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## Low Rates of Advance Care Planning (ACP) Discussions Despite Readiness to Engage in ACP Among Liver Transplant Candidates

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### Abstract

**Background:** Patients with end-stage liver disease (ESLD) awaiting liver transplantation (LT) are seriously ill and experience fluctuating periods of clinical decompensation. Discussion of a patient's advance care planning (ACP) wishes *early* in their dynamic disease course is critical to providing value-aligned care while awaiting LT. We aimed to evaluate current ACP documentation and assess readiness to engage in ACP in this population.

**Methods:** We conducted a retrospective study of adults undergoing LT evaluation from 1/17–6/17 and assessed characteristics associated with documentation using logistic regression. We then administered a survey to LT candidates from 3/18–5/18 to determine self-reported readiness to engage in ACP (range 1=not at all ready to 5=very ready).

**Results:** Among 170 LT candidates, median [interquartile range (IQR)] age was 58 (53–65), 65% were men, MELDNa was 15 (11–21), and Child Pugh A/B/C were 33/38/29%. Nine percent reported completing ACP prior to LT evaluation, but 0% had legal ACP forms or end-of-life wishes documented in the medical record. A durable power of attorney (DPOA) was discussed with 10%. In univariable analysis, white race (OR 4.16,  $p=0.03$ ) and female sex (OR 3.06,  $p=0.04$ ) were associated with ACP documentation, but Child Pugh score and MELDNa were not. Of the 41

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LT candidates who completed the ACP survey, 93% were ready to appoint a DPOA and 85% were ready to discuss end-of-life care.

**Conclusion:** There is a paucity of ACP documentation and identification of DPOA among LT candidates, despite patients reporting readiness to complete ACP and appoint a DPOA. These results reveal an opportunity for tools to facilitate discussions around ACP between clinicians, patients, and their caregivers.

### Keywords

liver transplant; advance care planning; surrogate decision maker; cirrhosis

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## INTRODUCTION

End-stage liver disease (ESLD) is a life-limiting illness associated with frequent hospitalizations, high symptom burden, and poor quality of life.(1–3) Patients with ESLD, characterized by complications of portal hypertension including ascites, variceal hemorrhage, and hepatic encephalopathy, have a poor long-term survival with median survival of 2 years without liver transplantation.(1, 4) Although liver transplantation can be an effective treatment for these complications, up to one in four patients awaiting liver transplantation die prior to transplant or become too sick for transplant.(5) Moreover, the clinical course of ESLD is one of gradually increasing disability with progressive fatigue, confusion, fluid retention, and muscle wasting that is punctuated by erratic episodes of severe decline.(6) This makes prognostication challenging given that death can seem likely during any acute health deterioration, and highlights the need for nuanced advance care planning (ACP) in this population.

ACP refers to the discussion of care preferences, values, and goals at end-of-life, as well as appointment of a substitute decision-maker.(7, 8) Early conversations on ACP and designation of a substitute decision-maker are critical in patients with ESLD who often suffer from hepatic encephalopathy which can lead to impaired decision-making, and acute declines in health that can be unpredictable.(6) Additionally, most discussions among patients with ESLD undergoing liver transplantation evaluation are focused on curative therapies with the intent to reach liver transplantation. While this may be true for a patient at the time of listing who has a high quality of life, this may change for a patient who is no longer well enough for liver transplant or is removed from the waitlist. Traditionally, successful ACP has only been measured by completion of an advance directive, however several studies have shown that ACP is complex and involves many behaviors from patients such as choosing a surrogate decision maker, discussing values with surrogates and clinicians, as well as completing advance directives.(9, 10) In this study, we aimed to: 1) evaluate ACP documentation practices at a liver transplant center and 2) assess readiness to engage in discussions on ACP among liver transplantation candidates.

