Occurrence of Advance Care Planning and Hospital Course in Patients Admitted for Coronavirus Disease 2019 (COVID-19) During the Pandemic

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Abstract

Introduction: The Coronavirus Disease 2019 (COVID-19) pandemic highlighted the importance of understanding patients’ goals, values, and medical care preferences given the high morbidity and mortality. We aimed to examine rates of advance care planning (ACP) documentation along with hospital course differences in the absence or presence of ACP among hospitalized patients with COVID-19. Methods: This retrospective cohort study was performed at a single tertiary academic medical center. All adults admitted between March 1, 2020, and June 30, 2020, for COVID-19 were included. Demographics, ACP documentation rates, presence of ACP forms, palliative care consultation (PCC) rates, code status, and hospital outcome data were collected. Data were analyzed with multivariable analysis to identify predictors of ACP documentation. Results: Among 356 patients (mean age 60.0, 153 (43%) female), 97 (27.2%) had documented ACP and 20 (5.6%) had completed ACP forms. In patients with documented ACP, 52.4% (n = 55) de-escalated care to do-not-resuscitate (DNR)-limited or comfort measures. PCC occurred rarely (<8%), but 78% (n = 21) of those consulted de-escalated care. Being admitted to the intensive care unit (ICU) (OR = 11.1, 95% CI = 5.9-21.1), mechanical intubation (OR = 15.8, 95% CI = 7.4-32.1), and discharge location other than home (OR = 11.3, 95% CI = 5.7-22.7) were associated with ACP documentation. Conclusions: This study found low ACP documentation and PCC rates in patients admitted for COVID-19. PCC and completion of ACP were associated with higher rates of care de-escalation. These results support the need for pro-active ACP and PCC for patients admitted for serious illnesses, like COVID-19, to improve goal-informed care.

Keywords

advance care planning, goals of care, COVID-19, palliative care, hospital admission, code status

Introduction

In light of the recent Coronavirus Disease 2019 (COVID-19) pandemic, healthcare systems around the world have had to grapple with a rapid shift in healthcare needs. During the early part of the pandemic, the overall cumulative COVID-19 hospitalization rate was 98.4 per 100,000, with individuals aged 65 years and older having the highest hospitalization rates (297.6 per 100,000).1 By end of June 2020, over 120,000 deaths were confirmed as a result of COVID-19.2 To date, in the US alone, COVID-19 has claimed more than one million lives, with the majority (nearly 75%) being 65 years and older.3,5 The pandemic strained healthcare resources and increased the awareness of medical providers and patients on end-of-life issues, cardiopulmonary resuscitation (CPR), and the importance of advance care planning (ACP) discussions and completion of ACP forms, especially in elderly, high-risk
individuals with multi-comorbidities, and in those with severe diseases necessitating hospital admission.8,9

ACP has been defined as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care;”7 and involves discussing and documenting a patient’s goals, wishes, and future health care preferences, particularly under medical crisis, along with selecting a surrogate decision-maker who can direct health care choices on behalf of the patient when they are unable to execute their own decisions.8,9 In randomized trials, ACP has been shown to positively influence patients’ care satisfaction and caregiver distress; however, health status (e.g., quality of life and mental health), rates of goal concordant care, and healthcare utilization outcomes have been mixed.10-13 In the setting of the COVID-19 pandemic, there have been multiple interventions developed, such as communication guides,14-16 new workflows17 and COVID-19 goals of care videos,18 to help providers conduct ACP discussions in the context of COVID-19 infection.19-23 However, despite the overwhelming consensus on their necessary roles during the COVID-19 pandemic, the rates of ACP for patients admitted for COVID-19 remains understudied.6,8,24-26

In the setting of the acute risk for death, rapid deterioration, and poor outcomes related to COVID-19, ACP has become more important than ever in patients admitted to the hospital. This pandemic has highlighted the importance of understanding and documenting patients’ personal goals, values, and future medical care preferences. Thus, the goal of this study was to assess the rates of ACP within the electronic health record (EHR) prior to and during admission for COVID-19 during the early part of the pandemic, and to examine the hospital course between those with or without documented ACP.

