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Integrating Specialist Palliative Care in the Liver Transplant Evaluation Process: A Qualitative Analysis of Hepatologist and Palliative Care Provider Views

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Abstract

Background and Aims: Patients undergoing evaluation for liver transplantation face heavy burdens of symptoms, healthcare utilization, and mortality. In other similarly ill populations, specialist palliative care has been shown to benefit patients, but specialist palliative care is infrequently utilized for liver transplantation patients. This project aims to describe the potential benefits of and barriers to specialist palliative care integration in the liver transplantation process.

Approach and Results: We performed qualitative analysis of transcripts from provider focus groups followed by a community engagement studio of patients and caregivers. Focus groups consisted of 14 palliative care specialists and 10 hepatologists from 11 institutions across the US and Canada. The community engagement studio comprised patients and caregivers of patients either currently on the liver transplant wait list or recently post-transplant. The focus groups identified 19 elements of specialist palliative care that could benefit this patient population, including exploring patient's illness understanding and expectations; comprehensive assessment of physical symptoms; discussing patient values; providing caregiver support; providing a safe space to discuss non-curative options; and anticipatory guidance about likely next steps. Identified barriers included role boundaries, differences in clinical cultures, limitations of time and staff, competing goals and priorities, misconceptions about palliative care, limited resources, changes in transplant status, and patient complexity. Community studio participants identified many of the same opportunities and barriers.

Conclusions: This study found that hepatologists, palliative care specialists, patients, and caregivers identified areas of care for liver transplant patients that specialist palliative care can improve and address.

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Keywords

advance care planning; end stage liver disease; cirrhosis; focus groups; community engagement studio

Palliative care specialists improve the quality of life of patients with serious illnesses by managing symptoms, attending to psychosocial and spiritual distress, and facilitating communication around treatment decisions and advance care planning. Specialist palliative care can improve both patient-reported and clinical outcomes for patients with malignancy, and there is a growing body of evidence showing similar benefit in serious illnesses such as end stage organ failure.(1–5) In the case of end-stage liver disease (ESLD), retrospective and small prospective studies have demonstrated benefits from specialist palliative care, and a large multi-center trial of a specialist palliative care intervention for patients with ESLD is ongoing.(6–8)

A challenge in providing specialist palliative care to patients with ESLD is determining how specialist palliative care could be integrated into the care of patients awaiting liver transplantation. Patients undergoing transplant evaluation and those on the wait list have burdensome symptoms and high risks for hospitalization and death, potentially making them excellent candidates for specialist palliative care.(9, 10) However, palliative care is not often part of the transplant paradigm, and evidence is needed on how best to integrate specialist palliative care into the care of those being evaluated for liver transplantation.

To fill this evidence gap, we conducted a series of focus groups with palliative care providers and transplant hepatologists. These focus groups discussed three key questions: how specialist palliative care could be brought into the care of patients awaiting transplant, what are the barriers to palliative care integration, and how specialist palliative care providers might optimally team with hepatologists to provide care for these patients. We then augmented these focus groups with a community engagement studio (CES) of liver transplant patients and caregivers.

Methods

After obtaining IRB approval, we used the investigators' professional networks, to identify hepatologists and palliative care providers across 12 institutions interested in the intersection of hepatology and palliative care. Using email, the principal investigator (MCS) invited eligible participants to participate in an online focus group.

We conducted three focus groups with hepatologists and palliative care providers via Zoom. The principal investigators (MCS, MV) first presented to the group the elements of palliative care and potential ways that palliative care can fit into a longitudinal setting. (see Appendix A in the online supplement). The subsequent group discussion was led by a focus group moderator trained in qualitative methods (KB).

Using a semi-structured interview guide, the moderator asked open-ended questions along with follow-up questions for clarity and to facilitate detailed discussion. Following each

focus group, participants were sent a link to a REDCap (Research Electronic Data Capture) survey hosted at Vanderbilt University to rank elements of palliative care that were discussed in the focus groups.(11) Focus groups were audio recorded and transcribed.

Qualitative data coding and analysis was managed by the Vanderbilt University Qualitative Research Core, led by a PhD-level psychologist (DS). Data coding and analysis was conducted by following the COREQ guidelines, an evidence-based qualitative methodology(12). A hierarchical coding system was developed and refined using the interview guide and a preliminary review of the transcripts (See Appendix B). Two experienced qualitative coders first established reliability in using the coding system on one of the transcripts. Coding was compared and discrepancies resolved. Coders then independently coded the remaining two transcripts. The transcripts, quotations, and codes were managed using Microsoft Excel 2016 and SPSS version 27.0.

