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Abstract

Background: Despite the very high symptom burden, palliative care (PC) services are underutilized in patients with End-stage liver disease (ESLD). Herein, we investigated the disparities in the utilization of PC services among patients with ESLD hospitalized in the United States.

Method: We conducted a retrospective cohort analysis by utilizing the Nationwide Inpatient Sample from 2016 to 2020. All patients greater than 18 years old admitted with ESLD were included in the analysis. A multivariate logistic regression model predicting referral to PC was created.

Results: In our analysis, significant racial disparities were observed in the utilization of palliative care services among hospitalized patients with end-stage liver disease (ESLD). Specifically, Hispanic patients were less likely to receive palliative care consultations compared to White and African American patients, with utilization rates of 15.83%, 17.26%, and 17.23% respectively (p < 0.01). Additionally, disparities extended to hospitalization duration and costs; Hispanic patients experienced longer hospital stays (average 22 days) compared to Whites (average 20 days, p < 0.01) and incurred higher hospitalization costs (\$76,104 for Hispanics vs. \$66,737 for Whites and \$67,209 for African Americans, p < 0.01). Notably, mortality rates among patients receiving palliative care were significantly higher across all racial groups compared to those not receiving palliative care (52.76% for Whites vs. 13.95%, 55.45% for African Americans vs. 19.95%, 55.19% for Hispanics vs. 19.03%, all p < 0.01), which likely reflects the selection of patients with more advanced disease for palliative care.

Conclusion: There are significant racial disparities in the use of PC services. Further research on the causes of racial disparities is needed to improve access to PC services for the vulnerable ESLD population.

Keywords

End-stage liver disease, Palliative care, Racial disparities, Underutilization

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Conflict of Interest Statement

None

ARTICLE

Exploring Disparities in Palliative Care Utilization for Patients With End-stage Liver Failure: A Nationwide Cohort Analysis (2016–2020)

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Abstract

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Conclusion: There are significant racial disparities in the use of PC services. Further research on the causes of racial disparities is needed to improve access to PC services for the vulnerable ESLD population.

Keywords: End-stage liver disease, Palliative care, Racial disparities, Underutilization

E nd-stage liver disease (ESLD) is a life-threatening condition with severely debilitating symptoms and limited treatment options.¹⁻³ The prognosis for patients with ESLD is highly variable depending on the compensated versus decompensated status, etiology, and severity of the disease itself. However, with unpredictable complications,

ESLD has a poor trajectory owing to progressive functional decline and a high risk of mortality.^{4–6}

Palliative care (PC) is a specialized medical care service that focuses on symptom relief, improving the quality of life for patients with serious chronic illnesses.⁷ The goal of PC is to provide comfort and relief from physical distress, as well as the stress and

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emotional strain that patients and their families may experience.⁸ Studies have shown that palliative care intervention correlates with the reduction of symptom burden, depression scores, and overall nonmortality-related outcomes.⁹ Despite the benefits of PC, it is an often underutilized service in patients with ESLD.¹⁰

Previous research has demonstrated notable disparities in the utilization of palliative care (PC) services among patients with serious illnesses such as COPD, various cancers, and ESRD.¹¹ Data is limited regarding PC utilization in the context of ESLD and the few studies that have been conducted have shown poor usage of palliative care for patients suffering from ESLD.¹² There is a significant dearth of attention to the palliative care needs of patients suffering from ESLD as well as their attendants. In 2022, a study was conducted that laid out the guidelines for how to go about the palliative care route in patients with cirrhosis and concluded that palliative care needs to be made available to more patients in a more timely manner.¹³ It has also been documented that patients with ESLD have a high healthcare utilization rate at the end of life with a paucity of hospice and palliative care referrals and utilization.¹⁴ This study aims to investigate potential disparities in PC service utilization among hospitalized patients with ESLD in the United States.

 Table 1. The international classification of diseases, 10th revision, clinical modification (ICD10-CM) codes.

