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UNIVERSITY OF CALIFORNIA

Los Angeles

Advance Care Planning in Patients with Decompensated Cirrhosis at Liver Transplant Centers

A dissertation submitted in partial satisfaction of the requirements for the
degree Doctor of Philosophy in Health Policy and Management

by

Arpan Arun Patel

2020

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ABSTRACT OF THE DISSERTATION

Advance Care Planning in Patients with Decompensated Cirrhosis at Liver Transplant Centers

by

Arpan Arun Patel

Doctor of Philosophy in Health Policy and Management

University of California, Los Angeles, 2020

Emmeline Chuang, Co-Chair

Jack Needleman, Co-Chair

Individuals with decompensated cirrhosis (DC) in the United States (U.S.) receive costly, burdensome care at the end of life that may not be concordant with their goals and preferences. With a growing prevalence of individuals affected by liver disease over the past decade and limited capacity for performing liver transplantation (LT), solutions are critically needed. Advance care planning (ACP), a process that supports adults in understanding and sharing their personal values, life goals, and preferences regarding future medical care, is beneficial in helping patients with serious, life-limiting illnesses and their caregivers cope with the realities of their disease. Use of ACP has been associated with improved end of life outcomes, such as lower healthcare utilization and care consistent with goals. However, little is known about how often ACP occurs in patients with DC.

This dissertation explores the experience of ACP in patients with DC at LT centers. Semi-structured interviews were conducted with 42 patients with DC and 46 LT providers at three major LT centers in Los Angeles. Analyses focused on understanding the extent to which LT providers currently engage in ACP with patients with DC (Study 1), the experience of ACP from the perspectives of patients (Study 2), and barriers to ACP experienced by LT providers (Study 3). Results show that although most LT providers find early engagement in ACP acceptable, few providers engage in ACP in patients with DC at LT centers, and if goals of care discussions occur, they happen at the very end of life. Patients with DC similarly report limited conversations with providers at LT centers, but are mostly ready to have these conversations. The most common barriers faced by providers in performing ACP include an organizational culture that prioritizes transplants over other care (“transplant culture”), competing demands for provider time, role ambiguity, language barriers, and limited cultural competence. In light of these findings, we advocate for future research efforts to focus on identifying provider knowledge gaps and creating models of care that incorporate palliative care, as well as changes in policy. We believe this dissertation provides an important framework for understanding the current state of ACP in patients with DC and can direct the development of interventions that ultimately promote provision of goal-concordant care in this population.

The dissertation of Arpan Arun Patel is approved.

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DEDICATION

To my dearest family and friends, whose unwavering guidance, love, and support have allowed me to reach my goals and keep setting new ones.

To my mentors in medicine and health services research, who inspire me to always be critical, creative, and compassionate.

To my patients with liver disease and their caregivers, for allowing me to listen to your stories and for giving me the privilege to take care of you.

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Aby E., Winters, A, Lin, J, Bui, A, Kawamoto, J, Goetz M, Bhattacharya D, May, F, **Patel A.**, Benhammou, J. A telephone and mail outreach program successfully increases uptake of hepatocellular carcinoma surveillance. Accepted for publication to *Hepatology Communications*.

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Chapter 1: Introduction to the Dissertation

1.1 Dissertation Overview

This dissertation is a study that explores the experience of advance care planning (ACP) in patients with decompensated cirrhosis (DC) who are treated at liver transplant (LT) centers. This first chapter provides 1) an overview of the epidemiology and treatment options for DC in the United States (U.S.), 2) evidence of limited goal-concordant care for patients with DC, and 3) a summary of evidence supporting ACP for patients with serious, life-limiting illnesses, including patients with DC. This chapter also includes a summary of the Dissertation aims. Chapter 2 will provide a detailed description of the methods used in this study. Chapters 3, 4, and 5 will present the major findings of our study. Finally, Chapter 6 will provide a summary of our key findings, discuss the limitations of the dissertation, and suggest ways this study may help shape future research and inform policy. We believe this research will serve as an important foundation for research in ACP and palliative care (PC) for patients with serious illnesses affecting the liver.

1.2 The Rising Burden of Cirrhosis in the United States

Cirrhosis is a condition characterized by irreversible replacement of the liver by scar tissue, or fibrosis, as a response to persistent injury (Friedman 2000). It affects 633,000 individuals in the United States (U.S.), or about 0.27% of the population (Scaglione et al. 2015; Schuppan and Afdhal 2008). The most common causes of cirrhosis in the U.S. are Hepatitis C virus, alcohol abuse, and non-alcoholic fatty liver disease (NAFLD), which are present in 57%, 24%, and 9% of patients, respectively (Kim et al. 2002; Younossi et al. 2018). The burden of illness is expected to increase due to the rise of the obesity epidemic, increased prevalence of

alcohol use disorder over the past two decades, and the yearly increase in prevalence of Hepatitis C infections, despite the availability of highly effective new antiviral therapies (Beste et al. 2015; Younossi et al. 2011; Tapper and Parikh 2018). The condition also disproportionately affects ethnic minorities and patients of lower socioeconomic backgrounds. Twenty nine percent of patients with cirrhosis are Black and 34% are Latino, compared to 20% and 28.1% of patients without cirrhosis, and half of all affected patients report individual incomes less than \$25,000 per year (Scaglione et al. 2015).

1.3 Limited Treatment Options for Patients with Decompensated Cirrhosis

Every year, 5-7% of patients with cirrhosis will progress to decompensated cirrhosis (DC), a term that refers to the development of complications as a result of progressive fibrosis, ordinarily due to poorly controlled risk factors. Within 10 years of diagnosis, 75% of patients are estimated to progress to this state. Complications from this condition include the formation of ascites, hemorrhage from esophageal varices, and hepatic encephalopathy (D'Amico, Garcia-Tsao, and Pagliaro 2006). Table 1.1 summarizes these complications. The presence of hepatic encephalopathy and ascites are particularly associated with significantly reduced quality of life in patients and their caregivers. (Arguedas, DeLawrence, and McGuire 2003; Hansen et al. 2020).

The development of decompensated disease is also marked by a significant increase in morbidity and mortality. One-year survival reduces from 95% to 60% and 10-year life expectancy, from 12 to 2 years. (D'Amico, Garcia-Tsao, and Pagliaro 2006). Figure 1.1 displays differences in 1- and 2-year mortality between compensated and decompensated disease. In 2015, there were 38,170 deaths attributed to cirrhosis in the United States, making it the 10th leading cause of death in men, 6th in individuals between the ages of 25-44, and 4th in

individuals between the ages of 45-64 (QuickStats: Death Rates for Chronic Liver Disease and Cirrhosis).

In the U.S., patients are recommended to be considered for LT once conservative options for managing disease fail (Harrison 2015) and once laboratory tests indicate significantly impaired liver function, as indicated by a Model for End Stage Liver Disease-Sodium (MELD-Na) score of 15 or higher (Onaca et al. 2003; Martin et al. 2014). Outside of their use for determining timing of referral for LT and prioritization for listing, MELD-Na and other prognostic score models such as the Child-Pugh score are widely used to correlate clinical and laboratory biomarkers with the risk of death (Kamath, Kim, and Advanced Liver Disease Study 2007). The calculation and prognostic significance of MELD-Na and Child-Pugh scores are presented in Table 1.2.

Unfortunately, transplant is not an available option for most patients. In a study that used private insurance claims data from 2006-2014, only 15% of patients who are “transplant-eligible” were placed on the LT waiting list, and only 8% receive a LT within 3 years of diagnosis of developing decompensated disease (Goldberg et al. 2016). Disparities based on geography, such as distance from transplant centers, as well as race, ethnicity, and gender are well-recognized barriers to fair and equitable access to liver transplant centers (Mathur et al. 2014; Mathur et al. 2011; Bryce et al. 2009; Abt and Goldberg 2017; Goldberg et al. 2014; Goldberg et al. 2016; Goldberg et al. 2017). Guidelines from professional societies such as the American Association for the Study of Liver Diseases (AASLD) also indicate that lack of social support, persistent substance use, and life-limiting comorbidities are contraindications to liver transplantation as well (Martin et al. 2014), although the prevalence of patients denied access to liver transplant evaluation and wait-listing for each of these reasons is largely unknown.

In 2019, 8,896 LT surgeries were performed for all forms of liver disease (United Network for Organ Sharing (UNOS) Transplant Trends. <https://unos.org/data/transplant-trends/>. Accessed February 2). Since the adoption of the MELD score in 2002 for allocation, 5-year patient survival following LT has been reported as 70% in the United States (Dutkowski et al. 2015).

1.4 Burden of Illness for Patients with Decompensated Cirrhosis

Patients with DC, most of whom do not have access to liver transplant, experience profound suffering as their condition starts to deteriorate. Patients are frequently hospitalized and over a third are readmitted within a month of their hospitalization (Volk et al. 2012). The most common symptoms experienced are fatigue, pain, breathlessness, insomnia and fatigue (Peng et al. 2019). Psychological distress and significant social isolation are also common (Hudson, Hunt, et al. 2018). Uncertainty about what to expect from their illness along with a focus of their care on curing their disease, were noted as a large part of their experience (Kimbell et al. 2015).

This burden only intensifies near the end of life. Most patients with cirrhosis die from their underlying liver disease, typically in the setting of an infection, gastrointestinal bleeding, or complications from liver cancer (Ratib et al. 2015; Schlichting et al. 1983). Symptoms experienced at the end of life include jaundice, pain, insomnia, and lack of energy (Hansen et al. 2015). In many cases, patients die in ways that are unacceptable to most individuals (Singer, Martin, and Kelner 1999). In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), investigators demonstrated that patients with DC and a 6-month life expectancy experienced significantly more physical symptoms and generated greater caregiver burden nearing the end-of-life compared to patients dying of other chronic conditions.

The levels of uncontrolled pain and dyspnea experienced by these patients were, in fact, similar to symptom scores from patients with advanced lung and colorectal cancer. Patients were universally disabled and one third of their caregivers reported losing all their savings (Roth et al. 2000). Sixty seven percent of patients with DC also die in an institutionalized setting such as a hospital, nursing home, or long term acute care facility (Altaïi et al. 2018). Of those who die in the hospital, 56% of patients received mechanical ventilation and 16% receive hemodialysis, and these estimates are even higher in centers offering LT (Ufere, Halford, et al. 2019b; Kelly et al. 2017) (Patel et al. 2017). Medicare beneficiaries with DC are significantly more disabled and receive twice the amount of informal caregiving hours per week compared to age-matched controls during this timeframe (Rakoski et al. 2012).

There is growing interest by policymakers, patients, caregivers, and clinicians to ensure that the care delivered to seriously ill patients, such as those with DC, is not only high-value but also goal-concordant, or consistent with their goals and preferences (Sanders, Curtis, and Tulsky 2018; Kelley and Bollens-Lund 2018). However, much of the care delivered to patients with DC does not appear to be focused on their goals of care, both during their illness trajectory and at the end of life.

1.5 Introduction to Advance Care Planning

Advance care planning (ACP) is a process that supports adults in understanding and sharing their personal values, life goals, and preferences regarding future medical care (Sudore et al. 2017). The most important outcome of ACP is ensuring goal-concordant care (Sanders, Curtis, and Tulsky 2018; Sudore et al. 2018). Components of successful ACP include: 1) identifying an appropriate surrogate decision maker, 2) identifying values, goals, and preferences in the context of current quality of life and future health states, 3) becoming more informed

regarding one's own medical disease, including prognosis, and 4) documentation (Sudore et al. 2008; Billings and Bernacki 2014; Bekelman et al. 2017). Though the process of ACP can start with patients and their caregivers, healthcare providers should support this process and should particularly play a crucial role in sharing prognosis and helping patients develop treatment plans (Sudore et al. 2017). Providing ACP has been identified as an important process of care in medicine linked to improved end-of-life outcomes, including reduced caregiver burden, improved mental health, improved satisfaction of care, and reduced healthcare utilization in patients with life-limiting chronic illnesses (Brinkman-Stoppelenburg, Rietjens, and van der Heide 2014; National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. Pittsburgh).

Several published studies have identified the presence of patient, provider, and system-level factors that affect the performance of ACP. Demographically, patients who are older, attaining higher education, White, heterosexual, with advanced cancer, and with low functional status have higher rates of engagement in ACP than other populations. With regards to beliefs, preferences for communication, nature of social relationships, prior knowledge of ACP, and attitudes about death are all considered important factors (Lovell and Yates 2014). Providers that are more likely to engage their patients in ACP demographically are those of younger age and oncologists (Keating et al. 2010). Attitudes about timing of ACP, discomfort with conversations, lack of skill with communication, and fear of taking away hope are commonly reported barriers to bringing up these conversations (Lovell and Yates 2014; De Vleminck et al. 2013). Lastly, access to geriatric and palliative services has been seen as a major system factor associated with receipt of ACP (Lovell and Yates 2014). Lack of care coordination and lack of time to discuss ACP have been cited as barriers in previous studies (De Vleminck et al. 2015).

1.6 Advance Care Planning in Decompensated Cirrhosis: What is Known?

There are a limited number of studies that have characterized ACP in patients with DC (Table 1.3). Studies based on review of electronic health records and patient surveys reveal rare conversations about goals of care until the end of life and low rates of ACP documentation (Low et al. 2017; Najafian et al. 2019; Sprange et al. 2019). Presuming poor rates of ACP, other studies have investigated potential provider and patient-level barriers to ACP. A survey of transplant hepatologists in the U.S. confirmed limited discussion about goals of care and identified barriers such as insufficient cultural competency, insufficient training, stress of taking care of dying patients, and fear of legal liability (Ufere, Donlan, et al. 2019). A few qualitative studies have explored this topic as well. Studies featuring semi-structured interviews with patients concluded that patients with DC have poor knowledge of ACP and typically rely on family members for healthcare decisions (Carbonneau et al. 2018; Hudson, Hunt, et al. 2018). Interviews with providers have revealed that lack of confidence in performing discussions, prognostic uncertainty, and discontinuity of care were major barriers (Low et al. 2017)

1.7 Advance Care Planning in Decompensated Cirrhosis: What We Still Do Not Know

Prior research surrounding ACP in DC has relied on documentation from the electronic health record to demonstrate a lack of ACP, but this may not reflect the full experience of ACP from patients and providers, as informed by research from other illness populations (Yung et al. 2010). Similarly, though previous studies have investigated barriers to ACP using semi-structured interviews, the limited populations sampled (providers from a single transplant center, general practitioners, and patients ineligible for transplant) may not capture the full breadth of experiences needed to better describe these barriers. More fundamental work is needed to describe these phenomena, particularly in the U.S.

1.8 Dissertation Overview

This dissertation is comprised of three separate studies that collectively describe different factors influencing experience of ACP in patients with DC. **Study one** describes the experience of ACP at LT centers through the perspectives of providers. **Study two** examines patient experience of ACP, as well as patient-level barriers, facilitators, and preferences for ACP. Finally, **Study three** assesses provider barriers and provider preferences for ACP.

Table 1.1: Major Complications of Cirrhosis and Definitions

| Major Complication of Cirrhosis | Definition |
|-----------------------------------|---|
| Ascites | Development of fluid in the abdomen |
| Esophageal varices | Dilation of vessels in the esophagus with propensity to bleed |
| Spontaneous bacterial peritonitis | Development of infection in the ascitic fluid in the abdomen |
| Hepatic encephalopathy | Development of confusion due to toxic buildup of ammonia |
| Hepatorenal syndrome | Development of renal (kidney) failure |

Reference: Bosch et al. J. Hepatology 2000 and Butterworth. Hepatology 2000

Table 1.2: Calculation and Prognostic Significance of Model of End Stage Liver Disease-Sodium (MELD-Na) and Child-Pugh Scores

| Score | Variables | Calculation |
|------------------------|--------------------------------------|---|
| MELD-Na | Total Bilirubin (mg/dL) | $\text{MELD} = 0.957 \times \ln(\text{Creatinine}) + 0.378 + \ln(\text{Total Bilirubin}) + 1.120 \times \ln(\text{INR}) + 0.643$ $\text{MELD-Na} = \text{MELD} + 1.32 \times (137 - \text{Sodium}) - [0.033 \times \text{MELD}] \times [137 - \text{Sodium}]$ |
| | International Normalized Ratio (INR) | |
| | Creatinine (mg/dL) | |
| | Sodium (mEq/L) | |
| Child-Pugh | Total Bilirubin (mg/dL) | < 2 (1 point) |
| | | 2-3 (2 points) |
| | | > 3 (3 points) |
| | International Normalized Ratio (INR) | < 1.7 (1 point) |
| | | 1.7-2.2 (2 points) |
| | | > 2.2 (3 points) |
| | Serum Albumin (g/dL) | >3.5 (1 point) |
| | | 2.8-3.5 (2 points) |
| | | <2.8 (3 points) |
| | Ascites | Absent (1 point) |
| | | Slight (2 point) |
| | | Moderate (3 point) |
| Hepatic Encephalopathy | No Encephalopathy (1 point) | |
| | Grade 1-2 (2 points) | |
| | Grade 3-4 (3 points) | |

MELD-Na Score (3-month mortality rates):

9 or less (1.9%), 10-19 (6%), 20-29 (19.6%), 30-39 (52.6%), 40 (71.3%)

Child-Pugh score (1-and 2-year survival):

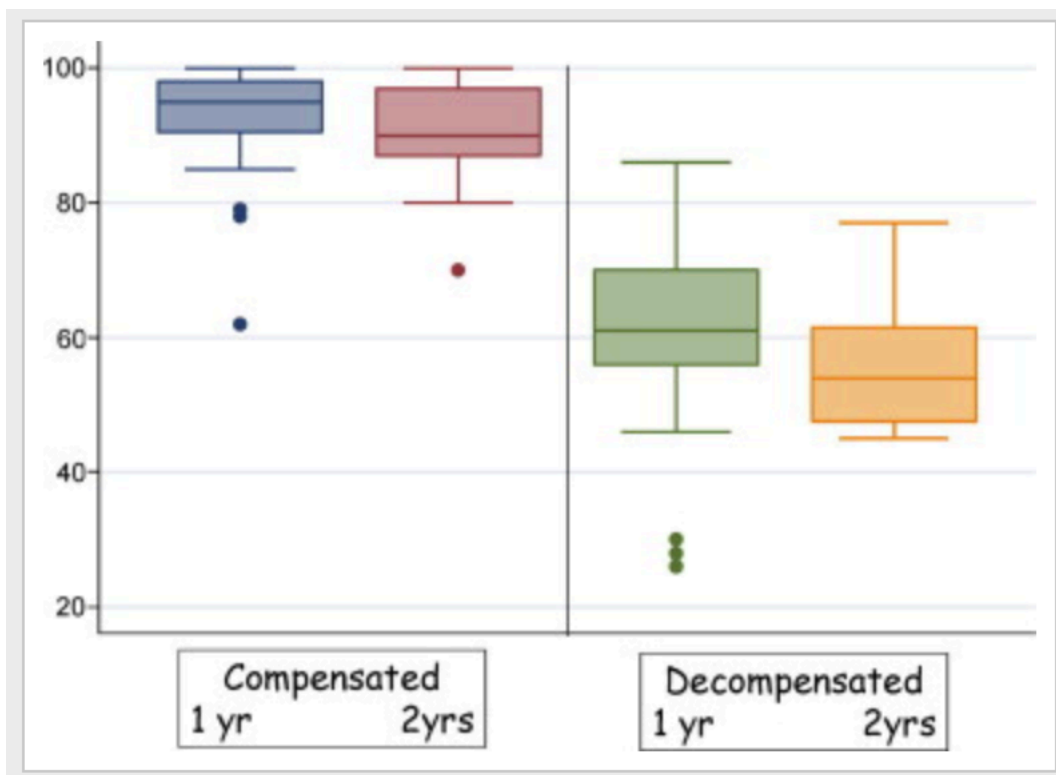
5-6 = Child Pugh A (100, 85%); 7-9 = Child Pugh B (80, 60%), 10-15 = Child Pugh C (45, 35%)

Reference: Biggins et al. Gastroenterology 2006; Durand et al. J. Hepatology 2005.