Methods
Study Design
This was a retrospective cohort study that included all adults aged 18 and older who had been admitted for COVID-19 to Wake Forest Baptist Medical Center (WFBMC), now Atrium Health Wake Forest Baptist, between the dates of March 1, 2020, and June 30, 2020. Patients were excluded if they were less than the age of 18 or did not have the primary diagnosis of COVID-19. WFBMC is an 885-bed tertiary-care hospital and Level 1 trauma center located in Winston Salem, North Carolina. WFBMC serves the Piedmont Triad area of North Carolina, which encompasses twelve counties, as well as portions of southern Virginia and eastern Tennessee. The population of this service area is estimated at 1.69 million, making it the 30th largest metropolitan area in the US.27 In this region, 22.2% of residents are African American, and 15.9% are aged 65 and older. WFBMC is the only academic medical center in this 12-county area. This study was approved by the Wake Forest Institutional Review Board, with a waiver of the requirement of informed consent.

Measurements
All data, except for documented ACP, presence of ACP forms (advanced directive, living will, medical power of attorney), completed Medical Order of Scope of Treatment [MOST] forms, and rates of in-patient CPR were directly extracted from the EHR by a blinded data abstractor with training in biomedical informatics. Information on all inpatient and emergency department encounters, including hospital-to-hospital transfers for admission were extracted from the EHR using a study-specific abstraction form. Comprehensive information including demographic (age, gender, and race) and behavioral characteristics (marital status and religion), all diagnosis codes to assess comorbidities, and primary and secondary hospital diagnoses were directly extracted from the chart. The following information was also collected throughout the patients’ hospital admission: patient healthcare utilization rates including, date of admission, date of discharge, hospital length of stay in days, intensive care unit (ICU) length of stay in days, mechanical intubation status, in-hospital CPR, in-hospital mortality, palliative care consult (PCC), and discharge disposition. Charleston Comorbidity Index (CCI) was calculated from comorbidities that were extracted from the EHR. A manual chart review was performed to confirm the primary diagnosis of admission was COVID-19, to confirm discharge location, in-hospital mortality rates, rates of CPR, and rates of mechanical intubation to ensure accurate and up-to-date information. In addition, a manual chart review was used to assess rates of ACP documentation and ACP form completion within the EHR within two years preceding hospital admission. ACP documentation and ACP form completion rates were recorded by individual review of patient notes, and by searching the medical record for the terms “advance care planning,” “goals of care,” “family meeting,” “advance directive,” “medical decision-maker,” “code status,” “mechanical intubation,” “chest compressions,” “surrogate decision-maker,” “MOST form,” “living will,” “cardiopulmonary resuscitation,” “end-of-life wishes,” “power of attorney,” and “quality of life.” The EPIC system was the EHR system utilized for this review; which contains both inpatient and outpatient medical records. We used Research Electronic Data Capture (REDCap) to record all study data.28

For this study, ACP documentation referred to documented conversations addressing the patient’s goals, values, treatment preferences, and end-of-life wishes, and/or having a detailed discussion about an ACP form. A separate researcher adjudicated any incomplete data or difference in interpretation. Charts were also manually reviewed to assess documented code status prior to and during COVID-19 hospital admission. If no documentation regarding pre-admission code status was available, we assumed the patient to be full code if the initial
documented code status was also full code within their admission orders. WFBMC currently has four tiers of scope of treatment orders: full code; do not resuscitate (DNR)-F (full scope of treatment); DNR-L (limited scope of treatment), and DNR-C (comfort care scope of treatment).

Statistical Methods

Means and standard deviations were calculated for normally distributed continuous measures, medians and interquartile ranges were calculated for non-normally distributed continuous measures, and percentages and counts were calculated for discrete measures. The demographic characteristics between patients that had ACP documentation and/or ACP forms either prior to, or during admission and those that did not were compared using chi-squared tests or Fisher’s exact tests for discrete measures, 2-sample t-tests for normally distributed continuous measures, and Wilcoxon rank-sum tests for non-normally distributed continuous measures. The comparisons of outcomes between age groups (18 - 64 years vs. ≥ 65 years) were calculated using chi-squared tests or Fisher’s exact tests.

Multivariate logistic regression was used after adjusting for age, gender, race, marital status, and CCI, to identify factors associated with ACP documentation. These were derived using backward selection, starting with a model including all variables with \( P < .05 \) in the univariate analysis, and sequentially removing non-significant variables until only variables with \( P < .05 \) remained. Statistical analysis was conducted with SAS software (version 9.4; SAS Institute).

