Original Article

Outcomes of Palliative Care Consultations for Hospitalized Patients With Liver Disease

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Abstract

Context. Although palliative care (PC) has been shown to improve symptoms and end-of-life (EOL) care for patients with cancer, data are lacking on the patterns of use and outcomes of PC consultations for hospitalized patients with liver disease.

Objectives. We sought to characterize the patterns of use and outcomes of PC consultations for hospitalized patients with liver disease compared with patients with cancer.

Methods. We conducted an observational study using data from the Palliative Care Quality Network (PCQN). The PCQN contains prospectively collected data on 135,197 hospitalized patients receiving PC consultations at 88 PCQN sites between January 2013 and December 2017. The PCQN data set includes patient demographics, processes of care, and patient-level clinical outcomes.

Results. The cohort included 44,933 patients, of whom 4402 (9.8%) had liver disease and 40,531 (90.2%) had cancer. Patients with liver disease were younger (58.9 years vs. 65.2 years, $P < 0.0001$) and had higher in-hospital mortality (28% vs. 16.8%, $P < 0.0001$). Patients with liver disease were more likely to receive PC consultations to address goals of care (81.7% vs. 67.9%, $P < 0.0001$) as opposed to pain management (10.9% vs. 34.9%, $P < 0.0001$). Both groups had similar rates of symptom improvement and change in resuscitation preferences after PC consultation.

Conclusion. Hospitalized patients with liver disease were more likely to have a PC referral to address goals of care compared with those with cancer and were more likely to die in the hospital. Despite late PC consultations, patients with liver disease experienced improvement in symptoms and clarification of their goals of care, similar to those with cancer.   J Pain Symptom Manage 2019;58:766−773. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words
Palliative care, cirrhosis, cancer, advance care planning, symptom management

Introduction

Liver disease is the 12th leading cause of mortality in the United States, resulting in almost 40,000 deaths in 2016.[1,2] Owing to symptoms such as fatigue, pruritus, muscle cramps, and pain, as well as complications such as ascites, hepatic encephalopathy, and variceal bleeding, patients with liver disease have a high symptom burden and limited life expectancy in the absence of liver transplantation.[3–7] In addition, patients with advanced liver disease such as decompensated cirrhosis are frequently hospitalized during the last

month of life and often receive intensive life-sustaining therapies such as mechanical ventilation and renal replacement therapy during their terminal hospitalizations.[8–14] As such, patients with liver disease often experience poor quality of life and aggressive medical care at the end of life (EOL).

Given their significant morbidity and mortality, patients with liver disease have substantial palliative care (PC) needs, but they are rarely referred to specialty PC services.[13–16] Although strong evidence exists demonstrating that inpatient PC can improve symptom burden and quality of life for hospitalized patients with cancer, it remains unknown if similar improvements in symptom burden and quality of life occur for hospitalized patients with liver disease receiving PC consultations.[17–21] Moreover, patterns of PC use for hospitalized patients with liver disease are currently unknown. Although recent data from national observational studies have shown that PC consultations during the terminal hospitalizations of patients with liver disease are associated with lower health care utilization and costs, further work is needed to characterize the specific contribution of PC consultations to the improvement of other outcomes in this population.[15,22]

Using data from the Palliative Care Quality Network (PCQN), a national PC quality improvement collaborative, we sought to characterize current patterns of use and outcomes of PC consultations for hospitalized patients with liver disease compared with patients with cancer.

Methods
The Palliative Care Quality Network
The PCQN is a national collaborative of interdisciplinary PC teams in the United States collecting standardized data to benchmark processes of care and patient-level outcomes to identify best practices and promote quality improvement.[23] As of December 2017, there were 88 teams in 17 states collecting and submitting data. PCQN member teams come from hospitals that vary in size (mean: 379 beds, range: 48–1126) and type (not-for-profit: 66%, teaching: 19%, public: 9%, for-profit: 1%, and other: 4%). For the purposes of the PCQN, a PC consultation is defined as the series of PC visits that occur for a single adult (age ≥ 18 years) patient during a single hospitalization.

Study Procedures
The data for this observational study were extracted on March 6, 2018, and include 135,197 patient encounters conducted by 88 PCQN member teams between January 1, 2013, and December 31, 2017. The study was reviewed and approved by the University of California, San Francisco Institutional Review Board (#16-18596).

Data Elements
The 23-item core PCQN data set includes patient demographics and clinical information, actions taken by the PC teams in the course of patient care, and patient-level clinical outcomes prospectively collected by PCQN members for every patient seen for an inpatient PC consultation.