Table 1.3: Summary of Studies Describing Advance Care Planning in Patients with Cirrhosis

| Author/Year | Country | Research Aims (Methods) | Sample | Key Findings |
|-----------------|---------|---|--|---|
| Low 2017 | UK | To understand the type of care and challenges in caring for patients with cirrhosis in last year of life (chart review, focus groups, semi-structured interviews) | Doctors, nurses, allied health professionals at single transplant center | Infrequent and late documentation of goals of care discussions; lack of confidence in performing discussions; late referral and misperceptions about palliative care. |
| Carbonneau 2018 | Canada | To investigate patient experience and perceptions about ACP(semi-structured interviews) | Patients with cirrhosis | Insufficient knowledge about disease; reliance on family members; preference for early conversations |
| Ufere 2019 | US | To understand barriers to ACP discussions (survey) | Transplant hepatologists | Insufficient goals of care conversations; cultural competence towards end of life; stress of caring for dying patients. |
| Najafian 2019 | US | To report frequency of ACP (chart review) | Visits at a post discharge clinic for patients with cirrhosis | No ACP discussions were documented |
| Sprange 2019 | Canada | To report frequency and preferences for ACP and GCD (surveys) | Patients with cirrhosis | 33% have advance directive and 14% report a goals of care discussion, overall supportive for having earlier conversations |

Figure 1.1: One and Two-year Mortality in Compensated and Decompensated Cirrhosis



Reference: D'Amico et al. Journal of Hepatology. 2006

Chapter 2: Overview of Dissertation Methods

2.1 Overall Approach

In order to address these exploratory aims, we used a qualitative approach. These methods are most appropriate for obtaining a detailed understanding of a phenomenon and exploring a diverse range of behavior—in this case, for advance care planning (ACP) (Creswell, Fetters, and Ivankova 2004). For this study, we performed and analyzed semi-structured interviews.

2.2 Sampling Strategy and Recruitment Procedures

The unit of analysis for our study were 1) patients with decompensated cirrhosis and 2) healthcare providers at LT centers. To be eligible for inclusion in the study, patients needed to be: 1) adults over the age of 18 years; 2) diagnosed with cirrhosis of the liver, 3) diagnosed with one major complication related to portal hypertension (ascites, variceal hemorrhage, hepatic encephalopathy), and 4) found to have a Model of End-Stage Liver Disease-Sodium (MELD-Na) score that ever was 15 or higher. Patients with a history of hepatocellular carcinoma were excluded because prior studies have shown that their experience in receiving palliative care is likely different from patients with DC (Sanoff et al. 2017; Woodrell, Schiano, and Goldstein 2017; Patel et al. 2017; Patel et al. 2020). Patients with signs of moderate to severe hepatic encephalopathy, defined as a West-Haven score of 3 or higher, were also excluded from the study. Lastly, patients who reported being unable to complete a full interview in English were excluded from the study. Providers in this study were defined as healthcare professionals responsible for overseeing the care of patients with DC during any component of a patient's illness trajectory. We did not, however, include healthcare providers who only saw patients after LT.

Patients and providers were sampled from three LT centers in the Greater Los Angeles area with different organizational structures, affiliations and racial/ethnic breakdown of patients (see Table 2.1 for more information). Stratified purposeful sampling, an approach that combines purposive sampling and quota sampling, was used to ensure inclusion of patients from each of the following strata: 1) too early (“not sick enough”) for LT evaluation, 2) currently undergoing evaluation for LT, 3) waitlisted for LT, and 4) not listed for LT due to contraindications such as advanced age, comorbid conditions, psychosocial barriers, or substance abuse. For providers, we used the following strata: 1) transplant hepatologists, 2) transplant/hepatobiliary surgeons, 3) transplant coordinators, and 4) social workers. (Otis-Green ; Walling, D'Ambruso, et al. 2017; Arnett et al. 2017). (Table 2.2) We planned on needing 10 informants per domain in order to hypothetically achieve theme saturation (Weller). We also used snowball sampling to capture the perspectives of providers who were thought to have more detailed knowledge of ACP, based on the responses of informants (Bernard).

We focused on LT centers since transplant status may affect experience of ACP (Walling et al., 2013; Patel et al., 2017). We sampled specifically from LT centers that each perform more than 100 LT surgeries per year and see among the most medically acute cases in the country. Over 20% of transplants occurring at these centers have a MELD-Na score greater than 30, compared to just 10% nationally. Additionally, over 50% of patients are hospitalized or in the intensive care unit (ICU) at time of transplant in all three centers, compared to 34% nationally (Scientific Registry for Transplant Recipients). Sampling centers that see the highest acuity of patients with DC increases the likelihood of having ACP discussions, since patients with lower functional status are more likely to engage in ACP and since guidelines are more likely to

recommend ACP in these seriously ill patients (Lovell and Yates 2014) (Walling, Ahluwalia, et al. 2017).

Different approaches were used to recruit patients and providers. Providers were either contacted by email or approached in person. Contact information was either publicly available, reported in local directories, or obtained through mutual contacts. Snowball sampling was used to recruit two additional informants, based on recommendations from previous informants. At each center, patients were recruited from multiple hepatologists (four from Center 1, three from Center 2, four from Center 3) using patient lists. Eligible patients (based on electronic health record review) were identified by the research team and confirmed by the referring hepatologist, or identified by the referring hepatologist alone. Patients were recruited using two strategies: 1) contacted prior to their appointment by a research assistant or 2) approached in person by the research team during their scheduled appointment. All patients were pre-screened by their hepatologist prior to being approached by the research team by phone or in person. The research team then performed a final screening to ensure patients met inclusion criteria prior to consent. Patients who requested caregivers to be present for the interview were included in the study, as long as caregivers consented to helping the patient convey his or her opinion rather than articulate their own opinion. Written consent was provided to each patient (and caregiver, if applicable) and provider just prior to interviewing. Patients were also asked to provide consent for data collection from the electronic health record. See Figure 2.1 for a visual representation of the recruitment process and Figure 2.2 for a diagram of all included informants.

2.3 Semi-Structured Interviews

2.3.1 Justification for Interviewing for Data Collection

Face to face, semi-structured interviews were chosen as the major data collection method for this study since interviews allow informants to speak candidly about their experiences and allow for possible comparisons between informants, as opposed to focus groups (Bernard).

2.3.2 Interview Guide Development and Pilot Testing

Interview guides for patients and providers were centered around understanding their experience of ACP. Questions were targeted towards how providers share and how patients experience the following five processes: 1) understanding prognosis, 2) choosing a surrogate decision maker, 3) choosing healthcare preferences, 4) documenting healthcare preferences, and 5) choosing values and goals (Sudore et al. 2008; Billings and Bernacki 2014; Bekelman et al. 2017; Berlinger). For provider interviews, questions centered around understanding the context, behavior, thoughts and decisions involved with each action (Ryan et al. 2009)) as well as better elucidating any barriers for behaviors that did not occur. For patient interviews, questions centered around understanding readiness for ACP first. Readiness was defined by the following stages: 1) pre-contemplation: having no specific intention to change behavior, 2) contemplation: thinking about changing behavior only, and 3) action: having performed a recent behavior(Sudore et al. 2008). See Figures 2.3 and 2.4 for a visual representation of 1) components of ACP and 2) readiness for ACP. For patients that spoke of an action (sharing their behavior with others), we further asked about the context, behavior, thoughts, and decisions with those actions, as well as any barriers and facilitators to those actions. Lead-in questions were used for both patient and provider interviews. Given that patients may generally be unfamiliar with themes of ACP, they were first asked about quality of life and general knowledge of their disease prior to engaging in further questions. Probes explicitly avoided themes of death, and the topic was only addressed if patients brought it up themselves. These practices are consistent

with a prior study looking at perceptions of ACP in advanced heart failure (Klindtworth et al. 2015). For provider interviews, we asked about the individuals' role at the transplant center before discussing other topics. Please see Table 2.3 for example questions from our interview guide. Please refer to the Appendix for our full interview guides with questions involving ACP. Content for both scripts were reviewed extensively by three qualitative research and two ACP content experts. Scripts were pilot tested with 10 participants (8 for provider interviews, 2 for patient interviews) and revised accordingly based on feedback and discussions with experts.

2.3.3 Conducting Interviews

After obtaining informed consent, all interviews were conducted by a single individual. All participants were granted permission to stop the interview at any time or erase or delete segments of the audio-recorded interview prior to transcription, if desired. Patients were permitted to have caregivers present during the interview if they found difficulty in answering questions. Caregivers were instructed to only speak for the informant but not include their own opinions, when possible. Social work contact information was provided in the event that any discomfort arises after the patient interviews, though this never occurred during interviews.

2.3.4 Interview Transcription

All audio-files were reviewed for accuracy to ensure that the full interview was captured. A professional, HIPAA-compliant transcription service was used to transcribe all audio-recordings from the session verbatim. Following transcription, all transcripts were reviewed for accuracy and adjusted accordingly for errors using audio files as a guide. All transcripts were loaded onto NVivo 12 Software (QSR International) for analysis.

2.4 Quantitative Data Collection

The intent of collecting quantitative data was to ensure that our sample had diverse socio-demographic and clinical characteristics. The following demographic variables were collected from patient charts with assistance of three chart abstractors: age, gender, race/ethnicity, insurance status, marital status, laboratory data, and presence of any ACP documentation in the electronic health record. For laboratory data, the following values were obtained closest to the patient's scheduled visit in order to calculate the Model for End-Stage Liver Disease-Sodium (MELD-Na) score: total bilirubin, serum sodium, serum creatinine, and international normalized ratio (INR).

2.5 Data Analysis

The primary goal of our data analysis plan was to describe themes regarding ACP in our studies. Study one focused on identifying extent to which LT providers reported engaging in ACP with patients. Study two focused on the experience and readiness of patients, as well as barriers, facilitators, and preferences. Study three focused on provider barriers and preferences. Our secondary goal was to determine which themes were common across informants at the three centers. To accomplish these goals, we used a multi-staged analysis process.

2.5.1 Stage 1: Coding

Following completion of all semi-structured interviews, a codebook was created and refined. The majority of codes were created from elements on the interview guide: 1) the experience of major domains of ACP, 2) readiness for ACP (patients only), 3) barriers and facilitators, and 3) preferences for ACP. This codebook was refined with assistance from an experienced qualitative researcher in palliative care. After resolving conflicts, each team member assigned codes to segments of texts for all transcripts. Coders met every week to discuss

any coding discrepancies and emerging themes. Codes from both coders were combined for the final analysis. Final codebooks are included in the Appendix.

2.5.2 Stage 2: Analyzing Coded Texts

Patient and provider texts were analyzed separately. For analyses focused on readiness and experience, a pile sorting technique was used (Bernard). This method involves printing text associated with specific codes onto slips of paper, which are then sorted into piles based on similarities and differences. Eventually, both team members came to a consensus regarding what thematic categories to include. For analyses focused on barriers, facilitators, and preferences, we used the qualitative data analysis software NVIVO 12.0. A similar method to traditional pile sorting was performed, in which groups of quotes were compared and categorized using secondary codes iteratively until categories were distinct and not overlapping. Sub-analyses were conducted that compared data between provider types (using same classification as in Table 2.2).

Table 2.1 Characteristics of Transplant Centers Included in Study

| Characteristic | Center 1 | Center 2 | Center 3 |
|--|-----------------|-----------------|-----------------|
| Patient Gender* | | | |
| Male | 64.6% | 50.2% | 58.3% |
| Female | 35.4% | 49.8% | 41.7% |
| Patient Age* | | | |
| 18-49 | 18.4% | 25.6% | 25.7% |
| 50-64 | 59.2% | 52.7% | 44.6% |
| 65+ | 22.5% | 21.6% | 23.5% |
| Patient Race/Ethnicity* | | | |
| Caucasian | 47.6% | 26.1% | 44.0% |
| Hispanic | 42.2% | 56.7% | 39.7% |
| Black | 1.4% | 2.0% | 4.2% |
| Asian | 4.8% | 13.8% | 11.4% |
| Other | 4.1% | 1.5% | 0.7% |
| # Transplants Per Year* | 111 | 123 | 154 |
| Center Structural Characteristics** | | | |
| # Hepatologists | 7 | 3 | 7 |
| # Nurse Practitioners | 2 | 6 | 2 |
| # Hepatobiliary Surgeons | 5 | 4 | 5 |
| # Transplant Coordinators | 5 | 4 | 9 |
| # Social Workers | 2 | 3 | 2 |
| Department Affiliations** | | | |
| Internal Medicine | Yes | Yes | No |
| Surgery | No | No | Yes |
| Transplant (separate) | Yes | Yes | No |

*data from 07/01/2018 to 06/30/2019 (SRTR data, previously referenced)

**data from 07/01/2017 to 7/1/2018 (publicly available data)

Table 2.2 Description of Informants

| Informant | Description |
|--------------------------------|--|
| Patients* | |
| Listed for transplant | Patients who are currently waitlisted for organ transplant after have been through the evaluation. Active for accepting organ offers |
| Evaluated for transplant | Patients who are currently undergoing evaluation to get listed for liver transplant. Their case has not yet deliberated on to decide whether they will be placed on the waitlist. |
| Not listed – “too early” | Patients who are not deemed ill enough to justify needing a liver transplant for cure. |
| Not listed – contraindications | Patients who are deemed to have contraindications to being waitlisted for a liver transplant, including non-hepatic or psychiatric comorbidities or substance use. |
| Providers** | |
| Transplant Hepatologists | Physician who has completed a residency in internal medicine and at least a fellowship in gastroenterology, transplant hepatology, or both prior to practicing. Hepatologists are responsible for caring for patients with DC and deciding whether they are eligible for a transplant evaluation. Our definition included nurse practitioners who practice clinical hepatology |
| Hepatobiliary surgeons | Physician who has completed a residency in general surgery and a fellowship in organ transplantation prior to practicing. Surgeons are responsible for evaluating patients prior to organ transplantation, performing the liver transplant itself, and treating immediate medical complications and consequences that arise quickly after surgery. |
| Transplant Coordinators | Registered nurse or nurse practitioner that is responsible for navigating a patient through the transplant evaluation and waitlist process. Their duties include handling access to medications, appointments, and medical staff that can answer or assess the patient’s concerns in an expedient fashion. |

| | |
|----------------|---|
| Social Workers | Practitioner that has obtained a master's degree in social work degree and is responsible for performing a psychosocial evaluation as part of a patient's transplant evaluation process and addressing a number of social issues that can arise, including financial assistance, housing, addiction rehabilitation, and mental health |
|----------------|---|

*(Volk et al. 2011)

** (United Network for Organ Sharing (UNOS) Bylaws)

Table 2.3 Topics and Example Questions from Interview Guide*

| Broad Topic | Specific Topics | Example Question |
|---|---|---|
| Patient | | |
| <i>Lead-in questions</i> | (1) Diagnosis of Cirrhosis, Past Experiences (2) Present Illness | (1) Can you tell me about how you became diagnosed with cirrhosis and what that experience was like? (2) If you had to pick 2-3 concerns you have about your experience with cirrhosis now, what would they be? |
| <i>Advance Care Planning – Main Questions</i> | (1) Prognosis (2) Surrogate Decision Making (3) Healthcare Preferences (4) Values and Goals (5) Documentation | (1) Have you thought about what may happen to you if you were not a candidate for liver transplant? [Readiness] Has this ever been brought up? [Action] (2) As you know, there are instances regarding your cirrhosis where you can get so sick that you may be unable to make medical decisions for yourself. Have you had discussions with your loved ones or medical team about who can specifically make medical decisions for you if that were to happen? What were those discussions like? |
| <i>Probes</i> | (1) Barriers (2) Facilitators (3) Preferences | (1) What are some reasons why you do not think that happens? (2) What made it easier for you to do? (3) How would you feel if someone from the medical team talked to you about that? |
| Providers | | |

| | | |
|---|---|--|
| <i>Lead-in questions</i> | (1) Job Description and Context | (1) Given that provider roles can vary across institutions, can you start by telling me a little bit about how you spend your professional time at the liver transplant center and the role you play in treating patients with cirrhosis? |
| <i>Advance Care Planning – Main Questions</i> | (1) Prognosis (2) Surrogate Decision Making (3) Healthcare Preferences (4) Values and Goals (5) Documentation | (1) Can you describe a typical conversation you will have with patients with decompensated cirrhosis about certain medical emergencies or events that can happen in the future? Can you explain any conversations you may have regarding a patient’s chance of dying? (5) How often do you check to see whether an advance directive has been filled out for a patient that you are seeing in clinic? What are circumstances where you would check?” Do discussions with patients about advance directives or POLST forms regarding their medical care ever come up? |
| <i>Probes</i> | (1) Barriers (2) Facilitators (3) Preferences | (1) What are some reasons why you think it never happens?” (2) What makes the conversation easier? (3) What are some ways you believe we can improve this? |

*Examples of questions used. There were adjustments in wording between interviews.