Quotes were sorted by code, and an iterative inductive/deductive approach was used to identify themes and to make connections between themes(13–15). Deductively, we used knowledge of clinical care, health care systems, and the Consolidated Framework for Implementation Research(16, 17). Social Cognitive Theory was used to understand psychosocial beliefs, behaviors, and environments for patients(18, 19). Inductively, we used the coded quotes as a source of detailed understanding of knowledge, attitudes, and behaviors of palliative care and hepatology providers.

Following completion of this analysis, a CES with liver transplant patients and caregivers was conducted. The CES is a “structured program that facilitates project-specific input from community and patient stakeholders to enhance research design, implementation, and dissemination.”(20) In this case, patients and their caregivers with recent experiences of being evaluated for liver transplantation were the target stakeholders. CES staff recruited these stakeholders using a combination of social media, patient advocacy group lists, and contacts from prior studios. The stakeholders were convened via Zoom to hear a brief presentation on the results of our focus groups and then to discuss integrating palliative care into the liver transplantation process. CES staff not affiliated with the research team led discussions and generated summaries.

Results

Participants.

There were 24 participants from 11 institutions across the United States and Canada in the three focus groups. Fourteen of the participants were palliative care specialists and 10 were hepatologists. There were nine males and 15 females. Focus groups lasted an average of 1 hour 37 minutes.

Conceptual Framework.

Figure 1 integrates the topics discussed in the focus groups into a framework for understanding the potential for integrating palliative care into the management of patient with severe liver disease. The center of the figure presents the elements of palliative care

relevant for this patient population. Integration of palliative care into the treatment of patients with severe liver disease involves these specific tasks.

At the top of the figure, the box represents the patient along with the identified important patient-related themes: knowledge, symptoms, behaviors, emotions, and social support. The left of the figure presents themes identified as barriers to integration of the palliative care team into patient management. The right of the figure shows the potential benefits of integrating palliative care into the management of liver disease. The final element of Figure 1 is communication, both interprofessional communication and patient-provider communication. Communication is influenced by patient factors, barriers to palliative care integration, and the potential benefits of integration. These episodes of communication may promote methods for implementation of palliative care.

Elements of Palliative Care.

Table 1 includes the results of the short survey that was administered after the focus groups. Participants ranked the 19 elements of palliative care (identified in the focus groups) and were asked to check which ones they considered high priority. 20 of the 24 participants responded. Seventeen of the 19 elements of palliative care were checked as high priority by at least one participant, and Table 1 includes the percent selecting each of the 17 items as high priority along with quotations from palliative care and hepatology participants talking about each of the elements of palliative care. More than 40% of the group endorsed: 1) Exploring patient's illness understanding and expectations; 2) Comprehensive assessment of physical symptoms; 3) Discussing patient values; 4) Providing caregiver support; 5) Providing a safe space to discuss non-curative options; and 6) Anticipatory guidance about likely next steps, major milestones or decision points that are upcoming.

The Patient.

Focus groups identified patient attributes that affect health care interactions: knowledge, symptoms, behaviors, emotions, social support. Important aspects of knowledge were the patient's understanding of their disease and prognosis. Symptoms of liver disease were a frequent subject in the focus group discussions. Important behaviors that were identified included minimizing substance use patterns, self-managing symptoms, maintaining social responsibilities, and attention to nutrition, rest, and physical activity. Coping with liver failure includes a range of emotions including anxiety, depression, guilt, anger, and shame. Social support, both instrumental and emotional, are important for persons with liver disease. Table 2 presents quotes from palliative care and hepatology participants related to knowledge, symptoms, behaviors, emotions, and social support.

Barriers to Palliative Care Integration.

We identified 8 major themes associated with barriers to integrating palliative care into the management of patients with severe liver disease (Table 3). Four barriers were focused on the interactions between the liver transplant team and the palliative care team: 1) overlap between the roles of the palliative care team and the hepatology team resulting in uncoordinated health care; 2) differing cultures between palliative care and transplant teams; 3) limitations of time and staff which make it difficult to attend to palliative care issues; and

4) competing goals and priorities, such as the best time to introduce the palliative care team, how much time each team should spend with patients, the extent to which palliative care should be involved in symptom management and if so which symptoms, and how to deal with overlap of services offered by both teams such as consults with psychologists, social workers, or dietitians.

