

# Disparities in Palliative Care Among Critically Ill Patients With and Without COVID-19 at the End of Life: A Population-Based Analysis

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## Abstract

**Background:** The surge in critical illness and associated mortality brought by the coronavirus virus disease 2019 (COVID-19) pandemic, coupled with staff shortages and restrictions of family visitation, may have adversely affected delivery of palliative measures, including at the end of life of affected patients. However, the population-level patterns of palliative care (PC) utilization among septic critically ill patients with and without COVID-19 during end-of-life hospitalizations are unknown.

**Methods:** A statewide dataset was used to identify patients aged  $\geq 18$  years with intensive care unit (ICU) admission and a diagnosis of sepsis in Texas, who died during hospital stay during April 1 to December 31, 2020. COVID-19 was defined by the International Classification of Diseases, 10th Revision (ICD-10) code U07.1, and PC was identified by ICD-10 code Z51.5. Multivariable logistic models were fitted to estimate the association of COVID-19 with use of PC among ICU admissions. A similar approach was used for sensitivity analyses of strata with previously reported lower and higher than reference use of PC.

**Results:** There were 20,244 patients with sepsis admitted to ICU during terminal hospitalization, and 9,206 (45.5%) had COVID-19. The frequency of PC among patients with and without COVID-19 was 32.0% vs. 37.1%, respectively. On adjusted analysis, the odds of PC use remained lower among patients with COVID-19 (adjusted odds ratio (aOR): 0.84, 95% confidence interval (CI): 0.78 - 0.90), with similar findings on sensitivity analyses.

**Conclusions:** PC was markedly less common among critically ill septic patients with COVID-19 during terminal hospitalization, compared to those without COVID-19. Further studies are needed to determine the factors underlying these findings in order to reduce disparities in use of PC.

**Keywords:** COVID-19; Sepsis; Palliative care

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## Introduction

Critical illness is common among hospitalized patients with coronavirus disease 2019 (COVID-19) [1] and is associated with high risk of death among those requiring intensive care unit (ICU) admission [1]. The disease and intervention-related burdens associated with critical illness among patients with COVID-19 have been compounded by the pandemic-induced staffing shortages and restriction of hospital visitation, separating patients from their families [2]. The latter trends may have adversely affected provision of concomitant palliative measures throughout the care of critical illness and at the end of life [3].

Palliative care is increasingly considered an integral part of comprehensive care in the ICU [4]. However, barriers to its use among the critically ill remain, driven among other factors, by prognostication uncertainty [5] and physicians' attitudes [6], resulting in use of palliative care predominantly in patients with high risk of death or when death appears imminent [6], though palliative care has been used infrequently even among the latter groups [7].

The substantial burdens affecting patients hospitalized with COVID-19 and their families [8], driven by the high morbidity and mortality of the former, have led to some advocating for use of palliative care for all affected patients requiring hospitalization [9]. Application of these recommendations is especially crucial at the end of life of the critically ill. However, evidence remains scarce on the patterns of palliative care utilization among the latter. The reported frequency of palliative care among critically ill patients with COVID-19 during terminal hospitalizations ranged from 57.7% [10] to 65% [11]. The corresponding palliative care utilization during terminal hospitalizations among critically ill patients in the general population during the pre-pandemic period ranged from 14.8% [12] to 36.1% [13]. However, the generalizability of the COVID-19-related studies is limited by small cohort size, single-centered data, and focus on academic centers. Crucially, comparisons of palliative care utilization patterns between critically ill patients with COVID-19 and historical controls may result in erroneous inferences because the pandemic-induced strains on the healthcare system can be expected to affect processes of care, including use of palliative care, of critically ill patients with and without COVID-19. There have not been, to our knowledge, population-level studies compar-

ing the patterns of palliative care utilization among critically ill patients with and without COVID-19 at the end of life in contemporaneous populations.

Thus, although palliative care would be expected to be deployed similarly, based on needs among critically ill patients at the end of life, irrespective of their COVID-19 status, it is unknown whether palliative care has been used equitably, as inequities in its use are well documented [14, 15]. Better understanding of the patterns of palliative care use among critically ill patients with and without COVID-19 at the end of life can inform future investigations to identify barriers to palliative care utilization, may help reduce disparities in its application, and can guide performance improvement efforts during pandemic periods.

