In this study, the presence of advance care planning documentation was defined as notes within the navigator, although advance care planning notes outside the navigator were also recorded by searching the medical record for the terms “advance care planning,” “ACP,” “goals of care,” and “GOC.” Data for each admission were abstracted by structured chart review and reconciled by two independent physician reviewers. Patient demographic and clinical information were obtained from the hospital’s clinical database. This study was conducted with approval from the Institutional Review Board of the University of California, San Francisco, IRB #19-29313. This study is reported under the STROBE guidelines.⁸

Differences in sociodemographic factors, clinical characteristics, and advance care planning documentation

were analyzed using unpaired *t* tests for continuous variables and Fisher's exact tests for categorical variables. Multivariate logistic regression was used to identify factors associated with advance care planning documentation among the aggregate cohort of both COVID-positive and COVID-negative patients. These were derived using backwards selection, starting with a model including all variables with $p < 0.05$ in the univariate analysis, and sequentially removing non-significant variables until only variables with $p < 0.05$ remained. Statistical analysis was conducted with R (Version 3.4.1, R Foundation for Statistical Computing, Vienna, Austria).

Results

Of 262 patients tested for SARS-CoV-2, 11.8% ($n = 31$) tested positive (COVID-positive); 88.2% ($n = 231$) tested negative (COVID-negative). Full sociodemographic and clinical characteristics are reported in Table 1. The median age of COVID-positive patients was 63 (interquartile range 51.5–76) years and 38.7% ($n = 12$) were of assigned female sex at birth. Most patients had a length of stay >48 h and were discharged home, with a trend toward higher rate of discharge to a skilled nursing facility in the COVID-negative group (17.7% [$n = 41$] vs 6.5% [$n = 2$], $p = 0.30$). COVID-positive patients had lower Elixhauser mortality index scores, a measure of comorbid conditions and risk of in-hospital death (7.0 [−0.5, 12.0] vs 11.0 [3.0, 9.0], $p = 0.009$). Compared to COVID-negative patients, COVID-positive patients were more likely to require supplemental oxygen (80.6% [$n = 25$] vs 56.7% [$n = 131$], $p = 0.011$) and ICU level of care (41.9% [$n = 13$] vs 23.8% [$n = 55$], $p = 0.047$). Only 12.9% ($n = 4$) of COVID-positive and 23.8% ($n = 55$) of COVID-negative patients had prior documentation in the advance care planning navigator ($p = 0.40$). Patients with COVID were more likely to transfer care between services (38.7% [$n = 12$] vs 18.2% [$n = 42$], $p = 0.016$).

Overall, 38.7% ($n = 12$) of patients with COVID-19 had advance care planning documented in the navigator prior to discharge or death, compared to 46.8% ($n = 108$) of patients without COVID-19 (Figure 1, $p = 0.45$). 0% ($n = 0$) of COVID-positive patients and 5.2% ($n = 12$) of COVID-negative patients had additional advance care planning documentation outside of the navigator ($p = 0.37$). Comparing advance care planning documentation between COVID-positive and COVID-negative groups, there were no significant differences in documentation of code status (100% [$n = 12$] vs 94.4% [$n = 102$], $p = 1.00$), surrogate decision-maker (58.3% [$n = 7$] vs 66.7% [$n = 72$], $p = 0.54$), prognosis (8.3% [$n = 1$] vs 29.6% [$n = 32$], $p = 0.18$), or other treatment wishes (41.7% [$n = 5$] vs 62.0% [$n = 67$], $p = 0.22$).

Amongst the aggregate cohort of both COVID-positive and COVID-negative patients, palliative care consultation (OR: 6.93 [2.07, 31.88], $p = 0.004$), non-full code status on

admission (OR: 5.79 [2.33, 16.49], $p < 0.001$), length of stay greater than 48 h (OR: 5.25 [1.97, 17.06], $p = 0.002$), housing security (OR: 2.28 [1.05, 5.23], $p = 0.043$), and older age (OR: 1.03 for each year increase [1.01, 1.05], $p = 0.002$) were associated with documentation in the centralized advance care planning navigator (Table 2).