Two barriers applied to both clinicians and patients. Both groups may have misconceptions about why a palliative care consult has been requested for transplant evaluation candidates, and what are the things they are supposed to do or expect. In addition, limited resources also affect patients and providers. Providers identified lack of physical space in the clinic as a resource limitation along with lack of reimbursement for services that focus on emotional and psychosocial needs. Patients and caregivers also face limitations in the resources available at home.

The final two barriers are related primarily to patient status. Being removed from the transplant eligibility list is a major challenge for patients and their caregivers that can negatively affect their physical wellbeing and change their relationship with the healthcare team. Patients with complex symptoms and comorbidities also create challenges for the care team. These complex patients may have needs that cannot be fully met by the transplant surgeons and hepatologists.

Benefits of Palliative Care integration.

We identified seven major themes related to the benefits of integrating palliative care into the treatment of patients with advanced liver diseases (Table 4).

1. Proactively, palliative care providers can work to clarify role expectations and by doing so provide services not currently provided by the hepatology team.
2. Interprofessional and patient-provider communication around the management of symptoms or psychosocial issues is another potential benefit of integrating palliative care into patient management. The expertise of palliative care clinicians around issues of emotional adjustment and quality of life can inform hepatologists about how their patients are doing.
3. Integration of palliative care can also enhance shared decision making. The palliative care team may be able to help patients better articulate their needs and preferences thus allowing them to have more input into shared decision-making. The extra time spent with palliative care providers can help patients better understand their values and needs and prepare them for making decisions should their symptoms worsen or should they be de-listed.
4. Integration of palliative care could reduce misconceptions and misunderstandings about what palliative care is and how the palliative care team can meet the needs of patients.
5. The integration of palliative care was seen as having the direct benefit of addressing a patient's mental health, emotional, and interpersonal needs. Palliative care providers are attuned not only to the common experiences of

anxiety and depression, but they are also able to address the more existential fear of dying. This level of support is especially important for patients whose condition worsens to the point of having to be de-listed.

6. The overall quality of patient care might be improved through integration with the palliative care team. This was seen as especially important when a patient's medical status changes over time which can introduce new emotional and interpersonal challenges. Having clinicians who can follow patients from evaluation to post transplant or to hospice care is an advantage of integrating the palliative care team.
7. Palliative care could help patients with advance care planning choices. Palliative care specialists have considerable experience with helping patients with advance care planning, especially when they can have an ongoing relationship over time.

CES

Six stakeholders (4 patients and 2 caregivers) participated in the CES, of whom 4 were female and 2 were male. The stakeholders agreed integrating palliative care into the liver transplantation process would be helpful, especially to deal with symptom control and to discuss prognosis, set expectations, and plan for the future, including end-of-life. Stakeholders also noted negative perceptions about palliative care would be a barrier to integration, but felt that with an appropriate introduction palliative care would be accepted and welcomed by both patients and caregivers. The stakeholders agreed that introducing palliative care early in the transplant evaluation process would be most helpful.

The stakeholders also presented needs for supportive care not discussed in much depth in the provider focus groups. They suggested palliative care integration could include informing patients of resources, especially electronic resources, to connect with other similar patients and to gather information on liver disease and liver transplantation. They expressed a desire for information and resources on financial toxicity from liver disease and transplantation. Finally, the stakeholders emphasized an ongoing role for support from palliative care after transplantation to help these patients navigate post-transplant complications, mental health concerns, and overall health management.

Discussion

This is the first study to our knowledge to elicit the expert opinion of hepatologists and palliative care clinicians on how to integrate specialist palliative care into the liver transplant evaluation and wait-listing process. Prior work has suggested that patients benefit from including specialist palliative care in this treatment paradigm and that specialist palliative care is underutilized for these patients.(6, 21) These focus groups provide insight into how to integrate specialist palliative care into these patients' management. Additionally, the focus groups illuminate the potential opportunities and pitfalls for such integration from both specialties.

Surveys of transplant physicians have revealed reluctance to consult specialist palliative care for wait-list patients despite widespread recognition that specialist palliative care could help many of these patients.(22–24) Several of the hepatologists in our focus groups reported misgivings about involving specialist palliative care clinicians in the care of wait-list patients. These misgivings included concerns about how patients would perceive these providers and how specialist palliative care involvement could create confusion about who manages which problems or may give patients messages that conflict with the message of the transplant team. Throughout the course of the focus groups, as the hepatologists and palliative care clinicians spoke more about how to integrate the two and how the palliative care clinicians could help, we observed increased enthusiasm for specialist palliative care from the hepatologists. By the end of each of the focus groups, the hepatologists were generally as enthusiastic as the palliative care clinicians for integrating specialist palliative care. This experience suggests dialogue among palliative care clinicians and hepatologists is a powerful means of increasing hepatologists' openness to including specialist palliative care in the management of wait-list patients.