Because the heterogeneity of critical illness may affect perceived need for palliative care, syndrome-based examination of palliative care utilization can enhance group comparisons for studied exposures. COVID-19-related organ failure is increasingly considered as sepsis of viral origin [16], most ICU admissions with COVID-19 are estimated to have sepsis [17], and sepsis due to COVID-19 was assessed as cause of death in nearly all COVID-19 decedents in a recent hospital cohort study [18]. Thus, sepsis is likely a key driver of the burdens of critical illness among patients with COVID-19. Here, we report a population-level association of COVID-19 with use of palliative care among critically ill septic patients during end-of-life hospitalizations during the first year of the pandemic.

## Materials and Methods

### Study design

This was a retrospective, population-based cohort study. Because we used a publicly available, deidentified data set, the study was determined to be exempt from formal review by the Texas Tech Health Sciences Center's Institutional Review Board. The reporting of the study findings follows the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines on reporting observational studies in epidemiology [19].

### Data source

We used the Texas Inpatient Public Use Data File (TIPUDF) to identify the target population. In brief, the TIPUDF is an administrative data set maintained by the Texas Department of State Health Services [20] and includes inpatient discharge data from state-licensed, non-federal hospitals, and captures approximately 97% of all hospital discharges in the state.

### Study population

Our study cohort included patients aged  $\geq 18$  years with a diagnosis of sepsis who were admitted to ICU in acute care hospitals during April 1 - December 31, 2020, and died dur-

ing their hospitalization. Sepsis was identified based on the International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM) codes for severe sepsis (R65.20) or septic shock (R65.21) [21, 22]. Admissions to ICU were identified by unit-specific revenue codes.

### Exposure and outcome

The exposure of interest of the study cohort was a diagnosis of COVID-19, defined by ICD-10-CM code U07.1 [23]. The primary outcome was use of palliative care, identified by ICD-10-CM code Z51.5 [24-26]. Palliative care involves management of physical and psychological symptoms, as well as spiritual and existential distress, prognostication, communication about care goals in relation to patient values and preferences.

### Risk adjustment

We collected data of the following covariates for risk adjustment, based on prior reports [27-29] and clinical plausibility: age, gender, race/ethnicity, primary health insurance payor, comorbid conditions based on the Deyo modification of the Charlson comorbidity index [30, 31], organ dysfunctions [32], use of mechanical ventilation, hemodialysis (Supplementary Material 1, 2, [www.jocmr.org](http://www.jocmr.org)), and hospitals' teaching status.

### Data analysis

Categorical variables were expressed as frequencies and percents, and continuous variables were expressed as mean and standard deviation (SD). The Chi-square and *t*-tests were used for group comparisons of categorical and continuous variables, respectively. We fitted multivariable logistic regression models to estimate the association of COVID-19 with use of palliative care among septic ICU patients during terminal hospitalization, with adjustment for all the abovementioned covariates. Model estimates are reported as adjusted odds ratio (aOR) and 95% confidence interval (95% CI). We probed the robustness of our primary analysis with six sensitivity analyses of both strata associated in prior reports with lower use of palliative care (younger patients (defined in our analyses as those aged  $< 65$  years) [27, 28], males [28], and racial/ethnic minorities [28] (examined as a group, excluding white patients)), and those reported to have increased rates of palliative care (mechanical ventilation [28], higher severity of illness [27] (defined in our analyses as  $\geq 3$  organ dysfunctions), and care in teaching hospitals [27, 29]), compared to a reference category in the cited studies (e.g., lower use of palliative care among males compared to females). We used for sensitivity analyses a similar modeling approach as for our primary analysis. Sensitivity analyses determine how different values (or specific categories) of an independent variable affect a particular outcome (dependent variable) under a given set of assumptions. As such, sensitivity analyses address the uncertainty in the output of primary study models (that is, those examining all

studied subjects). We chose the abovementioned criteria for sensitivity analysis to examine whether the differential patterns of palliative care utilization among septic critically ill patients with and without COVID-19 at the end of life will be affected within strata known from the pre-pandemic period to be associated with disparities in palliative care utilization. We have excluded correspondingly from the models for sensitivity analyses patients' age, gender, race/ethnicity, mechanical ventilation, organ dysfunctions, and hospitals' teaching status, respectively. Thus, the sensitivity analyses examined the association of COVID-19 with use of palliative care among septic ICU admissions within the following separate six patient strata: 1) those aged < 65 years; 2) males; 3) racial and ethnic minorities; 4) those undergoing mechanical ventilation; 5) those with  $\geq 3$  organ dysfunctions; and 6) those managed in teaching hospitals. Data management was performed using Microsoft Excel (Microsoft, Redmond, Washington), and statistical analyses were carried out with MedCalc v20.218 (MedCalc Software, Ostend, Belgium). A two-sided P value < 0.05 was considered statistically significant.