Patient demographic and clinical information includes age, gender, primary diagnosis, location at the time of referral (e.g. medical/surgical unit, telemetry/stepdown unit, critical care unit, and others), and functional status as measured by the Palliative Performance Scale score (higher scores indicate greater physical ability).[24] In the PCQN database, the PC clinician records the primary diagnosis prompting the referral. Data regarding patients with many different primary diagnoses are represented in the PCQN, including cancer, liver disease, heart disease, pulmonary disease, renal disease, neurological conditions, and others. In this study, we compared data for patients for whom liver disease was the primary condition prompting the PC consultation to those patients with cancer. In the PCQN data set, liver disease is defined as the presence of end-stage liver disease, cirrhosis, acute liver failure, hepatitis B, hepatitis C, primary biliary cholangitis, and other primary hepatic conditions, whereas cancer is defined by the presence of a solid tumor in any organ regardless of the stage of disease.

In the PCQN database, PC process measures include date of the PC referral and reason(s) for the PC consultation categorized as discussing advance care planning (ACP) and goals of care (GOC), symptom management, withdrawal of life-sustaining interventions, transition to comfort care, hospice referral, and providing patient/family with emotional and/or spiritual support. Multiple reasons for the PC consultation could be documented by the PC team. In addition, members of the PC team used screening questions directed at hospitalized patients and/or their families to identify PC needs at the time of consultation. PC needs were categorized as 1) symptom management, 2) psychosocial concerns, 3) spiritual concerns, and 4) ACP/GOC. Members of PCQN teams also documented when screening for PC needs was not possible because of patients' inability to communicate and/or their families declining or being unavailable for the discussion. Multiple PC needs could be screened by the PC team during the initial consultation.

PCQN members also collected data on resuscitation preferences during the hospitalization, as well as the

completion of ACP documents such as advance directive (AD) and physician orders for life-sustaining treatment (POLST) forms. Data on services arranged at the time of hospital discharge, including referrals to hospice, home-based PC, outpatient PC, and home health care, were also collected.

Patient-level clinical outcomes data include the following: 1) patient-reported symptom severity scores for pain, anxiety, shortness of breath, and nausea assessed daily by the PC team during hospitalization on a four-point scale ranging from none to severe; 2) resuscitation preferences at the time of PC consultation and at discharge; 3) survival to hospital discharge; and 4) disposition.

Because the PCQN is used primarily for quality improvement and data are collected by clinicians in the course of usual care, not all 23 data elements are entered for every patient seen. There is no effort to obtain missing data. A full list of the PCQN data elements is available at www.pcqn.org.

Statistical Analysis

Descriptive statistics including frequencies, means, and standard deviations (SDs) were used to examine the distribution of measures. Chi-squared (χ^2) analysis was undertaken to examine bivariate associations between categorical variables, and analysis of variance was undertaken to examine associations between categorical and continuous variables. McNemar-Bowker test was conducted to examine change in resuscitation preferences, which were defined as full (patient preference was to receive all available resuscitative efforts including chest compressions, cardioversion, and intubation), do not resuscitate and do not intubate (DNR/DNI), and partial (any limitation in resuscitation efforts short of DNR/DNI status) from first consultation to discharge. We defined improvement in symptom severity as an improvement by at least one level of severity within 72 hours in patients who reported moderate or severe symptoms at the initial PC assessment.[25,26] For all analyses, an alpha of <0.05 was used to determine statistical significance. There was no adjustment or imputation for missing data; analyses were performed only for patients for whom data were available for each specific data element. The Statistical Package for the Social Sciences, version 23, for Mac was used to conduct all analyses.

Results

Patient Characteristics

The cohort included 44,933 patients, of whom 40,531 (90.2%) had cancer and 4402 (9.8%) had liver disease as the primary diagnosis leading to PC consultation. Patients with liver disease were younger

(58.9 years vs. 65.2 years, $P < 0.0001$), had lower Palliative Performance Scale scores (34.6 vs. 42.3, $P < 0.0001$), and a higher percentage were men (59.6% vs. 49.1%, $P < 0.0001$) compared with patients with cancer (Table 1). Patients with liver disease were more likely to receive PC consultation in the critical care unit compared with those with cancer (27.9% vs. 12.5%, respectively). Patients with liver disease were significantly less likely to have an AD (14.7% vs. 21.2%, $P < 0.0001$) in the medical record at the time of the initial PC consultation.

