

Patient and Caregiver Perspectives on Palliative Care in End-Stage Liver Disease

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Abstract

Background: Specialty palliative care (PC) is underutilized for patients with end-stage liver disease (ESLD); however, studies exploring patient and caregiver perceptions of PC are lacking.

Objectives: To explore patient and caregiver knowledge, perceptions, and preferences about PC in ESLD management.

Setting/Subjects: Individuals with ESLD and their informal caregivers were recruited from a large academic medical center in the United States.

Design: We conducted semistructured interviews with 15 patients with ESLD and 14 informal caregivers. Purposive sampling was used to balance both transplant-listed and transplant-ineligible patients. We used a brief description of PC to explore participants' knowledge, perceptions, and preferences about PC. Two raters coded interviews independently ($\kappa=0.95$) using template analysis.

Results: Participants' knowledge about PC came primarily from their loved ones' experiences with PC, with many conflating PC with end-of-life care. Transplant-listed patients expressed concern that a PC referral would negatively impact their likelihood of receiving a liver transplant. After hearing a brief description of PC, nearly all participants believed that patients with ESLD should learn about PC soon after diagnosis to help support their illness understanding and coping.

Conclusions: Study participants reported limited knowledge of PC and often perceived it as hospice care. After receiving education on PC, nearly all participants, regardless of transplant eligibility, advocated for early introduction of PC in ESLD care. Interventions are needed to educate patients with ESLD and their caregivers on the potential role of PC to overcome misperceptions of PC and allow earlier integration of PC into ESLD management.

Keywords: caregivers; cirrhosis; palliative care; perceptions; qualitative research

Introduction

DUE TO SYMPTOMS such as hepatic encephalopathy, ascites, and variceal bleeding, patients with end-stage liver disease (ESLD) and their informal caregivers experience substantial physical and psychological symptom burden.^{1–4} Specialty palliative care (PC) has been shown to improve quality of life, symptom burden, and psychological distress in patients with serious illnesses such as advanced cancers and heart failure along with their caregivers.^{5–8} Despite the benefit of PC in other serious illnesses, it remains underutilized for patients with ESLD.^{9–11} Furthermore, when

PC is utilized for patients with ESLD, it is introduced late in the course of a patient's illness, often in the setting of end-of-life care.^{10,12–14}

Prior work has shown that clinicians caring for patients with ESLD believe patients' and caregivers' perceptions of PC are barriers to PC utilization.^{9,15} Specifically, in a cross-sectional survey of U.S.-based gastroenterologists and hepatologists, physicians believed a PC referral would lead to negative emotional reactions in patients with ESLD and their caregivers. Physicians were also concerned that patients with ESLD and their caregivers would associate a PC referral with end-of-life care and abandonment by the

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liver transplant team.¹⁵ However, to date there have been no qualitative studies exploring perceptions of PC directly from the perspectives of patients with ESLD and their caregivers based on patients' status on the liver transplantation waiting list.

In this qualitative study, we interviewed both transplant-listed and transplant-ineligible patients with ESLD and their informal caregivers to explore (1) their perceptions of PC; and (2) perceptions of when PC should be introduced to patients with ESLD.

Materials and Methods

We used qualitative methods described below in accordance with the Consolidated Criteria for Reporting Qualitative Research reporting guidelines.¹⁶ The Partners Institutional Review Board approved this study.

Participants

We recruited adult (age ≥ 18) patients with ESLD, defined as a diagnosis of cirrhosis complicated by ascites, hepatic encephalopathy, and/or esophageal variceal bleeding, who received outpatient hepatology care at the Massachusetts General Hospital.¹⁷ Patients were recruited in the outpatient setting, and convenience and purposive sampling was used to balance both transplant-listed and transplant-ineligible patients to explore perceptions of PC across the transplant spectrum.¹⁸ To examine patient and caregiver perceptions and knowledge of PC, we excluded patients who had received a prior referral to specialty PC or hospice. Additional exclusion criteria were as follows: non-English-speaking, presence of nonhepatic cancer, and the presence of significant medical or psychiatric comorbidity that would preclude ability to provide informed consent. We asked enrolled patients to identify an adult (age ≥ 18) informal caregiver (e.g., a close relative or friend who the patient had in-person contact with at least twice a week) who we invited to participate in the study. Patients without an enrolled caregiver were still eligible to participate. Patient and caregiver participants provided informed consent.

