

# PALLIATIVE CARE FOR PATIENTS WITH END STAGE LIVER DISEASE ON THE LIVER TRANSPLANT WAITING LIST: AN INTERNATIONAL SYSTEMATIC REVIEW.

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## ABSTRACT

**Background and Aim.** People with end stage liver disease on the liver transplant waiting list have high symptom burden, which can successfully be addressed by specialist palliative care. Potential tensions with the perceived curative nature of liver transplant make delivering specialist palliative care challenging. This systematic review seeks to establish what is known on the impact of specialist palliative care for patients on liver transplant waiting lists, healthcare professionals' perspectives of providing specialist palliative care for this population, and uptake of advance care planning (ACP). Medline, Embase and CINAHL were searched to 5th May 2020. Qualitative and quantitative findings were grouped together according to main relevant themes.

**Results:** Eight studies of mixed quality and mainly quantitative, were identified. Findings suggest early palliative care intervention improve patients' symptoms and prompt ACP conversations, but patients on the waiting list receive limited palliative care input. Liver physicians' lack of clarity on referral criteria and liver transplant patients' concerns of being abandoned, were reasons for reluctance to refer to specialist palliative care. They felt referral to specialist palliative care is appropriate only for patients receiving hospice or end of life care. Uptake and understanding of ACP and Goals of Care designation by patients is poor.

**Conclusions:** This review found evidence of benefit of specialist palliative care for patients on liver transplant waiting lists, but found in a limited understanding of their role. Evidence is limited to studies from North America. Future research is needed to understand better how palliative care could be provided into this clinical environment.

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Key words (MeSH terms): cirrhosis, palliative care, liver transplantation, advance care plans

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## INTRODUCTION

End-stage liver disease (ESLD) is a chronic and progressive illness, which is a growing international public health problem (1-4). It is currently the 12<sup>th</sup> most common of death in the United States (5). People with ESLD often have significant physical symptom burden, a high level of psychological distress and unmet psychosocial and informational needs that are often unaddressed (6). Liver health professionals recognise that they sometimes deliver sub-optimal care for this group in supporting them to manage their symptoms and/or that they lack confidence to communicate effectively with patients about their prognosis or the seriousness of their illness (6-8).

These issues are particularly relevant for people with ESLD who are eligible for the liver transplant (LT) waiting list. On one hand, LT is seen as the 'curative' option as it is the only treatment that can reverse deterioration of liver disease, but limited availability of suitable donor livers has meant strict rationing where certain clinical conditions need to be fulfilled before being accepted on the LT waiting list (9). At the same time, this group has deteriorating liver functioning, is highly symptomatic and is at increased risk of mortality. In the United States, it is estimated that 10% of people will die before they are able to have their transplant and another 10% will die within the first year of their transplant (10). In particular, patients over 65 years of age and with a higher Model for End-Stage Liver disease (MELD) score at listing are at greater risk of death. Older age is also identified as having a negative impact on post-transplant survival (11,12). Furthermore, patients awaiting LT are often mentally distressed, as they are uncertain of what the future holds particularly related to life and death issues (13, 14), so early discussion with patients and families regarding the potential severity of their illness is important.

This group of patients could potentially benefit from a palliative care approach (15, 16), which would aim to incorporate the following dimensions of care relevant to these patients: symptom management, psychological care, advance care plans (ACP), end of life care (17). Specialist palliative care (SPC), as delivered by suitably-trained health professionals working in palliative care), has been shown to

improve symptom management, increase quality of life and reduce depression in advanced cancer (18). A specialist palliative care approach has been implemented for patients with a variety of non-malignant advanced illness (19) and is particularly relevant in people receiving solid organ transplantation (20). It is feasible to deliver SPC to patients registered with LT services (which includes both pre- and post-LT patients) with support from all specialities involved (16). Nevertheless, tensions may exist in provision because of the perceived 'curative' nature of LT and the potential unaddressed palliative needs in this patient group, reflected by liver health professionals' reluctance to refer their patients on the LT waiting list to SPC (21-25), until their patients had either been de-listed or were actively dying and so required transfer to hospice care (26).

The reluctance to refer people on the LT waiting list to SPC, coupled with high symptom burden and unmet palliative care needs that this group has, means that it is vital to understand more on the reasons for the low referral and understand how better palliative care could be provided. Evidence from other non-malignant diseases indicate the benefits of SPC, but it is not clear in the case of people on the LT waiting list. It is important to explore the evidence to see if SPC can improve the outcomes of these people, which in turn would encourage hepatology health professionals to refer to SPC. A recent review has been published which purports to look at palliative care in ESLD patients (27). This review though does not focus on those on the LT list and in their analysis, the authors do not separate data from patients on the LT waiting list from those not listed, so it is difficult to determine which findings are specifically relevant to caring for patients on the waiting list (30). To our knowledge, there has been no systematic review of this specific area. Such a systematic review would clarify if SPC is potentially effective in improving the outcomes of patients in the LT waiting list and explore the potential barriers in accessing this care, in particularly in the delivery of advance care plans (ACP), an area seen as a key indicator of palliative care where healthcare professionals discuss with their patients about their future preferences for care. In addition, it is important to understand the perspectives of health professionals (liver and specialist palliative care) about how they think palliative care can be delivered to patients on

the LT waiting list and what they perceive as the barriers. This would offer a stepping stone in developing better service delivery models and exploring avenues of future research.