Reasons for PC Consultation

As compared with patients with cancer, patients with liver disease were significantly more likely to receive a PC consultation to address GOC/ACP (81.7% vs. 67.9%, $P < 0.0001$), withdrawal of life-sustaining interventions (3.5% vs. 1.5%, $P < 0.0001$), and transition to comfort care (7.6% vs. 5.6%, $P < 0.0001$). Patients with liver disease were significantly less likely to receive a PC consultation for pain management (10.9% vs. 34.9%, $P < 0.0001$) or other symptom management (10.2% vs. 21.7%, $P < 0.0001$).

Processes of Care

As shown in Table 2, patients with liver disease were less likely to be screened for pain (80.5% vs. 88.4%, $P < 0.0001$) and nonpain symptoms such as anxiety, nausea, and dyspnea (80.2% vs. 85.6%, $P < 0.0001$) but were more likely to be screened for ACP/GOC needs (93.6% vs. 90.4%, $P < 0.0001$). There were no differences in the rates of screening for psychosocial and spiritual needs between the patient populations.

Among those patients with liver disease who underwent symptom assessment screening during the initial PC consultation, 27.4%, 10.3%, 3.6%, and 5.8% reported moderate-to-severe pain, anxiety, nausea, and dyspnea symptoms, respectively. The proportion of patients with cancer who reported moderate-to-severe pain, anxiety, nausea, and dyspnea symptoms were 41.8%, 15.1%, 9.1%, and 10%, respectively.

Timing and Outcomes of PC Consultations

Timing and outcomes of PC consultations are shown in Table 3. Patients with liver disease had a significantly longer average length of stay in the hospital before the PC consult request than patients with cancer (6.8 days vs. 3.4 days, $P < 0.0001$), and they were less likely to receive "early" (within 24 hours of hospital admission) PC consultations than patients with cancer (34.1% vs. 49.0%, $P < 0.0001$). Patients with liver disease were also followed up by the PC service for a longer period of time after initial consultation (6.0 days vs. 5.5 days, $P = 0.02$).

Changes in resuscitation preferences for patients with liver disease and cancer from the time of PC

Table 1
Patient Characteristics at Time of Referral to Specialty Palliative Care for Hospitalized Patients With Liver Disease and Patients With Cancer

Characteristic	Liver Disease	Cancer	*P* value
Patients	*n* = 4402	*n* = 40,531	
Age, mean (95% CI), yrs	58.9 (58.5, 59.3)	65.2 (65.0, 65.3)	<0.0001
Male, *N* (%)	2621 (59.6)	19,879 (49.1)	<0.0001
	n = 3885	*n* = 35,787	
Mean Palliative Performance Scale score (95% CI)	34.6 (34.0, 35.2)	42.3 (42.2, 42.6)	<0.0001
Level of care at time of PC referral, No. (%)	*n* = 4336	*n* = 39,846	<0.0001
Critical care unit	1211 (27.9)	4985 (12.5)	
Telemetry/step-down unit	858 (19.8)	7651 (19.2)	
Medical/surgical unit	1886 (43.5)	21,854 (54.8)	
Other[a]	381 (8.8)	5356 (13.4)	
Reason for PC referral, No. (%)	*n* = 4359	*n* = 39,609	
Goals of care/advance care planning	3562 (81.7)	26,885 (67.9)	<0.0001
Pain management	476 (10.9)	13,839 (34.9)	<0.0001
Other symptom management	445 (10.2)	8587 (21.7)	<0.0001
Withdrawal of interventions	152 (3.5)	611 (1.5)	<0.0001
Assess for transfer to comfort care	330 (7.6)	2236 (5.6)	<0.0001
Hospice referral/discussion	789 (18.1)	6679 (16.9)	0.04
Support for patient/family	985 (22.6)	8291 (20.9)	0.01
Patients with AD at time of PC referral	*n* = 4259	*n* = 38,658	
No. (%)	624 (14.7)	8180 (21.2)	<0.0001
Patients with POLST at time of PC referral	*n* = 4236	*n* = 38,314	
No. (%)	356 (8.4)	3317 (8.7)	0.6
Patients' hospital LOS before PC referral request			
Mean (95% CI), days	6.8 (5.9, 7.7)	3.4 (3.8, 4.0)	<0.0001

AD, advance directive; LOS, length of stay; PC, palliative care; POLST, physician orders for life-sustaining treatment.
[a]"Other" consists of emergency department, labor & delivery, skilled nursing facility, pediatrics, or acute rehabilitation.

consultation to hospital discharge are shown in Figure 1. A large percentage of patients with liver disease and cancer had a significant change in their resuscitation preferences after PC consultation. Overall, 69.4% of patients with liver disease were full code at the time of PC consultation, and only 33.7% were full code at the time of discharge (*P* < 0.0001). Similar changes were seen for patients with cancer (from 64.1% to 32.5%, *P* < 0.0001). At the time of discharge, there were improved rates of ACP documentation in the form of POLST (12.9%) and AD (3.5%) for patients with liver disease, with similar rates of completion seen for patients with cancer.