Results

Patient Demographics

Between the dates of March 1, 2020, and June 30, 2020, a total of 356 adult patients were admitted for COVID-19. Of the 356 patients, 153 (43%) were female and 203 (57%) were male. The mean age of patients was 60 years, and the majority of patients were between 18 – 64 years (58.9%). The mean CCI was 2.5. The majority of patients (71.6%) self-identified as Christian. Table 1 outlines patient-level characteristics across all data, alongside comparing characteristics between patients with or without ACP documentation and/or ACP forms completed either prior to or during admission.

Table 1. Demographics.

|                     | No ACP (n = 259) | ACP (n = 97) | P-value |
|---------------------|------------------|--------------|---------|
| Age, years          | 56.2 (16.4)      | 70.2 (15.4)  | <.0001  |
| Age group           |                  |              |         |
| 18 to 39 years      | 43 (16.6)        | 3 (3.1)      |         |
| 40 to 64 years      | 134 (51.7)       | 30 (30.9)    |         |
| 65 to 74 years      | 46 (17.8)        | 24 (24.7)    |         |
| 75 to 84 years      | 27 (10.4)        | 20 (20.6)    |         |
| ≥85 years           | 9 (3.5)          | 20 (20.6)    |         |
| Female              | 113 (43.6)       | 40 (41.2)    | 0.6848  |
| Race                |                  |              |         |
| White or Caucasian  | 87 (33.6)        | 40 (41.2)    |         |
| Black or African-American | 70 (27.0)   | 25 (25.8)    |         |
| Latin American or Hispanic | 8 (3.1)   | 2 (2.1)      |         |
| Asian               | 12 (4.6)         | 4 (4.1)      |         |
| Other or Unknown    | 82 (31.7)        | 26 (26.8)    |         |
| Marital Status      |                  |              | <.0001  |
| Married or Life Partner/Significant | 115 (44.6) | 41 (42.3)    |         |
| Other               |                  |              |         |
| Separated or Divorced | 37 (14.3)   | 8 (8.3)      |         |
| Single, Never Married | 83 (32.2)   | 21 (21.7)    |         |
| Widowed             | 23 (8.9)         | 27 (27.8)    |         |
| Religion            |                  |              | 0.2993  |
| Christian           | 170 (70.0)       | 70 (76.9)    |         |
| Jehovah’s Witness or Muslim | 5 (2.1)    | 2 (2.2)      |         |
| Other religion      | 7 (2.9)          | 4 (4.4)      |         |
| Unknown or None     | 62 (25.4)        | 15 (16.5)    |         |
| Total Charleston Comorbidity Index (CCI) | 2.2 (3.2) | 3.4 (4.0)    | 0.0239  |
| Median (Q1, Q3) of CCI | 1 (0.3)    | 2 (0.6)      |         |
**ACP Rates**

Only 4.5% (n = 16) of the 356 patients admitted with COVID-19 had documentation of ACP prior to their COVID-19 hospital admission, and only 22.8% (n = 81) of patients had documentation of ACP during their COVID-19 admission (see Table 2). Twenty patients (5.6%) had completed and scanned ACP forms within the EHR either before or during admission with only 2.0% (n = 7) of overall patients having a completed MOST form within the EHR. The majority (67%) of patients with documentation of ACP and/or completion of ACP forms were 65 years or older. Palliative care was consulted in 28% (n = 27; P < .0001) of patients who had documented ACP or completed ACP forms either prior to or during hospital admission compared to zero in those without ACP.

**Hospital Course**

About one-fourth of patients (n = 90, 25.2%) died in the hospital and almost half of the patients (n = 151, 42%) spent time in the ICU during their admission with 19% (n = 68) requiring mechanical intubation. Nine patients (2%) required in-hospital CPR during their admission. The majority of patients were full code (n = 326, 91.6%) at the time of admission with 21.6% (n = 77) of patients being DNR at the time of discharge. In patients with documented ACP, 52.4% (n = 55) de-escalated care to DNR (either DNR-F, DNR-L, or DNR-C) during admission compared to only one patient without ACP. Eight (3.2%) of those without documented ACP at discharge were DNR, whereas, 70% (n = 68) of those with either documented ACP or completed ACP forms were DNR at the time of discharge. The majority (82%) of patients without ACP documentation were discharged home. Through multivariable analyses, Table 3 demonstrates that being admitted to the ICU (OR = 11.1, 95% CI = 5.9-21.1, P < .0001), requiring mechanical intubation (OR = 15.4, 95% CI = 7.4-32.1, P < .0001), and being discharged to a location other than home (skilled nursing facility (SNF), long term care (LTC) facility, hospice or expired) (OR = 11.3, 95% CI = 5.7-22.7, P < .0001) was associated with documentation of ACP within the EHR. Results also showed a trend for in-hospital mortality and DNR status at the time of discharge to be associated with ACP documentation. This information was not included in the multivariable analysis due to the low sample size in the non-ACP documentation group. Patients’ length of stay during their COVID-19 admission was not statistically different between those with or without ACP.