In this paper we present a systematic review that critiques the literature on palliative care in LT candidates by exploring evidence in the following areas:

1. What is known about impact of receiving palliative care input from SPC on patients on the LT waiting list?
2. What are the perspectives and attitudes of both liver and SPC healthcare professionals about the provision of SPC support for patients on the LT waiting list?
3. Do LT patients on the waiting list have ACP discussions with their liver clinicians?

## METHODS

### Search strategies

The main literature search was conducted in three databases: Medline (1963 to 2019), Embase (1974 to April 2019) and CINAHL (1996 to April 2019). This search was updated to 5<sup>th</sup> May 2020. Searches were performed using both subject heading and text word terms for the concepts of liver transplantation and palliative care, including synonymous terms such as terminal care, advance care planning, end of life care, hospice.

The following search strategy was used:

((liver\* or hepatic) (transplant\* or graft\* or allograft\*) or liver transplantation AND

[Palliative Care or Palliative Medicine or (terminal care / or hospice care) or "Hospice and Palliative Care Nursing" or Advance Care Planning] or Palliative or supportive care or end of life care or hospice or (advance\* (healthcare or care) plan\*]]. The full search strategies are provided in Appendix i.

**Inclusion criteria:**

- Participants: Adults aged 18 or over with ESLD, and are currently on the LT waiting list and/or health professionals involved in providing palliative care to patients on the LT waiting list. Health professionals could be liver-based professionals or in specialist palliative care.
- Written in English.
- Primary empirical studies using quantitative, qualitative or mixed methods, with palliative care and LT patients being a focus of the study. Studies will be included in the review provided data from patients on the LT waiting list can be dis-aggregated from other participants not on the LT waiting list.

**Exclusion criterion:**

- Participants who have either been de-listed from the LT waiting list or who are post-transplant patients.

**Study selection and data extraction**

SV and JL independently assessed citations against inclusion criteria. For citations where there was a disagreement about eligibility, further assessment was conducted independently by SV and JL. A final consensus of eligible articles was obtained by discussion between BC, SV and JL. SV and JL read through full text articles of all eligible articles and independently extracted the following data from included studies, where available: title, author(s), country of study, year of publication, study design, study setting; study population and participant demographics and baseline characteristics; themes/outcomes explored; key findings. SV and JL compared data extraction to obtain consensus. Any disagreements were resolved by BC. Final consensus for data extraction was obtained as part of group discussions

between SV, BC and JL. Where LT patients did not make up the whole study sample, authors were contacted to ensure that interpretation of results reflected perspectives of patients on the transplant list.

### **Critical appraisal, analysis and presentation**

To assess the quality of the studies, we used the checklist devised by Hawker et al (2002) (28). This checklist has previously been used to assess study quality in both qualitative and quantitative studies in palliative care reviews. It uses nine items to appraise papers: abstract and title, introduction and aims, methods and data, sampling, data analysis, ethics and bias, results, transferability or generalisability, and implications and usefulness. Each item has a maximum score of 4. A score of 1 indicates very poor, and a score of 4 indicates good (total maximum score of 36). We did not exclude studies based on a cut-off score on the Hawker checklist. However, we used the scores from the different items to critique the quality of studies available for the review and to assess the strength of the evidence derived from these studies.

Quality assessment was completed independently by two reviewers (SV and JL). In cases where disagreements existed, BC (an experienced systematic reviewer) acted as a third reviewer to give a final assessment.

For qualitative studies, the key findings were summarised thematically to in relation to our different research questions. Quantitative accounts were analysed narratively. Key findings from each eligible study answering any of the three research questions were extracted and imported into the relevant table. Qualitative and quantitative findings were grouped together according to the main themes relevant to this review.

### **Registration**



This review was registered with PROSPERO (registration number CRD42019137244) on 25<sup>th</sup> July 2019. [https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=137244](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=137244) (accessed 19<sup>th</sup> June 2020)

## RESULTS

The search strategy generated 1,100 unique citations, of which six studies met the inclusion criteria (Figure 1). One eligible study was identified in the updated search and the other was identified by a researcher with a special interest in the area. They comprised seven quantitative studies (three surveys, one quasi-experimental design, two case-note reviews, one mixed case-note/survey) and one qualitative description study. All studies came from North America, of which six out of seven were from the USA and one from Canada. HCP perspectives were explored in three studies, and patient perspectives in the other three. The quantitative survey studies assessed the attitudes and perceived barriers of both liver and SPC HCP in involving SPC for patients with cirrhosis on the LT waiting list. Two studies explored LT-eligible patients' perspectives of using ACP, and the quasi-experimental study looked at impact of an early palliative care intervention on improving patients' symptom burden. Three studies focused solely on patients on the LT waiting list.