There were no differences in the proportion of patients experiencing improvement in pain, anxiety, nausea, or dyspnea symptoms after PC consultation between patients with liver disease and cancer (*P* ≥ 0.1).

A significantly higher proportion of patients with liver disease compared with patients with cancer who were seen by PC died during their hospitalization (28% vs. 16.8%, *P* < 0.0001). Patients with liver disease were also less likely to be discharged to home (48.6% vs. 64.7%) and more likely to be discharged to a long-term acute care hospital or extended care facility (20.7% vs. 15.2%). Among patients followed up by the PC service who were discharged home, patients with liver disease were more likely to be referred to hospice (42.2% vs. 38.6%, *P* = 0.008) and less likely to be discharged with clinic-based (3% vs. 12.1%, *P* < 0.0001) or home-based (4.7% vs. 7.1%, *P* < 0.001) PC services.

Discussion

In this study, we examined current patterns of use and outcomes of PC consultations for hospitalized patients with liver disease compared with patients with cancer. Despite being younger on average compared with patients with cancer, patients with liver disease receiving inpatient PC consultations were sicker with poorer functional status, a higher likelihood of being in the critical care unit, and higher in-hospital mortality. These findings verify that patients with liver disease often receive PC referrals late in the course of illness

Table 2
Patients' Symptoms and Needs Screened at the Time of Specialty Palliative Care Referral

Characteristic	Liver Disease	Cancer	*P* value
Pain	*n* = 3073	*n* = 31,985	
No. (%)	2473 (80.5)	28,270 (88.4)	<0.0001
Nonpain symptoms	*n* = 3064	*n* = 31,188	
No. (%)	2457 (80.2)	26,695 (85.6)	<0.0001
Psychosocial issues	*n* = 3223	*n* = 29,504	
No. (%)	2723 (84.5)	24,575 (83.3)	0.08
Spiritual needs	*n* = 2789	*n* = 26,047	
No. (%)	2025 (72.6)	18,858 (72.4)	0.8
Advance are planning/ goals of care	*n* = 3708	*n* = 33,320	
No. (%)	3472 (93.6)	30,109 (90.4)	<0.0001

Table 3
Patient-Level Outcomes After Referral to Specialty Palliative Care

Outcomes	Liver Disease	Cancer	P value
AD completed during PC consultation	n = 4065	n = 37,964	
No. (%)	142 (3.5)	1375 (3.6)	0.7
POLST completed during PC consultation	n = 4064	n = 37,955	
No. (%)	526 (12.9)	4724 (12.4)	0.4
Symptom improvement from 1st to 2nd assessment, No. (%)[a]			
Pain	228 (64.9)	5184 (68.7)	0.1
Anxiety	66 (65.3)	1516 (67.9)	0.6
Nausea	33 (86.8)	1259 (78.7)	0.2
Dyspnea	37 (62.7)	935 (65.9)	0.6
In-hospital death	n = 4212	n = 39,073	
No. (%)	1179 (28.0)	6567 (16.8)	<0.0001
Discharge location, No. (%)	n = 2946	n = 31,777	<0.0001
Home	1432 (48.6)	20,557 (64.7)	
Long-term acute care hospital/extended care facility	609 (20.7)	4816 (15.2)	
Hospital inpatient (PC team signed off before discharge)	456 (15.5)	3246 (10.2)	
Other[b]	449 (15.2)	3159 (9.9)	
Services arranged for patients discharged home, No. (%)	n = 1383	n = 19,588	
Hospice	584 (42.2)	7565 (38.6)	0.008
Clinic-based PC	41 (3.0)	2362 (12.1)	<0.0001
Home-based PC	65 (4.7)	1380 (7.1)	0.001
Home health care	321 (23.2)	4845 (24.8)	0.2
No services	3878 (19.8)	368 (26.6)	<0.0001