Figure 2.1 Recruitment Process for Informants

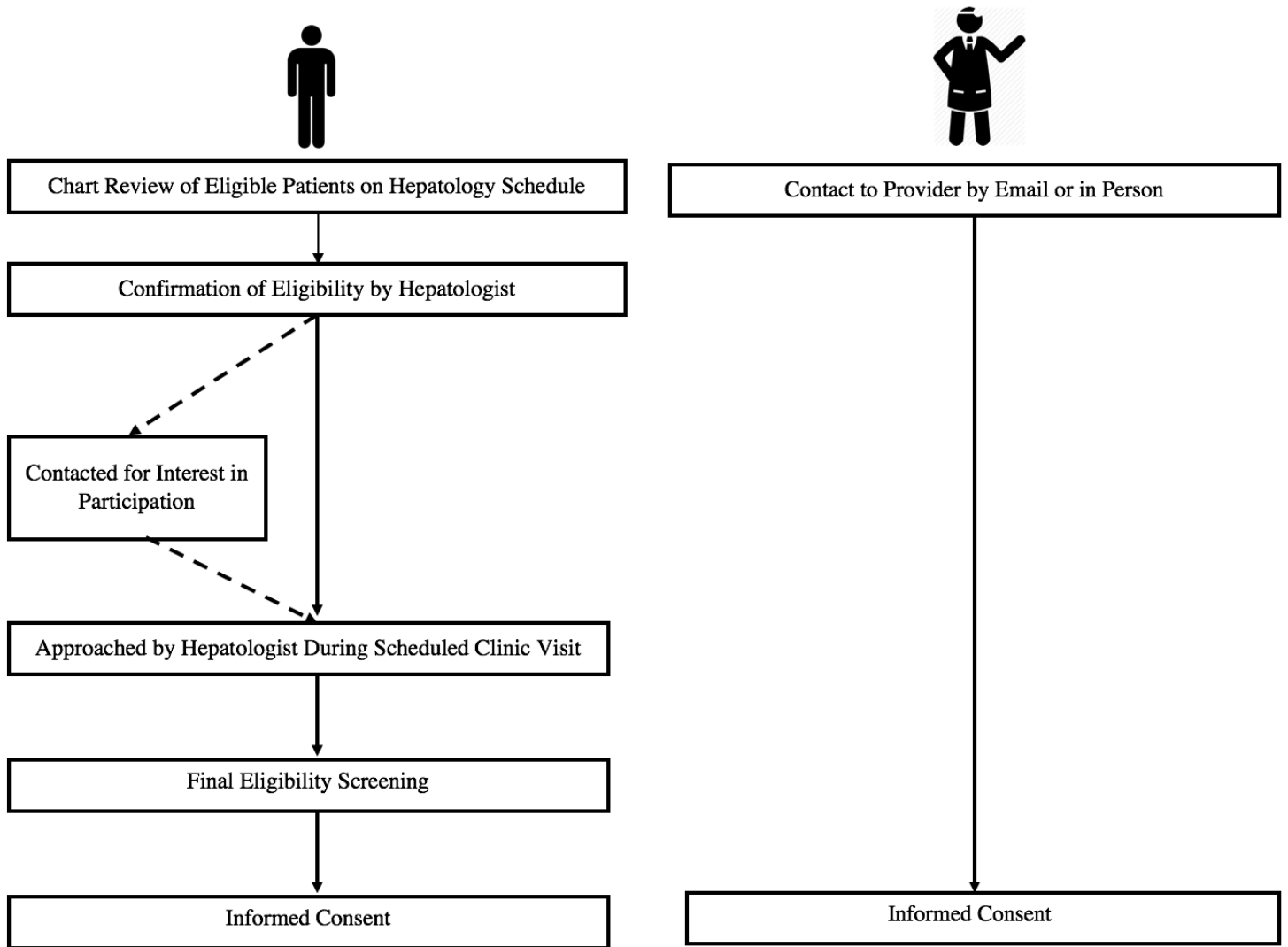
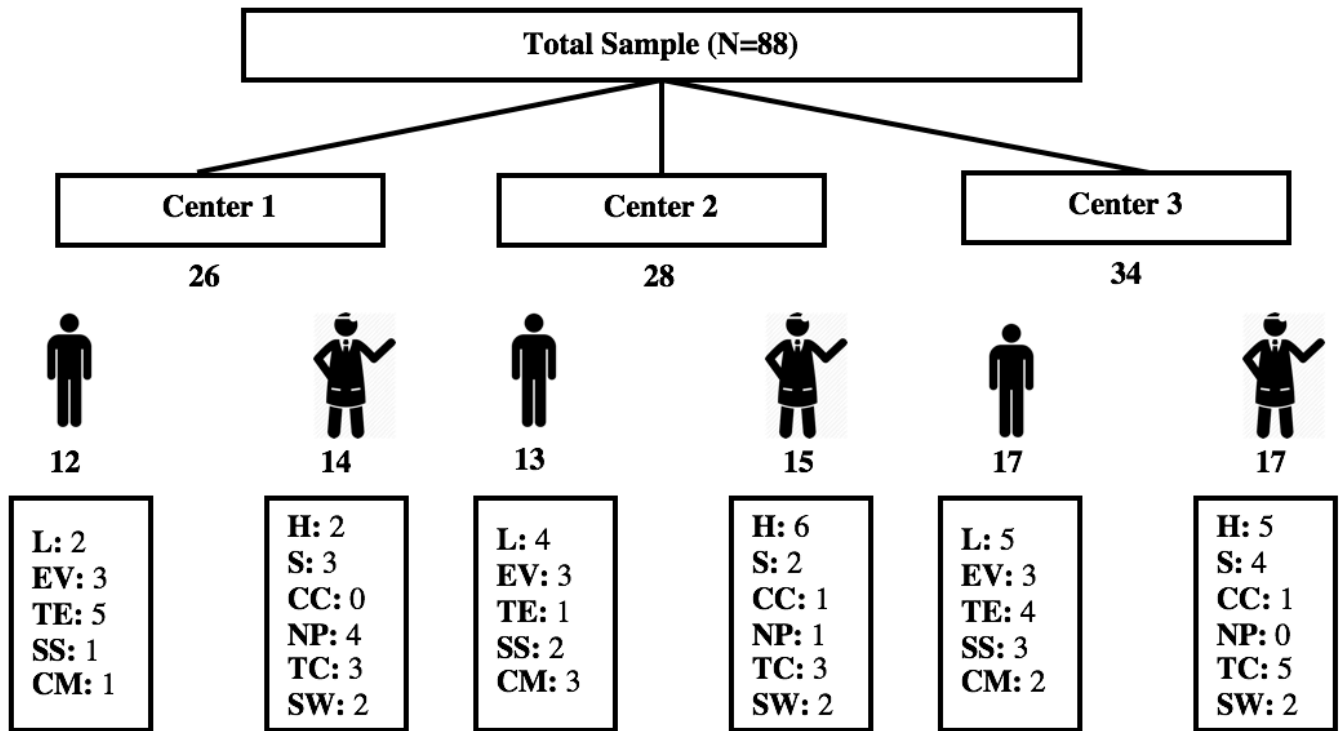


Figure 2.2 Final Recruitment of Informants, by Site



L: Patients listed for transplant
EV: Patients being evaluated for transplant
TE: Patients too early for transplant
SS: Patients not candidates due to social support/substance issues*
CM: Patients not candidates due to non-hepatic comorbidities*

H: Transplant hepatologist
S: Transplant/hepatobiliary surgeon
CC: Critical care specialist
NP: Nurse practitioner
TC: Transplant coordinator
SW: Social worker

Figure 2.3 Components of Advance Care Planning

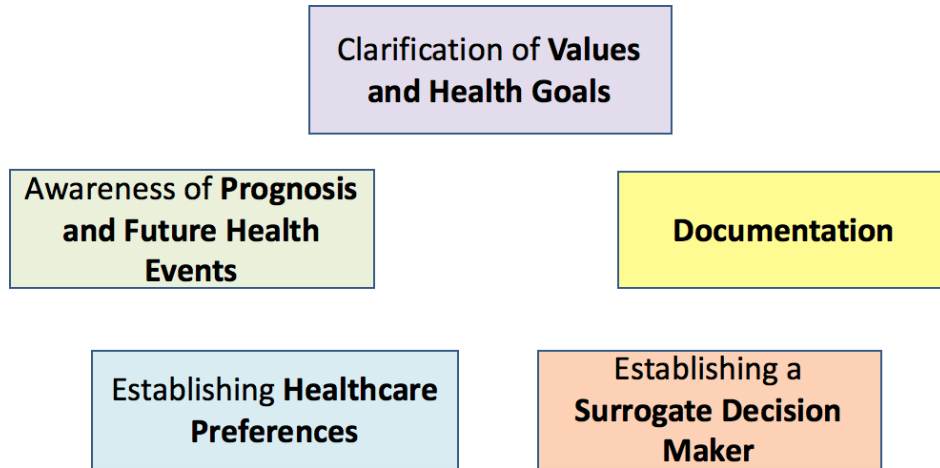
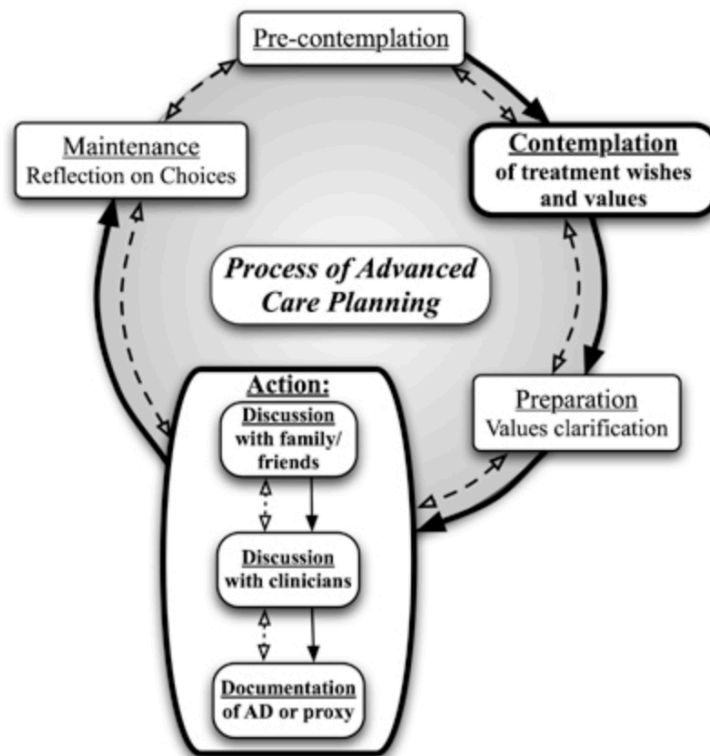


Figure 2.4 Readiness for Advance Care Planning



Reference: Sudore et al. Journ. of Am. Ger. Soc. 2008)

Chapter 3: Advance Care Planning in Decompensated Cirrhosis at Liver Transplant Centers: Provider Perspectives

3.1 Abstract

Introduction:

The burden of end of life care for cirrhosis is increasing in the United States, and the majority of patients are dying in institutionalized settings. Liver transplantation (LT) is a curative option, but it is not available for all patients. Advance care planning (ACP) has been associated with improved end of life outcomes in other chronic illnesses, but it has not been well-characterized in this population. The objective of this study is to describe extent to which LT providers report engaging in ACP in patients with decompensated cirrhosis (DC).

Methods:

Face to face, audio-recorded, semi-structured interviews were performed with 46 informants at three major LT centers. These included 13 hepatologists, 11 case coordinators, 9 hepatobiliary surgeons, 6 social workers, 5 hepatology nurse practitioners, and 2 critical care physicians. Recorded transcripts were analyzed using qualitative methods.

Results:

Provider engagement in ACP with patients was generally limited, with discussions about a patient's goals and values only performed consistently at the end of life, when care options are the most limited. ACP behaviors of providers also varied depending on a patient's chances of receiving a transplant. In particular, providers typically did not engage in ACP with patients whose transplant status was not well defined.

Conclusion:

Providers report inconsistent delivery of ACP throughout the trajectory of illness for patients with DC at LT centers. These findings may help explain poor prognostic awareness in

patients with DC and aggressive preferences for life-sustaining treatments at the end of life in this population.

3.2 Introduction

Cirrhosis of the liver is a leading cause of death and morbidity in the United States, and the number of deaths has increased by 65% from 1999-2016, with over 34,000 cases in 2016 (Tapper and Parikh 2018). Most public health, research, and clinical efforts have focused on preventive measures such as targeting alcohol use disorder and obesity, but there is growing attention being paid to addressing patterns of end of life care in this population (Patel et al. 2017; Hudson, Round, et al. 2018; Ufere, Halford, et al. 2019a). Though the number of Americans dying at home or in a hospice facility has risen (Cross and Warraich 2019), over 60% of patients with cirrhosis still die in an inpatient facility, nursing home, or long-term care facility (Altafi et al. 2018). Among those who die in a hospital, over half are mechanically ventilated and 16% receive hemodialysis (Patel et al. 2017). Liver transplantation (LT) is an effective cure for cirrhosis, and in 2019, 148 LT centers performed 8,896 LT surgeries for all forms of liver disease (United Network for Organ Sharing (UNOS) Transplant Trends. <https://unos.org/data/transplant-trends/>. Accessed February 2), but it is not a realistic option for most patients due to organ shortages and the fact that most patients are not suitable candidates to receive the operation.

Investigators from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) found that despite having similar life expectancies, patients with DC had higher preferences for aggressive resuscitation compared to patients with other chronic illnesses. (Roth et al. 2000). ACP supports patients in exploring their values, goals, and preferences to help future medical care, and it has been associated with improved end of life

outcomes, including healthcare utilization, caregiver burden, and mental health (Brinkman-Stoppelenburg, Rietjens, and van der Heide 2014). However, no major studies have provided an in-depth description of the process of ACP in DC.

The aim of this study is to describe the provider experience of ACP in patients with DC at LT centers, which have the highest volume of patients and resources to manage patients with DC, using qualitative methods.

3.3 Methods

3.3.1 Sampling and Data Collection

In order to address our exploratory study aims, we performed semi-structured interviews from three LT centers that perform a high volume of transplants and treat more acutely ill patients than other parts of the country. Centers varied significantly on demographic factors for the patients they treat and the structure of their organizations (see Table 2.1).

Informants were sampled from transplant centers using a stratified purposeful approach. This technique allowed us to sample based on provider role but also balance our cases across all three LT centers. All providers all LT centers have roles that are outlined and monitored by policy from regulatory agencies in the United States, such as United Network of Organ Sharing and Center for Medicare and Medicaid Services. A more complete description of these roles is displayed in Table 2.2.

Interview guides focused on understanding the context, behavior, thoughts, and decisions made by providers surrounding elements of ACP (discussing prognosis, healthcare preferences, values and goals, surrogate decision makers, and documentation) (Ryan et al. 2009; Sudore et al. 2008; Berlinger). Please see Figure 2.3 for this a visual representation of this framework. For each interview guide, lead-in questions with subsequent probes were used. Please see Table 2.3

for a list of topics and example questions. These guides were pilot tested in 8 informants and revised for content.

A gastroenterology fellow trained in qualitative methods performed 46 face to face semi-structured interviews between July 2017 and May 2018. Providers were approached either in person or via email for their participation. Informed consent was obtained from each informant, and all were provided a gift card incentive for their participation. All interviews were audio-recorded and transcribed. Data collection for this study was part of a larger investigation that also featured data collection and analysis of semi-structured interviews from patients at LT centers. The institutional review board of each medical center approved our study (IRB#17-000165). Please see Figure 2.1 for a visual representation of the recruitment process and Figure 3.1 for a flowchart of all included and excluded participants.

3.3.2 Data Analysis

The primary goal of our analysis was to describe themes that were common across all providers at all centers using a multi-stage process. First, a team comprising of a gastroenterology fellow and an experienced qualitative researcher in palliative care worked together to develop a codebook using codes corresponding to major domains of ACP. Each team member assigned codes to segments of texts for all 46 transcripts, which were then combined. Regular meetings were held between team members to resolve coding discrepancies. Next, a “pile-sorting” technique was used to generate themes. This technique involves printing quotes on individual slips of paper and iteratively categorizing quotes into piles based on thematic similarities. All data were imported to NVivo 12 Qualitative Data Analysis software (QSR International).

3.4 Results

Interviews from 46 informants, including 13 hepatologists, 11 case coordinators, 9 hepatobiliary surgeons, 6 social workers, 5 hepatology nurse practitioners, and 2 critical care physicians, were analyzed. Twenty-eight providers saw patients in both outpatient and inpatient settings, while fourteen providers cared for patients in the outpatient setting exclusively and four providers cared for patients in the inpatient setting exclusively. All 46 interviews described behaviors pertaining to ACP.

ACP occurred differently across three Phases, which were based on how providers perceive a patient's candidacy for LT. These included Phase 1: Liver transplant is an option being considered; Phase 2: There appear to be relative contraindications or barriers to wait-listing at this time; and Phase 3: Liver transplantation is not an option. In the coming sections, we will describe how ACP is performed within each Phase and describe how it changes as patients become more ill. Table 3.1 describes the number and type of providers whose quotes were used to shape the perspectives of each Phase.

Phase 1: Transplant is an Option

Some used cars are like used Mercedes – they look great, and they run great, and they're going to go a long time – whereas other used cars are a lot more like used Camrys. They're dented, the air conditioning doesn't work, the radio doesn't work, and the tires might need replacing, but the car is still going to go 300,000 miles. And then, there are cars like a Chevy Nova that are smoking or on fire by the side of the freeway, and I ask them, "What are you going to do if your car catches on fire on the freeway?..." "Well, we're going to have to get a new car." I go, "Aha! **You're going to need a new liver.** (Transplant Hepatologist)

This Phase refers to patients being evaluated or listed for LT. In the outpatient setting, patients are recommended to consider the option of LT once their bloodwork has reached the "critical" Model of End-Stage Liver Disease-Sodium (MELD-Na) score of 15, since chances of their liver recovering become uncertain. During the evaluation, hepatologists, transplant coordinators, and surgeons spend time educating patients about the benefits of transplant and share details about the procedure, the possibility of frequent hospitalizations, and the need for

immunosuppression. Providers also mention the long wait times needed to receive a transplant but do not explicitly discuss what would happen if they were not able to get a liver. One transplant coordinator demonstrates her approach to counseling patients during transplant education sessions:

TC: So, part of their education also mentions that this is how you'll be on the waiting list. Your MELD score is what can choose your position. I talk about if your MELD score remains 13, you will never get a transplant in this region...And you may wait years for a transplant. You may wait two days or depending on what the turnaround, or the liver may not become available in time.

AP: Is death ever mentioned?

TC: We do have, in our slides...we talk about the MELD score predicts the probability of death within three months. So, the higher it is, the more precarious your life is...I don't know that we maybe specifically tell them.

Social workers, on the other hand, will consistently engage patients in ACP, which is framed to patients as helping them prepare for both best and worst case scenarios. While all social workers discuss advance directives and surrogate decision making in depth with patients, most will also discuss goals of care:

I always try to take it back to comfort. What are you going to be comfortable with? What's really important to you? ...There's a lot going on in there. I think opening up and looking at the values of what's really important to them, sometimes people don't want to be a burden to their family financially. Sometimes people don't want help with their activities of daily living. It depends; everybody's different.

Social workers, however, find more difficulty with explaining life-sustaining treatment options to patients and will often defer these conversations. No other members of the transplant team report regularly bringing up this topic; in fact, it is only discussed if patients themselves suggest alternatives to aggressive care, such as hospice or limits to life-sustaining treatments. As one transplant coordinator explains, in these cases, patients are left to choose between the options of fully aggressive care or no aggressive care without much further discussion:

So here or there, because sometimes... [outside 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 want to be allowed to die naturally and at the same time saying I want you to do everything you possibly can, including a liver transplant to save my life. So, I have had the conversation with patients a couple of times. Do you still want to be transplanted because if you're on hospice, then that means that you don't want any extreme measures and

transplant would be considered a measure that's extreme. 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.

In the inpatient setting, conversations between providers and patients hopeful for LT (either listed or being evaluated) are often more ominous. Getting a transplant is explained as meaning the difference between life and death, as one transplant hepatologist describes:

I told her husband and parents, "She's on the tip of the iceberg. Anything could happen to push her off the cliff. We're doing as much as we can, but I wanted to let you know that things can just fall off the cliff. We have to make a decision. She might not be able to get a transplant and she might die.