**Discussion**

Our study showed that the occurrence of ACP among patients admitted with COVID-19 during the early part of the pandemic (March – June 2020) remains low with only 4.5% of patients having any ACP documented within the EHR prior to admission and only 22.8% during their COVID-19 admission. These were lower rates than was seen by Sun et al in their retrospective study comparing ACP rates for those admitted with and without COVID-19. The patients who had documented ACP within the EHR either prior to or during admission were older (mean age 70.2 years), more likely to be widowed, and had a higher number of comorbidities than patients without ACP. There were no differences seen in gender, race or religious status between those with or without ACP. We did find that having documented ACP or completion of ACP forms was significantly associated with care de-escalation prior to discharge, with 52% (n = 55) of patients de-escalating to either DNR-L or DNR-C. This is consistent with results of ACP trends and end-of-life care in dementia patients, where completion of ACP was associated with a reduced number of life-prolonging interventions. Interestingly, of the patients who had ACP or completion of ACP

### Table 2. ACP Documentation.

|                | 18-64 years (n = 210) | ≥65 years (n = 146) | Overall (n = 356) | P-value |
|----------------|----------------------|--------------------|-------------------|---------|
| ACP Prior to COVID-19 Admission | 4 (1.9)              | 12 (8.3)            | 16 (4.5)          | 0.0046  |
| ACP During COVID-19 Admission    | 28 (13.3)            | 53 (36.3)          | 81 (22.8)         | <.0001  |
| ACP Forms within the EHR         | 5 (2.4)              | 15 (10.3)          | 20 (5.6)          | 0.0014  |
| Medical Scope of Treatment (MOST) Form | 1 (0.5)              | 6 (4.1)            | 7 (2.0)           | 0.0147  |

### Table 3. Multivariable logistic regression for predictors of advance care planning documentation.

|                | No ACP (n = 259) | ACP (n = 97) | Overall (n = 356) | Odds Ratio (95% CI) | P-value |
|----------------|-----------------|-------------|-------------------|---------------------|---------|
| ICU Admission  | 76 (29.7)       | 76 (80.0)   | 152 (43.3)        | 11.1 (5.9,21.1)     | <.0001  |
| Mechanical Intubation | 23 (8.9) | 45 (46.4) | 68 (19.1) | 15.4 (7.4,32.1) | <.0001  |
| Discharge Location |                |             |                   |                     | <.0001  |
| Home           | 210 (82.0)      | 25 (26.0)   | 235 (60.5)        | 1.0                 |         |
| Other          | 46 (18.0)       | 71 (74.0)   | 117 (17.3)        | 11.3 (5.7,22.7)     | <.0001  |
forms prior to hospital admission, only seven patients had repeat ACP discussion during admission, which could be problematic given that goals can change with changing health status. Nevertheless, prior completion of ACP may also result in a less complicated end-of-life treatment course. Bhatia et al. utilized a system-wide ACP approach and found patients who completed ACP prior to hospitalization were less likely to require ICU admission. The majority of our patients (74%) who had documented ACP were discharged to a location other than home. More specifically, 49% of these patients were discharged to hospice or expired, 1% to assisted living, and 24% were discharged to SNF or LTC facilities. These results may be explained by the severity of COVID-19 illness experienced by these patients and their higher risk of morbidity and mortality and highlights the importance of proactive ACP discussion prior to admission for patients with serious illnesses like COVID-19.

The strongest predictor of ACP in recent COVID-19 studies was the receipt of a PCC. In our study, palliative care was rarely consulted, only in 7% of patients admitted for COVID-19; however, all patients (100%) who received a PCC had documented ACP discussions within the EHR. Interesting, but not surprising, none of the patients without ACP had a PCC. In consulted patients, 52% (n = 14) changed their goals to comfort measures, 26% (n = 7) changed their goals to DNR-L, and 22% (n = 6) remained full code. This is similar to what was seen by Sun et al. and Lopez et al.; but despite the benefits of PCC, there continues to be large workforce gaps to meet the needs of these patients. The field of palliative care has grown significantly over the last decade but there still remains a substantial imbalance between the demand of palliative care services and the availability of providers; which was further magnified during the COVID-19 pandemic.

