

Update on Palliative Hepatology Research from the United States



October 20, 2021

Pilot Randomized Controlled Trial of an Advance Care Planning (ACP) Video Decision Support Tool for Patients with Advanced Liver Disease

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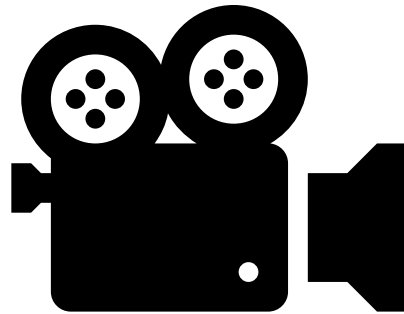
NnekaUfereMD

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

- Despite their poor prognosis, patients with advanced liver disease often receive high-intensity end-of-life care, regardless of transplant eligibility
 - Over 50% die in the inpatient setting
 - Over 50% receive ICU-level care at the end-of-life
 - Only 10% of patients with advanced liver disease who receive in-hospital CPR survive to hospital discharge, and only 3% are discharged home
- There is a critical need to optimize the quality of end-of-life care for patients with advanced liver disease

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

- Patients must receive **accurate** and **understandable** information about their medical options to make **informed decisions** about their medical care, including at end-of-life
- Videos can enhance patient's comprehension of complex health information



Advance Care Planning Video Decision Support Tools In Other Serious Illnesses

BMJ

RESEARCH

Circulation

Volume 134, Issue 1, 5 July 2016; Pages 52-61
<https://doi-org.treadwell.idm.oclc.org/10.1161/CIRCULATIONAHA.115.121111>

ORIGINAL RESEARCH

Randomized, Controlled Trial of
Advance Care Planning Video Decision Support
Tools in Advanced Heart Failure

Areej El-Jawahri, MD, Michael Lynne Warner Stevenson, MD, Michael Semigran, MD, Yuchiao Chang, MD, Jennifer S. Temel, MD, Hacho Bohossian, MD, Henry Ooi, MD, Eileen Mann, RN, and Angelo E. Volandes, MD, MPH

- ▲ Knowledge of end-of-life care options
- ▼ Decisional uncertainty
- ▼ Preferences to receive invasive, burdensome, and potentially non-beneficial care at end of life
- ▲ Goals of care conversations between patients and healthcare providers at 1- and 3-month follow-up

P O R T

ons With
ed Trial

el, Susan L. Mitchell,

A pilot randomized clinical trial to test the **feasibility**, **acceptability**, and **preliminary efficacy** of an educational intervention using a 5-minute ACP video decision support tool versus an ACP verbal narrative for transplant-ineligible patients with advanced liver disease (n=50)

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

- **Inclusion criteria:**

1. Established diagnosis of advanced liver disease
2. Deemed transplant-ineligible by their primary hepatologist
3. Ability to communicate in English
4. Score ≥ 7 on the Short Portable Mental Status Questionnaire (SPMSQ)

- **Exclusion criteria:**

1. Previous referral to specialty palliative care or hospice care
2. Severe cognitive impairment

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- The video was developed using the International Patient Decision Aid Standards
- Experts in hepatology, critical care, palliative care, decision-making, health literacy, and **3 patients with advanced liver disease** contributed to adapting the script of the video
- Scripted at a **fourth-grade level of health literacy** or less
- All patients included in the video (or their proxies) gave consent to be filmed

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease



ACP Decisions
ClinicalTrials.gov: NCT03557086

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease



LIFE PROLONGING CARE

LIMITED MEDICAL CARE

COMFORT CARE

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

**For most patients with
Advanced Liver Disease,
CPR does not work.**

LIFE PROLONGING CARE 

LIMITED MEDICAL CARE 

COMFORT CARE 



ACP Decisions
Ufere et al., Liver Int (2019)
ClinicalTrials.gov: NCT03557086

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LIFE PROLONGING CARE 

LIMITED MEDICAL CARE 

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LIFE PROLONGING CARE 

LIMITED MEDICAL CARE 

COMFORT CARE 

3:17 

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ClinicalTrials.gov: NCT03557086