AD, advance directive; PC, palliative care; POLST, physician orders for life-sustaining treatment.
[a]Includes patients who reported moderate-to-severe symptoms at the initial PC assessment who reported symptom improvement by at least one level of severity at the second assessment occurring within 72 hours of the initial assessment.
[b]"Other" consists of nonhospital inpatient setting, residential care, and respite/shelter.

to provide assistance when they are closer to death.[16,27] PC consultation for patients with liver disease was more likely to be requested to address EOL care needs such as discussing GOC/ACP, withdrawal of life-sustaining interventions, and referral to hospice, than pain and other symptom management
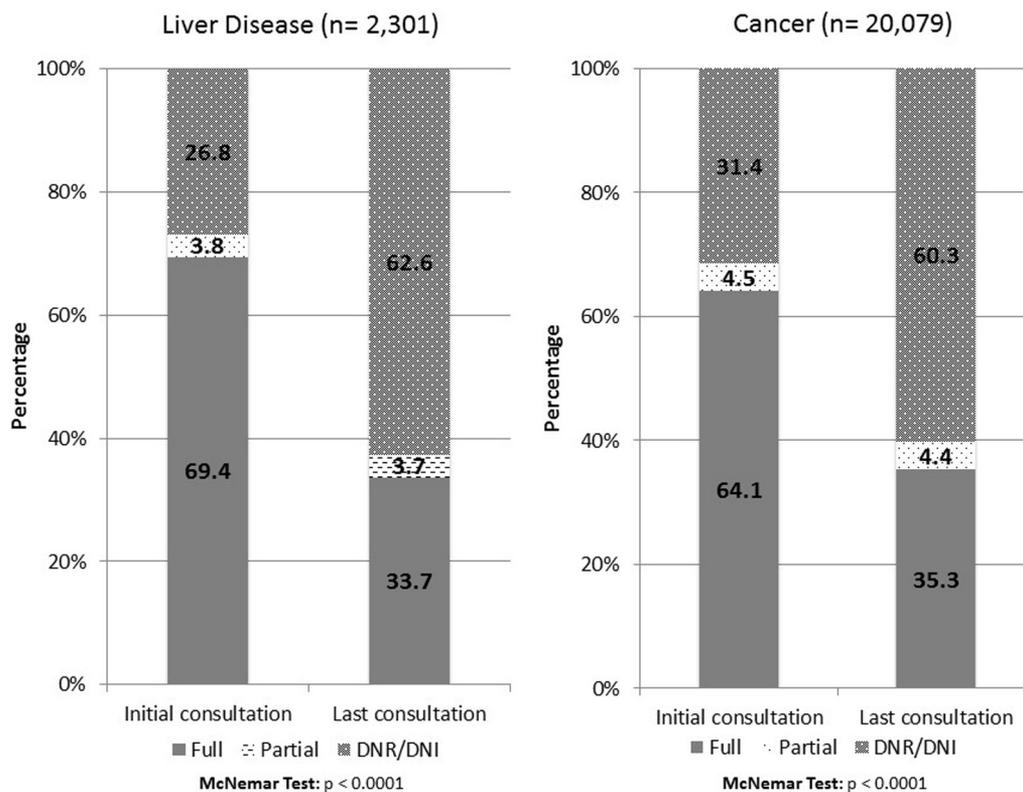

Fig. 1. Change in code status from time of palliative care consultation to hospital discharge for patients with liver disease versus patients with cancer. Partial indicates any limitation in resuscitation efforts short of DNR/DNI status. DNR, do not resuscitate; DNI, do not intubate.

compared with patients with cancer. However, patients with liver disease who received a PC consultation did experience symptom improvement and change in resuscitation preferences, which may suggest a potential supportive role for PC in this population.

Previous studies show and our study confirms that patients with liver disease suffer from substantial physical and psychological symptom distress and poor quality of life.[5,28,29] Despite their high symptom burden and poor functional status, hospitalized patients with liver disease spent twice as long in the hospital (6.8 days vs 3.4 days) before receiving a PC consultation as patients with cancer. As compared with patients with cancer, patients with liver disease may be more likely to present in the setting of an acute deterioration from liver failure, variceal bleeding, sepsis, or hepatic encephalopathy, and thus the most immediate focus of their hospitalization would be on acute management of complications of liver disease, including expedited evaluation for liver transplantation. In turn, patients with liver disease might only be receiving PC consultations once efforts to treat their acute conditions have failed to support transitions to EOL care.[14,16] Few data currently exist showing the benefit of PC involvement in addressing symptom burden in patients with liver disease. However, our study results demonstrate that patients with liver disease reported high rates of moderate-to-severe pain and anxiety symptoms and were equally likely as those with cancer to report symptom improvement, which suggests that reducing the time to PC consultation could improve their quality of care, regardless of their acuity of presentation or transplant eligibility. Given their significant unmet PC needs for symptom management, utilizing inpatient PC services for hospitalized patients with liver disease early and routinely in the illness trajectory, and not just for EOL care, may improve the quality of care delivered to this vulnerable patient population.