### Quality Assessment

The Hawker quality assessment of the seven studies is shown in Table 1 (see Appendix ii for fuller description). Using this tool to assess study quality, five studies were assessed as either good or fair in the reporting of details for all nine categories of the Hawker tool. Of the two remaining studies, one was rated as poor or very poor for four categories (data analysis, ethics and bias, findings/results and transferability/generalizability). In the other study, data analysis was assessed as poor in quality, and reporting of ethics and bias was assessed as very poor. Looking at each category individually, the following six were rated either as good or fair for all seven studies: abstract and title, introduction and

aims, methods and data, sampling, and implications and usefulness (a more descriptive assessment is shown in Appendix ii).

### **Study participants**

Quantitative studies had a total sample of 520 patients with a median size of 126 (range:41-170). The one qualitative study involved three patients on a LT waiting list (37). For studies where key demographic details were recorded, the sample consisted of a total of 250 male patients, 134 of whom had a diagnosis of Hepatitis C, with a mean MELD score of 13- 18. The total sample of health professionals was 1170 with a median sample of 392 (range: 88-690), all from quantitative studies. Of these 1170 health professionals, 791 were liver clinicians and 379 had a SPC background. From studies where details about professional experience could be extracted from 399 liver clinicians, there were 301 attending physicians/registrars. From data available in 707 liver HCPs, 414 of these were professionals who had 10 or more years' clinical experience.

### **What is known about the impact of specialist palliative care on improving palliative care for patients on the LT waiting list?**

Two studies provided some evidence relating to this question. One study looked at the impact of an early palliative care intervention (EPCI) in improving patient outcomes (29) (Table 2). This was a small quasi-experimental before and after study (n =50). This study reported that patients who received EPCI reported reduced symptom burden for the following five symptoms; pruritus, well-being, appetite, anxiety and fatigue at 6 months follow-up when compared with baseline. Patients with high symptom burden also reported an improvement in depressive symptoms, illustrated by a 8.89 point reduction in CES-D scores, a screening tool for depression. The other was a retrospective case note review looking at the uptake of SPC services in the last year of life (30), and so provides some data of what SPC input is currently being provided to patients on the LT waiting list. This study found that 25% of patients on the LT waiting list had an in-patient SPC consultation, which usually occurred in the last 10 days of their

life and only 4.5% of patients had an out-patient SPC consultation. Patients on the LT waiting list were less likely to receive in-patient consultations compared to those not on the LT waiting list.

**Perspectives of healthcare professionals (HCP) about providing specialist palliative care support for patients on the LT waiting list.**

Three quantitative studies captured the perspectives of health professionals in providing palliative care support for LT candidates (Table 3). They report that liver health professionals' understanding of the roles of SPC determined when liver health professionals were willing to refer to SPC. Most liver health professionals (70-80%) perceived that SPC services could provide patients on the LT waiting list with End of Life Care or hospice care (31), several health professionals (28%) noted that the goals of transplantation and SPC were contradictory to each other (32). In one study, most liver health professionals (70-80%) felt comfortable for SPC health professionals to provide psychological support to LT-eligible patients and to discuss End of Life Care and Goal of Care preferences about having aggressive curative treatments or comfort care. They were less comfortable for SPC health professionals to be managing ESLD complications, managing pain with unrestricted opioids and discussing prognosis. In contrast most SPC health professionals (>70%) felt comfortable with palliating portal hypertension complications, but fewer (43%) felt uncomfortable in avoiding opioids for pain relief. Generally, liver health professionals (20-30%) were less likely to refer LT-eligible patients to SPC service than SPC clinicians (75-85%) would in a similar situation (31). This may be explained by the lack of understanding by liver health professionals about what role SPC can play in caring for LT patients (31) and the lack of clear criteria available for referring LT patients to SPC (33). Other reasons for liver health professionals not referring to SPC included their concern that patients may feel abandoned if referred to SPC services (32) and difficulty of prognosticating the end of life (33). Discipline and professional status may also be a factor in determining referral to SPC, with attendings/medical consultants (38%) less likely than nurses (79%) or PGY1/medical trainees (91%) to consult SPC if patient was on LT waiting list (33).