In this setting, there is more attention paid by surgeons and hepatologists to confirming surrogate decision makers and checking on documentation. However, as one social worker notes, conversations with families about ACP appear to be more challenging than in the outpatient setting:

Typically, I ask what their plan is, what they would like to do if we say we're not going to put you on our list... Sometimes I see there's kind of almost a difference between what the patient wants and what the family wants. Most of the time the patient is kind of like, I'm done, I'm ready, I'm ready to go. It's the family that's really pushing. I try to remind the family, I know that's what you want. You love your loved one, but reminding them to also listen to what the patient says. Sometimes the patient will say, I don't want a feeding tube. I don't want to be intubated. I don't want lots of things but the family does. It's hard but you have to shift the focus onto the patient and what they want. Because they're able to right now tell us what they want. With liver disease, they can become confused in an hour.

Other members of the transplant team still do not report engaging in these conversations. These conversations are even avoided as patients are getting more acutely ill and their window for transplant is closing, as one social worker points out:

So, I've had several experiences where there's been a battle –how can I say this? I can think of at least three different situations where the patients have been saying, "I'm dying, I'm dying," and [the provider] is like, "No, you're not there yet," and eventually, they get to the point – So, the patient is like, "I know 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 provider] says, "No, not yet. I'm not ready to say that. There are still these options.

Phase 2: Transplant as an Option is Unclear

"What are the chances of that? One in a hundred million..." That's exactly the situation..."Oh, I know that it's unlikely, **but there's a chance.**" (Transplant Surgeon)

Patients who are denied or deferred LT with a chance to get back on the list are counseled by providers in both the outpatient and inpatient settings. During this period, most attention is paid towards addressing reasons why listing was not offered and providing options to patients for getting back on the list. These include: 1) overcoming addiction, mental health, or other social behaviors; 2) addressing frailty or comorbidity; 3) needed to getting sicker as to be more competitive for an organ, or 4) being evaluated at another center for an additional opinion. A transplant surgeon describes his method of counseling patients:

Mostly, I prepare them for what will be the next step. So, for example...if it's a question of obesity, I'll say, "If we decide not to go forward with the transplant, we'll continue to follow you in our hepatology clinic, and we'll see you probably in about a month, and we'll track your weight loss as part of those visits." ... So, a more complex medical question, heart attack or something like a bad coronary risk, I would probably say something very similar, that, "If you aren't approved, you'll keep following up with our hepatology team." So, I don't tell them a lot of details. Just who's going to contact them.

Some nurses and nurse practitioners at all centers have had the experience of patients asking what chances they have of getting back on the list. They often respond with optimism that patients can overcome their barriers or reply honestly that they are not sure what the future holds, as one nurse practitioner describes:

I just had somebody who...ended up with an [ejection fraction] of 31. They tried to put in an AICD, couldn't do it, he ended up with a dual chamber pacemaker... All this horrible stuff, and I call him and say look, I have to put you on internal hold. Your heart may recover but it may not...But if there's an offer for you tomorrow, you will not be able to be transplanted... We will still continue to follow you, and at any point, your liver condition appears like it's deteriorating or whatever, we'll talk about that. There are treatments that you may require, like removing fluid or whatever. If you develop a liver cancer, we will treat that, you will still get treatment, you just won't be able to be transplanted is what I explain to them.

Very few individuals (two hepatologists, one nurse, one nurse practitioner) mention counseling patients about the fact that they may die if they feel their chances of getting listed are low, as shown by this quote from a nurse practitioner:

I talk to them about the risk of mortality associated with liver disease without a transplant, and then I discuss whatever the things are that are going against them to be transplanted in my opinion at this time. And that they should have some real conversations with their family and with me so they will know how

to approach this going in. There are things that always can be done to extend your life, whether it's machines, medications, things like that, or if we see that this is futile, do you want us to do nothing?

However, the majority of providers reported no conversations about values, goals, surrogate decision making, or documentation during this period.

Phase 3: Transplant Is Not an Option

So, generally, the conversation's obviously not a happy conversation most people have. So, we generally say, "Hey, look." Whether it is because they are actively using drugs or actively dying, otherwise we tell them, "Hey, transplant as modality for **cure is off the table**. (Transplant Hepatologist)

In the outpatient setting, for patients who are no longer candidates or do not desire a transplant, most providers focus their treatment plans around addressing complications of liver disease and improving quality of life, but none report engaging patients about their goals of care. Some providers (9 hepatologists, 1 surgeon) bring up to patients that they may die, though over a protracted period of time, as one transplant hepatologist indicates:

It almost would be like, for someone that's decompensated, if you're taking that option of transplant away from them, you're, essentially, saying you're going to die. So, I think it's a conversation that needs to happen more often, I think, for those patients for sure. I think what ends up happening is I start turning the wheel a little bit, meaning that I start just managing whatever is happening, at the moment, perhaps because it's uncomfortable to say you're not going to get transplanted. So, chances are that you will die maybe in a few months or so.

Most providers do not engage in the conversation until they believe a patient has a short time left, during which they will bring up hospice. However, most of these conversations occur in the inpatient setting, as one social worker indicates:

AP: What are all the settings where goals of care discussions happen?

SW: In my experience, especially with transplant, those are conversations that we have at the very bitter end in the ICU, when there are no other options.

Providers on the LT service often rely on other outside teams, such as palliative care and critical care, to help support families when they are critically ill and hospitalized. Families often receive this news when their loved ones are unconscious and not participatory. In many cases, the context of these discussions involves patients just having been taken off or being told that

they cannot be accepted onto the LT waitlist. In most cases, a patient and families' goals are not well-defined, and providers such as this critical care specialist, try to elicit them from family members to shape next steps:

The question typically is, "Have you had discussions about what [your family member] would consider to be a good life?" And that is almost always true in patients with cirrhosis...We'd say, 'Help me understand what your loved one would see as the type of life that they'd like to lead.' What they think would be important, get them satisfaction, make them happy and they describe that and then typically what I would say in response to that, 'Well I'm very sorry to say this, share this news with you, that your loved one is not going to get back to that point.

Unfortunately, it is often the case that end of life options are sparse, with little support left to help families of patients who are rapidly deteriorating, as indicated by another critical care specialist:

There are only handful of people that say they wanna go home, and then when you say, 'Okay, you wanna go home, this is what it's gonna kinda look like,' a lot of people actually end up backing out of that situation and they end up doing inpatient hospice instead of outpatient hospice... That non-aggressive care at home still seems daunting. I actually sometimes picture this and it looks like it's going to be a disaster; they live in a house with five other people, three of them are under the age of 12, so you're just gonna bring dad home to die, and he's gonna die, he's gonna bleed, he's gonna bleed to death, it's gonna be a scene, how is that going to happen? He's going to fall into a coma, oftentimes it doesn't even seem like a situation you really wanna push for.

Lastly, social workers find that, at the end of life, families find significant difficulty in making decisions on a patient's behalf when they are no longer participatory, even when there is some evidence of prior ACP:

I've had a few cases where my patient has already signed the advance directive. He's already picked his healthcare agent and it was very hard for the family – they always say "pull the plug" or "discontinue care." Those are the hard parts where the family knows that they're the agents, but they have feelings of guilt. I run into that a lot. No one wants to feel like they killed their family member, even though it's not what it is. Having that conversation, having to remind them that's not what it is. This person will pass. Medically, they're not going to get better. You're just helping them ease into being comfortable until they get to that place. I think that's hard for patients, they feel guilty.

3.5 Discussion

In this multi-center qualitative study, we found that providers report engaging patients in ACP during early stages of their evaluation at LT centers, but that meaningful conversations

about their goals of care do not occur throughout their trajectory of illness and are typically conducted only at the end of life. Most of early ACP is supported by social workers across all transplant centers, especially when patients are being evaluated or listed for transplant. As the chance of transplant becomes less certain, however, transplant teams altogether paradoxically provide less guidance to patients and families about realistic scenarios they may expect in the future, deciding to focus instead on pathways to getting them onto the waitlist. It is not until transplant is no longer an option that some providers begin re-introducing the concept of death to their patients, and only when patients are acutely ill, that values and goals are elicited consistently, though often in situations where care options are far more limited.

A notable finding in our study is how components of ACP are conspicuously absent during Phase 2, when the chances of transplant are unclear. Providers treating patients in this Phase seem focused on keeping options open for patients to get back on the list, but ideally providers should also counsel patients on their chances of successfully reaching this goal and what tradeoffs that may require. There are several reasons why these discussions may not occur in practice, which will be the focus of a later study. However, there are tools available to providers that can at minimum help them frame prognosis, such as MELD-Na and Child-Pugh scores (Biggins et al. 2006; Albers et al. 1989), or assessments of frailty and sarcopenia (Lai et al. 2014; Hanai et al. 2015), during these periods of uncertainty.

Even across the other Phases, components of ACP are performed in a disorganized fashion. Conversations that involve eliciting values and goals are conducted by social workers during Phase 1 and only become the focus of most other providers in Phase 3, near the end of life. There are, however, many missed opportunities to engage in these discussions. For instance, when patients report preferences for care that seems inconsistent (hospice and LT),

providers can use this as a chance to explore these motivations. Instead, patients are asked to choose between fully aggressive or non-aggressive care without further discussion, as noted in our results. Inattention to these crucial conversations throughout the illness trajectory suggests that care is unlikely to be goal-concordant (Sanders, Curtis, and Tulskey 2018), and more attention should be paid to handling nuanced conversations. Interestingly, there is also no standard or uniform national policy that states that patients considered or waitlisted for solid organ transplant must submit to all aggressive measures. In fact, several professional organizations, including the American College of Surgeons, have stated that policies that lead to automatic enforcement or disregarding of DNR orders do not support a patient's right to self-determination (of). Despite this, several LT centers have endorsed the belief that patients on the waitlist can only be accepted if they are "full code"(Semer 2015). Such informal policies may contribute to delays in nuanced discussions with patients and families regarding values, goals, and preferences in the event of "worst-case" scenarios, and future work should address this issue.

This study provides some clarity to several investigations that have reported high-rates of life-sustaining treatment use, low rates of hospice utilization, and poor quality of end of life care delivered to patients with cirrhosis who are both considered and not considered LT (Patel et al. 2017; Ufere, Halford, et al. 2019a; Kelly et al. 2017; Kathpalia, Smith, and Lai 2016; Walling et al. 2013). The absence of prognostic conversations when transplant candidacy is uncertain, as well as delay in discussions about values and goals, can explain these patterns, and may even corroborate the findings of poor prognostic awareness and aggressive preferences for patients in SUPPORT (Roth et al. 2000).

Our study has several strengths. This qualitative study is the first to provide an in-depth description of the specific behaviors reported by providers regarding ACP in patients with DC.

Perspectives from several types of providers contributed to the richness of the data, as well as the sampling from three different LT centers.

Despite these strengths, there were some notable limitations. We did not capture perspectives from all informants involved in the process of ACP, including specialty palliative care teams and primary care providers. However, we believe this study provided useful understanding as to the framing of ACP at LT centers. As this is a qualitative study, we are unable to represent frequencies of these behaviors in all informants, and they cannot be generalized for all participants. However, we believe that similar findings over different cohorts of providers largely contributes to the validity of findings. We conducted this study at three LT centers in Los Angeles, and practices at these centers do not necessarily reflect the experience at transplant centers elsewhere. In addition, it does not reflect the experience of centers that do not offer LT. However, the fact that providers at LT centers report more comfort with ACP discussions than community providers(Ufere, Donlan, et al. 2019) suggests that there is likely a need for improvement at these centers as well, though barriers may be different.

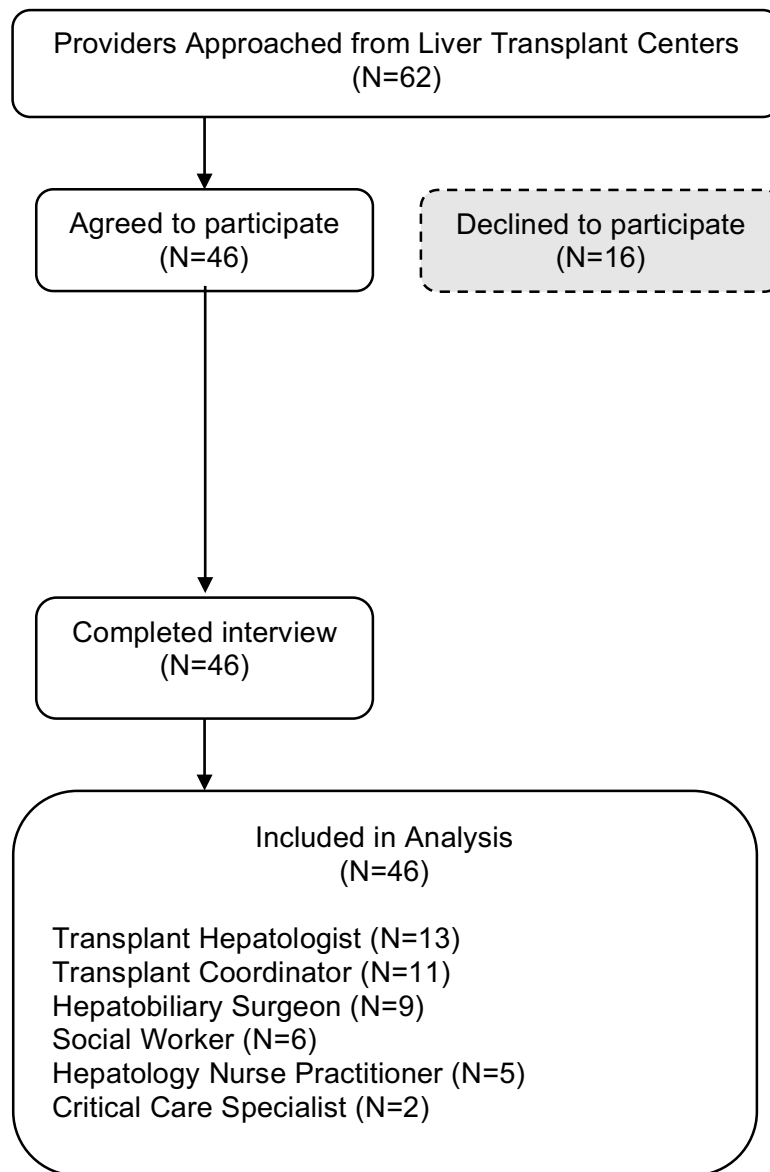
For all patients, particularly those living with serious illnesses, ensuring that the care provided to them is consistent with their values, goals, and preferences is a priority. Conducting ACP conversations have been supported by major public health reports such as “Dying in America”(2015) as well as subspecialty societies treating patients with advanced cancer(Levy et al. 2001), heart failure(Hunt, American College of, and American Heart Association Task Force on Practice 2005), dementia(Fazio et al. 2018), chronic obstructive pulmonary disease(Vogelmeier et al. 2017), and chronic kidney disease(Renal Physicians and American Society of 1997), though this has not been supported by any subspecialty organization treating patients with liver disease. This study highlights the critical lack of ACP in patients with DC

and should inform future work that aims as reducing barriers and implementing solutions that can provide care to these patients that is both high-value and goal-concordant.

Table 3.1: Number of Providers Contributing Quotes to Transplant Phases

| Provider Type | Total N | Patient Phases | | | | |
|-------------------------------|-----------|----------------|-----------|-----------|------------|-----------|
| | | Phase 1 | | Phase 2 | Phase 3 | |
| | | Outpatient | Inpatient | | Outpatient | Inpatient |
| Transplant Hepatologist | 13 | 13 | 2 | 7 | 12 | 6 |
| Transplant Coordinator | 11 | 10 | 2 | 7 | 4 | 2 |
| Hepatology Nurse Practitioner | 5 | 4 | 1 | 5 | 2 | 0 |
| Hepatobiliary Surgeon | 9 | 6 | 8 | 3 | 2 | 7 |
| Social Worker | 6 | 6 | 6 | 4 | 3 | 3 |
| Critical Care Physician | 2 | 0 | 0 | 0 | 0 | 2 |
| Total | 46 | 39 | 19 | 26 | 23 | 20 |

Figure 3.1: Flowchart of Participant Recruitment - Providers



Chapter 4: Advance Care Planning in Decompensated Cirrhosis: Patient Perspectives

4.1 Abstract

Introduction:

Patients with decompensated cirrhosis (DC) often experience long, arduous hospitalizations and unwanted care at the end of life, but for unclear reasons. Providers at liver transplant (LT) centers report infrequent conversations with patients about death until the end of life; however, little is known about how patients with DC report their experience with advance care planning (ACP), as well as any attitudes or preferences they may have towards these conversations.

Methods:

We performed face to face, audio-recorded, semi-structured interviews in 42 patients across three LT centers. This included patients listed for LT (N=11), undergoing evaluation (N=9), too early for transplant (N=10), not listed due to comorbidities (N=6), and not listed due to substance abuse or psychosocial issues (N=6). Recorded transcripts were analyzed using qualitative methods.

Results:

Patients with DC reported infrequent conversations with LT providers about dying, though many of them reported conversations with their caregivers about their values and end of life preferences. Communication about surrogate decision making was reported across all patient groups; however, preferences for end of life care and surrogate decision making are rarely available in the electronic health record (5/42=12%). Most patients report (34/42) that

conversations about ACP would be acceptable to them and cite lack of provider recommendation (25/42) as a major barrier.

Conclusion:

Most patients discuss values and end of life preferences, but not with LT teams, though most find conversations about these topics acceptable. These findings highlight opportunities to improve ACP in this population.

4.2 Introduction

Cirrhosis of the liver affects less than 1% of the United States population but is the 9th leading cause of death in the U.S. and the 4th leading cause among individuals between the ages of 45-65 (Scaglione et al. 2015; QuickStats: Death Rates for Chronic Liver Disease and Cirrhosis). Due to the increasing prevalence of alcohol-related liver disease and non-alcoholic steatohepatitis, the number of deaths is expected to rise over the next decade; thus, the burden of end of life care (Tapper and Parikh 2018). Unfortunately, patients with DC often die in hospitals after long and arduous hospital courses, with most receiving mechanical ventilation and 16% of patients receiving hemodialysis (Patel et al. 2017).

The mechanisms that drive these patterns of care, in a population of which only 8% are eligible for liver transplantation (LT), are largely unknown (Goldberg et al. 2016). In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), investigators found that patients with DC often desired more aggressive treatments at the end of life compared to patients with other chronic conditions (Roth et al. 2000). Surveys of hepatologists at LT centers have suggested poor communication between patients and providers regarding goals of care (Ufere, Donlan, et al. 2019), which may help explain these observations. However, few studies have fully described the nature of advance care planning (ACP)

conversations. Our semi-structured interviews of providers at LT centers suggest that conversations about goals of care are infrequently performed throughout the trajectory of patient's illnesses and mostly occur at the end of life. However, the experiences of patients with DC regarding ACP and their own views regarding these conversations have not yet been fully explored. The aim of our study is to describe the experience of ACP in patients with DC, who receive treatment at LT centers, along with barriers, facilitators, and preferences for ACP.