Several studies have been published that have shown the benefit of ACP during the COVID-19 pandemic. Ye et al. showed that proactive ACP conversations increased nursing home residents’ decision to do-not-hospitalize (DNH) from 6% to 52% and that residents with a DNR status also rose from 41% to 88%. Similar results were also seen by Canter et al., which showed a substantial increase in DNR, do-not-intubate (DNI), and DNH orders after ACP conversations. Through a systematic proactive ACP initiative, Berning et al. showed that the use of structured discussion guides and training increased new DNH directives to 39% with only 5% of those orders being revered after diagnosis of COVID-19. In addition, several studies have shown the benefit of the use of telehealth to promote ACP conversations and the completion of forms like electronic medical orders for life-sustaining treatments during the pandemic. Thus, further highlighting the importance of proactive ACP discussion to ensure patients do not receive unwanted medical care along with not placing an unnecessary strain on the healthcare system for patients who do not wish to be re-hospitalized.

Even though the COVID-19 pandemic brought ACP into a new light regarding their urgency and importance, there continues to be several patient, provider, and system barriers that often limit ACP discussions and documentation as was highlighted in the low rates of ACP seen in our study. The COVID-19 Communication and Care Planning Tool was developed for long-term care residents and their families to provide a structured approach to ACP with specific regard to COVID-19 infection and anticipated outcomes; however, discussions around resuscitations, specifically mechanical intubation, remained difficult. Volandes et al. showed that the use of an ACP video could help increase ACP documentation rates during the COVID-19 pandemic, especially among African Americans and Hispanics; though rates were low with only 23.8% completing ACP. Interestingly enough, though health care teams understood the importance of ACP during the COVID-19 pandemic when patients were surveyed, only 7% of older adults noted that COVID-19 was a motivating factor for having ACP discussions, highlighting the large knowledge gap. Auriemma et al. highlighted the need for adapting ACP conversations for patients with acute vs chronic serious illnesses. Hirakawa et al. commented on the struggle in completing legal documents when many businesses closed or limited their hours. Additional identified barriers included visitor restrictions which may have limited the availability of family and caregivers to participate in ACP, as well as clinician uneasiness in communicating with patients on a novel disease. These concerns further compounded the pre-existing difficulties, including the lack of resources available to providers to guide ACP discussions, lack of information distributed to patients to accurately inform them of treatment choices, inconsistent documentation practices, and patient and provider discomfort with these topics. A study by Grant et al., reviewing public perceptions on ACP, palliative care, and hospice care, showed that most people were aware of ACP (80-90%) but few had either a designated health care agent or ACP documents completed (34%). In addition, they found most people did not know about palliative care (66-71%), and those that did, had misconceptions about it. This could explain the low rates of PCC that we saw in our study. These barriers have also been used to explain poor rates of ACP in previous studies and may also be extended to our study.

Limitations

Our study is not without limitations. This was a single-center, retrospective study, which may affect the generalizability of the results and make it difficult to determine causal effects for the outcomes described. The incidence of ACP discussions and completion of ACP forms was based on documentation within the EHR, which rates could have been higher than was documented and scanned, particularly given the chaotic and stressful nature of providing care during the pandemic. In addition, some of the outside institutions had different EHR
systems; thus also resulting in possible underrepresentation of the occurrence of ACP prior to admission. In addition, this study occurred early during the COVID-19 pandemic, rates, and documentation of ACP may have subsequently changed later during the pandemic. Thus, further studies are needed to compare ACP documentation early within the pandemic versus later to see if there were any substantial changes in practices.

Conclusion

Patients admitted with COVID-19 had low rates of ACP documentation and low rates of PCC. Incidence of ACP was higher in those who were older, who had more comorbidities, and those who were widowed. ACP documentation and PCC were associated with higher rates of care de-escalation when admitted for COVID-19. These findings reinforce the need for pro-active ACP conversations before and during admissions for serious illnesses like COVID-19 along with the need for proactive PCC to improve goal-informed care. Additional work is needed to understand barriers to implementation of ACP to improve the occurrence of ACP discussions and documentation within the EHR during acute illness and to also improve PCC rates for more patients with serious illnesses like COVID-19.

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.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Center for Advancing Translational Sciences (UL1TR001420) and National Institute of Aging (1K23AG070234-01A1).

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