## Results

Among 20,244 patients with sepsis who were admitted to ICU during terminal hospitalization, 9,206 (45.5%) had COVID-19. The characteristics of ICU patients with and without COVID-19 are detailed in Table 1. Compared to those without COVID-19, patients with COVID-19 were older (aged  $\geq 65$  years, 60.8% vs. 60.2%), more commonly male (62.1% vs. 52.9%) and of racial/ethnic minority (66.2% vs. 47.5%), but had lower burden of comorbid conditions (mean (SD): Deyo comorbidity index 1.8 (2.0) vs. 3.4 (2.7)) and lower mean (SD) number of organ dysfunctions (3.8 (1.2) vs. 4.0 (1.3)). The frequency of reported palliative care among critically ill septic patients with and without COVID-19 was 32.0% vs. 37.1%, respectively. Following adjustment for confounders, the odds of palliative care use were 16% lower among patients with COVID-19 (aOR: 0.84, 95% CI: 0.78 - 0.90);  $P < 0.0001$ ). The findings on sensitivity analyses were consistent with the primary analysis (Table 2).

## Discussion

In this population-based study we found that use of palliative care was considerably lower among septic critically ill patients with COVID-19 during end-of-life hospitalizations, compared to those without COVID-19. This comparative underuse of palliative care among patients with COVID-19 was robust across multiple sensitivity analyses.

These findings were unexpected, as palliative care use may be expected to be applied comparably among critically ill septic patients at the end of life, irrespective of their COVID-19 status or, alternatively, at a higher rate among those with COVID-19 [10, 11]. As noted earlier, no prior studies have compared the use of palliative care among critically ill patients vs. without COVID-19 at the end of life in contemporaneous

populations.

The pandemic-driven strains in meeting patients' and families' palliative care needs, with reported volume of palliative care consults increasing four to seven folds in some health care settings [33], took place with pre-pandemic shortages of palliative care clinicians. This unprecedented demand has led to numerous local innovative initiatives (including, among others, virtual palliative care support [34] and embedding palliative care clinicians in ICUs [35]) by critical care and palliative care teams, as well as by hospitals. Our findings suggest, however, substantial gaps at the population level in provision of palliative care to dying critically ill patients with COVID-19, compared to their contemporaries without COVID-19. Nevertheless, there have been no reports, to our knowledge, showing that strains related to shortages of palliative care clinicians were a contributor to inequities in palliative care use between critically ill patients with COVID-19 and their contemporaneous counterparts without COVID-19.

The factors contributing to the relative underuse of palliative care among patients with COVID-19 in this population are unclear and the administrative dataset used in our study precludes direct mechanistic inferences. However, several potential contributors to the observed disparity of palliative care utilization may be considered. First, the widespread pandemic-related restrictions of family visitation have forced a transition of physician-family communication from in-person to electronic means (e.g., telephone, video conferencing). The latter changes have led, not unexpectedly, to reduced quality and frequency of communication on patients' condition, as perceived by both physicians and families [36]. Moreover, the restrictions on visitation were associated with increased mistrust in the healthcare team by families [37, 38], especially during goals of care discussions [39], including concerns about unilateral restrictions of care by physicians [40]. Thus, it was noted that isolation from families had particularly injurious consequences on palliative care [41]. Although restrictions of family visitation have affected families of patients with and without COVID-19, it may be postulated that the resultant family stress and risk of mistrust could have been greater among the former. Such greater stress and mistrust may have stemmed from the novel, incompletely understood disease, with unclear outcome expectations for the resultant critical illness. These latter factors were coupled with lack of a demonstrably effective COVID-19-specific interventions, and uncertainties about clinicians' decision-making, given the widespread discussions about unproven pharmaceutical alternatives in mass media. Against this background, the well-documented pre-pandemic public misconceptions about the role of palliative care in patient care (e.g., "accepting palliative care means giving up"; "if you accept palliative care, you must stop other treatments" [42, 43]) may have further increased mistrust among families of critically ill patients with COVID-19, which could have in turn adversely affected physicians' use of palliative care in these critically ill patients, compared to those without COVID-19.