Discussion

In this study of hospitalized patients early in the COVID-19 pandemic, less than half of both COVID-positive and COVID-negative patients had an advance care planning discussion documented in a centralized navigator prior to discharge or death. Of the advance care planning notes completed, nearly all identified code status and approximately half named a surrogate decision-maker or documented other treatment wishes. There was a trend toward more nuanced conversations in the COVID-negative group with prognosis and other treatment wishes more frequently addressed, though this study was not powered to detect these between-group differences in documentation quality. Finally, factors associated with advance care planning documentation included palliative care consultation and non-full code status (e.g. DNR/DNI or partial code) on admission.

In both groups, there was little advance care planning documentation elsewhere in the EMR, suggesting that the low rates found in this study were not attributable to lack of familiarity with the navigator itself. Palliative care consultation may have been associated with higher rates of advance care planning documentation due to higher illness severity prompting consultation, increased palliative care provider bandwidth for these discussions, or familiarity of palliative care providers with use of the advance care planning navigator.

There is mounting evidence that COVID-19 is a multi-system disease with long-term sequelae that may require additional clinical care. A large U.S. case series demonstrated that at least 9% of patients hospitalized for COVID-19 were readmitted to the same hospital within 2 months of discharge.⁹ Given these high rates of complications, accurate and accessible advance care planning documentation is paramount to the care of patients with COVID-19.

Reasons for low advance care planning rates

Although not every hospitalized patient requires in-depth advance care planning documentation, these discussions are warranted in patients at high risk for complications including ICU care, life-sustaining treatment, and death—such as those hospitalized with COVID-19.⁵ We believe there is a universal need for inpatient advance care planning in this population, but found that actual rates were

Table 1. Sociodemographic and clinical characteristics of COVID-19 positive and negative patients

	COVID-19 positive (n = 31)	COVID-19 negative (n = 231)	p-Value
Female sex (%)	12 (38.7)	100 (43.3)	0.70
Age, median (IQR), years	63 (51.5–76)	66 (53–77)	0.87
Self-identified race (%) (n = 28, n = 230)			
American Indian or Alaska Native	0 (0.0)	2 (0.9)	0.37
Asian	9 (32.1)	60 (26.1)	
Black or African American	3 (10.7)	39 (17.0)	
Native Hawaiian or Other Pacific Islander	0 (0.0)	2 (0.9)	
White or Caucasian	9 (32.1)	100 (43.5)	
Other	7 (25.0)	27 (11.7)	
Self-identified Hispanic or Latino ethnicity (%) (n = 29, n = 230)	5 (17.2)	19 (8.3)	0.16
Primary language (%)			
Chinese	0 (0.0)	32 (13.9)	0.014*
English	26 (83.9)	183 (79.2)	
Spanish	3 (9.7)	6 (2.6)	
Other	2 (6.5)	10 (4.3)	
Housing insecure (%)	2 (6.5)	44 (19.0)	0.13
Length of stay ≤48 h (%)	2 (6.5)	31 (13.4)	0.39
Elixhauser mortality index score, median (IQR)	7.0 (−0.5, 12.0)	11.0 (3.0, 19.0)	0.009*
Discharge disposition (%)			
Deceased	1 (3.2)	13 (5.6)	0.30
Home	26 (83.9)	156 (67.5)	
Hospice	0 (0.0)	6 (2.6)	
Skilled nursing facility	2 (6.5)	41 (17.7)	
Other	2 (6.5)	15 (6.5)	
Required supplemental oxygen (%)	25 (80.6)	131 (56.7)	0.011*
Required intubation and mechanical ventilation (%)	7 (22.6)	25 (10.8)	0.07
Required ICU level of care (%)	13 (41.9)	55 (23.8)	0.047*
Transfer of care between services (%)	12 (38.7)	42 (18.2)	0.016*
Palliative care consulted (%)	2 (6.5)	18 (7.8)	1.00
Code status on admission (%)			
Full code	29 (93.5)	191 (82.7)	0.43
DNR/DNI	2 (6.5)	34 (14.7)	
Partial code (DNR only or DNI only)	0 (0.0)	6 (2.6)	
Code status on discharge (%)			
Full code	27 (87.1)	169 (73.2)	0.21
DNR/DNI	3 (9.7)	53 (22.9)	
Partial code (DNR only or DNI only)	1 (3.2)	9 (3.9)	
Prior completed POLST (%)	3 (9.7)	39 (16.9)	0.44
Prior advance care planning documentation (%)			
None	27 (87.1)	176 (76.2)	0.40
Recent (≤3 months)	2 (6.5)	36 (15.6)	
Distant (>3 months)	2 (6.5)	19 (8.2)	