Diagnosis	ICD-10
End Stage Liver Failure	K72
Palliative Care Consult	Z515
Do Not Resuscitate Status	Z66

1. Method

We obtained our study population from the National Inpatient Sample (NIS) dataset (2016-2020), which is part of the Healthcare Cost and Utilization Project (HCUP) supported by the Agency for Healthcare Research and Quality (AHRQ).¹⁵ The NIS is the largest publicly accessible healthcare database in the United States for inpatient encounters and contains a representative sample of 20% of non-federal US community hospitals, covering almost 95% of the US population.¹⁶ The dataset includes approximately 7 million unweighted records and roughly 35 million weighted hospital encounters annually, enabling us to estimate national figures.¹⁶ The NIS uses de-identified hospital discharges as samples, with prior approval from an ethical committee, eliminating the need for Institutional Review Board (IRB) approval in this study.

2. Study cohort

To identify patients with End Stage Liver Failure (ESLF) who were 18 years or older, we utilized the International Classification of Diseases, 10th Revision, Clinical Modification (ICD10-CM) codes, which are listed in Table 1. ICD-10 codes have been shown to yield a positive predictive value of 92.8% for cirrhosis,¹⁷ which is an improvement from the ICD-9 codes which were associated with an 85.7% positive predictive value for detecting end-stage liver disease in a previous study.¹⁸ We also categorized patients into four racial groups, as depicted in Table 2. Palliative care referral was identified using the ICD-10-CM code Z515 (encounter for palliative care), which has demonstrated high validity in other

Table 2. Disparities in-hospital outcomes of end stage liver failure patients with palliative care collaboration: A nationwide cohort analysis (2016–2020).

	Whites (176,950, 61.81%)	African Americans (47,975, 16.76%)	Hispanics (38,670, 13.51)	Others (16,610, 3.7 1)	P Value
Age (Median, IQR)	64 (55-72)	62 (53-70)	61 (50-70)	62 (52-72)	0.0007
Female	41.43%	43.10%	37.34%	40.11%	< 0.0001
Palliative Care Consult	17.26%	17.23%	15.83%	17.86%	< 0.0001
Do Not Resuscitate Status	61.97%	16.45%	13.79%	3.87%	< 0.0001
In Hospital Mortality with	52.76%	55.45%	55.19%	57.78%	< 0.0001
Palliative Care Consult					
In Hospital Mortality without	13.95%	19.95%	19.03%	21.11%	< 0.0001
Palliative Care Consult					
Disposition					< 0.0001
Routine	3.52%	3.93%	5.40%	3.43%	
Transferred To Other Hospital	30.84%	30.09%	23.63%	25.86%	
SNF/ICF Transfer	29.48%	28.33%	22.49%	24.80%	
Home Health Care	12.61%	10.47%	15.54%	12.40%	
LOS (Median, IQR)	20 (17-28)	21 (17-29)	22 (17-30)	21 (17-31)	< 0.0001
Total Hospitalization Cost in USD (Median, IQR)	66,737.85 (40,935.84– 111,002.50)	67,209 (43,297.78– 115,589.58)	76,104.63 (4722.90– 131,422.13)	78,526.08 (48,193.83– 145,696.15)	<0.0001

studies, with 84% sensitivity and 98% specificity in an analysis of veterans' administrative data.^{19,20}

We collected demographic data and information on palliative care consultations, as well as data on code status, comorbidities, in-hospital mortality, disposition, length of hospital stay, and duration of hospitalization.

3. Data analysis and statistics

We used survey procedures with discharge weights provided in the HCUP-NIS database to generate national estimates. Descriptive statistics were presented as frequencies with percentages for categorical variables and as medians with interquartile ranges for continuous variables. We compared baseline characteristics using the Pearson x2 test and Fisher's exact test for categorical variables and the Mann-Whitney U Test for continuous variables, presented as the median and interguartile range (IQR). We determined statistical significance using a two-tailed p-value of <0.05. We followed the analysis methodology recommended by the NIS-HCUP as described in previous studies.²¹ All statistical analyses, including propensity matching, were performed using SAS 9.4 (SAS Institute, Inc., Cary, North Carolina).

