Received: 25 October 2021 | Accepted: 17 February 2022

DOI: 10.1002/hep4.1939

ORIGINAL ARTICLE

# Palliative care experience and perceived gaps in training among transplant hepatology fellows: A national survey

**Maureen P. Whitsett**[1] | **Nneka N. Ufere**[2] | **Arpan Patel**[3,4] | **Judy A. Shea**[5] | **Christopher A. Jones**[6] | **Oren K. Fix**[7] | **Marina Serper**[8,9,10]

[1]Division of Gastroenterology and Hepatology, Cleveland Clinic, Cleveland, Ohio, USA

[2]Liver Center, Gastrointestinal Unit, Massachusetts General Hospital, Boston, Massachusetts, USA

[3]Vatche and Tamar Manoukian Division of Digestive Diseases, Department of Medicine, David Geffen School of Medicine at UCLA, Los Angeles, California, USA

[4]Veterans Affairs Greater Los Angeles Healthcare System, Los Angeles, California, USA

[5]Division of General Internal Medicine, Department of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania, USA

[6]Department of Internal Medicine, Duke University School of Medicine, Durham, North Carolina, USA

[7]Division of Gastroenterology and Hepatology, University of North Carolina, Chapel Hill, North Carolina, USA

[8]Division of Gastroenterology and Hepatology, University of Pennsylvania Perelman School of Medicine, Philadelphia, Pennsylvania, USA

[9]Corporal Michael J. Crescenz VA Medical Center, Philadelphia, Pennsylvania, USA

[10]Leonard Davis Institute, University of Pennsylvania Perelman School of Medicine, Philadelphia, Pennsylvania, USA

**Correspondence**
Marina Serper, Division of Gastroenterology and Hepatology, University of Pennsylvania Perelman School of Medicine, 3400 Spruce St, Dulles Building 2nd floor, 19104, Philadelphia, PA USA.
Email: marinas2@pennmedicine.upenn.edu

**Funding information**
National Institute of Diabetes and Digestive and Kidney Diseases: Grant/Award No. K23DK115897

## Abstract

Despite the likely benefits of palliative care (PC) for patients with cirrhosis, physician experiences and perspectives about best practices are variable. We aimed to assess PC experience and gaps in training among transplant hepatology fellows. We conducted a national survey of all transplant hepatology fellows enrolled in accredited fellowship programs during the 2020–2021 academic year. We assessed the frequency of PC provision and comfort with physical and psychological symptom management, psychosocial care, communication skills, advance care planning, and end-of-life care. A total of 45 of 56 (79%) of transplant hepatology fellows responded to the survey; 50% (n = 22) were female. Most trained at centers performing over 100 transplants per year (67%, n = 29) distributed evenly across geographic regions. Most fellows (69%, n = 31) had a PC or hospice care rotation during residency, and 42% (n = 19) of fellows received education in PC during transplant hepatology fellowship. Fellows reported feeling moderately to very comfortable with communication skills such as breaking bad news (93%, n = 41) and leading family meetings (75%, n = 33), but nearly one-third (30%, n = 13) reported feeling not very or not at all comfortable assessing and managing anxiety and depression (30%, n = 13) and spiritual distress (34%, n = 15). Nearly

**Abbreviations:** ACGME, Accreditation Counsel for Graduate Medical Education; EoL, end of life; GI, gastroenterology; GoC, goals of care; LT, liver transplantation; OSCE, objective structured clinical examination; PC, palliative care; QoL, quality of life.

one-quarter (22%, n = 10) had never discussed or documented advance care plans during fellowship. Fellows wished to receive future instruction on the assessment and management of physical symptoms (68%, n = 30) and anxiety and depression (64%, n = 28). *Conclusion:* Our survey highlights gaps in PC experience and education during transplant hepatology fellowship, lack of comfort in managing psychological distress and advance care planning, and desire to improve skills, particularly in symptom management. Future studies should investigate how to enhance transplant hepatology competencies in these PC domains and whether this impacts clinical care, advance care planning, or patient experience.