Data collection

Four authors (N.N.U., MD—gastroenterologist, female; J.D., BS—study coordinator, male; L.T., PhD—psychologist, female; and A.E., MD—oncologist, female) all trained in qualitative methods developed patient and caregiver semistructured interview guides that explored participants': (1) experiences since patient was diagnosed with ESLD; (2) transitional care needs; (3) supportive care needs; and (4) perceptions of PC (see Supplementary Appendices SA1 and SA2). The interview guide was informed by a comprehensive review of the literature that describes the palliative and supportive care needs of patients with ESLD as well as our prior work exploring physicians' perspectives on PC for patients with ESLD.^{4,9,15,19–22} The interview guide was pilot tested both internally and via expert assessment.²³ Aspects of the interview that explore participants' transitional care needs are the focus of a separate study. To explore perceptions of PC, participants were asked to define PC in their own words and what thoughts or emotions they had when hearing the term. They were subsequently pro-

vided a standardized definition of PC from the *Center to Advance Palliative Care* (Table 1)²⁴ and asked whether their perceptions of and attitudes about PC changed upon hearing this definition. To explore potential triggers for PC referral for patients with ESLD, participants were asked when the optimal timing would be for patients with ESLD to learn about PC. Enrolled participants were invited to a 30-minute phone interview.

Two authors (N.N.U. and J.D.) conducted the interviews between April 2019 and May 2019. All interviews were conducted by phone to reduce the transportation burden on participants, and all participants were at home at the time of the interview. Patients and caregivers were interviewed separately. Interviews were audio-recorded, transcribed verbatim, and deidentified. Demographic and clinical data were collected from surveys of patients and caregivers and the electronic health record.

Data analysis

We used template analysis, an iterative coding process that allows the flexibility to integrate *a priori* and *a posteriori* codes within the coding structure to analyze the data.²⁵ Two coders (N.N.U. and J.D.) identified several codes *a priori* grounded in the study aims and semistructured interview guide and developed an initial codebook to help guide the analysis. Transcripts were iteratively reviewed and *a priori* codes were refined with additional codes emerging after exploration of the data. Transcripts were coded independently by the two coders using NVivo data analysis software version 12 (QSR International). Coding discrepancies were adjudicated by consensus via three investigators (N.N.U., J.D., and L.T.). Codes were organized into themes and subthemes and transcripts were reviewed multiple times throughout this process to ensure that themes reflected original data. The final kappa ($\kappa = 0.95$) indicated a high level of agreement between coders. At a sample size of 15 patients and 14 caregivers, data redundancy, where no new codes or themes emerged, indicated that thematic saturation was achieved. The final code book is available upon request.

In this article, participant quotes are identified by participant role (P=patient, C=caregiver) followed by their assigned numerical code.

Results

Respondent characteristics

During the study, we approached 20 patients and 17 agreed to participate. Each of the 17 patients identified an informal caregiver, and 14/17 of the caregivers agreed to participate.

TABLE 1. STANDARDIZED DEFINITION OF PALLIATIVE CARE PROVIDED TO PARTICIPANTS¹⁹

Palliative care is specialized medical care for people facing a serious illness that focuses on providing patients with relief from symptoms and stress of a serious illness with the goal of improving quality of life for the patient and the family.
Palliative care is appropriate for patients at any age and at any stage in a serious illness and can be provided along with curative treatment.

Two patients subsequently did not complete the study interview due to worsening health and loss of contact. Among the 15 patients and 14 caregivers who participated in the study, 12 were patient/caregiver dyads. Most patient/caregiver relationships were spousal. Mean interview duration was 27 minutes (range 12–49 minutes).

Participants' demographic and clinical data are depicted in Table 2. Patients were primarily female (10/15, 67%) with a median age of 60 years (range 29–68). Alcohol was the most common etiology (7/15, 47%) of their underlying liver disease and the median MELD-Na (Model for End-Stage Liver Disease-Sodium) score at the time of interview was 14 (range 9–24). Over half (8/15, 53%) of patients were on the liver transplantation waiting list at the time of the interview.