A second potential contributor to the observed lower use of palliative care among critically ill patients with COVID-19 in this study may have stemmed from the prevalent uncertainty among physicians about prognostication of critically ill patients with COVID-19 [44]. Such uncertainty may have

**Table 1.** The Characteristics of ICU Patients With Sepsis During Terminal Hospitalization, With and Without COVID-19

Variables	COVID-19 <sup>a</sup> (N = 9,206)	Non-COVID-19 <sup>a</sup> (N = 11,038)	P value
Age, years			< 0.0001
18 - 44	516 (5.6)	860 (7.8)	
45 - 64	3,092 (33.6)	3,537 (32.8)	
≥ 65	5,598 (60.8)	6,641 (60.2)	
Gender			
Female	3,489 (37.9)	5,199 (47.1)	< 0.0001
Race/ethnicity			< 0.0001
White	3,112 (33.8)	5,798 (52.5)	
Hispanic	4,258 (46.3)	2,571 (23.3)	
Black	974 (10.6)	1,680 (15.2)	
Other	862 (9.4)	989 (9.0)	
Health insurance			< 0.0001
Private	4,354 (47.3)	4,380 (39.7)	
Medicare	3,149 (34.2)	4,497 (40.7)	
Medicaid	535 (5.8)	832 (7.5)	
Uninsured	631 (6.9)	1,084 (9.8)	
Other	537 (5.8)	245 (2.2)	
Deyo comorbidity index <sup>b</sup>	1.8 (2.0)	3.4 (2.7)	< 0.0001
Selected comorbidities			
Chronic lung disease	1,599 (17.4)	2,348 (21.3)	< 0.0001
Congestive heart failure	2,259 (24.5)	4,294 (38.9)	< 0.0001
Renal disease	2,814 (30.6)	3,714 (33.6)	< 0.0001
Diabetes	5,084 (55.2)	4,239 (38.4)	< 0.0001
Malignancy	400 (4.3)	2,319 (21.0)	< 0.0001
Liver disease	508 (5.5)	1,516 (13.7)	< 0.0001
Number of organ dysfunctions <sup>b</sup>	3.8 (1.2)	4.0 (1.3)	< 0.0001
Type of organ dysfunctions			
Respiratory	9,058 (98.4)	9,594 (86.9)	< 0.0001
Cardiovascular	8,094 (87.9)	10,102 (91.5)	< 0.0001
Renal	7,115 (77.3)	8,104 (73.4)	< 0.0001
Hepatic	1,137 (12.4)	2,354 (21.3)	< 0.0001
Hematological	2,555 (24.5)	3,376 (30.6)	< 0.0001
Neurological	2,998 (32.6)	5,035 (45.6)	< 0.0001
Mechanical ventilation	5,725 (62.2)	6,072 (55.0)	< 0.0001
Hemodialysis	1,511 (16.4)	1,785 (16.2)	0.7012
Teaching hospital	2,834 (30.8)	3,627 (32.9)	0.0014
Palliative care	2,948 (32.0)	4,096 (37.1)	< 0.0001

<sup>a</sup>The parenthesized figures represent percents, except for Deyo comorbidity index and number of organ dysfunctions. <sup>b</sup>Mean (standard deviation). Percentage figures may not add to 100 due to rounding. COVID-19: coronavirus virus disease 2019; ICU: intensive care unit.

prompted physicians, when coupled with the abovementioned challenges in goals of care discussions with families, to keep pursuing aggressive organ support interventions even in the

face of high likelihood of death much longer than for critically ill patients without COVID-19 [45], which may have further reduced use of palliative care in those with COVID-19.

**Table 2.** Sensitivity Analyses of the Use of Palliative Care Among ICU Patients With Sepsis During Terminal Hospitalization, With and Without COVID-19

Patient group	aOR (95% CI) <sup>a, b</sup>	P value
Age < 65 years	0.72 (0.64 - 0.80)	< 0.0001
Male	0.81 (0.74 - 0.88)	< 0.0001
Racial/ethnic minority	0.86 (0.79 - 0.94)	0.0017
Mechanical ventilation	0.86 (0.78 - 0.93)	0.0006
≥ 3 organ dysfunctions	0.85 (0.79 - 0.91)	< 0.0001
Teaching hospital	0.84 (0.75 - 0.95)	0.0054

<sup>a</sup>Adjusted odds ratio (aOR) and 95% confidence interval (CI); Patients without COVID-19 were used as reference group. <sup>b</sup>All estimates are based on multivariable logistic regression models. Models of younger patients, males, racial/ethnic minorities, those undergoing mechanical ventilation, those with ≥ 3 organ dysfunctions, and those admitted to teaching hospitals were performed after exclusion of age, gender, race/ethnicity, mechanical ventilation, organ dysfunction, and hospitals' teaching status, respectively. COVID-19: coronavirus virus disease 2019; ICU: intensive care unit.