## INTRODUCTION

The increasing prevalence of decompensated cirrhosis in the United States has led to a substantial societal burden affecting patients, caregivers, providers, and health systems.[1] When compared to patients with other serious illnesses such as congestive heart failure and chronic obstructive pulmonary disease, patients with cirrhosis experience longer hospital length of stays and higher rates of readmissions.[2] Despite this frequent exposure to health care, patients and caregivers often have palliative needs that remain unaddressed. Patients with decompensated cirrhosis frequently report pain, insomnia, fatigue, depression, and anxiety.[3,4] Caregivers report a high level of emotional distress and impaired quality of life (QoL) as a result of the psychosocial burden incurred when caring for those with cirrhosis.[5]

Palliative care (PC) is a model of care delivery centered on the alleviation of physical, emotional, and spiritual suffering, which can improve patient QoL, clarify wishes and goals of care (GoC), and provide support to caregivers and family members.[6] Nephrology and pediatrics specialties have incorporated PC training into their curricula or have adapted existing PC educational tools to their disciplines.[7,8] Other specialties, such as cardiology, surgery and hematology oncology, have recognized the importance of education in primary PC provision through guidance statements released by professional organizations.[7–12] In national surveys of trainees in oncology, cardiology, surgery, and obstetrics and gynecology, most trainees understand the value and importance of PC but few have received formalized PC instruction.[13–17]

There is a growing recognition of the need for PC-specific education within the field of gastroenterology (GI) and hepatology.[18,19] In a descriptive study of GI fellows' performances during a liver-specific, objective structured clinical examination (OSCE), fellows failed to discuss important aspects of end-of-life (EoL) care during the encounter, and over two-thirds of fellows felt that they performed poorly.[20] Attitudes or comfort with providing PC among hepatology trainees are unknown, and to date, there is no formalized PC curriculum during hepatology training.[21] Our study objectives were to understand transplant hepatology fellows' prior educational and clinical experiences with PC, perceived level of comfort with PC provision, and perceived needs for future training.

## METHODS

### Study design

This was a national survey of U.S. transplant hepatology fellows conducted from April to May 2021. The institutional review board at the University of Pennsylvania approved the study with a waiver of consent, because responses were anonymized.

### Survey development

The survey was adapted from several published instruments and designed to reflect the domains of PC provision in the National Consensus Guidelines for Palliative Care, which are applicable to the practice of hepatology and transplant hepatology. These domains include the physical, psychological, social, cultural, and religious/spiritual aspects of care in addition to ethical and legal considerations and EoL or hospice care.[15,22,23] The initial content and structure were iteratively developed after discussion with two medical education experts (J.S., O..F), one PC expert (C.J.), and two hepatologists with PC expertise (N.N.U., A.P.). The survey was then pilot-tested among six practicing transplant hepatologists who provided critical insight and suggestions for refinement. The final survey (see Supporting Information) consisted of three initial screening questions along with additional questions that assessed fellows' prior educational experience with PC, frequency of provision of various aspects of PC-related care, experience with formal observation during transplant hepatology fellowship, comfort with PC provision in the clinical setting and symptom management, and desire for future training. Final questions included demographics,

training program characteristics, and questions about PC services offered at the training program.

## Participants

Participants were third-year GI fellows enrolled in a dual GI/transplant hepatology training program and transplant hepatology fellows enrolled in an Accreditation Counsel for Graduate Medical Education (ACGME) program for the 2020–2021 academic year in the United States. Program directors' and program coordinators' contact information were obtained through a list of 52 active transplant hepatology fellowship programs found on the American Association for the Study of Liver Disease (AASLD) and ACGME websites. Participant email addresses were obtained via contact from program director and program coordinators, the AASLD member directory, or via searched on public platforms such as Twitter and training program websites. Fellows were individually sent survey invitations via email with an embedded link, and two follow-up emails were sent in the event of no response.