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- **Control:** Patients assigned to the verbal narrative control arm listened to the same description of the 3 goals-of-care used in the video arm read out loud one time by the research assistant

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

- **Feasibility (Primary):**
 - **$\geq 60\%$ enrollment rate**
- Acceptability
- Knowledge of end-of-life care options
- CPR and intubation preferences

- Research staff member: “My name is (state name) and we are working on a project about **what people prefer when receiving medical care at the end of life**. The goal of this project is to understand what people think and what they like better when getting medical care for advanced liver disease”

Hagen et al., J Pain Symptom Manage (2011); Ufere et al., Liver Transpl (2019)

ClinicalTrials.gov: NCT03557086

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

- Feasibility (Primary):
 - $\geq 60\%$ enrollment rate
 - **Acceptability**
 - Knowledge of end-of-life care options
 - CPR and intubation preferences
- Was the video **helpful** in improving your understanding about your choices for medical care?
 - Did you feel **comfortable** seeing the video in order to help you answer the questions regarding medical care?
 - Would you **recommend** the video to other patients with advanced liver disease who are facing a similar decision?

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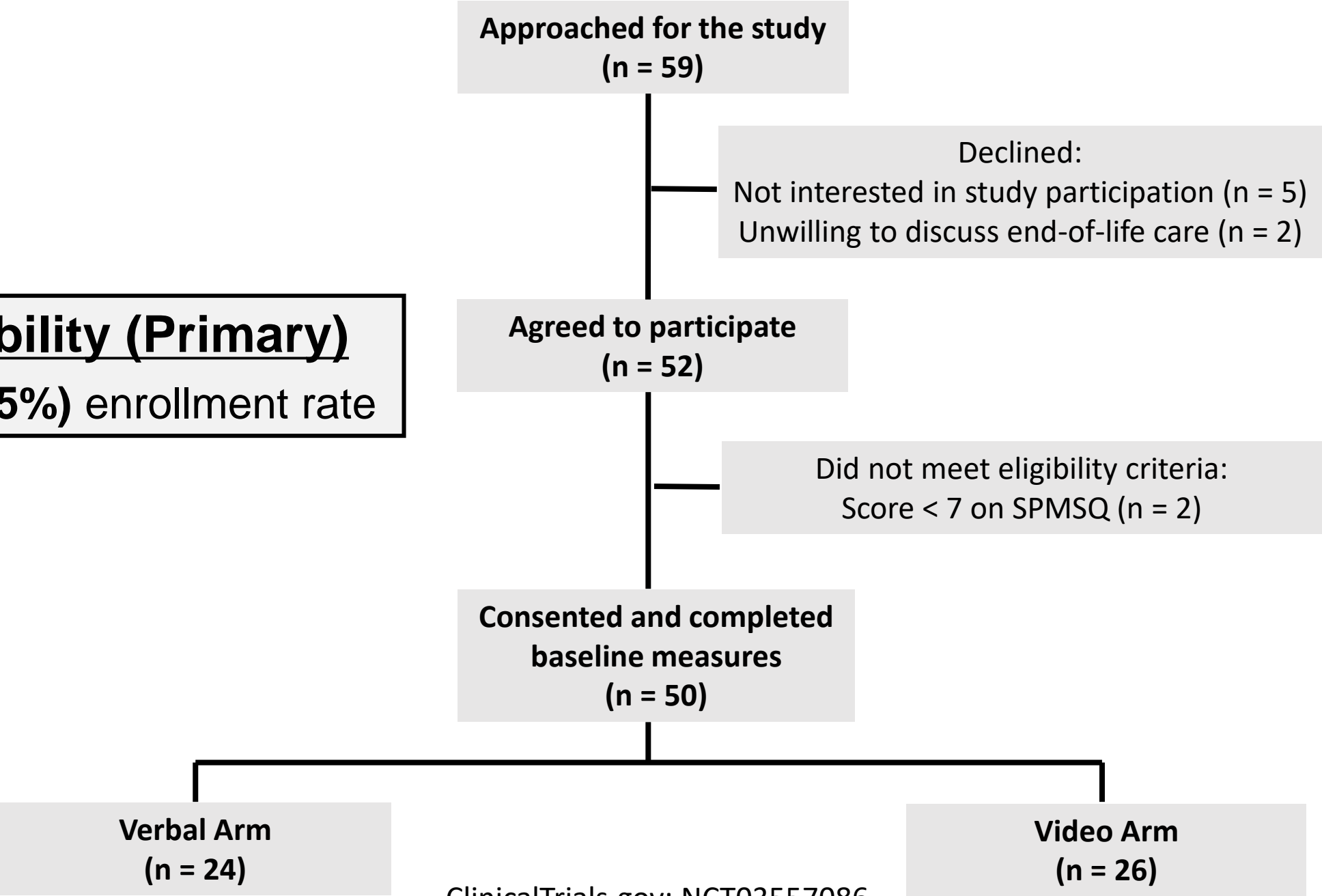
Knowledge Assessment Questionnaire