Transplant listing has been associated with more aggressive end-of-life care compared with non-listed ESLD patients.(21, 25) A recent qualitative study found numerous barriers to effective advance care planning for ESLD patients at transplant centers.(26) Not surprisingly, our focus groups identified one role of specialist palliative care providers would be assisting patients in advance care planning and helping patients who do not receive transplantation to manage their end of life care. Discussions centered around the importance of this aspect of palliative care and how it would fill a vital need in the care of these patients. However, several important points of caution were discussed, including the need to make sure advance care planning did not unduly distress patients and their families and the importance of palliative care specialists' careful coordination with the transplantation team to make sure patients receive consistent information about their prognoses. Clearly, assisting with advance care planning would be an important role of the palliative care clinician for transplant wait-list patients, but would require a great deal of sensitivity to timing and wording of these discussions so that they do not disrupt the therapeutic alliance between the patient and the transplant team.

These provider perspectives in many ways matched those of the patient and caregivers who participated in the CES. Both CES stakeholders and the provider focus groups shared enthusiasm for the possibilities of palliative care integration for improved symptom management, advance care planning, and communication. The CES stakeholders also noted patient perceptions of palliative care to end of life care as a potentially surmountable barrier to palliative care integration. In addition, the stakeholders identified other supportive care needs amenable to palliative care not discussed by the provider focus groups: dealing with financial toxicity, connecting to information and peer resources, and post-transplantation support.

This qualitative study has several limitations. Although focus group participants were recruited nationally, we cannot guarantee that these participants were representative of the wider hepatology and palliative care communities. Nevertheless, with this number and diversity of participants, we expect that their contributions capture the range of

opinions in these larger communities. Both palliative care and transplantation are inherently multidisciplinary, but this project focused on just one type of caregiver from each of these multidisciplinary fields. Further work is needed to receive input from the stakeholders from other disciplines within transplantation (such as transplant surgeons, transplant coordinators, transplant social workers, and transplant psychologists) and within palliative care (such as chaplains and palliative care social workers). The CES was similarly nationally recruited, but not necessarily representative of the wider population of liver transplant patients and caregivers. The CES process also does not allow for the granular analysis of transcripts that the focus groups allowed, which means themes might have been missed in the summary prepared by the CES staff. Future qualitative research on patient and caregiver perspectives on the role of palliative care would be helpful to provide a more thorough understanding of their perspectives. The input from patients or caregivers who were de-listed or deemed ineligible for transplant would be especially important in future research as the CES was not able to recruit any of these stakeholders.

Despite these limitations, this study provides important preliminary information on how to integrate specialist palliative care into the management of ESLD patients awaiting liver transplantation. These results can help leaders design clinical programs of palliative care for this population. These results could also inform the content of specialist palliative care interventions to be tested in the transplant wait list population. These data are an early step in effectively addressing the demonstrated palliative care needs of these patients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

ESLD	End-stage Liver Disease
CES	Community Engagement Studio
REDCap	Research Electronic Data Capture

