

Update on Palliative Hepatology Research from the United States



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Deficits in Advance Care Planning (ACP) for Patients with Decompensated Cirrhosis at Liver Transplant centers

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ACP Patterns at Liver Transplant Centers

- Patients considered for LT have ACP less frequently documented
 - Inpatient / intensive care setting
 - **31%** Goals of care discussions
 - **28%** documented decisions about withdrawing life-sustaining treatments
 - Outpatient
 - **0%** had ACP forms documented
- Patient and provider barriers reported but not specifically with regards to care at liver transplant centers

Study Aims

- 1.** To describe the experience of ACP for patients with decompensated cirrhosis at liver transplant centers from patient and provider perspectives
- 2.** To describe the barriers to advance care planning from patient and provider perspectives

JAMA Internal Medicine

Original Investigation

March 15, 2021

Deficits in Advance Care Planning for Patients With Decompensated Cirrhosis at Liver Transplant Centers

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Methods

Sampling

- Exploratory , multiple case study design

Recruitment

Sampling LT Centers

- Goals: ↑ diversity of informants with sicker patients, LT-hopeful patients, non-hepatologist providers

Interview

Data Analysis

UCLA

USC



- All perform >100 LT surgeries per year
- Sicker patients (% ICU and MELD-Na at LT)
- Different socio-demographics and structures

Methods

Sampling Patients and Providers

(stratified purposeful approach)

Sampling

Recruitment

Interview

Data Analysis



- ✓ Age ≥ 18
- ✓ History of MELD-Na ≥ 15
- ✓ No HCC, overt HE
- ✓ English-speaking
- ✓ Caregivers ok



1. Currently being evaluated
2. Listed for liver transplant
3. "Too early"
4. Denied or not evaluated
 - Comorbid conditions
 - Lack of social support/insurance
 - Active substance use

1. Hepatologists
2. Hepatobiliary Surgeons
3. Social Workers
4. Case Managers

Methods

Sampling

Clarification of **Values**
and **Health Goals**

Recruitment

Awareness of **Prognosis**
and **Future Health**
Events

Documentation

Interview

Data Analysis

Establishing **Healthcare**
Preferences

Establishing a
Surrogate Decision
Maker

1. Main questions = **Experience, Readiness (patients)**
2. Probes = **Barriers, Facilitators, Preferences**
3. Lead-in questions

Methods

Sampling

Pilot Testing (**8 providers, 2 patients**)

Recruitment

Audio-recorded Interviews (**88 total**)

Patient (22-54 min)

Providers (28-61 min)

Interview

Professional Audio-file Transcription

Data Analysis

Review of Transcripts and Adjustments

Uploading of Transplants into
Qualitative Data Analysis Software (**NVivo**)