IQR: interquartile range; ICU: intensive care unit; DNR: do not resuscitate; DNI: do not intubate; POLST: physician orders for life-sustaining treatment.

*Significant results ($p < 0.05$).

much lower than anticipated. There were many possible reasons for this. In hospitals, visitor restrictions may have limited the ability of loved ones to participate in in-person advance care planning discussions.¹⁰ Personal protective equipment requirements and high clinical volume may have reduced the time available to providers to spend in the room with each patient.¹¹ Clinician discomfort in

counseling patients on a novel disease may also have posed a barrier to nuanced bedside conversations.¹² Additionally, patients with COVID-19 were more likely to transfer between services, primarily between hospitalist and critical care services, leading to care fragmentation and limited provider continuity.¹³ Finally, by some measures the COVID-positive patients in this study may have

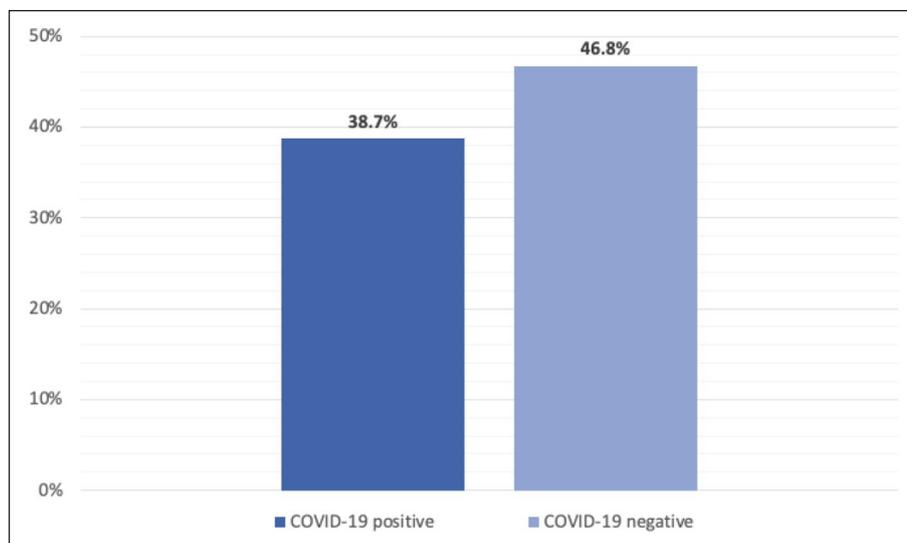


Figure 1. Frequency of advance care planning documentation among COVID-19 positive and negative patients. Between-group differences are not statistically significant.

Table 2. Multivariable logistic regression for predictors of advance care planning documentation in the centralized navigator amongst the aggregate cohort of COVID-positive and COVID-negative patients.

Predictor	OR [95% CI]	p-Value
Palliative care consultation (yes vs no)	6.93 [2.07, 31.88]	0.004
Code status on admission (DNR/DNI or Partial vs Full)	5.79 [2.33, 16.49]	< 0.001
Length of stay > 48 h (yes vs no)	5.25 [1.97, 17.06]	0.002
Housing security (yes vs no)	2.28 [1.05, 5.23]	0.043
Age (as continuous variable)	1.03 [1.01, 1.05]	0.002

OR: odds ratio; CI: confidence interval; DNR: do not resuscitate; DNI: do not intubate.

been less severely ill given the lower Elixhauser comorbidity score, though this score may not adequately reflect the illness severity of a novel disease.