### **Advance care planning (ACP) with patients on the LT waiting list**

One qualitative (34), two quantitative (21, 35) and one quasi-experimental (29) study contributed to the theme of ACP with patients on the LT waiting list (Table 4). These studies highlighted that although patients report that they are ready to engage in the process of ACP (34, 35), there is little evidence of this taking place with one study showing that 9% of these patients reported completing an ACP prior to their LT evaluation, and only 10% reporting having a Durable Power of Attorney written in their medical notes (35). Patient participants remember receiving information about the risk of death whilst they were on the LT waiting list but were not aware of receiving information about making a decision about a Goals of Care Designation i.e. having their wishes about their choice of future care written in their medical notes, if they were taken off the list (34). Participants reported that they lacked understanding of the role of ACP processes and were unsure about the differences between legal wills, Personal Directives and Goals of Care Designation (34). They felt that the language on Goals of Care Designation was too complex to understand and wanted the explanations used to be made in a step-wise manner consistent with their stage of illness (34). Participants felt that ACP/Goals of Care Designation conversations should happen outside of hospital, not during periods of acute illness, and that ACP/Goals of Care Designation video resources should be customised specifically for those with cirrhosis (34). These findings are reflected in another study which showed that patients on the LT waiting list were less likely to have timely discussion about goals of discussion on ICU admission (31% vs 53%) or have their decisions about withholding/withdrawing life-sustaining treatment documented (28% vs 43%) when compared to those not on the LT waiting list (21). There are no specific ACP-based interventions for this population, but a quasi-experimental study suggested that patients receiving counselling about healthcare powers of attorney, were more likely to have an advance directive documented in medical notes (29).

## DISCUSSION

This review explored the impact of SPC input in providing palliative support to patients on the LT waiting list from the perspectives of both patients, and liver and SPC health professionals, the issues in providing this type of care with the aim of improving it and use of ACP for patients on the LT waiting list. Although there are some clinical reviews in this area (27, 36), as far as we are aware, this is the first international systematic review to focus specifically in this area. Systematic reviews are important in looking at specific evidence for the population concerned (in this case people on the LT waiting list). They can establish what the evidence base is for a care service and, the best way if required of moving the research forward to help inform better practice.

Our findings showed that liver HCPs recognise that SPC can play an important role in End of Life Care for people on the LT waiting list, particularly in managing their symptoms and engaging in ACP and Goals of Care discussions at an earlier stage. Liver health professionals have a limited understanding of the SPC role with many liver health professionals viewing the goals of transplantation and palliative care as contradictory to each other. Liver health professionals were unclear about referral to SPC for people on the LT waiting list. Patients' understanding of the processes of ACP and Goals of Care Designation were poor, reflected by poor completion of ACP. This finding about ACP goes contrary to findings from a recent on-line survey with post-LT recipients, which suggest both a high completion rate for ACP while on the LT waiting list and a willingness of these patients to think about end of life issues, although there was greater reluctance amongst these patients to discuss end of life issues prior to transplantation (37). However, this study was methodologically limited by both its small sample size and poor response rate from a single centre site, and further work needs to explore the delivery of ACP for people on the LT waiting list. It was not possible to assess if people on LT waiting lists received adequate palliative care support, though the limited evidence suggests that early involvement of SPC for this group is deliverable and has the potential to improve symptom burden and psychological morbidity. Limited evidence

suggest that people on the LT waiting list often receive SPC input in the last days of life and were less likely to be referred to SPC than a person not on the LT waiting list.

This review suggests that whilst liver health professionals appeared comfortable with allowing SPC to support patients with symptom management and discussing ACP and Goals of Care, they were unclear about how to refer to SPC or about the other roles that SPC could play in managing patients with ESLD. Despite this uncertainty, these findings provide some indication of liver health professionals' acceptance of providing palliative care for patients requiring active treatment. These findings focus specifically on barriers to implementing SPC in people on the LT list and not on facilitators to improving SPC access. However, several recommendations could be considered as first steps to improve practice in this area. There should be greater opportunities for joint working between SPC and liver health professionals caring for patients on the LT waiting list. This would potentially enable health professionals from both disciplines to explore how SPC could be introduced to this group at an earlier stage. Joint working could also support both liver and SPC health professionals to establish clear referral criteria for people on the LT waiting list, which would help liver health professionals to be more aware of situations when it is appropriate to refer to SPC. Such explorations would be useful in developing shared care models, which may enable better symptom management and earlier discussion of ACPs, Goal of Care and Goals of Care Designation. It may provide liver health professionals with more confidence that SPC can reduce symptom burden to liver patients. Patients' understanding of their disease and the processes involved in ACP was poor. This suggests that greater patient involvement is required to develop appropriate material using language that is more user-friendly. Such moves would be a first step towards ensuring that information about the process of ACPs/Goal of Care/Goals of Care Designation is more user-friendly and understandable, which in turn would potentially support patients in making future plans for their own care.

All included studies were published after 2015, suggesting this is a fairly new area of research interest. Using the Hawker scoring system (28), most studies were judged to be of mixed quality, ranging from fair to good. The identified quantitative studies were either surveys or case-note reviews. The quality of data available were limited. In the one included qualitative study looking at patient perspectives, we could only use data that came from three participants on the LT waiting list. The methodological limitations of these studies limits the conclusions that can be drawn from the findings. The scope of the review presented in this paper had an international focus, but all identified studies came from North America, mainly from USA. This potentially limits the applicability of the review findings to other settings with different health care systems, as the perception, communication, culture and access to health care may be different in other countries. Our findings, predominantly from studies using survey methodology, have illustrated that liver professionals are worried that patients may feel abandoned if they are referred to SPC. However, this type of data is limited as it only allows participants to give fixed responses and does not allow patients to give a richer and more expansive perspective of their experience. There has been only one intervention study conducted in this population (29) as a pre-post study design (not an RCT) which limits the scope of the review to primarily descriptive/observational analyses. To date, there has been no definitive trial evidence on effectiveness of the provision of SPC or good quality qualitative studies exploring how different stakeholders (health professionals, patients and family members) perceive there to be barriers to accessing these services or suggesting ways in which these services can improve.