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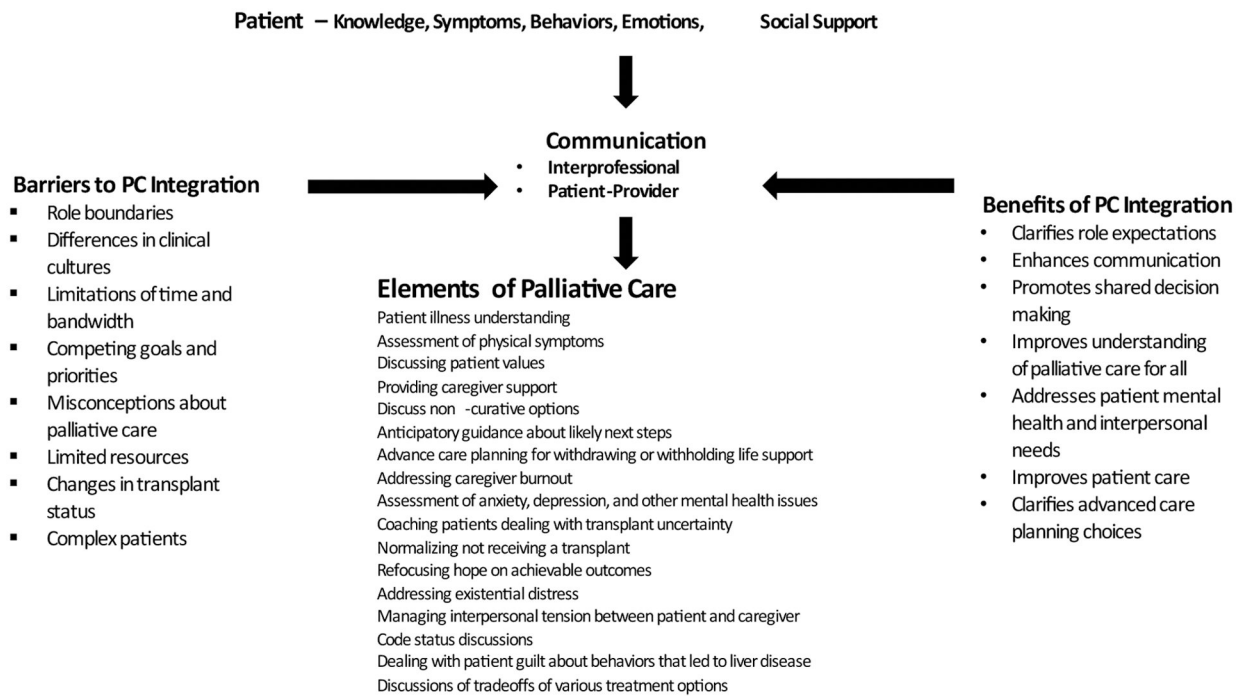


Figure 1:
 Conceptual Framework to Understand Integration of Palliative Care into the Management of Severe Liver Disease

Table 1:

Elements of Palliative Care

Element of Palliative Care	Percent Priority	Palliative Care Quote	Hepatology Quote
Exploring patient's illness understanding and expectations	75%	... there's a huge knowledge gap among patients and caregivers about what to expect or the inability to know what to expect. It does not necessarily have to be palliative care providers that fill that gap, but it could be. (Group 1)	patients and caregivers often feel like, even though we do our best to try to relay what's going on and explain the whole process, they often want more and they want it broken down into terms they can understand. (Group 3)
Comprehensive assessment of physical symptoms	55%	I think the easiest in-road would be symptoms. All these patients, I've yet to see a liver patient that doesn't have symptoms. So, that's an easy way to build rapport. (Group 1)	... if you did a comprehensive assessment at the time of a transplant evaluation and had an introduction to the palliative care team during the transplant evaluation, it sets that standard and continuity. (Group 1)
Discussing patient values	55%	... we build alliances with patients first around symptoms and then get to know them, get to know what's important to them, get to know what sort of things provide meaning and fulfillment in their lives, what they value. And that naturally leads into goals of care discussions (Palliative care, Group 1)	the palliative care physicians that I've worked with are very good at identifying what is that particular individual needs (Hepatology, Group 3)
Providing caregiver support	45%	... the caregiver and the patients as a unit, a dyadic unit, that really what we know from research is really they are interdependent, right? (Palliative care, Group 3)	So, I think the psychosocial needs of the caregivers in a way, need more help from the palliative care team...there is really nobody there to support the caregiver. (Hepatology, Group 2)
Providing a safe space to discuss non-curative options	40%	...If we want this longitudinal relationship, then hopefully we are advocating and providing a safe space and having all these nuanced discussions over time. (Palliative care, Group 1)	... we just don't give room for patients to feel uncertain for patients to struggle with their decision-making. And until we allow that vulnerability and separate it from the transplant listing process itself, that's going to be a fundamental barrier that we face. (Hepatology, Group 1)
Anticipatory guidance about likely next steps, major milestones or decision points that are upcoming	40%	...we provide guidance and conversations around anticipatory events and around it... Events and around advanced care planning ... (Palliative care, Group 1)	I think there are lots of ways that you can be very helpful, but this takes a lot of time and energy and interest... (Hepatology, Group 1)
Addressing caregiver burnout	35%	... the palliative care team can have expertise in caregiver burnout assessment and caregiver support throughout the process, and that might be a helpful place for palliative care teams to help. (Palliative care, Group 3)	...so the patients got transplanted, caregivers were so burned out that the patient was doing fine after transplant. They finally said, "Okay, this is getting better. They can manage by themselves." And they divorce the patient. (Hepatology, Group 2)
Advance care planning for withdrawing or withholding	35%	You may want to do advanced care planning and then use the palliative care specialist for symptoms. And then when it starts advancing some, maybe the hepatologist stay	I would put advanced care planning (as important), but specifically identification of a decision maker as probably the top... I cannot believe the number of people I see who have