Third, an increased physician workload may have contributed to our findings. A recent report by Lin et al [46] showed that the rate of placing a do-not-resuscitate order for ICU patients decreased substantially with an increasing patient-physician ratio. It may be postulated that the increased workload brought by the high number of critically ill patients with COVID-19 during pandemic waves may have affected the propensity of physicians to address the palliative care needs of these patients, compared to those without COVID-19, whose numbers have decreased [47, 48].

Last, and perhaps more foundational contributor to the lower use palliative care for the critically ill patients with COVID-19 at the end of life may have been the well-documented rise in mental stress, emotional exhaustion [49] and, critically, related burnout among physicians during the pandemic [50], reported to affect especially those caring for patients with COVID-19 [50, 51], including among those working in the ICU [52]. Burnout is known to affect the quality of care delivered by physicians [53], as well as their empathy [54]. The latter consequences of burnout may have impacted care priorities of affected clinicians tasked with caring for critically ill patients with COVID-19 toward those requiring less emotional engagement, possibly resulting in lower use of palliative care.

Our findings have important implications for health policy and clinical practice. Although the COVID-19 pandemic has been officially declared to be over in the United States, concerns about its resurgence and, as importantly, new infectious pandemics remain. Our findings suggest critical need to re-examine public health policy on infection control during pandemic periods to avoid the downstream adverse impact of restrictions of hospital visitation policies deployed extensively during the early phases of the COVID-19 pandemic to help contain spread of the infection. Similarly important will be efforts to more effectively mitigate the foreseeable impact of pandemic-related strains on health care systems, with the re-

sultant widespread effect on healthcare teams' well-being and risk of burnout. In addition, steps to improve future communication by public health authorities and other government organizations about pandemic-related issues are sorely needed to address the widely documented public uncertainties and mistrust, which can adversely impact population health in general, as well as patients' families and patient care.

Our study has several strengths. It is the largest study to date, to our knowledge, to examine the patterns of palliative care utilization among critically ill patients with and without COVID-19 at the end of life, capturing a cohort in a state with a large (over 29 million), diverse population. The use of a statewide, all-payer, high-quality data set of consecutive hospitalizations allowed transcending local variation in case mix and practice patterns. We adhered closely to reporting guidelines and used statistical methods to limit confounding and enhance trustworthiness in measures of association.

The study has, however, important limitations, mostly related to the retrospective design and use of administrative data. First, the use of ICD codes may have led to group misclassifications. However, there have been no reports, to our knowledge, indicating that coding of palliative care use differs systematically among critically ill patients with and without COVID-19. Second, our data set does not include information on palliative care processes and delivery methods, other specific end-of-life care interventions, and clinicians' decision-making. Thus, we cannot exclude residual confounding in our models. Last, the generalizability of our findings to other states and regions is unknown.

## Conclusions

Use of palliative care was markedly lower among septic critically ill patients with COVID-19 during terminal hospitalization, compared to those without COVID-19. This gap in use of palliative care at the end of life in patients with COVID-19 persisted within patient groups previously noted to have either lower or higher use of palliative care than reference categories. Further studies, using more granular data are needed to determine the factors underlying our observations in order to inform future strategies to increase use of palliative care and to reduce disparities in its use in the critically ill.

## Supplementary Material

**Suppl 1.** International Classification of Diseases, Tenth Revisions, Clinical Modification (ICD-10-CM) codes used to identify organ dysfunctions.

**Suppl 2.** International Classification of Diseases, Tenth Revisions, Procedure Coding System (ICD-10-PCS) codes used to identify procedures.

## Acknowledgments

None to declare.

## Financial Disclosure

None to declare.

## Conflict of Interest

None to declare.

## Informed Consent

The study was based on publicly available deidentified data and thus considered by the Texas Tech University Health Sciences Center's IRB exempt from formal review, and the need for an informed consent requirements were waived by the IRB.

## Author Contributions

Conceptualization, data curation, formal analysis, methodology, project administration, resources, software, supervision, validation, writing - original draft, writing - review and editing: LO.

## Data Availability

The data supporting the findings of this study have been deposited in the Texas Inpatient Public Use Data File, created by the Texas Health Care Information Collection Center, Texas Department of State Health Services for Health Statistics.

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