Our data demonstrate that despite being relatively young, patients with liver disease receiving inpatient PC consultations represent a very debilitated population receiving intense care with high rates of in-hospital death and substantial EOL care needs. Almost 30% of inpatients with liver disease receiving a PC consultation were seen in the intensive care unit, and they had a mean Palliative Performance Scale score of 34.6 at the time of consultation, corresponding to being completely bedbound and requiring total care.[24] Despite their significant morbidity and higher in-hospital mortality, patients with liver disease had lower rates of ACP documentation at the time of PC referral compared with those with cancer. These findings may be attributed to several important factors. First, liver disease disproportionately affects adults under the age of 65, with recent

striking increases in mortality seen in young adults aged 25−34 due to alcohol-related liver disease.[30] Younger patients with incurable disease may find it difficult to accept the imminent loss of lifetime opportunities, which could delay ACP. Second, patients with liver disease often have an unpredictable clinical trajectory, in which progressive decline is frequently punctuated by acute and life-threatening decompensations due to complications of liver failure.[28,31,32] Thus, the younger age and unpredictable illness trajectory in this population often makes prognostication difficult and may leave these patients and their families with little time to adequately prepare for EOL. Despite this, our findings demonstrate that inpatient PC consultations improved AD and POLST form completion underscoring the potential role of inpatient PC for helping patients with liver disease and their families clarify their preferences for EOL care.[33] Futher randomized trials are needed to demonstrate the impact of PC referrals on ACP documentation in this patient population.

Our study has limitations. For one, we are unable to ascertain the timing of the PC referral relative to the timing of patients' primary diagnosis—patterns of PC utilization may differ between patients presenting with acute vs. chronic disease. Furthermore, because data collection is performed by the PC teams, there may be opportunity for bias in reporting outcomes of PC consultations. Notably, the PCQN database only contains information on patients who received PC consultations during their hospital admissions. As such, information on the PC needs and outcomes of hospitalized patients with liver disease and cancer who were not followed up by the PC team service are not known. In addition, the PCQN inpatient data set does not include information about symptoms such as fatigue, muscle cramps, insomnia, depression, and others that are associated with poor health-related quality of life in patients with liver disease, thereby underestimating the disease burden for these patients.[14,34−36] The PCQN data set is purposely focused on the most prevalent symptoms to reduce the burden of data collection and is not meant to limit the number of symptoms that PC teams assess. Because symptom management is a core tenet of PC practice, it is likely that PC teams evaluate and treat more symptoms than are included in the data set, further supporting the potential benefits of PC consultation for this patient population. Importantly, the database does not include data on patients' transplant candidacy, medical comorbidities, disease complications, social backgrounds, psychosocial support, stage of illness, or Model for End-Stage Liver Disease scores, and additionally, it is unknown whether patients with hepatocellular carcinoma were classified as having liver disease versus cancer. The impact of transplant

candidacy in particular on patterns of PC use for hospitalized patients with liver disease is an important area meriting further study. These data would help us to understand better the needs of specific populations of patients with liver disease and target PC services accordingly. Finally, we did not assess whether patterns of PC utilization differed based on clinical setting, such as academic or community hospitals, an important area that will require future study.

In conclusion, our study demonstrates that hospitalized patients with liver disease receiving a PC consultation were younger on average than patients with cancer and suffered from poorer functional status and higher in-hospital mortality. When compared with patients with cancer, patients with liver disease were more likely to receive a referral to PC later in their hospital course, and consults were requested to address goals of care rather than symptom management. Despite this difference, patients with liver disease referred for PC consultations had similar improvements in their symptoms and documentation of their goals of care as patients with cancer. These data suggest that routine screening of hospitalized patients with liver disease for PC needs and referring those with significant needs to PC teams early in their hospital course may improve symptoms, clarify preferences, and improve the quality of care for this very sick population of patients.

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