4. Results

4.1. Baseline characteristics

We analyzed a total of 280,205 hospitalizations in patients with end-stage liver disease (ESLD). The majority of these patients were white (61.81%), followed by African Americans (16.76%), Hispanic (13.51%), and other races (3.71%). The mean age of ESLD patients was 62 years, and approximately 40% of the patients were female.

4.2. Low utilization of palliative care services

Palliative care (PC) consultation was only noted in 17% of ESLD patients receiving PC. In the PC group, the inpatient mortality rate was 52.76% for whites, 55.45% for African Americans, and 55.19% for Hispanics. Meanwhile, in the no-PC group, the inpatient mortality rate was 13.95% for whites, 19.95% for African Americans, and 19.03% for Hispanics.

4.3. Racial disparities in the provision of palliative care and expression of resuscitation status

Our analysis revealed that Hispanic patients were less likely than white and African American patients to receive palliative care services (15.83% compared to 17.26% and 17.23% for white and African American, respectively; p < 0.01). Furthermore, compared to whites and other ethnicities, Hispanics and African Americans were less likely to have a do-not-resuscitate (DNR) status (61.97% for whites versus 16.45% for African Americans and 13.79% for Hispanics, p < 0.01).

4.4. Racial disparities in length of stay, hospitalization costs, and disposition plans

The Hispanic patient population also had significantly higher lengths of stay in the hospital (22 days in Hispanics versus 20 days in the White population, p < 0.01). Total hospitalization cost was also significantly higher (p < 0.01) in Hispanics (76,104 United States Dollars) compared to the White (66,737 United States Dollars) and African Americans population (67,209 United States Dollars).

Additionally, our analysis revealed that compared to whites, African Americans, and other ethnicities, Hispanics were less likely to be referred to other hospitals or skilled nursing facilities and more likely to be discharged home. For example, only 12.61% of whites were discharged home, compared to 15.54% of Hispanics who were referred for home health care services. Table 1 provides a summary of our findings.

5. Discussion

Despite the high symptom burden and expensive trajectory of ESLD, PC services were only utilized in 17% of patients with ESLD. Hispanic patients had lower palliative care utilization, and longer hospital stays with higher costs than white and African American patients. They were also less likely to have a do-not-resuscitate status and more likely to be discharged home than whites. This data demonstrates differences exist in the utilization of palliative care services between different racial groups.

The negative impact of underutilization of palliative care services in the management of ESLD patients has been reported in the literature.^{22,23} For instance, Rossaro et al. discovered that patients removed from the liver transplant list often do not receive palliative and hospice care, leading to feelings of abandonment and a rapid decline in health.²⁴ Moreover, there is a lack of defined best practices in the care of ESLD patients and utilization of PC services since clinical indicators of advanced liver disease are not included in the Gold Standards Framework, a UK guideline that focuses on endstage illnesses such as cardiac, pulmonary, renal, and neurologic diseases.²⁵ This indicates numerous opportunities for exploring palliative care in the context of ESLD.

Rogal et al. conducted a study in 2022 that laid out guidelines on when a patient needs to be referred for palliative care. It was delineated in this publication that palliative care can go side by side with life prolonging treatments and that it is not synonymous with hospice care in any way.¹³ They also emphasized the imperative role that hepatologists need to play in palliative care to improve outcomes for patients with ESLD and clarified that patients can be introduced to palliative care at any stage of their illness.¹³ In a different study conducted by Poonja et al., it was concluded that patients who were taken off the liver transplant waitlist were very infrequently referred for palliative care despite a significant symptom burden at the end of life.²⁶ In literature, palliative care has constantly been found to be underutilized in both patients receiving curative treatments as well as those with guarded prognoses.