## PATIENTS AND METHODS

Given the two distinct goals in this study, we analyzed data from two different cohorts for each study aim. The following study cohorts assessed were as follows:

1. ACP documentation for liver transplant candidates: Medical charts were consecutively reviewed and sampled for adults ( 18 years) with ESLD undergoing initial liver transplantation evaluation from January 2017 to June 2017 at a single high-volume liver transplantation center.
2. Engagement around ACP among liver transplant candidates: Adults ( 18 years) with ESLD undergoing initial evaluation for liver transplantation were recruited for the study from March 2018 to May 2018 at a single high-volume liver transplantation center. Patients were excluded if they did not speak English. A total of forty-six patients were approached to participate in the study and five patients declined to participate.

Discussions and documentation of ACP were assessed through manual review of the transplant hepatologist, transplant surgeon, and social worker notes at the initial transplant evaluation by a single reviewer. To qualify as a documented ACP discussion, the presence of any of the following in the provider's notes was required: prognosis discussion (e.g. goals of care, end-of-life), advance care planning or advance directive discussion, physician order for life-sustaining treatment (POLST) form discussion or completion, code status discussion, or surrogate decision maker (or durable power of attorney [DPOA]) discussion. Scanned documents were searched for advance directives, living wills, DPOA forms, and POLST forms. Medical charts were reviewed for demographics and clinical data. Participants were considered to have a medical comorbidity (e.g., hypertension, diabetes) if reported in their electronic health record. The degree of ascites – graded as none, mild/moderate, or refractory – was assessed and ascertained from the patient's hepatologist's recorded physical examination or the management plan. Hepatic encephalopathy was determined by the hepatologists' documented treatment plan.

Adults undergoing liver transplantation evaluation were administered a survey with a total of 15 questions to determine readiness and confidence engaging in ACP based on a validated survey, the ACP Engagement Survey.(11, 12) The survey was verbally administered prior to clinical visits with transplant providers. In order to focus on patient's self-reported level of readiness and confidence, we utilized the same questions and simplified the response options. We used 5-point Likert scales (score 1="not ready at all" or "not confident at all"; 2="not ready" or "not confident"; 3="undecided"; 4="ready" or "confident"; 5="very ready" or "very confident"). The scales were also dichotomized as ready or not ready based on Likert scores of 4 out of 5. Statistical analyses were performed using univariable logistic regression to assess association between patient characteristics and completion of ACP. Multivariable logistic regression was not performed due to low rates of ACP completion and concern for statistical over-fitting.

The statistical software program, STATA® (v13, Stata, College Station, Texas), was used to analyze the data;  $p < 0.05$  was considered a significant difference. The Institutional Review Board at University of California, San Francisco approved this study.

## RESULTS

### Baseline characteristics

A total of 170 patients undergoing liver transplantation evaluation with medical charts reviewed (Aim 1) and 41 patients undergoing liver transplantation evaluation who completed the survey to evaluate readiness and confidence to engage in ACP (Aim 2) were included in the analyses. Baseline characteristics of each cohort are shown in Table 1. The majority were men (65%) and non-Hispanic white (52%), with median age of 58 years and median MELDNa of 15. The etiology of liver disease was chronic hepatitis C (HCV) in 36%, alcohol in 26%, and non-alcoholic fatty steatohepatitis (NASH) in 17%. With regards to portal hypertension complications, 41% of patients had ascites while 34% had hepatic encephalopathy. Liver transplant candidates who completed the survey had median age of 58 years, 63% were men, 58% were non-Hispanic white, and median MELDNa was 14. In this cohort, 27% had HCV, 34% had alcoholic liver disease, and 29% had NASH. Hepatic encephalopathy was present in 39% of the cohort, and ascites was present in 19%.

### Association between patient characteristics and ACP completion

During the initial liver transplant evaluation 9% of patients (n = 15) reported completion of ACP (yes/no question) prior to liver transplant evaluation, however 0 (0%) of these patients had documentation of end-of-life wishes or ACP forms (e.g. advance directive, living will, Provider Orders for Life-Sustaining Treatment [POLST]) entered into the medical record (Table 2). Documentation of discussion of ACP was found only in the social worker notes, but not in the transplant hepatologist or transplant surgeon notes. The minority of DPOA was discussed with 17 (10%) of the 170 patients evaluated for liver transplant. Among these 17 patients, the DPOAs documented in the medical record included partner (n = 7, 41%, adult child (n = 5, 29%), parent (n = 2, 12%), and sibling (n = 2, 12%) (Table 2).