4.3 Methods

4.3.1 Sample and Data Collection

In order to address our exploratory study aims, we performed semi-structured interviews from three LT centers that perform a high volume of transplants and treat more acutely ill patients than other parts of the country. Centers varied significantly on demographic factors for the patients they treat and the structure of their organizations (see Table 2.1).

Informants were sampled from transplant centers using a stratified purposeful approach. This technique allowed us to sample specific patient groups but also balance our cases across all three LT centers. The sampling of patients was based on a prior study highlighting groups of patients that are denied LT at academic medical centers and arranged into 4 distinct groups: 1) patients listed for LT, 2) patients evaluated for LT, 3) patients too early for LT, and 4) patients not listed due to comorbidities, substance use, or psychosocial factors (Volk et al. 2011).

Interview guides focused on patient readiness for components of ACP (defined as discussing prognosis, healthcare preferences, values and goals, surrogate decision makers, and documentation). Stages of readiness were classified as the following: 1) pre-contemplation: having no specific intention to change behavior, 2) contemplation: thinking about changing behavior only, and 3) action: having performed a recent behavior. For patients who performed

an action, we asked questions focusing on the context, behavior, thoughts, and decisions made by patients surrounding those elements of ACP (Ryan et al. 2009; Sudore et al. 2008; Berlinger). Please see Figures 2.3 and 2.4 for visual representations of these frameworks. The interview guide contained lead-in questions with subsequent probes. Please see Table 2.3 for a list of topics and example questions. These guides were pilot tested in 2 informants and revised for content.

A gastroenterology fellow trained in qualitative methods performed a total of 42 face to face semi-structured interviews between July 2017 and May 2018. Adult patients with a clinical diagnosis of DC and history of a Model of End Stage Liver Disease-Sodium (MELD-Na) score of 15 or higher were recruited to participate in our study. Patients who were unable to carry a full conversation in English, with a history of hepatocellular carcinoma (HCC), or with overt hepatic encephalopathy (West Haven Criteria Grade 3 or higher) were excluded. Patients meeting eligibility criteria were first approached by their continuity transplant hepatologist during their regularly scheduled clinic visit, and then pre-screened by the research team by chart review. Written consent was obtained from each informant, and all were provided a gift card honorarium for their participation. All interviews were audio-recorded and transcribed. Please see Figure 2.1 for a visual representation of the recruitment process and Figure 4.1 for a flowchart of all included and excluded participants.

Information on patient demographics, clinical characteristics, and laboratory data used to calculate a recent MELD-Na score were abstracted from the electronic health record. The institutional review board of each medical center approved the study (IRB#17-000165).

4.3.2 Data Analysis

The primary goal of our analysis was to describe themes that were common across all providers at all centers using a multi-stage process. First, a team comprising of a gastroenterology fellow and an experienced qualitative researcher in palliative care worked together to develop a codebook using codes corresponding to major domains of ACP. Each team member assigned codes to segments of texts for all 42 transcripts, which were then combined. Regular meetings were held between team members to resolve coding discrepancies. Next, themes were generated using multiple methods. For coded texts regarding personal experience and readiness for ACP, a “pile-sorting” technique was used, which involves printing quotes on individual slips of paper and iteratively categorizing quotes into piles based on thematic similarities. Coded text involving barriers, facilitators and preferences were stored in data matrices and re-categorized into themes and sub-themes until categories no longer overlapped. For parts of our analysis, we also re-classified patients into separate categories, based on our prior study, to look for unique comparisons of ACP among phases: Phases: 1) transplant is an option, 2) transplant as an option is unclear, 3) transplant is not an option. Descriptive statistics for quantitative data was generated using Stata 14.2 (College Station, TX). All qualitative data were imported to NVivo 12 Qualitative Data Analysis software (QSR International).

4.4 Results

Patient Characteristics

Forty-two patients were interviewed. The average age was 58 years (SD=11), and most informants were men (67%), Medicare-insured (50%), and married (55%). Most patients had a history of ascites (76%) and hepatic encephalopathy (69%). The average MELD-Na score for the sample closest to time of interview was 15.9 (SD=7.3) and most patients were Child-Pugh

status B (52%). Twenty-one patients were classified in Phase 1, 13 in Phase 2, and 8 in Phase 3. The sample was fairly well-distributed with regards to race/ethnicity, etiology of liver disease and reason for transplant (See Table 4.1).

Personal Experience and Readiness for Advance Care Planning

Prognosis

Most patients recalled conversations about prognosis that were focused on only favorable outcomes (26/42), regardless of whether or not they were listed for transplant. For those who are not listed, conversations focused on their stable or improving liver function. For others, conversations centered on the process of transplant or waiting for a new liver, as noted by this patient getting evaluated:

This is what they told me. This is a process. Usually what happens if they list me, they're pretty positive they probably will, if a liver becomes available, they have to fly to a certain location, they have to look at the liver, then they have to fly the liver back, then I have to be available 24/7 by my phone, but they're not going to exclude other possibilities...But it's like anything else. It could happen tomorrow, it could happen in a month, could happen in six weeks. I believe it will happen, and that's why I've been waiting, and we'll see. I do have enough issues to get me a liver, so that's where we're at.

Conversations about morbid or less optimistic outcomes (11/42) were mostly with providers outside of the LT team, such as hospitalists, palliative care specialists, nurse practitioners, and referring gastroenterologists. Though most patients simply remember being told that they were going to die, others had more meaningful experiences, as this patient (not listed for transplant) describes:

Also, when the palliative care came...I thought about things too, about being in the nursing home, or having to have someone care for me 24/7 in that way. It scared me, and I cried... being asked those questions put me in that state of reference and state of mind. So, I did think about all of those factors...I think that's really helped as well through the process.

Only three patients recall providers on the LT team talking about death as “a possibility” while waiting LT or during the operation. Only one patient, not listed for transplant due to comorbidities, recalled having an in-depth conversation with a LT provider regarding next steps:

[My hepatologist] asked me if something doesn't work, what would I do... I said, 'I don't wanna live'.. That ... he said, "What are your plans?" "I said, if nothing works and doesn't get better, then I don't wanna live anymore." That's it.

Despite not having this conversation with members of their transplant team, most patients (25/42) stated that they have contemplated the idea of not making it to transplant or dying, as described by this patient who is on the waitlist:

They're always really optimistic and say don't worry, of course a lot of people don't make it up there, a lot of people do, but they told me to go to a support group, they gave me a pamphlet to go to a support group, there's a lot of people on the list and a lot of people post-operative, so maybe we can get a little support and a little bit of a rainbow or something...I think about it a lot, because as I said, I don't seem myself ever making it to the top of the list for whatever the reason is, I might just not be thinking positively but I don't see it.

Most patients in Phase 1 (13/21), Phase 2 (6/13), and Phase 3 (6/8) have contemplated dying, though only a single patient in Phase 3 has spoken to their LT provider about this topic.

Sharing Values, Goals, and Preferences Regarding End of Life

All but four patients expressed insights regarding their values, goals and preferences at the end of life. Most have shared conversations with family members about these preferences or documented them. Only two had reported sharing this information with their providers. The most common topic regarded life-sustaining treatments. Patients often expressed that they would not want their life prolonged in cases of futility, as one patient being evaluated for transplant shared:

I'm not going to sit there and lie there as a vegetable. If I'm a vegetable, turn it off. If I'm not a vegetable, and I will get better, then of course that's another decision. But I'm not going to allow myself to be in a position where I'm not going to recover or get sicker. I don't want it, and she knows it.

Many patients also expressed preferences for where they would die or how their body would be preserved, such as through cremation or burial processes. Fewer patients reported speaking to anyone about this topic, though one patient listed for transplant reported doing so:

I already know that it just happens, you have a life, they have lives. And I start to wonder if I should just in the future put me somewhere so someone can take care of me so that I'm not a burden, and [my

husband] always says no, he says, 'our culture, we take care of our elders, and if you have to have them on hospice at home, then whatever that's the way it is.' He says we're going to do like we did with his parents and my mom and my father and they all died in hospice at home and I just wonder if that's how I'm going to go, or if I'm going to go another way? Different options.

Not wanting to be a burden on their family or caregivers was also an important concern.

Many stated that they wanted their families to be financially stable and have mentioned this to their loved ones. Other patients were concerned about the emotional toll it would have on their families, as one patient being evaluated for LT mentioned:

And one of the doctors came in and told my wife that I was real sick. And he didn't think I was going to still be alive. So, she told me. And I told her if that happens, let me go. I don't want the kids to see me in the hospital with all of the stuff...It probably hurt her, but I told her I don't want to live like a vegetable... I just told them I don't want to be like a burden to my family to have to go see me. And I can't talk to them. I can't do nothing for them.

Less common concerns raised by patients were wanting to be active and independent, wanting control over the dying process, leaving in God's hands, and being remembered with happiness. Most patients in Phase 1 (12/21), Phase 2 (7/13), and Phase 3 (6/8) have either shared or documented their care preferences with family members. Two patients in Phase 3 shared these preferences, one with their primary care doctor and the other, with their hepatologist.

Selecting a Surrogate Decision Maker

All but two patients expressed insights regarding choosing a surrogate decision maker. Most report having a conversation with a family member and nearly half report completing documentation. Most conversations about surrogate decision makers with providers occurred during acute hospitalizations, as recalled by a patient not listed due to comorbidities:

AP: Did you have discussions while you were hospitalized or after you were hospitalized?

Patient: Both. While I was in there and we talked about it later...But it was only because of an advanced directive was put in our face and that's what, more or less prompted... the discussion. I believe it was a social worker...It made me a little nervous, like, "What's this for?" But they were just telling me, "This is in case something happens." And they wanted to know who was gonna make the decisions.

Out the patients who reported completing documentation, only four have an advance directive uploaded in the medical record, while 1 individual who did not reported any documentation had an uploaded directive. In total, only 5 (12%) patients had available documents. Most patients in Phase 1 (17/21), Phase 2 (10/13), and Phase 3 (5/8) have either reported documenting or sharing preferences for a surrogate decision maker with family members.

Attitudes and Preferences for Advance Care Planning

Half of all patients stated that getting sick or hospitalized as a consequence of their liver disease was a strong motivator for them to participate in different elements in ACP. They recall receiving support from several individuals, including family members as well as office and hospital staff, as noted by a patient waitlisted for transplant:

Well, early on...we didn't really have [discussions] because I was asymptomatic, and it was something that was easy to compartmentalize and you don't have to deal with it. The first time I really got sick, and got cholangitis, I remember my kids coming in to my room at home, and my youngest one asked me if I was going to die. I said, "No, not today sweetie." That kind of triggers those kinds of conversations because you realize that there's a cause an effect relationship there and you go, 'All right, this shouldn't be a difficult conversation because these are my thoughts and this is what I want, but I need to make you guys aware of that, so that if I'm incapable of directing that, that you can communicate my wishes to my health team.

Other factors affecting patients' decisions to engage in ACP include having the experience of having illnesses in the family, financial motivations, and cultural or religious attitudes about dying. Most patients (25/42) reported a lack of provider recommendation to participate in ACP activities as a significant barrier. Many of them perceived that providers were either not bringing up the topic either because the patient themselves were doing clinically well or it is not an important issue for them altogether, as noted by a patient not listed due to comorbidities:

AP: Have you had explicit conversations with any of your doctors about what type of care you would want?

“Patient: No, I don't believe we have...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...I think it would be very good to have...I believe they should bring it up, and go over the conditions which may call for life saving operations, procedures, what things would happen. Whether they are familiar with cirrhosis, or cirrhosis patients, or patients with similar maladies, that they should bring it up.

Fewer patients did not feel ready to have the discussion until they were sicker, felt emotional about handling these conversations, or felt that ACP was not important. However, most patients (34/42) reported that future conversations regarding ACP would be acceptable to them at any time, while 7 preferred to wait until they were sicker, and 1 patient did not prefer having any such conversation. One-third of patients (14/42) welcomed any provider to have a conversation with them, while fewer preferred their hepatologist (9/42) or primary care doctor (8/42).

4.5 Discussion:

In this study, we demonstrated, from the patient perspective, a lack of conversations between LT providers and patients regarding ACP, though notably, many patients demonstrated readiness and shared their values and preferences for end of life care and surrogate decision making with their caregivers. Most patient also report sharing their preferences for surrogate decision making with LT teams, though these documents were found to be rarely available. Most patients found ACP conversations acceptable and cited lack of provider recommendation as a major barrier.

The fact that nearly all informants in this study reported that they have expressed preferences for end of life care and find these conversations acceptable suggests that this is a topic that patients and caregiver value. This finding is also supported by a study conducted at two specialty cirrhosis clinics in Canada, in which the majority of patients with cirrhosis found goals of care discussions (76%) and advance directives (96%) to be at least moderately important facets of their care(Sprange et al. 2019). Many of our informants in this study have shared their

values and end of life preferences with caregivers, an important ACP quality indicator (Sinuff et al. 2015), but few had shared this information with providers, which patients claim may be due to the fact that the conversation is never brought up.

Our finding that conversations and documentation about values, goals, and end of life care preferences are nearly absent at LT centers raises questions about whether care provided to them at the end of life truly respects their wishes. Several patients in our study had preferences regarding life-sustaining treatments, their location of death, and not being a burden on their family, which are common concerns for patients at the end of life (Singer, Martin, and Kelner 1999). However, prior studies have shown that patients with DC receive care at the EOL that may not satisfy these concerns, such as the fact that 67-80% of patients die in an institutionalized setting (Altafi et al. 2018; Ufere, Halford, et al. 2019b), more than half of patients receive a life sustaining treatment (Patel et al. 2017), and 33% of caregivers report lose all their savings (Roth et al. 2000). Our previous study of semi-structured interviews in LT providers also showed that values, goals, and preferences regarding end of life care are only elicited at the very end of life, when care options are limited, supports this finding.

In our study, we also found that ACP in this population was frequently triggered by hospitalizations and declines in their functional status. This observation mirrors studies that have shown and recommended ACP around sentinel events, since patient preferences regarding aggressive care can often change as their illness and prognosis evolve over time (Walling et al. 2008; Walling, Ahluwalia, et al. 2017). Future work should consider developing interventions around times of critical illness to maximize uptake of ACP. Findings from our patient interviews largely match the content of interviews from providers at LT centers. Between both studies, we have found and confirmed a lack of critical conversations between patients and providers at LT

centers about dying, though practices to support the process of surrogate decision making are present.

There are many strengths to our study. This is the first qualitative study to provide a detailed description of the experiences face by patients regarding ACP. The fact that data from patient and provider interviews supported each other's claims suggests successful triangulation. Lastly, we believe that drawing perspectives from patients at different stages of LT evaluation contributed to the validity of our findings.

Despite our strengths, there are limitations. Our study only recruited patients seen in the outpatient setting; thus, findings from our study cannot be generalized to hospitalized patients. Next, the experience of patients who are not seen at a LT center may be different from those of our cohort's, though many patients in our study have had experiences both in and out of these centers. Given that this study is qualitative, the frequencies we report in behaviors for our informants cannot be generalized to the population of patients with DC.

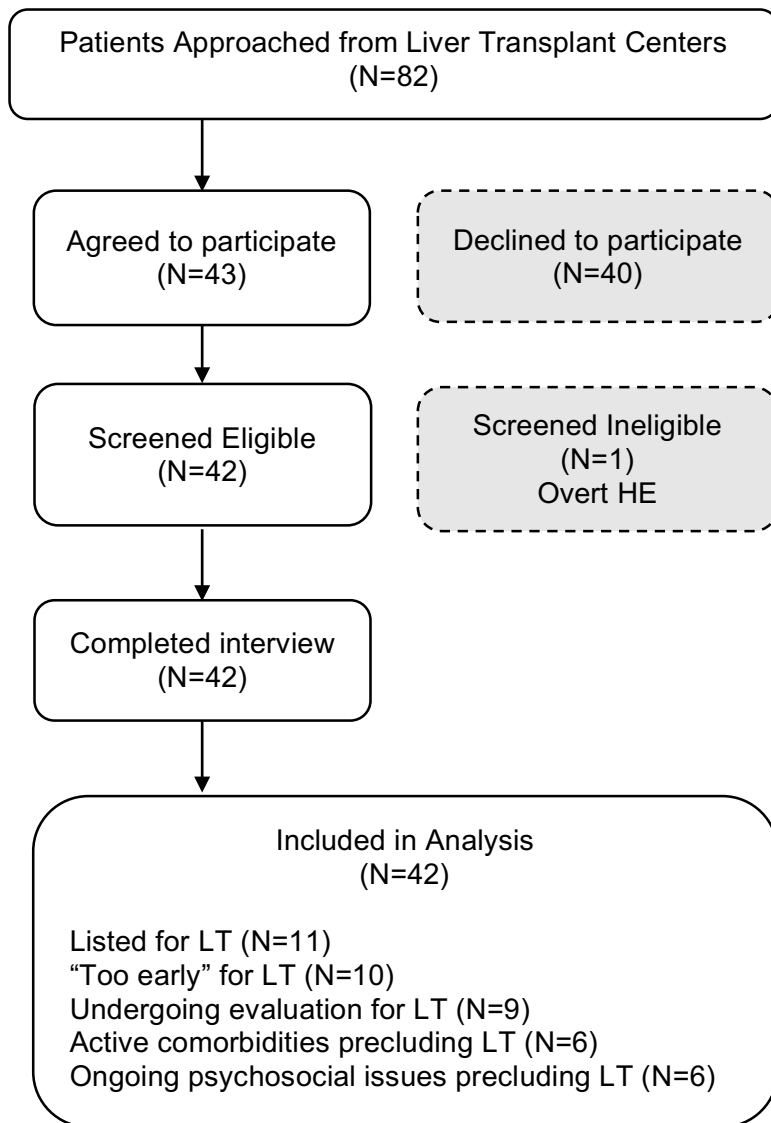
The Hastings Center defined the goals of medicine as 1) the prevention of disease and injury and the promotion of health; 2) the relief of pain and suffering caused by maladies; 3) the care and cure of those with a malady and the care of those who cannot be cured; and 4) the avoidance of a premature death and the pursuit of peaceful death(Callahan 1999). The field of hepatology has enjoyed enormous successes, such as treatments for viral hepatitis and the rise in LT, that have improved the quality of life and extended survival for patients with various liver diseases. However, the field has not done as much to satisfy our goals of hearing our patients and helping them pursue a peaceful death. Increasing research for end of life care, engaging multiple stakeholders, and investing in cultural change will be part of the solution needed to ensure that we provide the best possible care that imbues all goals of medicine.