The lower likelihood of Hispanic patients receiving palliative care (PC) services compared to White and African American patients aligns with previous studies that showed racial disparities in PC utilization across healthcare settings. It was discovered by Smith AK et al. in a study published in 2008 that Hispanics and African Americans were less likely to acknowledge their terminal prognosis and more likely to request futile life prolonging treatments.²⁷ It was reported in another study that non-white ethnicities had a greater mistrust of healthcare services and were less likely to opt for life-shortening palliative drugs. Hispanics and African Americans were more likely to spend their last days in the hospital rather than in palliative care facilities or hospice through personal choice.²⁸ Concerns arise regarding equitable access to endof-life care and its potential impact on patient outcomes,^{29,30} as highlighted by Born et al.'s study on knowledge, attitude, and benefits of end-of-life care in Hispanic and African American patients. This study reported low utilization of hospice due to a lack of awareness, with language barriers reported by Hispanics and mistrust of the system reported by African American patients.³¹

The hospital stay duration was significantly longer in Hispanic patients compared to the White population, potentially due to delayed access to palliative care (PC) services. This delay could also contribute to the higher hospitalization costs observed among Hispanics, as PC services have been shown to reduce healthcare expenses for patients with advanced illnesses. These findings indicate that earlier access to PC services can enhance the quality of life for ESLD patients and generate cost savings for healthcare systems. In a 2009 study by Henchate et al., average end-of-life care costs were \$20,166 for white individuals, \$26,704 for African American individuals (a 32% increase), and even higher at \$31,702 (a 57% increase) for Hispanics.³²

Racial disparities in ESLD care have significant implications for healthcare providers and policymakers. Among the contributing factors are substantial disparities in accessing palliative care (PC) services, particularly affecting Hispanic patients who are at higher risk of being underserved.³³ To address these disparities, interventions such as cultural sensitivity training, patient education, and strategies to overcome language barriers can be implemented.³³ The provision and acceptance of palliative care has also been hindered by the stigma that agreeing to palliative care is akin to foregoing curative treatment. Additionally, healthcare provider biases, limited awareness of PC services among patients, and systemic inequities are identified as key factors. Better provider education and training can play a significant role in imparting palliative care when needed.^{10,13} Hawley's review suggests that "rebranding" PC to focus on early integration and improved communication with patients and caregivers, using visual representations, could help bridge gaps in understanding.³⁴ Furthermore, cultural and spiritual variances may influence decisions to abstain from life-sustaining procedures.³⁵ By recognizing and actively addressing these barriers, healthcare providers and policymakers can work collaboratively to mitigate racial disparities and ensure equitable access to PC services for all individuals diagnosed with ESLD, calling for further research in this area.^{10,33–37}

While the use of a nationally representative sample allows for power and generalizability, this study has limitations. The NIS database is based on hospitalization data, potentially leading to multiple admissions for the same patient and overestimating the rate of palliative care referral. Coding errors are also possible due to the use of ICD-9-CM codes. The NIS captures inpatient data only, omitting post-discharge information such as outpatient palliative care encounters and mortality. The database does not provide insights into clinicians' or patients' preferences, religious and cultural influences, and residual confounding factors cannot be ruled out. These limitations should be considered when interpreting the findings, and future research should address these gaps by using comprehensive patient-level data and incorporating qualitative research methods.

6. Conclusion

Our study highlighted the significant racial disparities in the utilization of palliative care services among patients with end-stage liver disease in the United States. Efforts to improve palliative care utilization for all ESLD patients, particularly for Hispanic patients who are at a higher risk of being underserved are warranted. Further research is needed to identify the underlying causes of these disparities and develop targeted interventions to improve access to PC services for this vulnerable patient population.

Funding and Conflict of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Authors contribution

SM: Conception of study idea.

SM, MF: Collection and curation of data.

SM, MF: Data analysis and statistics.

SM, AS: Drafting of initial manuscript and editing. All authors: Reviewing, editing for intellectual content and final approval of manuscript.

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