This review was undertaken because of an awareness of the high symptom burden experienced by people on LT waiting lists and the potential benefits of palliative care support. We were unable to adequately answer our review questions because of a dearth of relevant studies. The main finding from this review is a call to action to improve the state of the science in palliative care research in hepatology in general, and in particular, to improve the quality of future studies for patients on the LT waiting list. As current research is very limited, research could follow several directions. More studies are needed

taking a greater perspective of patients on the LT waiting list, using in-depth qualitative methods as a way of exploring their perspectives about what their unmet needs are, their understanding of supportive and palliative care and to see if they share the same anxieties as liver professionals about the involvement of SPC. Qualitative studies are also needed to explore what barriers may exist for liver health professionals in referring their LT patients to SPC. One potential barrier may be the belief that patients on the LT waiting list should be full code (ie. for full cardio-pulmonary resuscitation). At the same time, there is a dearth of clinical trials looking at the effectiveness of SPC interventions in people on the LT waiting list. There is a research culture not recognizing the need to assess this patient group, as demonstrated by a high-profile US study (PCORI) currently being conducted in this field that specifically excludes people on the LT waiting lists from receiving SPC interventions (38). These trials play an important role in determining the effectiveness of SPC interventions in improving patient outcomes, but to ensure that these interventions are fit for purpose and are sensitive to the needs of the patient groups concerned, further development work using qualitative methods is needed to improve quality of delivery of supportive and palliative care. It is important to understand the perspectives of both health professionals and patients in this area, in particular looking at what can facilitate the delivery of SPC from people on the LT list. Once appropriate SPC re interventions for people on the LT list have been designed from developmental work, more prospective studies need to be conducted to test their effectiveness in improving appropriate patient outcomes.

Very little is understood about either the lived experiences of both patients and liver and SPC professionals in this area, and different types of qualitative methodology may be needed to explore these phenomena, and identifying the barriers for these HCPs in delivering ACP and how care can be reconfigured to address these barriers. One particular methodology, ethnography, is particularly a novel way of exploring this. It has previously been used in people on the LT waiting list, to explore the uncertainties of waiting for a suitable donor liver (39). Further studies are required using this



methodology, to fully understand the experience of these patients and the potential role of SPC in this situation, and the cultural context in which care is delivered to people waiting for a liver transplantation.

Co-production studies are needed, utilising appropriate qualitative methods and recruiting the different stakeholders involved in delivering and receiving this care, namely the patients and their close family, and HCPs from the relevant specialities such as SPC, hepatology and primary care. These co-production studies would aim to identify and develop the components of the intervention to ensure that all stakeholders are comfortable with the sensitivity and practical elements of the intervention. Once these are in place and provided these interventions have undergone successful pilot work, appropriate methodologies such as a randomised control trial can be used to evaluate the impact of the intervention, specifically targeting the selective recruitment of patients on the LT waiting list. This type of approach is useful in exploring how ACP can be delivered to people on the LT waiting list, where there is an assumption that ACP is a good idea, but our findings studies suggest that they are difficult to implement. Larger multi-centred studies are needed to determine baseline completion rates of ACP amongst patients on the LT waiting list, which will help monitor the effectiveness of initiatives aimed at improving ACP completion.

## ABBREVIATIONS

ACP	Advance Care Planning
ESLD	End stage liver disease
LT	Liver transplant
MELD	Model of End-Stage Liver disease
SPC	Specialist Palliative Care

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Figures and tables

Figure 1 - The review process

Table 1 - Assessment of study quality using Hawker et al (2002) scoring – summary of scores.

Table 2 – Palliative care support for patients on the LT waiting list

Table 3 - Perspectives and attitudes of healthcare professionals about providing palliative care support for patients on LT waiting list

Table 4: ACP discussions with LT candidates

Appendix I - Search Strategy:

Appendix II - Assessment of study quality using Hawker et al (2002) scoring –detailed description



Table 1 – Assessment of study quality using Hawker et al (1995) scoring – summary of scores.