Table 4.1: Patient Characteristics (N=42)

| <u>Variables</u> | <u>Total (Mean, SD) or (N,%)</u> |
|--|---|
| Age, in Years | 58.2 (11.2) |
| Sex | |
| Male | 28 (67%) |
| Female | 14 (33%) |
| Race/Ethnicity | |
| Hispanic or Latino | 17 (40%) |
| Non-Hispanic White | 16 (38%) |
| Non-Hispanic Black | 2 (5%) |
| Asian | 1 (2%) |
| Other/Unknown | 6 (14%) |
| Insurance Status | |
| Medicare | 21 (50%) |
| Private | 15 (36%) |
| Medicaid | 6 (14%) |
| Marital Status | |
| Married or Has Life Partner | 23 (55%) |
| Single | 10 (24%) |
| Divorced | 5 (12%) |
| Widowed | 4 (10%) |
| Etiology of Cirrhosis | |
| Non-Alcoholic Steatohepatitis | 14 (33%) |
| Alcohol-Related | 12 (29%) |
| Hepatitis C | 11 (26%) |
| Autoimmune Hepatitis | 4 (10%) |
| Other/Cryptogenic/Unknown | 5 (12%) |
| Has More Than One Etiology | 3 (7%) |
| Manifestations of Portal Hypertension | |
| History of Ascites | 32 (76%) |
| History of Hepatic Encephalopathy | 29 (69%) |
| History of Variceal Hemorrhage | 8 (19%) |
| MELD-Na Score | 15.9 (7.3) |
| 6-10 | 13 (31%) |
| 11-14 | 5 (12%) |
| 15-20 | 12 (29%) |
| 21-30 | 10 (24%) |

| | |
|---|----------|
| 31-40 | 2 (5%) |
| Child Pugh Score | |
| 5-6 (A) | 5 (12%) |
| 7-9 (B) | 22 (52%) |
| 10-15 (C) | 15 (35%) |
| Transplant Status | |
| Listed for Liver Transplant | 11 (26%) |
| Undergoing Evaluation for Liver Transplant | 9 (21%) |
| Too Early for Liver Transplant | 10 (24%) |
| Not Listed due to Comorbidities | 6 (14%) |
| Not Listed due to Active Substance Use or Psychosocial Issues | 6 (14%) |
| Patient Phases | |
| Phase 1: Transplant is an Option | 21 (50%) |
| Phase 2: Transplant as an Option is Unclear | 13 (31%) |
| Phase 3: Transplant is not an Option | 8 (20%) |

Figure 4.1: Flowchart of Participant Recruitment - Patients



Chapter 5: Provider Barriers to Advance Care Planning at Liver Transplant Centers

5.1 Abstract

Introduction:

Patients with decompensated cirrhosis (DC) often receive burdensome treatments at the end of life despite the fact that the majority are not candidates for liver transplantation (LT). Patients and providers report very little end of life communication, but specific barriers that providers face in conducting these discussions have not been explored among a diverse group of providers at LT centers. The aim of our study was to describe the major barriers facing providers in performing advance care planning (ACP) at three major LT centers using qualitative methods.

Methods:

Face to face, audio-recorded, semi-structured interviews were performed in 46 providers across 3 LT centers. These included 13 hepatologists, 11 case coordinators, 9 hepatobiliary surgeons, 6 social workers, 5 hepatology nurse practitioners, and 2 critical care physicians. Recorded transcripts were analyzed using qualitative methods.

Results:

We identified four unique barriers to ACP from our semi-structured interviews: 1) the goal of LT, 2) limited capacity to perform ACP, 3) role confusion and discontinuity, and 4) limited language and cultural competence. The first two barriers were reported by all providers while the latter two were more commonly reported by non-physicians on the transplant team. All but four providers believed that investing in early ACP is worthwhile.

Conclusion:

Providers face unique barriers to ACP at LT centers that are different from specialists treating other chronic illnesses. We discuss strategies that centers can use to overcome these barriers as well as future research to help guide implementation of ACP.

5.2 Introduction

The majority of patients with DC will not receive a liver transplant (LT), either due to the fact that they die on the waitlist or are unsuitable candidates for the operation (Goldberg et al. 2016; Goldberg et al. 2014). Despite this, patients with DC often die from their liver disease (D'Amico, Garcia-Tsao, and Pagliaro 2006) and receive burdensome care at the end of life, with over half of patients receiving mechanical ventilation and 16% receiving hemodialysis in the United States (Patel et al. 2017), with some receiving even more intensive care at single centers (Ufere, Halford, et al. 2019b). Despite these grim outcomes, The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) found that seriously ill patients with DC had inconsistent views about how aggressively to pursue their medical care, simultaneously requesting comfort care but also preferring to be resuscitated in the case of cardiopulmonary arrest until a brief period before the end of life (Roth et al. 2000). This finding can likely be explained by a lack of communication between patients with DC and their providers about the end of life, which was suggested by a survey of transplant hepatologists, of whom the majority reported a lack of goals of care discussions (Ufere, Donlan, et al. 2019). We also demonstrated this finding in our first two studies through interviews of patients and providers at LT centers.

Our interviews revealed that though patients were overall receptive to these conversations, most felt that the largest barrier was that no one had brought up the topic. A survey of transplant hepatologists in the U.S. cited potential physician-reported barriers,

including insufficient cultural competency, insufficient training, stress of taking care of dying patients, and fear of legal liability (Ufere, Donlan, et al. 2019). A few qualitative studies have explored this topic as well. Studies featuring semi-structured interviews with patients concluded that patients have poor knowledge of ACP, rely on family members for healthcare decisions, and believe that providers are focused on disease-directed care (Carbonneau et al. 2018; Hudson, Hunt, et al. 2018). However, these studies featured the experiences of a limited number of individuals at transplant centers. Given this, the aim of our study is to provide an in-depth description of barriers to ACP from the perspectives of multiple providers at LT centers using qualitative methods.

5.3 Methods

5.3.1 Sampling and Data Collection

In order to address our exploratory study aims, we performed semi-structured interviews from three LT centers that perform a high volume of transplants and treat more acutely ill patients than other parts of the country. Centers varied significantly on demographic factors for the patients they treat and the structure of their organizations (see Table 2.1).

Informants were sampled from transplant centers using a stratified purposeful approach. This technique allowed us to sample based on provider role but also balance our cases across all three LT centers. All providers all LT centers have roles that are outlined and monitored by policy from regulatory agencies in the United States, such as United Network of Organ Sharing and Center for Medicare and Medicaid Services. A more complete description of these roles is displayed in Table 2.2.

Interview guides focused on understanding the context, behavior, thoughts, and decisions made by providers surrounding elements of ACP (discussing prognosis, healthcare preferences,

values and goals, surrogate decision makers, and documentation)(Ryan et al. 2009; Sudore et al. 2008; Berlinger). Please see Figure 2.3 for this a visual representation of this framework. For each interview guide, lead-in questions with subsequent probes were used, specifically to capture barriers and preferences. Please see Table 2.3 for a list of topics and example questions. These guides were pilot tested in 8 informants and revised for content.

A gastroenterology fellow trained in qualitative methods performed 46 face to face semi-structured interviews between July 2017 and May 2018. Providers were approached either in person or via email for their participation. Informed consent was obtained from each informant, and all were provided a gift card honorarium for their participation. All interviews were audio-recorded and transcribed. Data collection for this study was part of a larger investigation that also featured data collection and analysis of semi-structured interviews from patients at LT centers. The institutional review board of each medical center approved our study. Please see Figure 2.1 for a visual representation of the recruitment process and Figure 5.1 for a flowchart of all included and excluded participants.

5.3.2 Data Analysis

The primary goal of our analysis was to describe themes that were common across all providers at all centers using a multi-stage process. First, a team comprising of a gastroenterology fellow and an experienced qualitative researcher in palliative care worked together to develop a codebook using codes corresponding to major domains of ACP, as well as barriers and facilitators. Each team member assigned codes to segments of texts for all 46 transcripts, which were then combined. Regular meetings were held between team members to resolve coding discrepancies. Next, coded text involving barriers and preferences were stored in data matrices and re-categorized into themes and sub-themes until categories no longer

overlapped. All data were imported to NVivo 12 Qualitative Data Analysis software (QSR International).

5.4 Results

Interviews were performed in 46 informants, including 13 hepatologists, 11 case coordinators, 9 hepatobiliary surgeons, 6 social workers, 5 hepatology nurse practitioners, and 2 critical care physicians. Twenty-eight providers saw patients in both outpatient and inpatient settings, while fourteen providers cared for patients in the outpatient setting exclusively and four providers cared for patients in the inpatient setting exclusively. All 46 providers mentioned barriers to ACP, with most (44/46) mentioning two or more barriers. The following were the major barriers reported: 1) the goal of transplant, 2) lack of capacity for performing ACP, 3) role confusion, and 4) language and cultural competence.

“Transplant Culture”

All but seven providers mentioned the goal of transplant as a major barrier to ACP. Providers across all settings, both inpatient and outpatient, mentioned that the focus of their center is getting patients transplanted, and issues such as ACP were seen as less relevant or of lower priority. Hepatologists and surgeons avoid conversations about dying since the notion seems counter to their goal, which is centered on fixing a problem and maintaining hope in patients. A transplant coordinator reflected on this issue:

It's uncomfortable for everyone, I guess. No one wants to bring up the uncomfortable “you might die” topic, and “we can't help you.” I think we all are in this because we want to help people. When we can't help them, it's difficult for us as well. So, I think it's probably a little bit provider-related in terms of how comfortable people are talking about death and what's going to happen and all of that. It's counterintuitive to what we want for the patient. Even though we know that's probably going to be the outcome, we can try to avoid it.

With this goal of transplant in mind, centers were focused on keeping the option of transplant open for their patients. Even when patients were denied at their center, providers

routinely offered the option of a second opinion to patients and their families. For patients who are listed at their center, transplant providers reported their frustration with outside referring providers who are sometimes not aggressive enough in offering the option transplant, which they suggested comes from a lack of experience, as noted by a transplant coordinator:

The culture – I’ve worked inpatient – when [other providers] make a transplant waitlist patient a DNR, the surgeons go bananas because they think that there’s a general misunderstanding about how sick a liver patient may look before they should just go to hospice. And we’ve seen those people look like the crypt keeper and then come back and, once they’re metabolizing protein or they’re manufacturing protein, whatever, they look so much better.

Transplant providers also expected the same level of aggressiveness from their patients, as anything less than “full code” makes them ineligible for transplant. This is an informal policy at all three transplant centers, with one center not even allowing patients to be transferred from other hospitals if they had a “do not resuscitate” code status. A transplant surgeon defended this policy, believing that it prevented patients from making decisions that threaten the principle of utility with organ allocation:

Just to clarify, you cannot be accepted for liver transplant if you don’t accept maximum aggressiveness, period. A liver transplant is the most maximally aggressive thing you can do. We will de-list somebody, literally, if they say that I want to DNR or I don’t want to be on the ventilator for more than a week, you’re off the list... So, if a family comes up to me, let’s say somebody comes and says 24 hours after a liver transplant, you know, I don’t like that my loved one is on a ventilator, let’s withdraw care. That’s not okay. We’re going to have a conversation. That’s not just their wishes. That’s not okay. They made a deal and this deal includes another organ. If it did not include another organ, they could do whatever they want, but there has to be some level of concurrence between what is being expected and what is reasonable, because public perception for organ donation is strongly fueled by how the public feels about the organs being used.” (Liver Transplant Surgeon)

At times, the idea of keeping all options open for patients was unsettling to a few members of the transplant team (mostly social workers and transplant coordinators). Some did not feel empowered to speak up if they disagree with the opinions of surgeons and hepatologists about the level of aggressiveness, and many felt that goals of care should be addressed earlier. A few members of the transplant team believed that this aggressiveness is motivated by the need to

increase the number of transplants at each center, though other believed that this behavior, rather, was used as a way to hide providers' discontent about failure, as reflected by a social worker:

Interviewee: I think that a lot of it stems from that place of we are, in our own way, delusional about what we do. I say that in the nicest way possible. To some degree, we all have to, the patients and the team included, operate under this delusion that all the stars are going to be aligned for this patient and we're going to get a transplant for them.

AP: Just believing that everyone's a rare exception.

Interviewee: Yeah. Because if not, then we open up ourselves as care providers, as clinicians to repetitive trauma.

Limited Training and Time to Perform Advance Care Planning

All but seven providers also noted a lack of training for performing these discussions.

Eight providers had misperceptions or negative views about advance directives. Some providers did not know that advance directives can be used to document both aggressive and less aggressive goals and preferences. Other providers, including this transplant surgeon, were simply frustrated by the fact that directives made delivering care more nuanced and less clear:

Rightfully so, advanced directives are not very specific because you would never want to exclude care from a person on a presumption of what might happen in the future. So, they're vague....So, as you start going through these, you realize there's very little value to advanced health directives. It's kind of all or none. "Do you wanna get better or not?" And the person says, Well, yeah. But I don't want X, Y, or Z." "Well, what is an allowable X, Y, or Z for the surgeon?" "I don't wanna be resuscitated." Well, that's tricky. I don't even know what that means. Does that mean – "I don't want dialysis." Okay. What if it's short term dialysis? "I don't wanna be stuck on a ventilator." "Well, I don't want you to be stuck on a ventilator either. But what if I think I can get you off the ventilator?"

Many providers also noted person discomfort with having conversations with patients about prognosis or preferences. They report unease with bringing up events that have not yet happened, as noted by this transplant hepatologist:

They're not easy conversations. And I think, at least from a personal level, I'm thinking he or she is doing okay. I'm not going to bring that up right now because I don't want to say, if your kidneys fail, and you need dialysis, I don't think you should get dialysis. Maybe not in that way, but still I feel, sometimes, that if the event hasn't happened, then, the discussion about it may be uncomfortable

They also fear overstepping boundaries with other providers and worry about how patients may react to the topic of death. Perhaps based on their experience in witnessing

emotional reactions from patients confronting death in the hospital, many providers, including this transplant hepatologist, assume that their patients simply want everything done and broaching this topic may reduce a patient's confidence in the transplant team.

The only thing I can see is if we don't communicate it correctly what the patients perception of how we're taking care of them. If we tell them about the options of end of care and we focus on some of those things, they may think to themselves, "Hey, are they really trying to take care of me, or are they really waiting for me to die?" That's the perception I can see and it really depends on obviously the receiver as well as someone who is giving this information, because I have seen it practiced in both ways. It's really in we have the power because of the position that we're in of how we deliver news is a huge – and we have our own opinions. As much as there's a team, the person delivering the news can really sway patients' families...I can see it may fracture some of that patient care... the way [you] deliver news and the way you receive news may make an impact on the therapeutic relationship.

Lastly, they reported not having enough time and space to have these conversations, which often related to the time-constrained nature of practicing medicine, along with the focus of the visit, as noted by another hepatologist:

Interviewee: No, I do not talk to my patients about their code status. Many times, we focus on particular medical management – active medical issues, fluid volume status, encephalopathy – really, not the issues we're trying to address in their code status.

AP: Why do you think that is the case?

Interviewee: I think it's just the way you practice. It's the culture of your practice. Even if you go to private practice, you have ten minutes to see the patient. You don't want to talk about code status for ten minutes instead of actively managing the medical issues. If we set up five minutes in general practice to talk about code status and what they want in their life, that might change the practice.

Lack of consistent training for ACP and goals of care discussions were noted by almost a third of participants.

Role Ambiguity

Nearly half of all informants stated it was often unclear whose role it was to have these conversations or participate in decisions about end of life care. Many times, this issue created conflicts with outside referring providers, as noted by a transplant coordinator:

Now, we have to figure out what the next step is because it may be sometimes we say okay, you need to get an appointment with your primary doctor. But then, sometimes, the primary doctor turfs it back to us because we haven't seen the patient. So, sometimes, it becomes a war because the PCP needs to get involved. It may be appropriate for them to now send them to hospice. So, we may, in our minds, know

what the next steps should be. But now, we're in a war of who should take ownership of that, if that makes sense.

This confusion may have stemmed from the fact that transplant centers may no longer be able to see patients for follow-up since many insurances do not cover future visits if the patient is not a transplant candidate. A few mentioned that this, in turn, makes providers less motivated to develop a continuity relationship with patients. Breaks in continuity are also noted in the inpatient setting. When patients are no longer deemed candidates for LT, the responsibility of performing ACP and goals of care discussions was either not explicitly delegated or assumed to be the role of any one team, as noted by a social worker, before being affiliated with the transplant team:

It was hard because I would keep asking. Because I wasn't on the team, I'd keep asking the social workers or the PAs, can we get supportive care involved? The patient and the family know what's going on. I got a lot of pushback...some of the surgeons don't like talking about end-of-life...sometimes when we know that the patient and their family is going to have a difficult reaction or we know the patient and the family is difficult, we tag team. The social worker goes with the [physician assistant]. Sometimes if we just can't, I just go in by myself...there's no protocol, not at all.

Out of all interviewed providers, less than half of the providers (24/46) mentioned that they either currently perform ACP or saw it as part of their role. Among those who did not consider it their role, most believed it was the role of primary care providers or the inpatient primary team (11/22), social workers (8/22), or hepatologists (5/22).

Limited Language and Cultural Competence

Lastly, concerns were raised by 6 providers that health literacy and language issues were significant barriers to having conversations with patients about death, their preferences, or surrogate decision making. Some providers found it challenging to have patients adhere to basic recommendations about their medical care, so the idea of having discussions with them about dying seemed daunting. Other times, there may have been interactions between language,

culture, and medical illness that made these conversations challenging for both patients and providers, as noted by a transplant coordinator:

I try to go inside to see if the physician is initiating [the discussion]. But, sometimes, unfortunately, these patients are too sick to sometimes comprehend. And then, we do have patients that have – they come from a low income, so they don't really understand it completely. So, although the physician might tell them, "I just want you to know that the chances of you getting transplanted are very slim". I see them talking to them about that, but I don't think the patients understand because they turn around, and they call me on the phone, and they ask the same questions that the physician sort of tried to answer for them, but they still don't comprehend it due to their lack of understanding, their educational level. Although the physician tries to speak to them as simple as possible, they seem to not understand it completely.

Importance of Advance Care Planning

The goal of transplant and limited capacity for ACP were the most common barriers reported in each provider group. Role confusion was reported more often among non-physicians (14/22) than physicians (10/24). Nearly half of the individuals who reported cultural competence as a barrier were social workers (3/7). Among all providers, 42/46 believed that integrating early ACP in practice was a worthwhile effort to pursue for these patients.

5.5 Discussion

In this study, we report major barriers to performing ACP through analyzing interviews of providers performed at three LT centers. The goal of getting patients to receive LT and limiting training to have these discussions in both outpatient and inpatient settings were barriers reported by all provider groups. Ambiguity about whose role it is to perform ACP and issues with language and cultural competence were more commonly reported by non-physicians and social workers, respectively. All but four providers believed that early ACP is an important goal to achieve in their patients with DC.