Summary of themes and subthemes

Three main themes emerged from the data. (1) Patients and caregivers commonly had no or limited knowledge of PC; (2) patients and caregivers perceived PC as the end of active medical therapy; and (3) patients and caregivers had a preference for early introduction of PC in ESLD management. A description of each theme and their respective subthemes are as follows.

TABLE 2. PARTICIPANT CHARACTERISTICS

Patient characteristics	n = 15
Age, median [range], years	60 [29–68]
Male, n (%)	5 (33)
Etiology of cirrhosis, n (%)	
Alcohol	7 (47)
NASH	5 (33)
Other	3 (20)
MELD-Na, median [range]	14 [9–24]
Clinical features, n (%)	
Ascites	13 (87)
Hepatic encephalopathy	12 (80)
Esophageal variceal bleed	4 (27)
Listed for liver transplantation, n (%)	8 (53)
Months since diagnosis of ESLD, median [range]	25 [3–122]
Employment status, n (%)	
Employed	2 (13)
Unemployed	2 (13)
Unable to work due to illness	8 (53)
Retired	3 (20)
Caregiver characteristics	n = 14
Age, median [range], years	60.5 [23–69]
Male, n (%)	8 (57)
Relationship with patient, n (%)	
Spouse	12 (86)
Child	1 (7)
Parent/guardian	1 (7)
Employment status, n (%)	
Employed	9 (64)
Unemployed	1 (7)
Retired	3 (21)
Student	1 (7)

ESLD, end-stage liver disease; MELD-Na, model for end-stage liver disease—sodium score; NASH, nonalcoholic steatohepatitis.

Theme 1: Patients and caregivers commonly had no or limited knowledge of PC. Respondents' knowledge of PC was limited. They commonly had no knowledge of PC, stating that they did “not know what the term meant” or that they had “never heard it before” ($n = 11$), with no differences noted between patients and caregivers or between patients based on transplant eligibility.

Respondents rarely received education from physicians on PC. Only two respondents, a patient/caregiver dyad, had ever received education directly from a physician on PC.

Last August [the patient] was in the hospital and he was really, really sick and he was hospitalized and there was a really, really good doctor... And he's the one who talked to us about palliative care. And he said whatever the patient's dreams are to make them happen and to make the person comfortable. So that is the first time I even heard that word. (C1)

Knowledge of PC came primarily from loved ones' experiences. The majority of respondents who reported having some knowledge of PC had a loved one who had received PC in the setting of a serious illness ($n = 9$).

[My daughter] has sarcoma cancer right now. So I know she's in palliative care.... that's the only reason I know what that is. (C16)

Theme 2: Patients and caregivers perceived PC as the end of active medical therapy

PC was often perceived as end-of-life care. When respondents were asked to define PC in their own words, they often described end-of-life care, specifically comfort-focused care ($n = 11$). The majority ($n = 6$) of these respondents had at least one loved one who they believed had received PC during the terminal phase of a serious illness.

[Palliative care means] that you're at the end. And that they'd rather just make you comfortable. They're not going to go to any extremes. That's what I think of palliative care because that's what I saw with both my parents. (P11)

Respondents expressed concerns about loss of active therapy. For transplant-eligible patients and their caregivers, there was a concern that receiving a referral to PC from their physicians would negatively impact their chances of receiving a liver transplant. Specifically, these participants felt that a referral to PC would represent “giving up,” “losing hope,” and the end of receiving active medical care.

One time when I was in a hospital, a doctor explained [palliative care] to me. But maybe I didn't understand it thoroughly. It sounded like if I went down that road, I'd be less likely to get a liver transplant. So I really wasn't much interested in that...it basically would mean to me that they had given up hope. And so that would frustrate me. (P1)

I think [the patient] is kind of afraid that palliative care means that, oh, you're gonna die and they're not going to treat you and all that. (C4)

It's kind of like losing hope and stuff somewhat... [palliative care] would feel like the medical field has given up on me and not going to try to help and improve things. (C7)

Education led to changes in perception of PC. After hearing the definition of PC, respondents' changes in perception of PC focused on clarification of the misconception that PC negatively impacts medical treatment or precludes liver transplantation. Common responses to the definition included terms such as "that's different than I thought of it," and reflected new awareness that PC would "focus on quality of life" or that it could be "provided with curative treatment" (Table 3). We saw no difference in this theme between patients and caregivers or between patients based on transplant eligibility.