Source paper	Title of paper	Abstract and title	Introduction and aims	Methods and data	Sampling	Data analysis	Ethics and bias	Findings /results	Transferability/generalizability	Implications and usefulness	Scoring
Walling et al 2013 (21)	Impact of consideration of transplantation on End-of-Life care for patients during terminal hospitalisation	4. Good	3. Fair	4. Good	3. Fair	4. Good	2. Poor	4. Good	3. Fair	3. Fair	30/36
Baumann et al (2015) (29)	Benefit of early palliative care intervention in ESLD patients awaiting liver transplantation.	3. Fair.	4. Good.	3. Fair.	3. Fair.	2. Poor.	1. Very poor.	3. Fair.	3. Fair.	3. Fair.	25/36
Ufere et al (2020) (30)	Health care utilization and end-of- life care outcomes for patients with decompensated liver cirrhosis based on transplant candidacy	4. Good	4. Good	4. Good	3. Fair	4. Good	3. Fair	3. Fair	3. Fair	3. Fair	30/36
Esteban et al (2019) (31)	Attitudes of liver and palliative care clinicians towards specialist palliative care consultation for patients with ESLD	3. Fair.	3. Fair.	4. Good.	4. Good.	4. Good.	2. Poor.	3. Fair.	3. Fair.	3. Fair.	29/36
Ufere et al (2019) (32)	Physicians' perspectives on palliative care for patients with ESLD: A national survey.	4. Good.	4. Good.	4. Good.	4. Good.	4. Good.	3. Fair.	4. Good	3. Fair.	4. Good.	34/36
Beck et al (2016) (33)	Use of palliative care consultation for patients with ESLD: survey of liver transplant service providers.	4. Good.	4. Good.	4. Good.	4. Good.	4. Good.	4. Good	4. Good.	3. Fair.	4. Good.	34/36
Carbonneau et al (2018) (34)	Patient views on advanced care planning in cirrhosis: A qualitative analysis.	3. Fair.	4. Good.	4. Good.	4. Good.).	4. Good.	4. Good.	4. Good.	3. Fair.	3. Fair.	33/36
Wang et al (2020) (35)	Low rates of Advance Care Planning (ACP) Discussions Despite Readiness to Engage in	4. Good.	4. Good	3. Fair.	3. Fair.	3. Fair.	3. Fair	4. Good	3. Fair.	3. Fair.	30/36



**Table 2.** Palliative care support for patients on the LT waiting list

Authors (Year), Country	LT candidate /Total sample in study	Site of recruitment	Demographic details 1) Male (%); 2) Mean age (SD) yrs; 3) Liver diagnosis (%); 4) Liver severity;	Study design	Aims	Intervention	Outcomes	Main Findings
<b>Baumann et al 2015 (29)</b>  <b>USA</b>	50/79  30 assessed at baseline  20 assessed at baseline and 3-6 mth	One LT outpatient centre	1) 56; 2) 59; 3) HCV 46, ARLD 46, NASH 20, Cryptogenic 5, Other 20; 4) Mean MELD: 13 - 15	Quantitative  Quasi-experiential	To assess if EPCI improved patients' symptom burden and depression.	2 outpatient consultations delivered at baseline and 3-6 months with nurse coordinator & SPC physician.  Assessment with CES-D, ESAS and other symptoms, psychosocial wellbeing, spiritual care, care coordination, GOC, HCPOA	Symptoms: ESAS  Depression: CES-D	<ul style="list-style-type: none"> <li>• Patients presented with 5 symptoms at baseline.</li> <li>• Patients with the following symptoms (pruritus, well-being, appetite, anxiety and fatigue) showed a statistically significant reduction in burden for these symptoms following EPCI.</li> <li>• Patients with significant depressive symptoms showed 28% improvement in their mean CES-D scores (p= 0.003) after EPCI.</li> <li>• No increase in use of anti-depressants during the study period.</li> <li>• Patients with high symptom burden showed a 9 point improvement in CES-D scores (p&lt;0.01) after EPCI</li> </ul>

ARLD - Alcohol-related liver disease; CES-D – Center for Epidemiologic Studies Depression Scale; EPCI – Early Palliative Care Intervention; ESAS – Edmonton Symptom Assessment Scale; HCV – Hepatitis C virus; MELD – Model for End stage Liver disease; NASH – Non-Alcoholic Steato-Hepatitis; SPC – Specialist palliative care; N/A – not applicable , LT – liver transplant; LOS – length of stay; SPC – specialist palliative care

<b>Ufere et al 2020 (30)</b>  <b>USA</b>	133/230	9 acute hospitals	1) 66; 2) 58.1 (8.3); 3) ARLD 26, NASH 19, HCV 26, ARLD +HCV 14, other 17; 4) Mean MELD: 18	Quantitative  Chart review	To assess the impact of transplant candidacy on end of life care utilisation in the last year of year	N/A	Utilisation of SPC services: In-patient consultations  Out-patient consultation  Hospice care	<ul style="list-style-type: none"> <li>• 25% of LT patients received an in-patient SPC consultation, usually a median of 10 days before death.</li> <li>• 4.5% of LT patients received an out-patient SPC consultation in the last year of life.</li> <li>• 22% of LT patients were referred to hospice care, with a median LOS of 6 days before death.</li> <li>• LT patients were less likely to be referred to SPC in-patient consultation than non-LT patient. No statistical difference found between LT and LT patients in utilising hospice care or out-patient SPC consultation.</li> </ul>
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ARLD - Alcohol-related liver disease; CES-D – Center for Epidemiologic Studies Depression Scale; EPCI – Early Palliative Care Intervention; ESAS – Edmonton Symptom Assessment Scale; HCV – Hepatitis C virus; MELD – Model for End stage Liver disease; NASH – Non-Alcoholic Steato-Hepatitis; SPC – Specialist palliative care; N/A – not applicable , LT – liver transplant; LOS – length of stay; SPC – specialist palliative care