## Statistical analysis

Descriptive statistics were calculated for all variables. Distributions of responses to each survey item were evaluated visually. Bivariate comparisons were conducted with Fisher's exact test. To provide a visual representation of data distribution, violin plots were created for two questions: one regarding desire for more training and level of comfort treating various symptoms (Supporting Information). Analyses were performed with Stata 15.1 (StataCorp, College Station, TX).

# RESULTS

## Respondent characteristics and prior training

The survey was distributed to 56 fellows from 52 U.S. ACGME-accredited programs with 44 of 56 (79%) response rate. Table 1 provides respondent characteristics and information regarding prior training. Half of the respondents were women (50%, n = 22) and over half of fellows trained at centers that performed over 100 liver transplants (LTs) yearly (67%, n = 29).

Nearly all fellows (91%, n = 40) had inpatient specialty PC services (e.g., PC primary service, inpatient hospice, PC social worker) available at their training institution, and only 14% (n = 6) reported having multidisciplinary inpatient rounds with PC in the inpatient setting. Sixty-nine percent of fellows (n = 31) reported participation in a PC or hospice care rotation during residency. Only one fellow (2%) reported having a PC rotation during transplant hepatology fellowship, and four fellows (9%) reported having a PC rotation during GI fellowship.

**TABLE 1** Respondent characteristics (n = 45) and prior training

| | N (%) |
|---|---|
| TH fellow | 41 (91%) |
| Third-year GI fellow combined program | 4 (9%) |
| Female | 22 (50%) |
| *Geographic location* | |
| Northeast | 14 (32%) |
| South | 10 (23%) |
| Midwest | 14 (31%) |
| West | 6 (14%) |
| *LT center volume* | |
| <50 | 4 (9%) |
| 50–99 | 11 (25%) |
| 100–150 | 18 (42%) |
| >150 | 11 (25%) |
| *PC services at training institution* | |
| Inpatient PC services | 40 (91%) |
| Multidisciplinary PC rounds | 6 (14%) |
| Outpatient PC services | 28 (63%) |
| Multidisciplinary grand rounds | 14 (32%) |
| *PC rotation* | |
| Residency | 31 (69%) |
| GI fellowship | 4 (9%) |
| TH fellowship | 1 (2%) |
| *Didactic curriculum* | |
| Lecture by PC specialist | 12 (27%) |
| Independent online learning module | 5 (11%) |
| Standardized patient interaction | 5 (11%) |
| Communication skills workshop | 7 (16%) |
| Other | 4 (9%) |

Abbreviations: GI, gastroenterology; LT, liver transplant; PC, palliative care; TH, transplant hepatology.

## PC experiences and education during transplant hepatology fellowship

Figure 1 shows the percentages of respondents who selected different frequencies (never, 1–2 times, 3–5 times, > 5 times) for performing certain PC-related tasks. Over 75% of fellows reported having done any of the listed tasks at least once during their fellowship training. More than half of fellows reported performing the following practices more than 5 times during their training year: discussing poor prognosis with patients (80%, n = 36), assessing patients' level of health literacy (62%, n = 28), and assessing decisional capacity