Theme 3: Patients and caregivers had a preference for early introduction of PC in ESLD management

Most respondents believed PC should be introduced early in the disease course. After hearing the definition of PC, respondents were asked, "When do you think patients with liver disease should learn about PC?" Most respondents believed patients should learn about PC early, using terms such as "right away" or "as soon as they know" their diagnosis ($n=16$). Among respondents who used these terms, there were no differences in responses based on transplant-eligibility. A few respondents believed that a PC referral should be triggered by a change in a patient's disease course,

such as when their symptoms "progress to a real serious state," or when "quality of life starts to diminish" ($n=6$). All of these respondents were either transplant-listed patients or their caregivers.

Respondents perceived PC as a service to address their supportive care needs. Respondents' rationales for the early introduction of PC were focused on additional support, particularly regarding improving their illness understanding and coping ($n=14$). Similar themes were observed for both patients and caregivers, and no differences were noted between patients based on transplant eligibility.

[Palliative care] probably needs to be brought forward very early...I mean I wasn't aware of how drastic some of the changes were going to be in myself, in me... And I think if you got that information from the front end, say these are things that happen to a lot of people, a lot of people get really depressed, a lot of people have a hard time with attention span...that kind of stuff would be nice to hear early on versus all of a sudden you yourself feeling alone. (P7)

If you know that their MELD score is low and they have a long wait, they should have palliative care so that they can start doing some of the things to boost them, to give them hope. But otherwise it's doom and gloom because their MELD score is low, they're not getting the liver, they are down. (C1)

TABLE 3. CHANGES IN PATIENT AND CAREGIVER PERCEPTIONS OF PALLIATIVE CARE AFTER HEARING A STANDARDIZED DEFINITION OF PALLIATIVE CARE

P1

Before definition: "I feel a little angry because it basically would mean to me that they had given up hope. And so that would frustrate me."

After definition: "Well I don't think I heard the emphasis on curative treatment. In fact, I heard probably just the opposite originally. So that answer doesn't—I mean, what your definition is, it doesn't really bother me that much... A little bit like we were working toward the same goals."

P3

Before definition: "I mean, I don't know what the term is."

After definition: "If I got it, it would feel good... Because it would be another—I don't know how to put it. It's another way of helping me along with it. Hoping they understand what I'm going through, and somebody that actually knows about it. I mean, my kids, they have tried to learn but they still don't—all you ever hear is, how are you feeling, how are you feeling? I just need more understanding. And something like palliative care may teach them to understand what I'm going through more."

P4

Before definition: "What do you mean by palliative care?"

After Definition: "I wish I knew sooner or I wish I knew more... The more I know, "... the more I like it."

P5

Before definition: "Well, that [the term, palliative care] kind of scares me. I mean, it makes me feel like I would be out of control like I'd be—I don't know. I guess, to me that feels like you're kind of losing it. Like you're heading out the exit door, so."

After definition: "So that's not quite hospice level... with liver disease, it's just kind of like it just kind of sits there. And sometimes, it might just pop up to a rather unexpected level, and then it quiets down again.... And if somebody can make my life easier for me like a team of medical doctors, then I'm all for it."

P11

Before definition: "That you're at the end. And that they'd rather just make you comfortable. They're not going to go to any extremes. That's what I think of palliative care because that's what I saw with both my parents."

After definition: "Oh, okay. I didn't realize that you can get it with a curative treatment. I thought this was it, you know?"

C11

Before definition: "It's kind of like it's giving up and it's the end of things and stuff like that. It's kind of like losing hope and stuff somewhat."

After definition: "It gives a little more hope if it's included with still trying to find either a cure or a way to extend life and make it better."

P14:

Before definition: "I have not [heard of palliative care]."

After definition: "A little bit more comfortable. Because I mean, unless I'm understanding it incorrectly again, I mean, your terminology is basically more of the support systems and how you aid patients that have a serious illness as opposed to just basically assuming that they're destined for death."