Element of Palliative Care	Percent Priority	Palliative Care Quote	Hepatology Quote
life support in the future		calm because the initial things have been addressed, there's advanced care planning in place. (Group 2)	a liver put into them without having had a healthcare proxy identified. (Group 1)
Assessment of anxiety, depression, and other mental health issues	30%	I see comprehensive mental health assessment, but I think depression and anxiety should be specifically named on this list. (Group 1)	... mental symptoms are huge and often under-recognized, we can tell from even doing a ESAS or the Edmonton symptom assessment scale, these guys are off the charts...and other symptoms that go unnoticed unless they're asked about it and often unmanaged. (Hepatology, Group 1)
Normalizing the possibility of not receiving a transplant	25%	... but many of these folks, many, most will not get a transplant in any given year and what will happen to them then? Who will follow them? If they have a palliative care team following them, then they will have a team dedicated to following them and following their caregivers over time... (Group 1)	...in the beginning of these evaluations, everything looks rosy. And then when things get complicated, we just bail out. Why isn't there someone taking our hand, taking the patient's hand once they're no longer a candidate and helping them through that phase? (Group 1)
Coaching patients on how to deal with the uncertainty of whether or not they will get transplanted	25%	So, what if I get a transplant? That would be so great. What if I don't get a transplant, and then I die from this disease?...what our skillset allows us to do, is helping people over time, sort of integrate these two truths about their lives at that time. (Group 1)	There's a lot of uncertainty involved ...And that uncertainty that sort of hangs over all of our patients is very anxiety-provoking. (Group 2)
Addressing existential distress	20%	And, often it begins with some symptom management, but that's just the entryway into digging deeper into ... existential distress either with the patient themselves or the caregiver, and every patient is completely different. (Group 1)	And they need a space to be vulnerable and... supported. ... there's no one there that they feel can hold their words close to the chest and support them to be vulnerable and learn how to cope with the distress that they're undergoing. (Group 1)
Refocusing hope on achievable outcomes	20%	...the idea of refocusing hope that we talked a lot about, we talk a lot about in our field, which is basically at a time of crisis and it's most effective when you have rapport already, you help people sort of make the best of a really challenging situation. (Group 1)	... people come to a transplant center because they have life limiting illness and oftentimes they come without having that explained to them. ... So they come very full of hope, but also without any grounding in reality that this is a process that may not end up with a transplant. (Group 2)
Code status discussions	15%	I've done a consult before where the patient was like, "I do not want you to do CPR. My wife knows that I do not want CPR, but I need you to put full code, so it doesn't raise any alarm bells." (Group 2)	...nobody talked about code status, I realized that, as a resident, we had to do it all the time. And I read some of the early palliative care works, and you have to really establish a rapport with the patient before you even start to talk about these more difficult things... (Group 3)
Managing interpersonal tension between patient and caregiver	15%	... it does not surprise me in the least that people divorce when the patient's more stable...I mean, it is an enormous burden. (Group 2)	Once our patients develop decompensation... their care needs ship to their caregivers... And in some cases can lead to tensions between patients and caregivers as they're going through this process. (Group 1)
Dealing with patient guilt about behaviors that led to liver disease,	10%	... there's a well of anxiety and fear and sometimes shame, especially if there's been substance use that's contributed to the transplant that could be helped by palliative care... (Group 2)	I see depression and anxiety all the time in my patients ...and I see a lot of overlay with addiction and these processes and a lot of them come out during the transplant process, feelings of guilt that are really complex and hard to manage when patients are acutely ill.