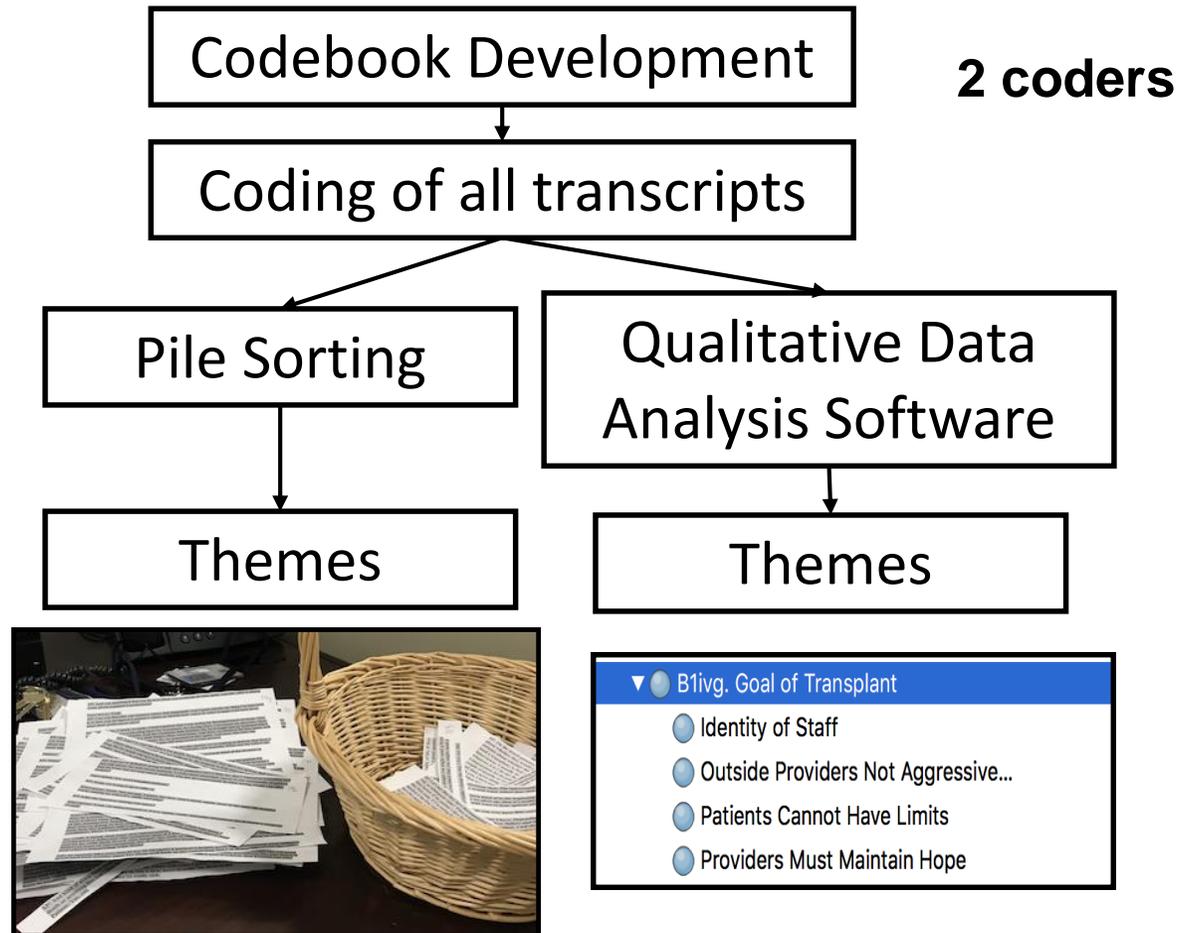
Methods

Sampling

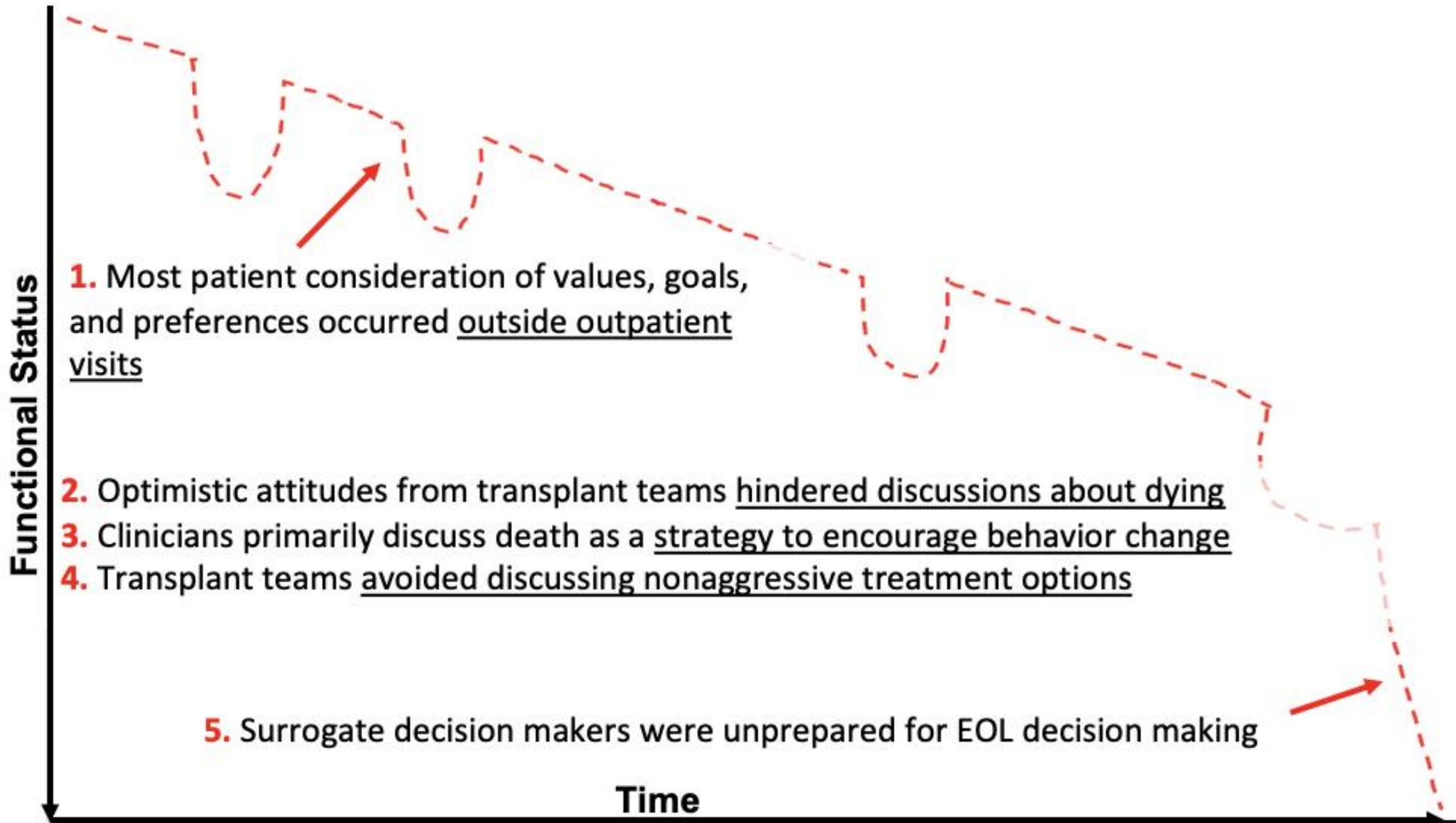
Recruitment

Interview

Data Analysis



Major Themes from Aim 1: The Experience of ACP



Representative Quotes from Themes

2. *Optimistic attitudes from transplant teams hindered discussions about dying*

“I can think of many situations where the patients have been saying, “I’m dying, I’m dying...I don’t want to live like this. This is not the kind of life I want to live. I’m done. But [the clinician] says, “No, not yet. I’m not ready to say that. There are still these options” (Social worker)

Representative Quotes from Themes

3. Clinicians primarily discuss death as a strategy to encourage behavior change

“We are very honest with all of them. The people that end up usually not being transplant candidates are drinkers, and we say, “You’re going to die without a liver” or “You’re going to die if you don’t stop drinking.” We’re very straightforward about it.” **(Transplant hepatologist)**

Representative Quotes from Themes

4. *Transplant teams avoid discussing non-aggressive treatment options*

“Some doctors want to put patients on hospice because with hospice, you get all these other services that the patient maybe needs. But you can't both be on hospice and be listed. You can't say I want the minimal done to save my life...I'm doing everything we possibly can to save your life and if you're wanting to be allowed to go, then transplant is not something that's for you.” (Transplant Coordinator)

“No, I don't believe we have had that conversation...I've wondered about that once or twice. I think that doctors...I've actually convinced myself that they're not that concerned with that part of their practice...” (Patient, not listed due to comorbidities)

Aim 2: Barriers to Advance Care Planning (Manuscript in Progress)

***Transplant
Culture***



**Optimistic attitudes from transplant teams
hindered discussions about dying**

**Clinicians primarily discuss death as a strategy
to encourage behavior change**

**Transplant teams avoided discussing
nonaggressive treatment options**

Limitations and Strengths

- **Reflexivity**
 - Influence on study design, sampling, data collection, and analysis
 - **Sampling Approach**
 - Persons who did not want to be interviewed may be different
 - **Generalizability**
 - Patients with HCC, limited English proficiency; caregivers
 - Non-LT settings
 - Other LT centers
- ✓ Large qualitative study conducted in patients with cirrhosis
 - ✓ Included a diverse range of perspectives from informants across multiple LT centers
 - ✓ Focused on a broader definition of ACP compared to other studies.