Discussion

In this study, patients with ESLD and their caregivers reported having minimal knowledge of PC, with personal experiences, mostly limited to end-of-life care for loved ones with terminal illnesses, often guiding their perception. In turn, most participants perceived PC as equivalent to hospice care. After participants were given a standardized definition of PC, the majority were more open to PC after learning that PC focuses on improving quality of life and could be provided along with curative treatment. Nearly all respondents believed that PC should be integrated into the care of patients with ESLD early in their disease course to support them as they cope with their illness. Our findings underscore the gap in knowledge of PC among patients with ESLD and their caregivers, and the need for simple education regarding PC to overcome misperceptions of PC among this population.

Consistent with studies of patients with other serious illnesses and their caregivers, respondents' knowledge of PC was generally lacking and many conflated PC with end-of-life care.^{26–28} Over one-third of the participants had no knowledge of PC, and of those who were familiar with PC, the majority associated PC with comfort care or hospice care. These findings corroborate prior work showing that an important barrier to physicians referring patients with ESLD to specialty PC is the concern that patients believe that PC is for the imminently dying.^{9,15} Notably, only two respondents had received direct education on PC from a physician, corroborating findings from prior studies that PC is underutilized for this population despite their high symptom burden and poor prognosis.^{9–14}

Our findings suggest that a basic description of PC given to patients with ESLD and their caregivers could clarify misperceptions of PC, particularly for transplant-eligible patients and their caregivers. Before hearing a definition of PC, patients listed for liver transplantation expressed concern about how PC could affect their listing status. Upon hearing the PC definition, both patients and caregivers expressed relief that PC could address their quality of life without affecting transplant eligibility or their active medical care. Notably, after hearing a brief definition of PC, nearly all respondents believed that patients with ESLD should learn about PC early in their disease trajectory to augment their illness understanding and coping. These findings suggest that simple education for patients with ESLD and their caregivers can overcome misperceptions of PC that have been recognized barriers to its utilization in this population and should reduce clinicians' reluctance to introduce PC to this population.

Although findings from this study suggest that early education for patients and caregivers on PC could make them receptive to a referral to PC services, such education may not occur if physicians themselves are reluctant to provide it. In a national survey study of hepatologists, the majority of respondents believed that patients would feel abandoned by the liver transplant team if they were referred to PC.¹⁵ Notably, while almost all hepatologists in that study indicated that they would use PC services for patients who were ineligible for liver transplantation, less than half indicated they would refer patients who were active on the liver transplantation waiting list. If physicians are unwilling to introduce PC to patients with ESLD listed for liver transplantation, it may remain a

service only provided to patients once they are deemed transplant-ineligible. Therefore, despite the various dimensions of care that PC could provide for patients on the transplant list, it may remain for them a service limited to end-of-life care.

Our work does have several limitations. All participants were recruited from a single academic center, with most participants identifying as white; different themes regarding perceptions of PC may have been obtained in more culturally diverse populations. Our sample size was limited; however, we had a sufficient number of participants to be able to achieve thematic saturation. Lastly, most of the patient and caregiver dyads were spousal relationships, and therefore, results may have differed if the patient/caregiver relationship were different or if the majority of patients did not have an identified caregiver.

Conclusion

To conclude, in the sample of patients with ESLD and their caregivers, many participants reported limited knowledge of PC, with many perceiving PC as hospice care. Notably, transplant-eligible patients with ESLD associated PC with the end of active medical care. After receiving education on PC, all participants believed that PC could help to support their illness understanding and coping. Further research is needed to develop scalable interventions to improve patient and caregiver education on PC to overcome misperceptions of PC in the ESLD population and allow earlier integration of PC into ESLD management.

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Authors' Contributions

Each author approved the final submitted draft of this article. Study concept and design: J.D., N.N.U., L.T., and A.E.-J. Analysis and interpretation of data: J.D., N.N.U., L.T., and A.E.-J. Drafting of the article: J.D. and N.N.U. Critical revision of the article for important intellectual content: J.D., N.N.U., T.I., V.J., R.T.C., L.T., and A.E.-J.

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Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Appendix SA1
Supplementary Appendix SA2

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