Table 3 shows the univariable analysis for associations with ACP completion. In univariable analysis, female sex (OR 3.06; p=0.04) and non-Hispanic white race (OR 4.16; p=0.03) were associated with completion of ACP and there was a trend towards significance for increasing age (OR 1.07 per year; p=0.10). However, MELD-Na (OR 1.02 per year; p=0.64), Child-Pugh score (A: reference; B: OR 4.34, p=0.07 ; C: OR 2.30, p=0.35), and etiology of liver disease (alcohol: reference; HCV: OR 1.52, p=0.57; NASH: OR 1.64, p=0.56; other: OR 0.98, p=0.98) were not associated with prior completion of ACP. DPOA was discussed with 17 of 168 patients (10%). Given the very low rates of ACP completion and concern for statistical over-fitting, multivariable analysis was not performed.

### Assessment of readiness and confidence to engage in ACP

The self-reported readiness and confidence survey was completed by 41 patients with ESLD during initial liver transplant evaluation. Table 4 shows the mean score using 1 to 5-point Likert scales for each domain of the survey. Mean score for confidence in identifying a decision maker was 4.5 (standard deviation [SD] 0.6), discussing care at end-of-life was 4.5 (SD 0.6), discussing how much flexibility to grant decision makers in making decisions was 4.5 (SD 0.6), and asking doctors questions to make informed decisions was 4.5 (SD 0.7). 93% of patients reported being ready (Likert score = 4 out of 5) to appoint a surrogate

decision maker, 85% were ready to discuss end-of-life care, 83% were ready to grant flexibility to decision makers, and 93% were ready to ask physicians questions about medical decisions around medical care. The mean score for readiness in appointing a decision maker was 4.6 (SD 0.7), discussing goals for end-of-life care was 4.5 (SD 0.7), discussing how much flexibility to grant decision makers was 4.4 (SD 0.8), and asking doctors questions about medical care was 4.5 (SD 0.8). Similarly, 93% of patients felt confident (Likert score 4 out of 5) to appoint a substitute decision maker, 88% felt confident to discuss end-of-life care, 93% felt confident to grant flexibility to decision makers, and 93% felt confident to ask physicians questions about medical decisions. In a sensitivity analysis excluding patients with greater than mild hepatic encephalopathy, there were no significant differences in the mean Likert scores for each domain of the survey.

## DISCUSSION

Our data reveal a paucity of completion of ACP among liver transplant candidates with no documentation of goals of care or end-of-life wishes for patients at initial transplant evaluation. Furthermore, our study demonstrated infrequent identification of a surrogate decision maker despite 34% of patients having hepatic encephalopathy at the time of evaluation. This raises concern as hepatic encephalopathy may limit patients' ability to fully comprehend and navigate complex conversations around transplant care without the support of a surrogate decision maker. The findings of our study highlight an unmet need for discussions on ACP to occur in clinical transplant practice.

There is increasing focus on the integration of ACP into modern health care with the goal of providing value-aligned care for patients during serious and chronic illness such as in ESLD. The process of ACP involves clinicians informing patients and surrogate decision makers about disease trajectory, care options, and health outcomes, while allowing patients to share personal values, goals, and preferences for future medical care.(7) As a result, patients and surrogate decision makers can better manage expectations and balance treatment options with disease progression. While data are scarce, goals of care and ACP are rarely discussed among patients with ESLD. Several studies of hospitalized patients with ESLD have demonstrated low rates of documentation of end-of-life wishes by assessing do-not-resuscitate (DNR) orders.(13, 14)

Additionally, our patients with ESLD undergoing liver transplant evaluation reported high levels of readiness and confidence to engage in ACP. Patients were confident and ready to ask questions about medical care, appoint a surrogate decision maker, discuss care at end-of-life, and complete official documentation for ACP at time of transplant evaluation. There is an apparent disconnect between patients and transplant clinicians for discussions on ACP and this may be due to patients assuming clinicians will raise the issue of ACP or end-of-life care when or if the need arises.(15) It is also worth noting that discussion and documentation of ACP during transplant evaluation only took place with social workers, but not with transplant hepatologists or surgeons. In a study examining patient perceptions of ACP, patients with advanced cirrhosis preferred to have ACP discussions with their cirrhosis clinician.(16) The involvement of transplant clinicians is important as they can better provide prognoses and medical context regarding a patient's medical condition.