1. **True or False:** Cardiopulmonary resuscitation or CPR is a medical procedure that is done on patients whose heart stops beating in an attempt to restart their heart. **(True)**
2. **True or False:** Most patients with advanced liver disease that get CPR in the hospital survive and get to leave the hospital. **(False)**
3. **True or False:** Most patients with advanced liver disease who survive CPR and being placed on a breathing machine have very few complications from these procedures. **(False)**
4. **True or False:** Comfort care is a type of medical care that can only be provided for patients with advanced liver disease living in hospice. **(False)**
5. **True or False:** Once you tell your doctor what kind of medical care you want if your liver disease becomes very advanced, you cannot change your wishes in the future. **(False)**
6. **Multiple Choice:** How many patients with advanced liver disease that get CPR in the hospital survive and get to leave the hospital?
 - a. almost all (more than 90%)
 - b. about half (about 50%)
 - c. very few (less than 10%) **(correct answer is c)**

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

- Feasibility (Primary):
 - $\geq 60\%$ enrollment rate
 - Acceptability
 - Knowledge of end-of-life care options
 - **CPR and intubation preferences**
- If your liver disease were very advanced and you were to get so sick that your heart stopped beating, would you want doctors to do chest compressions and CPR to try to make your heart start again?
 - If your liver disease were very advanced and you were to get so sick that you could not breathe on your own, would you want doctors to place you on a breathing machine to help you breathe?

Feasibility (Primary)
50/59 (85%) enrollment rate



Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

Baseline Characteristics

- Median age: 60 years (29-87 years)
- 50% Male
- 96% White
- 64% Alcohol-related liver disease
- 50% with hepatic encephalopathy
- 14% had been previously evaluated for liver transplantation
- 92% had code status of “full code” at time of study enrollment
- Setting of recruitment: 48% (outpatient), 52% (inpatient)

Advance Care Planning Video Decision Support Tool for Transplant-Ineligible Patients with Advanced Liver Disease

Acceptability of the video (n=26)

- ✓ **21 (81%)** were “very comfortable”, and 5 (19%) were “somewhat comfortable” watching the video
- ✓ **19 (73%)** found the video “very helpful”, 5 (19%) found it “somewhat helpful”, and 2 (8%) found it “a little helpful”
- ✓ **24 (92%)** would “definitely recommend”, and 2 (8%) would “probably recommend” the video to other patients with liver disease

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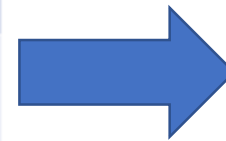
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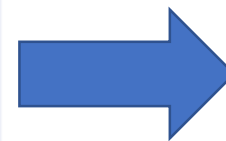
b. about half (about 50%)

c. very few (less than 10%) **(correct answer is c)**



9/50 (18%)
answered correctly at baseline

Baseline knowledge scores were similar between video and verbal arms (3.2 vs. 3.3, p=0.45)