Table 3: Perspectives and attitudes of healthcare professionals about providing palliative care support for patients on LT waiting list

Authors (Year), Country	Respondents/Total sample invited in the study	Site of recruitment	Demographic details of health care professionals 1. Male (%); 2. Years of experience in hepatology; 3. Primary role (%)	Study design	Aims	Main Findings
<b>Esteban et al 2019 (31)</b> <b>USA</b>	690/9696  Hepatology & LT clinicians (n=311)  SPC clinicians (n= 379)	Members of AASLD and AAHPM	<b>1.</b> Not Reported; <b>2. Years in practice:</b> 0-5 years 26%; 5-10 years, 15%; 10-20 years 20%; > 20 years 37%; <b>3. Hepatology &amp; LT clinicians:</b> Attending/registrar 71%, Advanced Practice Provider 13%. Trainee 4%, Other 1%  <u>SPC clinicians:</u> Attending/registrar 82%, Advanced Practice provider 8%, Trainee 6%, Other 4%.	Quantitative  Cross sectional survey	To assess Hepatology & LT and SPC clinicians' attitudes toward SPC consultation and consultant roles in ESLD patient care.	<ul style="list-style-type: none"> <li>• Hepatology &amp; LT clinicians less likely to refer LT-eligible patients to SPC than SPC clinicians.</li> <li>• Most Hepatology &amp; LT clinicians felt comfortable for SPC consultants to provide the following care to LT eligible patients: psychological and emotional support, and discussion of EOLC preferences and GOC. Most SPC consultants were comfortable in discussing these topics.</li> <li>• Hepatology &amp; LT clinicians were less comfortable for SPC consultants to manage PH complications, manage pain with opioids and discuss prognosis. Most SPC consultants felt comfortable with palliating PH complication, but were less comfortable about avoiding opioids for pain relief.</li> <li>• 30% of Hepatology &amp; LT clinicians deferred SPC consultation due to lack of clarity in SPC role.</li> </ul>

Abbreviations: AAHPM - American Academy of Hospice and Palliative Medicine; AASLD - American Association for the Study of liver Disease; EOLC – End of life care; LT – liver transplant; GOC – Goals of care; PH – portal hypertension; SPC - Specialist Palliative Care

<b>Ufere et al 2019</b>  <b>(32)</b>  <b>USA</b>	392/1236	Members of AASLD membership directory (practicing in the USA)	<b>1.</b> 73; <b>2.</b> <10 years 39%, 10 to 20 years 22%, > 20 years 33%, Missing 2%  <b>3.</b> Transplant hepatologist (60%), General hepatologist (30%), Gastroenterologist (9%), Missing (2%)	Quantitative  Cross sectional survey	To assess physicians' attitudes about SPC for patients with ESLD	<ul style="list-style-type: none"> <li>• 47% physicians disagreed with the statement, "all patients with end stage liver disease, including liver transplant candidates, should receive concurrent SPC".</li> <li>• Many physicians (28%) felt that the goals of LT and SPC were contradictory.</li> <li>• Many physicians (19%) indicated that patients on LT waiting list were ineligible for SPC.</li> <li>• Most physicians (70%) perceived patients and their caregivers would feel abandoned by the liver transplant team if they were referred to SPC.</li> </ul>
Beck et al 2016  <b>(33)</b>  USA	88/200	One academic LT service	<b>1.</b> 22; <b>2.</b> LT experience: <1 year – 11%, 1-3 yr – 15%, 4-5 yr – 13%, >6y – 49%; <b>3.</b> Intensive care Nurses - 53, Post graduate Year 1 interns (PGY1) – 26; Attending physicians/registrar – 21.	Quantitative  Cross sectional survey	To evaluate LT providers' attitudes of perceived barriers to SPC	<ul style="list-style-type: none"> <li>• Attendings/registrars (38%) less likely than nurses (79%) or PGY1 (91%) to consult SPC if patient was on LT list, but were more likely to perceive that SPC was discussed on rounds.</li> <li>• Many HCPs found it difficult to refer to SPC, due to lack of clear criteria for referral and difficulty in prognosticating EoLC in patients.</li> <li>• Most HCPs felt SPC helped improve quality of care and that patients were grateful for SPC input.</li> <li>• Nurses and PGY1 were more likely than attendings/registrars to feel that patients not receiving SPC consultation would have benefitted from one.</li> <li>• Attendings/registrars (93%) were more likely than PGY1 (67%) and nurses (55%) to describe SPC to their patients as EoLC and hospice care (p=0.03)</li> <li>• Attendings/registrars (50%) were least likely to perceive SPC as improving QoL compared to nurses or PGY1 (70-80%).</li> </ul>