To our knowledge, the beliefs that drive "transplant culture" have never been previously described. These include the notions that 1) getting patients transplanted is the key focus of these centers, 2) patients are not permitted to have limits to aggressive care, 3) provider

experience drives decisions about candidacy and futility, and 4) members of the transplant team operate in an environment filled with hope, against all odds. Components of this culture draw similarities to barriers to ACP reported by other medical specialists, whose efforts are mostly focused on cure and technological advancements(Granek et al. 2013; Green et al. 2011; Grubbs et al. 2017; Gott et al. 2009). In these studies, specialists also report that they are driven to maintain hope in their patients. The distinct difference between transplantation and other specialties, however, are the mandatory acceptance of all aggressive care by patients and the subjective nature of candidacy and futility, which are preferentially determined at LT centers. The notion that patients on the transplant waitlist should accept all aggressive care sharply conflicts with the finding in our former study that many patients have either contemplated or discussed limits to aggressive care with their families, including patients who are undergoing evaluation or listed for LT. The fact that providers at LT providers also believe that internal assessment at their centers is needed in order to gauge transplant candidacy and futility also raises questions about how outside providers are expected to initiate end of life care without this proper deliberation. Future work should aim at clarifying discrepancies between the beliefs of patients and provider at LT centers regarding what limits to aggressive care are acceptable by both parties. More work is also needed in improving handoffs with referring providers, which may include greater access to transplant providers outside of face to face visits or developing more descriptive definitions of futility and transplant candidacy that can be implemented by outside centers.

Limited training and time to perform ACP was also noted as a significant barrier to these discussions, which included knowledge gaps regarding advance directives, discomfort in performing conversations, and lack of time and space to perform these discussions. Though

knowledge gaps were reported in only 8 providers (7 physicians and one transplant coordinator) in this study, it is possible that more individuals on the transplant team have similar issues. Poor knowledge about advance directives have been noted in prior surveys of physicians and nurses and serves as a critical barrier to ACP(Morrison, Morrison, and Glickman 1994; Crego and Lipp 1998). Most providers in this study also noted discomfort with ACP, which mostly stemmed from concerns about patient and family perceptions regarding these conversations, which has also been reported in other studies of specialist attitudes(Selman et al. 2007; Granek et al. 2013; Grubbs et al. 2017). Surprisingly, our analysis of interviews from patients with DC revealed that most patients in the outpatient setting were willing to have these conversations and often already had these conversations with their caregivers or family members. Lastly, providers noted that there were significant time and space constraints to having these conversations, which is a system-level issue that has been reported in providers treating other chronically ill populations(Curtis et al. 2000). Given that many providers noted a lack of consistent training in ACP, future work should focus on measuring gaps in knowledge and communication skills as a needs assessment for this training. Though analyses of our patient interviews suggest acceptability of these discussions in the outpatient setting, the acceptability of these conversations in patients and their families in inpatient settings should also be determined.

Role ambiguity and limited language and cultural competence were also commonly reported in our study. Though continuity of care is seen as an important priority for patients receiving ACP(Munday, Petrova, and Dale 2009), providers reported that additional visits to the transplant center following deliberation are not always covered by insurance, which may reduce motivation by providers to perform ACP. Within our population, this clearly represents an important opportunity to explore local insurance policies and practices; however, transplant

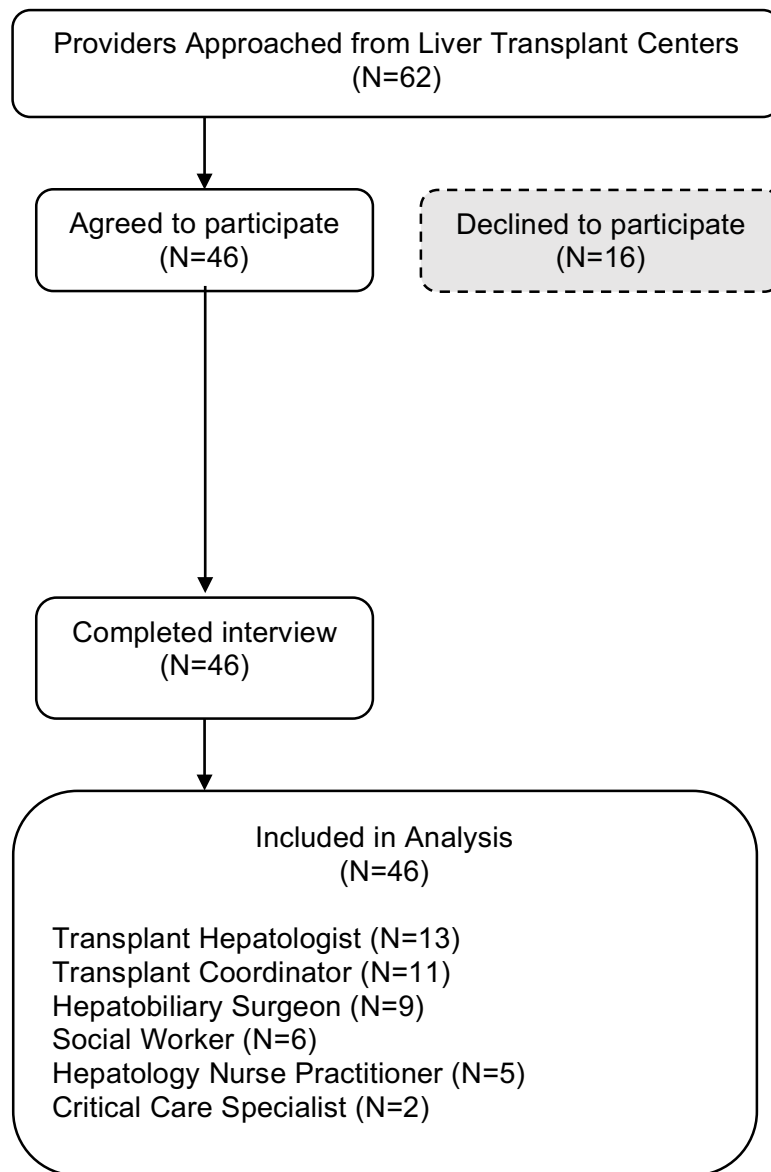
centers should also consider refining handoffs with referring providers about a patient's best estimates of prognosis and chances of receiving a LT if they are unable to follow up. Confusion about whose role it is to perform ACP within transplant centers was also reported. Providers treating other chronic illnesses have reported similar issues with the diffusion of responsibilities among multiple providers(Granek et al. 2013; Gott et al. 2009; Green et al. 2011). In our study, this barrier was noticed most commonly by social workers, nurse practitioners, and transplant coordinators, as compared to physician providers, which is not surprising given the expanding role of these practitioners in ACP, particularly in community settings(Jeong, Higgins, and McMillan 2007; Seymour, Almack, and Kennedy 2010; Stein, Cagle, and Christ 2017). It is essential for transplant centers to both define the full breadth of each provider's role clearly and incorporate the value of an interdisciplinary teams in ACP (Dyess, Tappen, and Hennekens 2014). Issues with cultural and language competence for ACP were also raised in this study, which is not surprising given that 48% of the population of Los Angeles is non-White(U.S. Census Bureau. Quickfacts - Los Angeles. <https://www.census.gov/quickfacts/losangelescalitycalifornia>. Accessed March 1) and 54% speak a primary language other than English in households(Proficiency and by Los Angeles County Service Planning Area. <https://advancingjustice-la.org/sites/default/files/LASpeaksLanguageDiversity.pdf>. Accessed on March 1). Rates of ACP are particularly low in racial ethnic minorities and groups with limited English proficiency(Harrison et al. 2016; Krakauer, Crenner, and Fox 2002), and a true prevalence of these populations within transplant centers should be determined so that interventions could be appropriately tailored.

There are several strengths to our study. This is the first qualitative study to provide a detailed description of the barriers faced by multiple providers on the LT team with regards to ACP. A prior survey of transplant providers found that insufficient communication about the end of life and insufficient training among transplant providers were major barriers to ACP(Ufere, Donlan, et al. 2019). Our study expanded on this to also include detailed descriptions regarding the goal of transplant, role confusion, and language and cultural competence as barriers. Drawing perspectives from several different types of providers at multiple different transplant centers contributed to the validity of our findings.

Despite our strengths, there are some notable limitations. Our study only included providers within LT centers and did not include interviews with primary care physicians, palliative care specialists, or referring gastroenterologists, who also provide much of the care to patients with DC. Given that this study is qualitative, the frequencies we report in beliefs and attitudes for our informants also cannot be generalized to the entire population of transplant providers. Despite these limitations, however, we believe our study accurately represents a rich and diverse group of perspectives regarding the current barriers to ACP in these transplant center settings.

Having iterative discussions with patients and families about their prognosis and goals of care appears to be a daunting challenge for providers treating patients with DC, a population with several barriers at the system level. However, cultural change in adopting ACP is feasible, and overcoming these barriers in a systematic, evidence-based fashion will help drive that change.

Figure 5.1: Flowchart of Participant Recruitment - Providers



Chapter 6: Dissertation Discussion

6.1 Discussion Overview

The aim of this dissertation was to describe the experience of advance care planning (ACP) in patients with decompensated cirrhosis (DC) at liver transplant (LT) centers and describe any barriers and preferences for this practice. To accomplish this, we performed semi-structured interviews of patients and providers at three major LT centers in Los Angeles and analyzed transcripts using qualitative methods. In Paper 1, we provide a description of ACP practices from provider perspectives. In Paper 2, we provide both a description of ACP practices, as well as barriers, facilitators, and preferences about ACP from patients. In Paper 3, we describe barriers and preferences identified by providers in performing ACP. In this section, we will provide a summary of each paper individually. Next, we will discuss the limitations of the dissertation. Finally, we will discuss the important implications this study has on future research and policy.

6.2 Advance Care Planning Is Infrequently Offered at Liver Transplant Centers

Our first study provides evidence that ACP is not offered throughout the trajectory of illness for patients with DC at three major LT centers. Our analysis of semi-structured interviews of providers revealed that the practice of ACP largely depends on whether the patient is perceived to be a LT candidate, which is characterized by 3 Phases. Patients who are getting evaluated for a LT or listed (Phase 1) only receive discussions about goals of care and surrogate decision making from a limited number of providers, mostly social workers. Patients' concerns about their personal limits to aggressive care are not handled in a nuanced fashion by most members of the transplant team. Patients who are denied or deferred with a chance to get re-listed (Phase 2) have a near absence of ACP provided to them. Patients who have no chance of

being listed for LT (Phase 3) experience late conversations about dying with their providers, and their goals of care are not fully explored until the end of life. Social workers also report a difference between conversations in the outpatient setting and those in the inpatient setting, where bringing up topics like preferences and goals of care to patients and families can be more complicated.

The overall lack of ACP offered at these LT centers has not been described previously but mirrors observations from other disease populations, where providers report infrequently discussing goals of care or patient preferences(Grubbs et al. 2017; Gott et al. 2009; Selman et al. 2007). The lack of nuanced approaches to handle discussions regarding limits to care in patients who are waitlisted for transplant has not been explicitly identified, and it may partially explain the lower quality of end of life observed in patients on the transplant waitlist versus non-transplant patients seen in one study(Walling et al. 2013). The fact that support for any ACP diminished once patients are no longer candidates and goals of care discussions are initiated late signals that further work also needs to be done in this population. The difference in difficulty between conversations in the outpatient and inpatient setting also reinforces an observation noted in previous studies and policy briefs, including *Dying in America*, that ACP conversations are best handled in non-acute settings(2015).

Since the intention of this first study solely involved describing the experience of ACP, hypotheses about reasons why this occurs are notably absent. A fuller description of patient perspectives regarding ACP and provider barriers are needed, which are presented in the subsequent chapters.

6.3 Patients Report Most Discussions Relevant to Advance Care Planning Occur Outside of Liver Transplant Centers

Our second study also demonstrated a lack of communication between patients with DC and LT providers regarding goals of care and their end of life preferences, from the perspective of patients. In their interviews, patients reported either having contemplated or shared their goals, values, and preferences for end of life care with family members. However, none of these preferences were shared with a LT provider, and only one patient reported having a meaningful conversation about dying with their LT provider. While many more patients stated that they discussed or shared their preferences for surrogate makers with their LT teams, only 5/42 (12%) of patients had an uploaded document in the medical record. The most common barrier to these conversations was the fact that providers do not bring them up, though the majority (34/42) of them found the topic acceptable to engage in at any time.

This interest in engaging in ACP among patients with cirrhosis has been shown in another study surveying patients with cirrhosis in Canada, though most of these patients were Child Pugh A and thus less seriously ill than our population (Sprange et al. 2019). The observation that many patients in our sample, even those hopeful for LT, have contemplated or expressed limits to aggressive care to their family members, is a new and important finding. Though it is not uncommon for patients to want limits to aggressive care, control where they die, and avoid being a burden on their caregivers at the end of life (Singer, Martin, and Kelner 1999), the fact that these issues are also true in patients who are hopeful for transplant suggests that innovative approaches for handling these simultaneous concerns in this population are critically needed. The fact that most patients report a lack of provider recommendation as a common barrier to these conversations suggests that fixing this issue will require providers to pay most attention to their barriers, which is the focus of our last chapter.

6.4 Providers Report Several Barriers to Performing Advance Care Planning

Our last paper highlights four unique barriers to ACP that are reported by providers: 1) the goal of transplant and “transplant culture”; 2) the lack of training and time for ACP; 3) role ambiguity; and 4) lack of language and cultural competence. “Transplant culture” consists of a steady focus on getting a patient to transplant, requiring no limits to aggressive care, continually reinforcing hope, and recommending that a center’s assessments of futility and transplant candidacy (which are often subjective) are followed. The lack of training to perform advance care planning includes lack of provider knowledge on advance directives, concerns over patient perceptions, and a reported lack of time and space for conversations. Role ambiguity was reported both between transplant centers and referring providers as well as within transplant teams. Both role issues and a lack of language and cultural competence were more often reported by non-physicians on the LT team.

This study’s detailed description of “transplant culture” from multiple perspectives is the first of its kind in peer-reviewed literature. Two concerning components of this “culture” are the fact that patients are required to have no limits to aggressive therapy and that the definition of futility, thus transplant candidacy, is often subjective. Efforts to better define futile care in critical care settings (Huynh et al. 2013) should be extended to patients being considered for LT since the difference between life and death is often subtle and not respecting a patient’s wishes for limits to care during cases of futility is an immediate threat to their right to self-determination at the end of life. The fact that conversations about goals of care and dying are seen as a threat to this culture suggests that there are parts of this culture that need to change, which will be outlined in later segments. Our findings from Study 2 highlights the fact that patients find ACP acceptable, which should reduce concerns that providers have about these conversations, as

shown in Study 3. On the other hand, there may need to be greater attention paid to the knowledge gaps that providers may have regarding the importance of ACP and regarding strategies for incorporating it in their practice. The findings of role ambiguity and lack of cultural and language competence are system barriers that also require significant attention and will be addressed in a later segment as well.

6.5 Synthesizing the Findings

The findings of all studies put together highlight both a significant absence of ACP at LT centers and key barriers identified by patients and providers that are worth addressing to help solve this problem. Most ACP discussions currently occur between patients and their families and outside of their clinical care (Study 2). The only health professionals that appear to have a consistent role in ACP at LT centers are social workers, and they receive little to no support from other providers to continue this process as patients become sicker or when they are no longer candidates, until the end of life (Study 1). Among the barriers identified in these studies, lack of training and knowledge regarding ACP appears to be the most fundamental. The idea of “transplant culture” also seems to elevate the idea that conversations about death and dying should be avoided since they detract from the goal of getting a new liver.

Based on our findings in Study 2, ACP is a topic that patients with DC both value and find acceptable to discuss with their providers. Thus, we believe that there should be broad support for integrating ACP in the care of patients with DC early in their disease course and throughout their illness trajectory, regardless of whether they are candidates for LT or not. Contemporary views of ACP stress the importance of identifying a patient’s values, goals, and preferences to help guide medical treatment (Sudore et al. 2017). A broad approach to this process may emphasize understanding a patient’s values and goals first, as many patients often

avoid wanting to document strict medical preferences for end of life care (Rosenfeld, Wenger, and Kagawa-Singer 2000; Doukas and McCullough 1991; Hawkins et al. 2005). The capacity to address goals of care should be maintained, particularly around sentinel events such as a change in health status or a change in transplant candidacy (Walling, Ahluwalia, et al. 2017). Delivering this care within a health system and across health systems for this population pose unique challenges (Naik et al. 2019). As we will mention in coming segments of this discussion, next steps for incorporating ACP should target 1) improving provider education both within and outside LT centers and 2) developing care models that incorporate palliative care.

6.6 Dissertation Limitations

We recognize several limitations to this dissertation, which will be highlighted.

6.6.1 Reflexivity and its Influence on The Research Process

Dr. Patel is a physician who primarily cares for patients with serious illnesses affecting the liver. He has been interested in better understanding how palliative care can be integrated in the care of this population since 2014. It is important to recognize the influence that Dr. Patel's background and experience exerted on aspects of the study design, data collection, and data analysis strategy for this study.

6.6.1.1 Influence on Study Design

One of the study's major aims was to determine how ACP, an important component of palliative care, is experienced by patients with DC and their providers. One of Dr. Patel's motivations was to identify any potential gaps in care to better understand whether they can be fixed.

6.6.1.2 Influence on Sampling and Data Collection

Dr. Patel interviewed both healthcare providers and patients for this study. He has treated patients at two of the three LT centers from where he performed interviews, and had worked professionally with 9 of the 46 interviewed providers in the study. He had no direct prior contact with any of the patients interviewed in this study. His prior relationship with providers and familiarity with the LT setting provides an –emic perspective that in some ways may have been an asset since informants could have been more comfortable with sharing their knowledge and perspectives. However, it may have also introduced a social desirability bias with responders who may have provided more favorable answers to questions that touch on clinical judgment, ethics, and professionalism.(Bergen and Labonte 2019) For his interviews with patients, the same issue may have also led to mixed responses. Patients may have found questions about medical topics approachable with someone who is familiar with their disease process; however, they may have felt hesitant to provide answers that were too critical if they felt their responses would impact their relationship with their provider (despite being communicated verbally and in writing that Dr. Patel would have no impact on their clinical care).

6.6.1.3 Influence on Data Analysis and Presentation

Dr. Patel and Dr. Diana Tisnado, an experienced qualitative researcher in palliative care, were involved in developing codebooks, the coding process, and analyzing codes. Similarly to Dr. Patel, Dr. Tisnado has an interest in improving palliative care in patients with serious illnesses. Dr. Patel’s personal knowledge of transplant settings and both of their interest in palliative care may have influenced the presentation of findings, which largely conclude that there is a greater need for palliative care in the studied population.

Despite these biases, we believe that the overall impact of Dr. Patel and Dr. Tisnado’s perspectives was positive towards improving the validity of our findings.

6.6.2 Sampling Approach

We were largely able to meet our targeted sample size of 10 providers in each informant group; however, in our final sample of interviewees, we only interviewed 9 hepatobiliary surgeons and 9 patients evaluated for transplant. We also interviewed only 6 social workers, but this was the maximum number of individuals that could be interviewed in this group. We do not believe this significantly affected the validity of our results. The intent of sampling patients and providers from three different LT centers and from multiple different groups was to capture a diverse set of perspectives surrounding the topic of ACP for this population. Patients who met inclusion criteria but were not ultimately interviewed dropped out due to unclear reasons (such as not being interested, not having time to be interviewed, or feeling exhausted, among others). It is possible that these patients may have had different perspectives from those who were ultimately interviewed from the study. Similarly, providers who were approached but not ultimately interviewed due to nonresponse or lack of interest may have also had different perspectives from those who were interviewed. However, given the intent of this study was not to produce population-level estimates, we do not believe that this compromised the validity of our final results.