PALLIATIVE CARE RESEARCH COOPERATIVE GROUP

Liver Disease Special Interest Group

Leadership Team

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National Institute
of Nursing Research

Our Journey to PCRC

Academic Productivity

35 Original Research Articles
25 Review Articles
4 Book Chapters

Funding

PCORI PLC-1609-36714 (**Verma**)
NIH 1R01NR016017-01 (**Hansen**)
ACS Mentored Research Scholar (**Woodrell**)
AASLD Clinical, Translational and Research Outcomes
Award (**Ufere**)

Palliative Care Education, Advocacy,
and Research in Liver Disease
(**PEARL**) Workgroup [2017]

PCRC Liver Disease Special
Interest Group

Engagement and Practice Change

AGA Guidance (**Tandon, Walling**)
AASLD Webinar: What is PC? (**Rakoski, Hansen**)
AASLD Webinar: ACP (**Patel, Verma**)
AASLD Webinar: EOL Communication (**Ufere, Woodrell**)
Pending: AASLD Guidance

Development of Research Priorities

- Pain and physical symptoms
- Psychological and social well-being
- Caregiver burden
- Advance care planning & end of life care

Patel et al. *Hep Communications* 2021

Goals for PCRC Liver Disease SIG



Engage researchers to develop a collaborative community



Engage funders to sustain high-impact research



U.S. Department
of Veterans Affairs



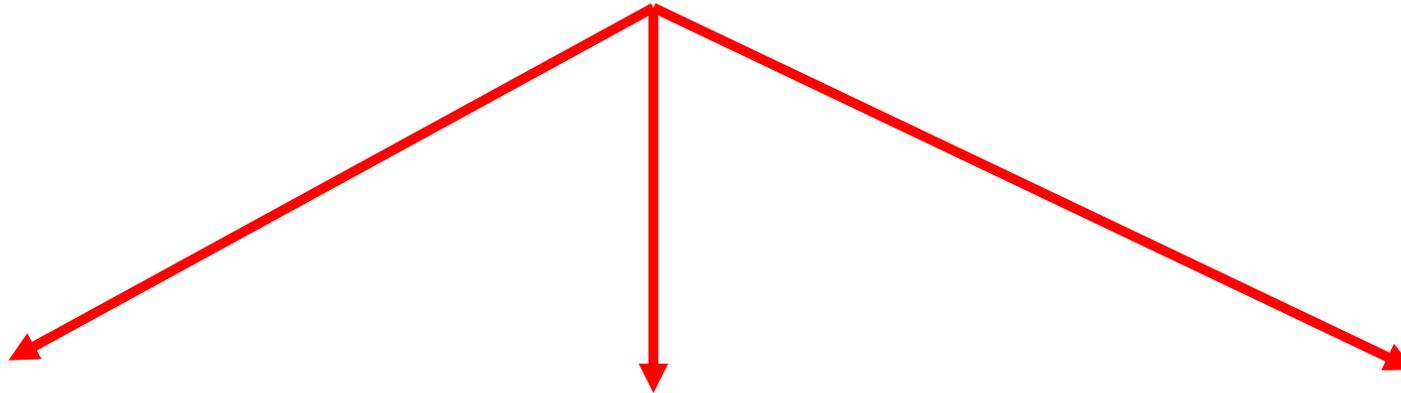
Engage stakeholders to promote practice change



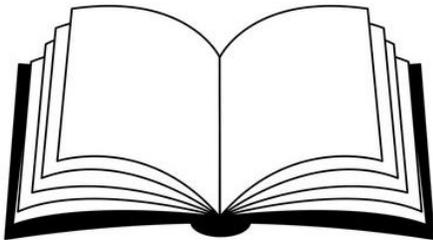
Goals for PCRC Liver Disease SIG



Engage researchers to develop a collaborative community



Journal Club



Works-In-Progress



Multi-Institutional projects



How to Join?

1. Become a PCRC Member:

<https://palliativecareresearch.org/membership/becoming-member>

2 Join the Liver Disease SIG:

<https://palliativecareresearch.org/special-interest-groups>

Email ArpanPatel@mednet.ucla.edu or NGallopyn@mgh.harvard.edu with questions

Thank you!



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#palliativehepatology