Element of Palliative Care	Percent Priority	Palliative Care Quote	Hepatology Quote
especially substance use			(Group 1)
Engage in nuanced discussions of tradeoffs of various treatment options	5%	We know the nuances to where they've been in the past and where their values stand. And we can, we're set up to help walk them through their decision-making. (Group 1)	a discussion of trade-offs that's a nuance ... And I just think that tide of (palliative) care doctors are able to have that conversation a little bit better... (Group 1)

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Table 2:

Qualitative Themes Describing the Influence of Patient Characteristics

Patient Characteristics	Palliative Care Quote	Hepatology Quote
Knowledge	...it's hard to tell them why this last hospitalization you weren't sick enough for a transplant but now you're too sick. And those kinds of things...there may be a way to prime people for the road ahead... (Group 2)	... I'm amazed at how the human brain will just forget those things...I try very hard to make sure my patients are grounded in reality, but once they go... If I've sent them to transplant, they almost never want to hear that again. (Group 2)
Symptoms but if they have insomnia, we might be focused on that. If they have overwhelming anxiety, we might be addressing that. (Group 2)	there are a lot of symptoms that hepatologists don't necessarily always do very well in dealing with because they don't have any management options. Like things as easy as sleep disturbances, muscle cramping. (Group 1)
Behaviors	It's not very scientific, but I would probably just listen to, who helps them make decisions and how they make decisions, and what they understand of their illness course, and what they understand of where they are so far. (Group 2)	We want them to continue to have some movement and try to maintain their nutrition. So, there's a lot of, there are a lot of different aspects to this that can be at least identified (Group 1)
Emotions	I would echo the anxiety and depression, and I completely agree about the caregiver role, but I also think there's a fair amount of existential distress from both the patient and or caregivers. (Group 1)	I see depression and anxiety all the time in my patients ...and I see a lot of overlay with addiction and these processes and a lot of them come out during the transplant process, feelings of guilt that are really complex and hard to manage when patients are acutely ill. (Group 1)
Social Support	And so many are far away from family and support and so I think that a lot of their psychosocial needs are not as met without that family and friend support close by. (Group 2)	... transplant hepatologists seeing a patient in workup or on the transplant list already have, at each visit, 10 different clinical issues to address, as well as all the transplant-related stuff, making sure ... their social support is good. (Group 3)
Resources	... the resources that they have and that's the bucket where you start saying, "What are their financial resources?" So then what you need to have for that union social worker. What are their psychological needs? Based on, again, what they've been told and where they feel they are so whether you need spiritual support at that point, or you need a psychologist, or you need a social worker. (Group 2)	And so I think it's hard obviously in a hepatology clinic space to be able to attend to those caregiver needs. When you have a limited appointment time with a patient and you have to focus on their medical issues. And so I do worry that there needs to be a space to support caregivers who are actually providing most of the direct care to their loved ones at home. (Group 1)

Table 3:**Barriers to Integrating Palliative Care into Liver Disease Management**

Barriers	Palliative Care Quote	Hepatology Quote
Role boundaries	<p>...in hepatology, I kind of hear that and they think, well, the hepatologists and the surgeons kind of want to control the message. And so that's, so those are those discussions happening with them. And then they also want to be in charge of the medications.</p> <p>(Group 1)</p>	<p>I would rather be the only person that really manages that, and the hepatic encephalopathy and titrating of lactulose. Some of that, you don't want too many cooks in the kitchen...</p> <p>(Group 2)</p>
Differences in clinical cultures	<p>... it seems there's like an original sin here and that the, it's called transplant clinic. It's not called management of people with advanced liver disease clinic, and so you fundamentally defined it from the outset by this surgical intervention, which may not happen.</p> <p>(Group 1)</p>	<p>So I'm a sort of a converted transplant hepatologist...The hepatologists are much more open-minded, so we have to educate the transplant team that yes, we actually need them, a palliative care team.</p> <p>(Group 2)</p>
Time and Staff limitations		<p>"Are there times when I'm overwhelmed with my patients?" The answer is of course I am. And if I've got a patient, they say, "Oh gosh, ... let me also talk about this. And let me also talk about this and let me also talk about this and let me also talk about this." Are there times when I'm kind of in my mind thinking, "Good grief, I've got 10 more people to see today?" I would be lying if I said no.</p> <p>(Group 2)</p>
Competing goals and priorities	<p>... it is really challenging in that initial evaluation phase to have a meaningful interaction because they do get really fatigued with three days of testing going all over the medical campus</p> <p>(Group 1)</p>	<p>...we have a team that provides a lot of what palliative care provides. And that it sometimes just adds an extra group of people that maybe don't need that at this time to be there.</p> <p>(Group 3)</p>
Misconceptions about palliative care	<p>...you bring up palliative care or say, "I want you to meet a palliative care doctor," that they'd instantly construe as, "Okay, well, now, they're giving up on me or I'm not going to qualify for this transplant."</p> <p>(Group 3)</p>	<p>So I don't want to just relegate you to end of life stuff where you, again, you become a hospice physician, not a palliative care physician who is integrated into the team at all levels.</p> <p>(Group 1)</p>
Limited Resources	<p>So, to try to find a space and also the funding for teams of physicians has been a real barrier.</p> <p>(Group 1)</p>	<p>... the more time we can spend with these people to answer questions and address these needs, the better it is. A problem is a time is not always reimbursed properly.</p> <p>(Group 1)</p>
Change in transplant status	<p>But the groups that even after they're deferred, somebody where they just can really put all that into perspective and then for the people who they're now declined, and then even a second follow-up based on what their needs are but just so they can rant and rave over not getting a transplant.</p> <p>(Group 3)</p>	<p>Again, the other transplant group that we've already discussed is those that are out there at the upper age limits, that have MELD scores that aren't going to get them transplanted. And as they rise, they become worst candidates and we have to really face the grim reality that we may not get there and having ... So, those are the two groups that I really like the most help with.</p> <p>(Group 3)</p>
Complex patients	<p>And then you have... A lot of them have dealt with alcoholism, substance abuse, where they are with that trajectory. Do they have something else that's important to them? We know a lot of transplant patients, specifically liver, who are not candidates because of their inability to give up certain things.</p> <p>(Group 2)</p>	<p>We sort of, kind of take it on ourselves to sort of manage a lot of the symptoms, fluid retention and hepatic encephalopathy, and the sort of misery associated with chronic liver disease. So who's the right person for the patient to talk to? I think having palliative care involved in our patients is super helpful. One in that, if somebody can't get a transplant, obviously then, they're all going to die.</p>