Limitations of the study

Limitations of this study include its small sample size and single-center nature. Testing algorithms, subject to external pressures of resource limitations and rapidly changing clinical information, changed frequently early in the COVID-19 pandemic, which may have also biased our sample. In addition, this study took place early in the pandemic and patterns of advance care planning conversations may have subsequently changed.

Conclusion

Patients admitted to an academic internal medicine service both with and without COVID-19 had low rates of documented advance care planning. Palliative care consultation was associated with increased rates of advance care planning documentation. The findings of this study reinforce the urgency of advance care planning conversations

during the COVID-19 pandemic and the potential importance of palliative care involvement for COVID-19 patients. Given the many competing demands during an acute hospitalization, advance care planning should ideally occur prior to serious illness or loss of capacity. For these reasons, although our study examined in-hospital discussions of treatment preferences, it is preferable for these conversations to occur in advance of hospitalization.¹³ Further studies are needed to understand and quantify barriers to advance care planning during this public health crisis.¹⁴ While clinicians should always aim to provide goal-concordant care for their patients, these needs are magnified by the ongoing pandemic.

Acknowledgement

The authors would like to thank Yumiko Abe-Jones and Logan Pierce for their assistance with data acquisition.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Disclosures

This study was conducted with approval from the Institutional Review Board of the University of California, San Francisco.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Raphaela Lipinsky DeGette  <https://orcid.org/0000-0002-5921-9491>

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 Manag* 2017; 53(5): 821–832. e1.
2. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.
3. Dixon J, Matosevic T and Knapp M. The economic evidence for advance care planning: systematic review of evidence. *Palliat Med* 2015; 29(10): 869–884.
4. Waller A, Turon H, Bryant J, et al. Medical oncology outpatients' preferences and experiences with advanced care planning: a cross-sectional study. *BMC Cancer* 2019; 19(1): 63.
5. Curtis JR, Kross EK and Stapleton RD. The importance of addressing advance care planning and decisions about Do-not-resuscitate orders during novel Coronavirus 2019 (COVID-19). *JAMA* 2020; 323(18): 1771–1772.
6. Block BL, Smith AK and Sudore RL. During COVID-19, outpatient advance care planning is imperative: we need all hands on deck. *J Am Geriatr Soc* 2020; 68(7): 1395–1397.
7. Kantor MA, Scott BS, Abe-Jones Y, et al. Ask about what matters: an intervention to improve accessible advance care planning documentation. *J Pain Symptom Manag* 2021; 62(5): 893–901.
8. von Elm E, Altman DG, Egger M, et al. The strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *J Clin Epidemiol* 2008; 61(4): 344–349.
9. Lavery AM, Preston LE, Ko JY, et al. Characteristics of hospitalized COVID-19 patients discharged and experiencing same-hospital readmission - United States, march-august 2020. *MMWR Morb Mortal Wkly Rep* 2020; 69(45): 1695–1699.
10. Fried TR, Bullock K, Iannone L, et al. Understanding advance care planning as a process of health behavior change. *J Am Geriatr Soc* 2009; 57(9): 1547–1555.
11. Schickedanz AD, Schillinger D, Landefeld CS, et al. A clinical framework for improving the advance care planning process: start with patients' self-identified barriers. *J Am Geriatr Soc* 2009; 57(1): 31–39.
12. Ahluwalia SC, Levin JR, Lorenz KA, et al. Missed opportunities for advance care planning communication during outpatient clinic visits. *J Gen Intern Med* 2012; 27(4): 445–451.
13. Peck V, Valiani S, Tanuseputro P, et al. Advance care planning after hospital discharge: qualitative analysis of facilitators and barriers from patient interviews. *BMC Palliat Care* 2018; 17(1): 127.
14. Lee J, Abruken L, Flores S, et al. Early intervention of palliative care in the emergency department during the COVID-19 pandemic. *JAMA Intern Med* 2020; 180(9): 1252–1254.