6.6.3 Replicability

Our description of methods used in this study is satisfactorily transparent; future work may be interested in replicating our approach. This is most suitable for exact replication, which involves using both the same population and procedures for research. Exact replication would mostly prove difficult with regards to patient interviews, since patients' illness trajectories change over time, along with their perspectives. Empirical and conceptual replication involve using different populations and different procedures, respectively, while keeping the other

component the same. For researchers interested in discovering more about ACP in other illness populations (empirical replication), our interviews are transferable but the sampling approach would be different (Aguinis). For those interested in learning more about another phenomenon in patients and providers at LT centers, both sampling and interview procedures would likely both have to change. In general, there are notable challenges that were learned in this process regarding getting approval to perform this work at multiple transplant centers, recruiting patients during clinic visits, allowing caregivers to participate during data collection, and allowing stakeholders to be involved in parts of the study design and data analysis. Similar work in other settings will likely require investment from these stakeholders.

6.6.4 Generalizability

The interviews conducted in this study were limited to patients and providers at LT centers housed in large, academic institutions in Los Angeles. There were notable groups that we omitted from this study that are worth mentioning. Firstly, we did not interview patients with overt hepatic encephalopathy, those who did not speak English, and patients with hepatocellular carcinoma. Out of providers, we did not capture interview those outside of these LT centers in academic settings (primary care providers, palliative care specialists, or referring gastroenterologists) or in other practice settings (Veterans Affairs health system, transplant center in non-academic setting, community). We also did not explicitly interview caregivers.

The absence of patients with overt hepatic encephalopathy and non-English speaking patients in our group is particularly important, since patients with cognitive issues and patients of minority backgrounds, particularly those with limited English proficiency, have much lower rates of ACP compared to the general population (Sudore et al. 2010; Garand et al. 2011), and likely have barriers related to being able to communicate their preferences effectively. We also

purposefully omitted patients with hepatocellular carcinoma, since they appear to have different barriers to palliative care that are likely more nuanced (Woodrell et al. 2018). The fact that we sampled patients from one distinct geographic setting should also caution readers to generalize our findings to patients from other settings whose demographics and social background may be different, thus potentially influencing their beliefs on ACP. The omission of caregivers is a particularly important limitation since they are most likely to shape the experience of ACP for these patients (Fried and O'Leary 2008).

The findings from our patient interviews concluded that some patients do have ACP conversations with their primary care providers and community gastroenterologists, so future work should prioritize investigating these groups of providers for better characterization of ACP. In fact, community gastroenterologists and hepatologists reported less comfort with end of life discussions compared to providers in academic settings in one survey study, so understanding barriers in those settings may be relevant (Ufere, Donlan, et al. 2019).

Compared to other LT centers across the country, the centers including in our study treat patients that are overall sicker than other patients across the country, as suggested by the higher percentage of patients that are in the critical care unit when hospitalized and higher MELD-Na scores at transplant. As mentioned previously, we believed that a higher sample of seriously ill patients would increase the likelihood of ACP (Lovell and Yates 2014; Walling et al. 2008), though we found very little evidence of this overall in our study. These findings, along with data suggesting that end of life care practices are poor across several transplant centers in North America (Ufere, Halford, et al. 2019b; Poonja et al. 2014; Kelly et al. 2017; Kathpalia, Smith, and Lai 2016), suggests that this lack of ACP may be generalizable to other LT centers across the country.

6.7 Implications for Further Research

The findings of this our study have significant implications for further research, as well as quality improvement efforts.

6.7.1 Understanding and Addressing Specific Gaps in Provider Training for ACP

Further work should be aimed at understanding the specific gaps in knowledge and skills that providers have towards the process of ACP, which incorporates sharing prognosis, choosing a surrogate decision maker, exploring goals of care, and documentation. Targeting knowledge and skills may be a useful first step before addressing other barriers identified in our study, such as role ambiguity and language and cultural competence. Detailed surveys that assess provider knowledge and approach to ACP and goals of care discussions should be administered to providers. Data from these studies can be used to create items for the survey. Understanding these gaps in knowledge as well as skills (such as communication) will better help guide quality improvement and dissemination efforts. It is important that these gaps in knowledge and skill should be ascertained from a broad sample of providers in both transplant and non-transplant settings.

6.7.2 Developing Models of Clinical Care that Respect Curative and Palliative Goals

Next, more efforts should be placed in developing models of care that can be offered as an alternative or complementary to the current model of LT, which does not allow any limits to aggressive care. Though we know that patients with DC experience significant suffering at their health deteriorates, we have very little evidence in ways we can support their quality of life during this process. This is an important priority since ultimately most patients will not be LT candidate and we even found in Study 2 that even patients desiring LT often would prefer not prefer maximal therapy if the end of life is approaching. These models should ideally nuanced,

incorporate palliative care (such as assessments and care plans for physical symptoms, mental health symptoms, caregiver burden, spirituality, social aspects of care, etc.), and be constructed for both patients who are being considered and not considered for LT. One example of a nuanced approach is a model of care that involved a LT center referring patients waitlisted for transplant to hospice. Six patients were able to receive LT while receiving simultaneously aggressive and palliative care (Medici et al. 2008). Our next step will be to analyze content from our interviews that discusses integration of palliative care with disease-directed care at LT centers. This data can be used to create a shared mental model of how palliative care and LT specialists can collaborate to improve both aspects of care, which can then be incorporated into a pilot study.

6.8 Implication for Future Policy

Policies have been previously developed that help support greater ACP and palliative care involvement in patients who are being evaluated for aggressive disease-directed care. In 2013, the Center for Medicare and Medicaid Services (CMS) proposed a set of changes to the national coverage determination (NCD) for ventricular assist devices (VADs), a therapeutic option for patients with advanced heart failure that is either a bridge to heart transplantation or a final or “destination” therapy for those who are not candidates for heart transplantation. In these changes, they stated that palliative care specialists are a necessary member of the team responsible for deliberating decisions about VAD. This policy essential made it mandatory for palliative care specialists to get involved in the care of several patients for advanced heart failure and may be a strategy that can be used for patients with DC who are being evaluated for LT as well. Aligning reimbursements with mandatory palliative care consultation could incentivize centers to perform more ACP. As an alternative, CMS can also require that the current

procedure terminology (CPT) code be required as a mandatory component of the bundle payments for LT in order for centers to get reimbursed for evaluations.

Similar policies should be developed for patients not receiving aggressive disease-directed care. As we mentioned, further research is needed to pilot these models for the care of patients with DC, which may include specialty palliative care consultation, home-based palliative care, and home hospice. Improvements can also be made to the criteria in order to determine which patients with DC should be eligible for such programs. The current criteria used to determine hospice eligibility, for instance, in patients with DC fails to predict a 6-month prognosis (Fox et al. 1999). These criteria, as well as criteria to support the inclusion of palliative care, should be grounded in better data.

6.8 Conclusion

There is strong evidence that ACP helps patients and families prepare for the challenges they may face towards the end of life. DC is a serious, life-limiting condition where ACP may have broad benefits, given the fact that the chances of LT are overall small. Our study found that ACP is not performed at LT centers throughout the illness trajectory for patients with DC, despite the fact that patients often have goals, values and preferences for the end of life that they are willing to share. The unwavering focus of LT centers to get patients to LT and keep it available as an option for them is seen as a major barrier to ACP, along with poor infrastructure, training, and support for these discussions.

Though our study is limited to transplant centers at large, academic institutions, we believe that our findings have important ramifications. Specifically, we believe that future research efforts should focus on identifying gaps in training from providers who treat patients with DC and developing models of care that integrate palliative care. We also believe that

policies can be developed to incentivize the inclusion of palliative care and ACP into their care. By developing strategies around these issues, we can strive to deliver care to our patients that is not only high-quality but also goal-concordant.

6.10 Appendix

Interview Guides

Interview Protocol for Patients

Hello, and thank you for taking the time out of your schedule to meeting with me today. I am a physician researcher in the Department of Digestive Diseases and am conducting a study that looks at ways we can better improve how we talk with patients with cirrhosis about their illness and their future. Your input is very valuable to this project. I wanted to let you know that certain topics may come up in this interview that you either may or may not want your physician to know. I have the duty to inform your medical team if anything serious or life threatening is brought up. Otherwise, I will ask whether you would like me to bring up any details of the interview with your physician [keep a running tab of this]

I wanted to start off this interview by talking about how you got diagnosed with cirrhosis and your overall experience with the disease in the past year.

PART I: Diagnosis of Cirrhosis and Past Experiences

1. Can you tell me about how you became diagnosed with cirrhosis and what that experience was like?

“What else was going on with your life at the time you were diagnosed?”

“How did you react to the news of getting diagnosed?”

“How did getting diagnosed affect your life and quality of life at the time?”

Patients tend to have many different experiences after they get diagnosed for the first time—some can be routine, like going to see a lot of doctors, while others can have somewhat traumatic experiences, like getting hospitalized.

2. Can you describe what experiences you have gone through since diagnosis or in the past year of having the disease?

“Over what period of time have all these events occurred?”

“What impact did these events have on your life since getting diagnosed?”

“How has your relationship been with medical providers after being diagnosed and living with this disease?”

PART II: Present Illness

We’re going to switch gears and talk about what it’s been like living with cirrhosis now. First, I wanted to talk about things that worry you about your cirrhosis, since many patients tend to have worries.

3. **If you had to pick 2-3 concerns you have about your experience with cirrhosis now, what would they be?**

[If unable to come up with enough...]

“Have you had any issues concerning your quality of life?”

“Do you have any questions about how to manage aspects of your disease?”

“Do you have concerns about your prognosis or what can happen to you in the future?”

4. **At the moment, how comfortable do you feel about your level of understanding about what cirrhosis is and what can happen as a result of the disease? I will preface in saying that I may not be able to answer all your questions.**

“Do you understand what causes your symptoms and why you take certain medications that are prescribed to you?”

“What aspects about cirrhosis are you still unclear on or need more clarification about?”

“Who do you normally approach to find information about your liver disease?”

5. **Can you tell me about whether you are a candidate for liver transplant or if you have ever been evaluated?**

PART III: Future Illness Planning

Cirrhosis is often an unpredictable illness, and I wanted to ask you some questions about certain events that can happen in the future with your liver disease and how prepared you feel about them.

6. **What kind of conversations do you have with your physicians about your quality life and current goals for treatment?**

“Who often brings up these discussions?”

“Is a priority for you to discuss this during your visit with the healthcare team?”

“Has there ever been a discussion about what makes a good quality of life or bad quality of life for you?”

7. **As you know, there are instances regarding your cirrhosis where you can get so sick that you may be unable to make medical decisions for yourself. Have you had discussions with your loved ones or medical team about who can specifically make medical decisions for you if that were to happen?**

[If they have had these discussions]

“What were those discussions like?”

[If they have not had any of these discussions]

“How would you feel if someone from the medical team talked to you about that?”

8. **Some patients, particularly when they are healthy, also have discussions with their loved ones or healthcare team about the types of invasive medical procedures they would be willing to tolerate? Have you ever had these discussions?**

[If they have had these discussions]

“What were those conversations like?”

[If they have not had any of these discussions]

“How would you feel if someone from the medical team talked to you about these procedures and asked you about what you preferred?”

9. **Have you ever had discussions with your family or healthcare team about other unfortunate events that can happen, like if you were so sick that you couldn’t walk or needed so much assistance that you would potentially have to consider staying at a nursing home?**

[If they have had these discussions]

“What were those discussions like?”

[If they have not had any of these discussions]

“How would you feel if someone from the medical team talked to you about that?”

10. **[For patients with a chance of being evaluated for liver transplant] Have you thought about what may happen to you if you were not a candidate for liver transplant? Has this ever been brought up?**

“Have your medical team or loved ones talked to you about what would be important to you if this were to ever happen?”

[If they have had these discussions]

“What were those discussions like?”

[If they have not had any of these discussions]

“How would you feel if someone from the medical team talked to you about that?”

[For patients with little or no chance of being re-evaluated for liver transplant] How has being unlikely to receive a liver transplant affected your plans for the future?

“What discussions have you had with your family or medical team about this?”

[If they have not had any of these discussions]

“How would you feel if someone from the medical team talked to you about that?”

11. **[Only if death has been mentioned as a worry]
Have you thought about what you may want if you were told that you may die in the next 6 months?**

“Have you had discussions with your medical team about this?”

“Have your medical team or loved ones talked to you about what would be important to you if this were to ever happen?”

[If they have had these discussions]

“What were those discussions like?”

[If they have not had any of these discussions]

“How would you feel if someone from the medical team talked to you about that?”

12. **Have you heard of an advance directive? Some people know about it and some people don't. Have you had conversations with your providers about advance directives or filled one out?**

[If unfamiliar with an advance directive]

These are medical documents that allow you to document what type of care you would want if you're unable to make medical decisions and what individuals you would want to make medical decisions for you. They are a flexible and changeable document.

[If have had conversations with the medical team]

“How was this brought up to you and what was that experience like?”

“Were there things about having conversations that made it difficult?”

“Were there things that you found made it easier to do?”

[If they have filled out an advance directive]

“Was filling out an advance directive challenging?”

“Why or why not?”

[If there have not been any conversations with the medical team or advance directives]

“How would you feel if someone from the healthcare team brought it up?”

“What do you feel is the best time for providers to bring up any of these issues?”

Final Question: Is there anything else you would like to mention that has not been said?

Interview Protocol for Providers

Hello, and thank you for taking the time out of your schedule to meeting with me today. I am a physician researcher in the Department of Digestive Diseases and am conducting a study that looks at how members of the healthcare team perform goals of care discussions with patients with end-stage liver disease. I know that you have been involved in taking care of these patients yourself and so your input is very valuable to this project.

PART I: Job Description and Context

1. Given that provider roles can vary across institutions, can you start by telling me a little bit about how you spend your professional time at the liver transplant center and the role you play in treating patients with cirrhosis?

Probes:

“How long have you been involved in coordinating care for patients with decompensated cirrhosis?”

“Can you describe your general day-to-day responsibilities?” → such as clinical, administrative, research time?

“Can you describe the different trajectories of a patient’s liver disease you are involved with from time of diagnosis to transplant or the end of life?”

PART II: Advance Care Planning: Prognosis Discussions, Treatment Preferences in Future Health States, and Values

We treat many patients with decompensated cirrhosis that typically are sick and whose clinical state is quite fragile and in many circumstances, unpredictable. I want to ask some questions about how you prepare patients for certain events that can happen in the future.

2. Can you describe a typical conversation you will have with patients with decompensated cirrhosis about certain medical emergencies or events that can happen in the future?

Probe:

Can you explain any conversations you may have regarding a patient’s chance of dying?

3. Regarding your discussion about future event, will you ever explore what sort of care they would like to receive if they were unable to make decisions?

Probes:

If YES, “Can you describe those conversations”? In what ways do you incorporate a patient’s values in making those decisions?

If NO, “When may those conversations be appropriate along the trajectory of a patient’s care?”
What ordinarily prompts those conversations? Whose role would it be and why?

For [any of the other future events that were not mentioned], why do you believe these topics are not brought up?

PART III: Advance Care Planning: Surrogate Decision Maker

4. *As mentioned previously, some patients along the trajectory of disease may lose the ability to make medical decisions for themselves. Do discussions with patients about assigning a healthcare decision maker ever come up in the care of these patients?*

Probes:

“Tell me more about when you have these discussions and who usually brings them up”

“Can you describe how you approach these discussions?”

“Do you ever revisit these discussions? If so, when?”

“Do you feel that it is your role to have these discussions?”

“What factors prevent you from having these discussions?”

“How do you think we can fix this issue?”

PART IV: Advance Care Planning: Documentation of Medical Preferences

I’m going to transition now to talk about advance directives.

5. **How often do you check to see whether an advance directive has been filled out for a patient that you are seeing in clinic?**

“What are circumstances where you would check?”

“What are some reasons why you think it never happens?”

6. **Do discussions with patients about advance directives or POLST forms regarding their medical care ever come up?**

“Who usually brings up these conversations?”

“Describe your approach to having these conversations.”

“Do you ever revisit these discussions?”

“What are some reasons why you think it never happens?”

“Whose role do you feel it is to ensure that a patient has these documents filled out and

updated?”

“What are some reasons why these topics don’t come up in conversation?”

“What are other challenges you face? Do you feel comfortable with having these discussions? Do you find that these conversations make any difference?”

“How do you think we can fix this issue?”

7. **Do discussions with patients about goals and values come up?**

“Who usually brings up these conversations?”

“Describe your approach to having these conversations.”

“Do you ever revisit these discussions?”

“What are some reasons why you think it never happens?”

8. **What are some ways you believe we can improve how we communicate with patients about future health events, choosing a healthcare proxy, and filling out advance directives?**

Final Question: **Is there anything else you would like to mention that has not been said?**

Codebook

| Parent Code | Sub-Code | Description |
|---|--|--|
| Actual Conversations or Reported Practices | | These quotes capture the patient and/or provider's lived experience re: components of advance care planning; this captures their description, views, and opinions about events that already happened or reported to happen regularly (in the case of providers). |
| | Discussions about Surrogate Decision Makers | Surrogate decision maker is someone who makes decisions for someone when they cannot make them for themselves |
| | Discussions about Prognosis and Future Health Events | Prognosis includes an indication of mortality or "months left". Future Health Events are events that could potentially happen to the informant. |
| | Discussions about Documentation | Documents such as advance directives, living wills, MOLST/POLST |
| | Discussions about Healthcare Preferences | Discussions about specific medical practices and procedures |
| | Discussions about Health Goals and Values | Discussions about their quality of life, how patients define a good life, or how aggressively they pursue curative treatments. |
| Readiness for ACP (Patients Only) | | These quotes capture readiness/motivation such as "I want her to be my decision maker and sign the directive now". |
| | Readiness to Choose Surrogate Decision Maker | Surrogate decision maker is someone who makes decisions for someone when they cannot make them for themselves |
| | Readiness to Discuss Prognosis and Health Events | Prognosis is indication of mortality or "months left". Future Health Events are events that could potentially happen to the informant. |
| | Readiness to Document ACP | Documents such as advance directives, living wills, MOLST/POLST |
| | Readiness to Make Decisions about Healthcare | Discussions about specific medical practices and procedures |
| | Readiness to Define Health Goals of Values | Discussions about their quality of life, how patients define a good life, or how aggressively they pursue curative treatments. |
| Preferences | | This involves patients or providers views about specific interventions (such as specialty palliative care) that can improve ACP |
| Barriers and Facilitators | | These are broad reasons why ACP does or does not happen according to providers |

| | | |
|--|---|--|
| | Discussions about Surrogate Decision Maker | Surrogate decision maker is someone who makes decisions for someone when they cannot make them for themselves |
| | Discussions about Prognosis and Health Events | Prognosis is indication of mortality or "months left". Future Health Events are events that could potentially happen to the informant. |
| | Discussions about Documentation | Documents such as advance directives, living wills, MOLST/POLST |
| | Discussions about Healthcare Preferences | Discussions about specific medical practices and procedures |
| | Discussions about Health Goals and Values | Discussions about their quality of life, how patients define a good life, or how aggressively they pursue curative treatments. |

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