0/50 (0%)
answered correctly at baseline

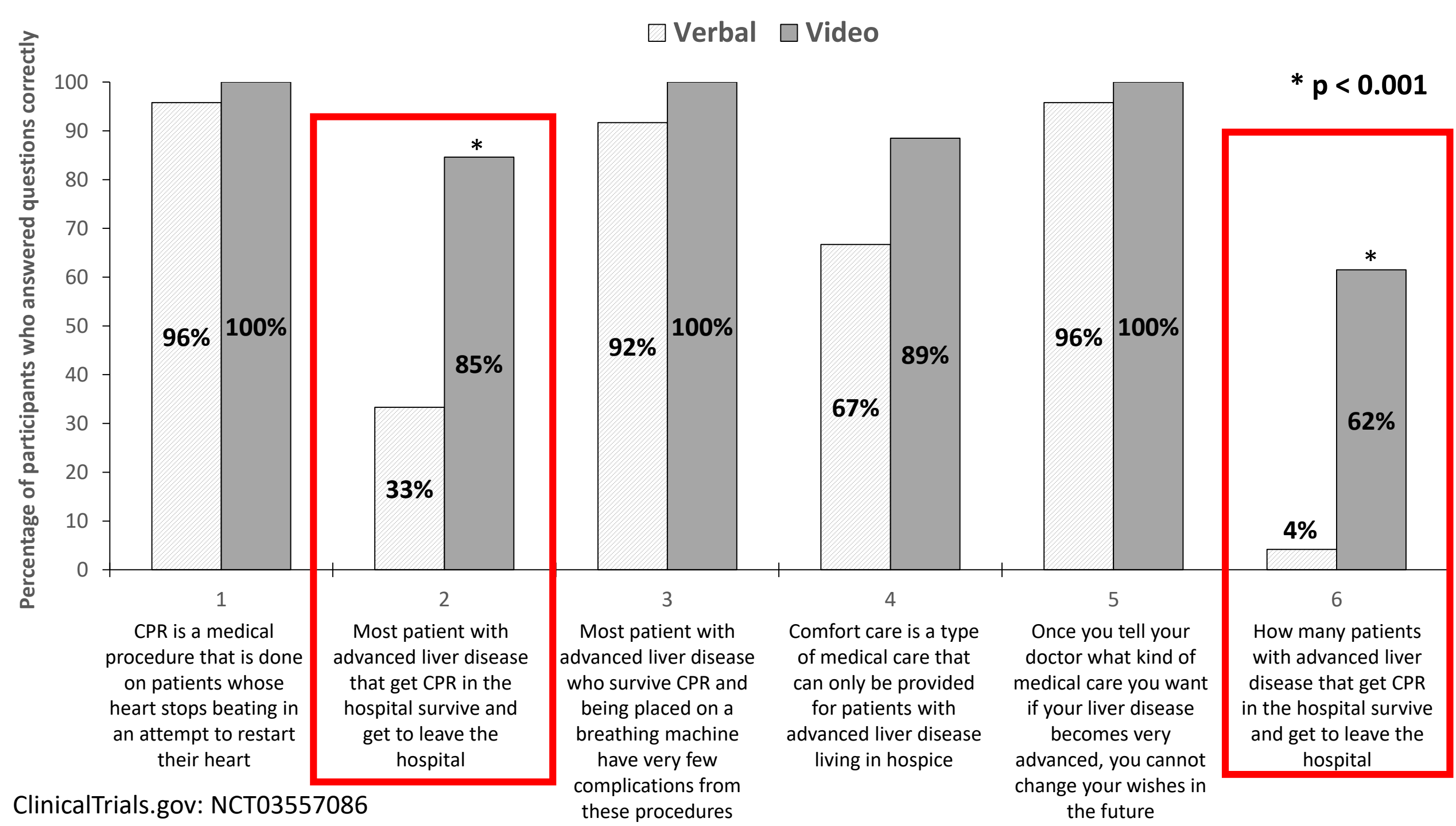
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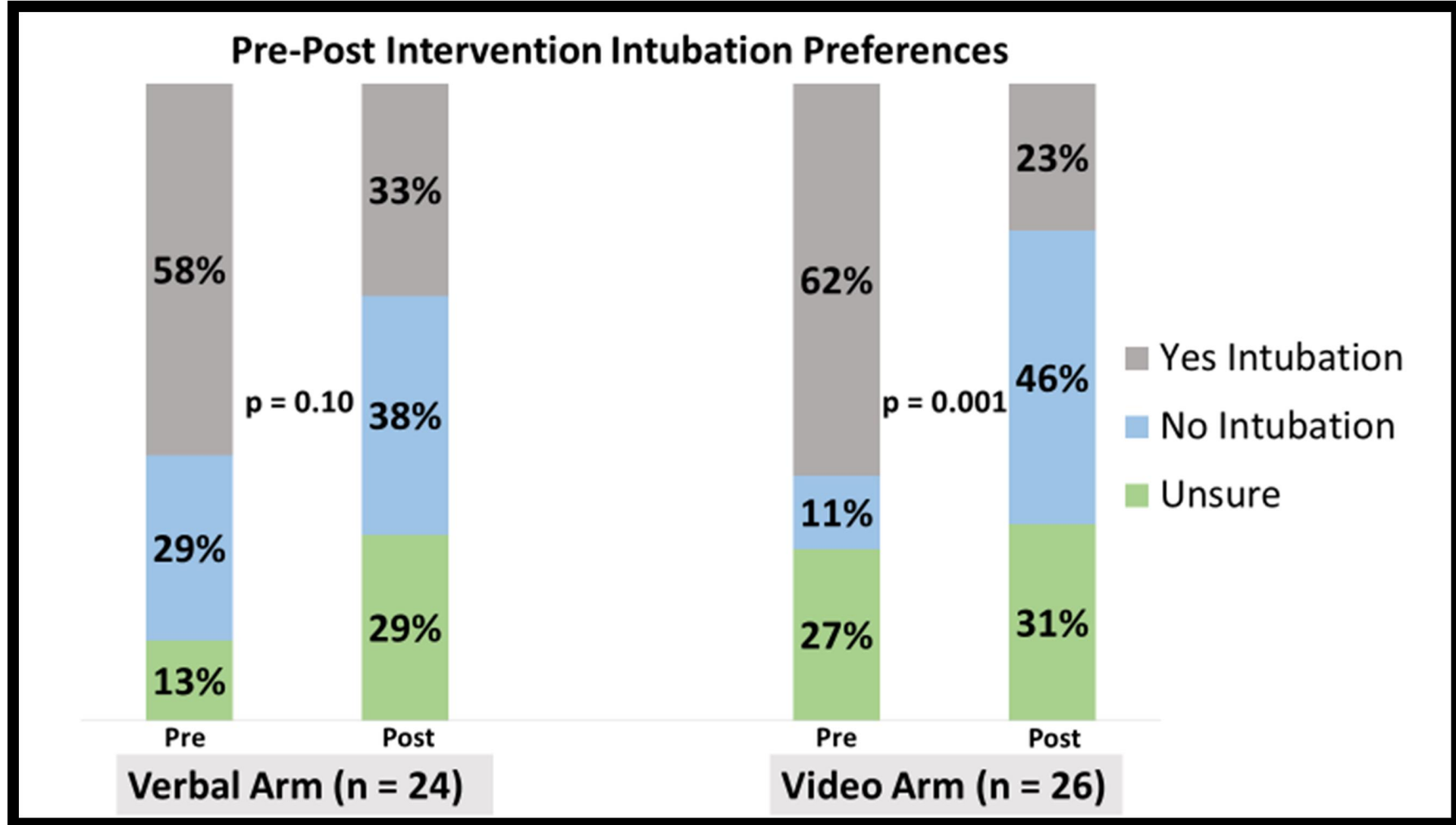
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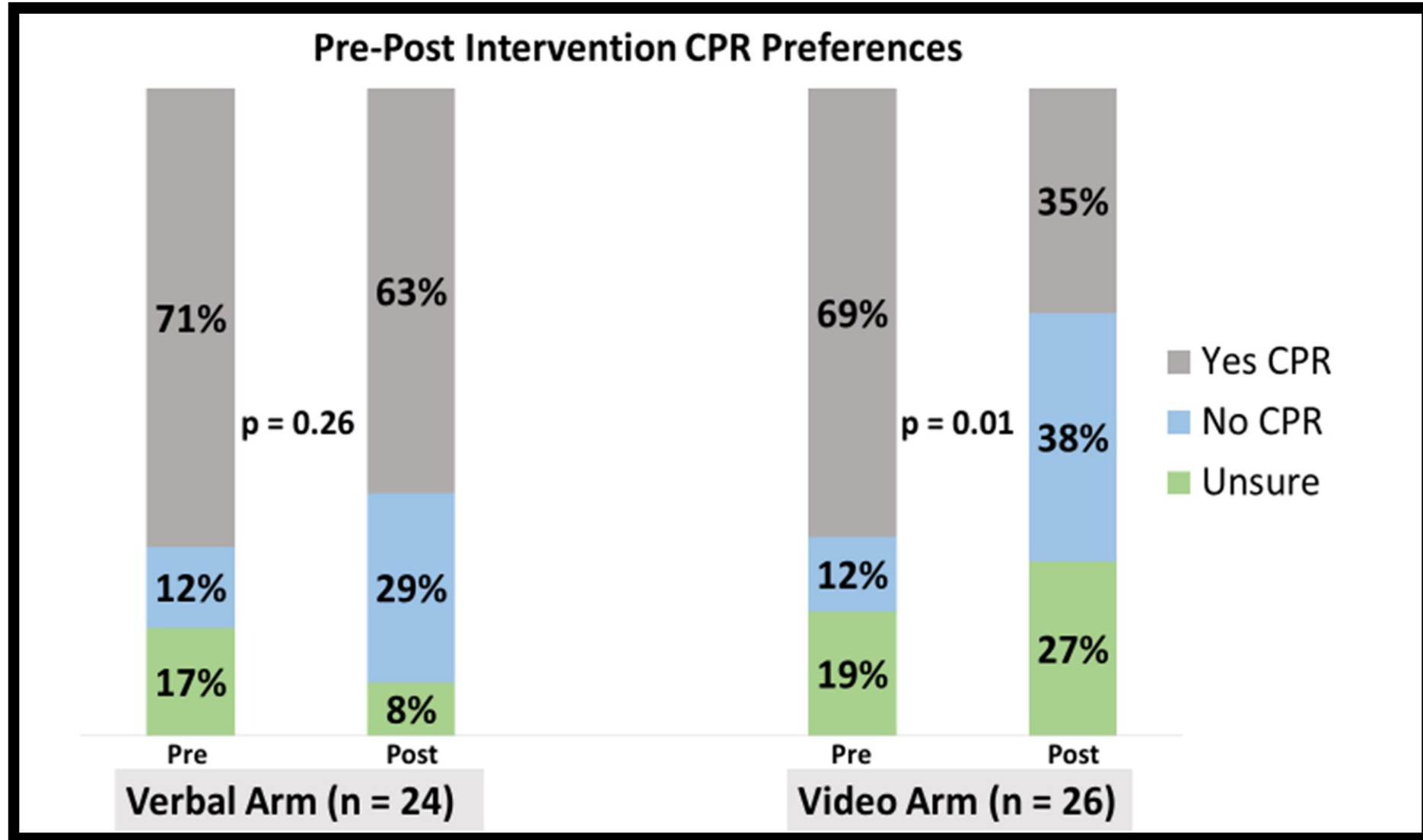
Post-intervention knowledge scores were different between video and verbal arms (5.7 vs. 4.8, $p<0.0001$)



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- An ACP video decision support tool to improve knowledge about and preferences for end-of-life care is both feasible and highly acceptable to transplant-ineligible patients with advanced liver disease with a high enrollment rate and promising preliminary efficacy
- The results of this trial will inform a future multisite efficacy trial to examine the impact of the ACP video on patients' end-of-life care preferences and end-of-life care delivery