Abbreviations: AAHPM - American Academy of Hospice and Palliative Medicine; AASLD - American Association for the Study of liver Disease; EOLC – End of life care; LT – liver transplant; GOC – Goals of care; PH – portal hypertension; SPC - Specialist Palliative Care

Table 4: ACP discussions with LT candidates

Authors (Year), Country	Patients on LT waiting list/Total sample	Site of Participants recruitment	Patient demographic details 1) Male (%); 2) Mean age (SD) yrs; 3) Liver diagnosis (%); 4) Liver severity.	Study design  Data collection method	Aims	Main Findings
Carbonneau et al (2018) (34) Canada	3/17	One university-based cirrhosis care clinic.	1-3) Not Reported; 4) Mean MELD – 15.3.	Qualitative description  Focus group/ interviews  Purposive	To investigate patient experiences and perceptions of advance care planning (ACP).	<ul style="list-style-type: none"> <li>• Participants were ready to engage in ACP and understood the rationale for them.</li> <li>• Participants lacked understanding about disease trajectories and the ACP processes. They were unsure about the differences between legal wills, Personal Directives and GCD.</li> <li>• All participants felt that the language on the GCD form was too complex for them to understand.</li> <li>• Participants had either prepared their PD or had talked about doing one.</li> <li>• All ACP/GCD conversations should happen outside of hospital, and not during periods of acute illness.</li> <li>• Participants received information about risk of death on waiting list, but received little information about considering a GCD decision if they were unable to receive a transplant.</li> </ul>

						<ul style="list-style-type: none"> <li>All participants wanted ACP/GCD video resources to be customising specifically to those with cirrhosis.</li> </ul>
Walling et al (2013) (21) USA	126/496	One academic medical centre	1-4) Not available	Quantitative – retrospective observational	1) To evaluate how consideration of transplantation affects end of life care to patients.	<ul style="list-style-type: none"> <li>Patients on the LT waiting list received less recommended goals of care than those not on the waiting list</li> <li>In particular, patients on the LT waiting list are less likely to have a timely discussion of goals of discussion on ICU admission (31% vs 53%), less likely to have their decisions documented about withholding/withdrawing life-sustaining treatment (28% vs 43%) and less likely to have documented their preference for mechanical ventilation.</li> </ul>
Wang et al (2020) (35) USA	170 (chart review) 41 (survey)	One university LT clinic	Chart review: 1) 65; 2) 58; 3) HCV - 36. Alcohol 26, NASH 17, Cholestatic 3, other 18; 4) MELD – 15  Survey:	Quantitative  Chart review & Cross sectional survey	1) To evaluate current ACP documentation practices in the liver transplant setting.  2) To assess readiness to complete ACP among liver	<ul style="list-style-type: none"> <li>Only 9% of patients reported completing an ACP prior to LT evaluation. None had this information recorded on their medical notes.</li> <li>Durable Power of Attorney was discussed with 10% of LT candidates and recorded in medical notes.</li> <li>Univariate analysis suggested being female and non-Hispanic white was associated with ACP completion.</li> </ul>



			1) 61; 2) 58; 3) HCV – 28. Alcohol NASH 29 Cholestatic 3 Other 18 4) MELD-14.		transplant candidates	<ul style="list-style-type: none"> <li>93% of patients (from survey) reported that they are ready to appoint a surrogate decision maker or ask physicians about medical decision around medical care.</li> <li>85% of patients (from survey) ready to discuss end of life issues. 83% were ready to grant flexibility to decision makers</li> </ul>
Baumann et al (2015) (29)  USA	50/79  30 assessed at baseline  20 assessed at baseline and 3-6 mth	One LT outpatient centre	1) 56; 2) 59; 3) HCV 46, ARLD 46, NASH 20, Cryptogenic 5, Other 20; 4) Mean MELD: 13 -15	Quantitative Quasi-experiential  Data collected on HCPOA and ACP documentation in medical records	To assess whether EPCI improves symptom burden and depression symptoms	<ul style="list-style-type: none"> <li>During the first EPCI intervention, 90% received HCPOA counselling, after which 56% had HCPOA documented in their medical record.</li> <li>17% had documented advance directives on study completion.</li> </ul>

ACP – Advance Care Planning; ARLD - Alcohol-related liver disease; CES-D – Center for Epidemiologic Studies Depression Scale; DPOA - designated durable power of attorney for health care; EPCI – Early Palliative Care Intervention; ESAS – Edmonton Symptom Assessment Scale; GCD - Goal of care designation; HCPOA - healthcare power of attorney; HCV – Hepatitis C virus; LT – liver transplant; MELD – Model for End stage Liver disease; NASH – Non-Alcoholic SteatoHepatitis; PD – Personal directive; SPC – Specialist palliative care