Barriers	Palliative Care Quote	Hepatology Quote
		(Group 2)

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Table 4:**Benefits of Integrating Palliative Care into the Management of Sever Liver Disease**

Benefits	Palliative Care Quote	Hepatology Quote
Clarifies role expectations	Well palliative care has changed. So definition is important. (Group 1)	But maybe one of the top things is, clear definition of who you are and what your role is as part of the team. (Group 1)
Enhances communication	And that sort of goes back to the communication, the importance of communication between the different treating clinicians (Group 1)	I think that's where the palliative care can help to sort of define more granularly, what's causing the misery of our patients...I would get an alert, by the way, things are not going so well. So they are very good at identifying the problem and find the solution for the patient. (Group 2)
Promotes shared decision making	...then get to know them, get to know what's important to them, get to know what sort of things provide meaning and fulfillment in their lives, what they value. And that naturally leads into goals of care discussions around trade-offs, should they become more seriously ill, and a lot of the communication issues here. (Group 1)	I worry that we just don't give room for patients to feel uncertain for patients to struggle with their decision-making. And until we allow that vulnerability and separate it from the transplant listing process itself, that's going to be a fundamental barrier that we face. (Group 1)
Improves understanding of palliative care for all	the palliative care person or people really need to be in close communication with the liver team, preferably attending the case conferences. (Group 1)	...until we explain exactly where palliative care could play a role in improving the lives of our patients and potentially even some hard outcomes, I think until we get to that point, palliative care will still be underutilized by patients. (Group 1)
Addresses patient mental health and interpersonal needs	I would echo the anxiety and depression, and I completely agree about the caregiver role, but I also think there's a fair amount of existential distress from both the patient and caregiver. (Group 1)	...we still have our patients suffering so much. And we also have their caregivers having a significant amount of distress, shows that even with multiple disciplines who are involved in the care of these patients, we still have many gaps in improving their quality of life while they're on the transplant list. And I think one of the big spaces that palliative care could play a role... (Group 1)
Improves patient care	...the main focus is that not that we can do any one of these things, but that we can provide a supportive longitudinal support, a longitudinal support for the patient. (Group 1)	And if we can show that there's a real benefit of outcomes as far as quality of life and quality of care, I think, that'd be awesome. (Group 2)
Clarifies advance care planning choices	...making sure we understand where the patient is and their understanding of the disease and the prognosis, so that if we find out, say, this patient really doesn't understand their prognosis, then we can help. Well, we can inform the liver transplant team. (Group 3)	You sort of have to get a feel for them and you have to say, "Here's what we plan to do. We're going to everything we can, but we also know that you have a life-threatening condition and maybe we need to have somebody come and talk about all the options that we move through." (Group 3)