What are the barriers to discussion of ACP among transplant practitioners? Notably, a study of inpatient liver transplant service providers, including nurses, housestaff, fellows, and attending physicians identified the attending physicians as the main barrier to involving palliative care services, an approach to care that focuses on patient-centered goals and quality of life for patients facing life-limiting illness and often assists with ACP discussions. (17, 18) The infrequent use of palliative care services may be a result of transplant clinicians' perceptions that palliative care is for patients with ESLD who are not transplant candidates, and that patients on the transplant waiting list are ineligible for palliative care as a recent study using survey data to evaluate providers' attitudes towards palliative care consults revealed.(19) Another recent study evaluating survey data on hepatologists' views of ACP and palliative care listed competing demands for clinician's time, unrealistic expectations from patients about their prognosis, and cultural factors affecting perception of ACP and palliative care as common barriers to ACP discussions.(20) Interestingly, 81% of respondents also reported that discussions on ACP occurred too late in the disease course, insufficient communication between clinicians and patients and their families about goals of care, and insufficient training about end-of-life care among hepatologists suggesting providers recognize the need and are open to increased education on ACP.(20)

We acknowledge several limitations to our study. There were few patients undergoing liver transplant evaluation with documented completion of ACP. While there is the possibility that this may in part be related to low rates of ACP documentation in the electronic health record, we believe that this reflects the infrequent discussion of ACP among patients with ESLD during these visits, a similar finding to prior studies.(13, 21) As a result, this limited our ability to assess associations and adjust for confounders in our analyses. However, our findings are similar to prior studies that have demonstrated that patients of male gender and ethnic minorities are less likely to engage in ACP.(22, 23) We used a survey based on the validated ACP Engagement Survey with different responses to the validated survey questions which future studies should use. Although most patients had no hepatic encephalopathy or mild hepatic encephalopathy, the presence of hepatic encephalopathy could influence the accuracy of ACP engagement survey responses. Also, the small sample size of patients who completed the survey may impact the generalizability of our findings. Lastly, patients were only evaluated in the outpatient setting and our findings cannot be applied to inpatients, however, arguably the outpatient setting is likely a more appropriate and relevant context for discussion of ACP when patients are less acutely ill.

In conclusion, we identified an unmet need for ACP discussions using analysis of interactions with patients with ESLD at their initial liver transplant evaluation, despite patients with ESLD reporting confidence and readiness to engage in ACP discussions. Our data underscore the need to increase awareness among transplant providers that ACP should be integrated early on in the care of patients with ESLD, including those being evaluated for transplantation. While this study focuses on interactions at the initial liver transplantation encounter, further study is needed to better understand how ACP discussions occur throughout the clinical course as patients' disease trajectories evolve and patients' wishes may change over time. Documentation of these discussions is also crucial and quality improvement metrics could focus on improving documentation practices of ACP discussions in the electronic health record. Finally, these results reveal an opportunity for development

of tools to facilitate ACP discussions between transplant practitioners, patients, and their caregivers.

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### Abbreviations:

<b>ACP</b>	advance care planning
<b>CI</b>	confidence interval
<b>DNR</b>	do-not-resuscitate
<b>DPOA</b>	designated power of attorney
<b>ESLD</b>	end-stage liver disease
<b>HBV</b>	hepatitis B virus
<b>HCV</b>	hepatitis C virus
<b>IQR</b>	interquartile range
<b>MELDNa</b>	model for end-stage liver disease-sodium
<b>NASH</b>	nonalcoholic steatohepatitis
<b>POLST</b>	Provider Orders for Life-Sustaining Treatment
<b>SD</b>	standard deviation

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**TABLE 1.**

Baseline characteristics of patients undergoing evaluation for liver transplantation in each cohort: ACP documentation (n = 170) and ACP engagement survey (n = 41).

Characteristic*		ACP Documentation n = 170	ACP Engagement Survey n = 41
Age, years		58 (53–65)	58 (53–63)
Female		60 (35%)	15 (37%)
Race	White	88 (52%)	24 (58%)
	Black	6 (3%)	2 (5%)
	Hispanic	45 (26%)	11 (27%)
	Asian	23 (14%)	2 (5%)
	Other	8 (5%)	2 (5%)
	HCV	60 (36%)	11 (27%)
Etiology of liver disease	Alcohol	44 (26%)	14 (34%)
	NASH	28 (17%)	12 (29%)
	Cholestatic	6 (3%)	2 (5%)
	Other	30 (18%)	2 (5%)
Medical co-morbidities			
Hypertension		81 (48%)	19 (46%)
Diabetes		55 (32%)	12 (29%)
Laboratory tests			
MELDNa		15 (11–21)	14 (9–18)
Total bilirubin, mg/dL		1.9 (1.1–3.3)	2.3 (1.0–4.2)
INR		1.3 (1.2–1.6)	1.4 (1.2–1.6)
Creatinine, mg/dL		0.84 (0.70–1.12)	0.82 (0.68–1.00)
Albumin, g/dL		3.1 (2.7–3.5)	3.6 (3.1–3.9)
Hepatocellular carcinoma		65 (38%)	15 (37%)
Dialysis			
Ascites	None	101 (59%)	33 (81%)
	Mild/moderate	47 (28%)	7 (17%)
	Refractory	22 (13%)	1 (2%)
Hepatic encephalopathy	None	113 (66%)	25 (61%)
	Present	57 (34%)	16 (39%)
Child Pugh Score	A	56 (33%)	15 (37%)
	B	64 (38%)	17 (41%)
	C	50 (29%)	9 (22%)

\* Median (interquartile) or n (%)

**TABLE 2.**

ACP and DPOA documentation in the chart (n = 170).

Chart review		Patients n = 170
Prior completed ACP		15 (9%)
ACP documented in chart		0 (0%)
DPOA discussed		17 (10%)
DPOA listed	Partner	7 (41%)
	Child	5 (29%)
	Parent	2 (12%)
	Sibling	2 (12%)

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**TABLE 3.**

Predictors associated with completion of ACP

Predictors	OR (95% CI)	p-value
Age, per year	1.07 (0.99–1.15)	0.10
Female sex	<b>3.06 (1.03–9.06)</b>	<b>0.04</b>
White Race	<b>4.16 (1.13–15.3)</b>	<b>0.03</b>
<b>Etiology of Liver disease</b>		
Alcohol	Reference	
HCV	1.52 (0.36–6.44)	0.57
NASH	1.64 (0.31–8.76)	0.56
Other	0.98 (0.15–6.22)	0.98
MELD-Na, per point	1.02 (0.94–1.10)	0.64
<b>Child-Pugh score</b>		
A	Reference	
B	4.34 (0.90–21.0)	0.07
C	2.30 (0.40–13.2)	0.35

**TABLE 4.**

ACP Engagement survey results on a 5-point Likert scale (1="not at all confident/ready" and 5="very confident/ready").

Survey domains	ACP domains*	# of items	Mean score (+/- SD)
<b>Confidence</b>	Decision maker	1	4.5 (0.6)
	Quality of life	2	4.5 (0.6)
	Flexibility	2	4.5 (0.6)
	Ask questions	1	4.5 (0.7)
<b>Readiness</b>	Decision maker	3	4.6 (0.7)
	Quality of life	3	4.5 (0.7)
	Flexibility	2	4.4 (0.8)
	Ask questions	1	4.5 (0.8)
<b>Total Questions</b>		15	4.5 (0.6)

\* Decision maker refers to identifying an appropriate surrogate decision maker

Quality of life refers to identifying goals about end-of-life care

Flexibility refers to deciding how much flexibility to grant the decision maker in making decisions

Ask questions refers to asking doctors questions to make informed decisions