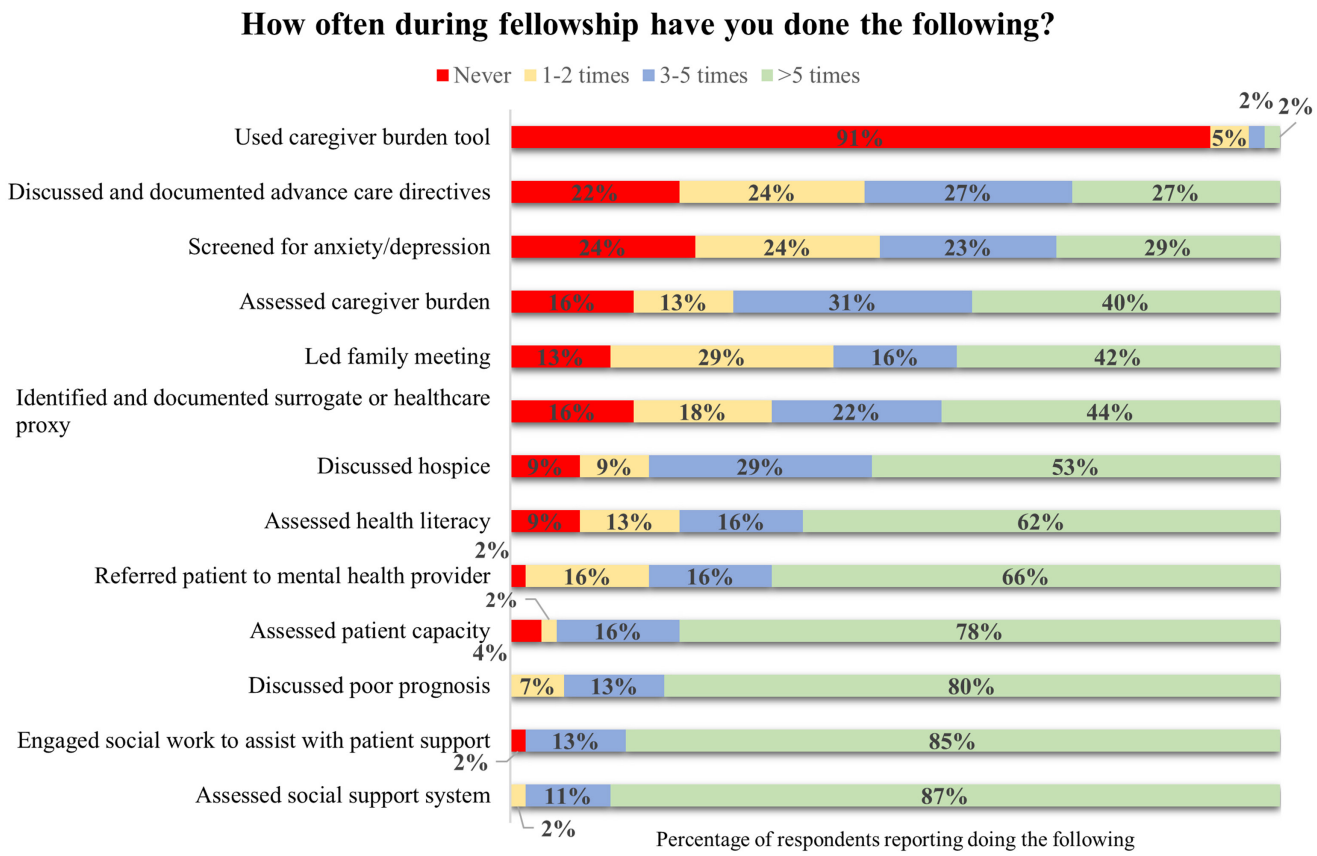


**FIGURE 1** Frequency of palliative care provision during hepatology fellowship

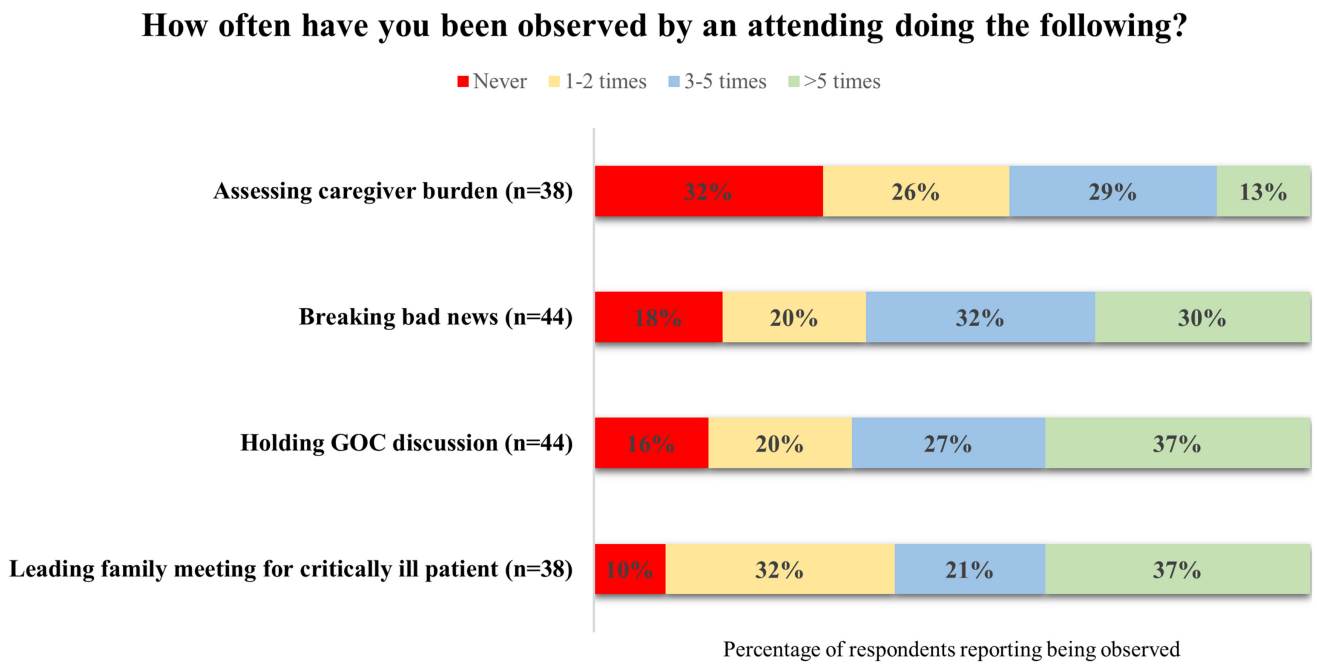


**FIGURE 2** Frequency of observed clinical encounters during hepatology fellowship. GoC, goals of care

(78%, n = 35). The frequency of fellows' responses was more evenly distributed in screening patients for anxiety and/or depression (24%, never; 24%, 1–2 times; 23%, 3–5 times; 29%, > 5 times) and documenting and discussing advanced care directives (22%, never; 24%, 1–2 times; 27%, 3–5 times; and 27%, > 5 times).

Figure 2 shows the percentages of respondents who reported being observed at different frequencies by an attending (never, 1–2 times, 3–5 times, > 5 times) while delivering PC to patients. With respect to observed experiences for PC education, 58% (n = 22) of fellows reported being observed by an attending leading a family meeting for a critically ill patient. Similarly, 66% (n = 28) of fellows have held GoC discussion with an attending present, and 62% (n = 27) of fellows have broken bad news to a patient while being supervised. During their transplant hepatology fellowship training year, 42% of fellows (n = 19) received some form of PC education, such as lectures by a PC specialist or via online learning modules (Table 1).

## Self-reported comfort with providing PC during transplant hepatology fellowship

Most fellows reported feeling moderately to very comfortable having difficult discussions with patients in the following domains (Figure 3): breaking bad news (93%, n = 41), discussing poor prognosis with patient wait-listed for LT (73%, n = 32) and not wait-listed for LT (89%, n = 39), leading a family meeting (75%, n = 33), discussing hospice (77%, n = 34), or recommending cessation of life-sustaining or aggressive medical care (64%, n = 28). Nearly one third of fellows reported feeling not at all or not comfortable assessing and managing anxiety and/or depression (30%, n = 13), and 34% of fellows (n = 15) reported being not at all comfortable assessing or managing spiritual distress. Although 57% (n = 25) expressed feeling moderately to very comfortable treating pain, more than half were somewhat or not at all comfortable managing insomnia (54%, n = 24), depression (61%, n = 27), anorexia (64%, n = 18), breathlessness (63%, n = 28), anxiety (66%, n = 29), and fatigue (77%, n = 34).

## Desire for further PC training during transplant hepatology fellowship

Greater than half of fellows agreed or strongly agreed that they wished they had more training on the assessment of pain and other symptoms (Figure 4) (68%,

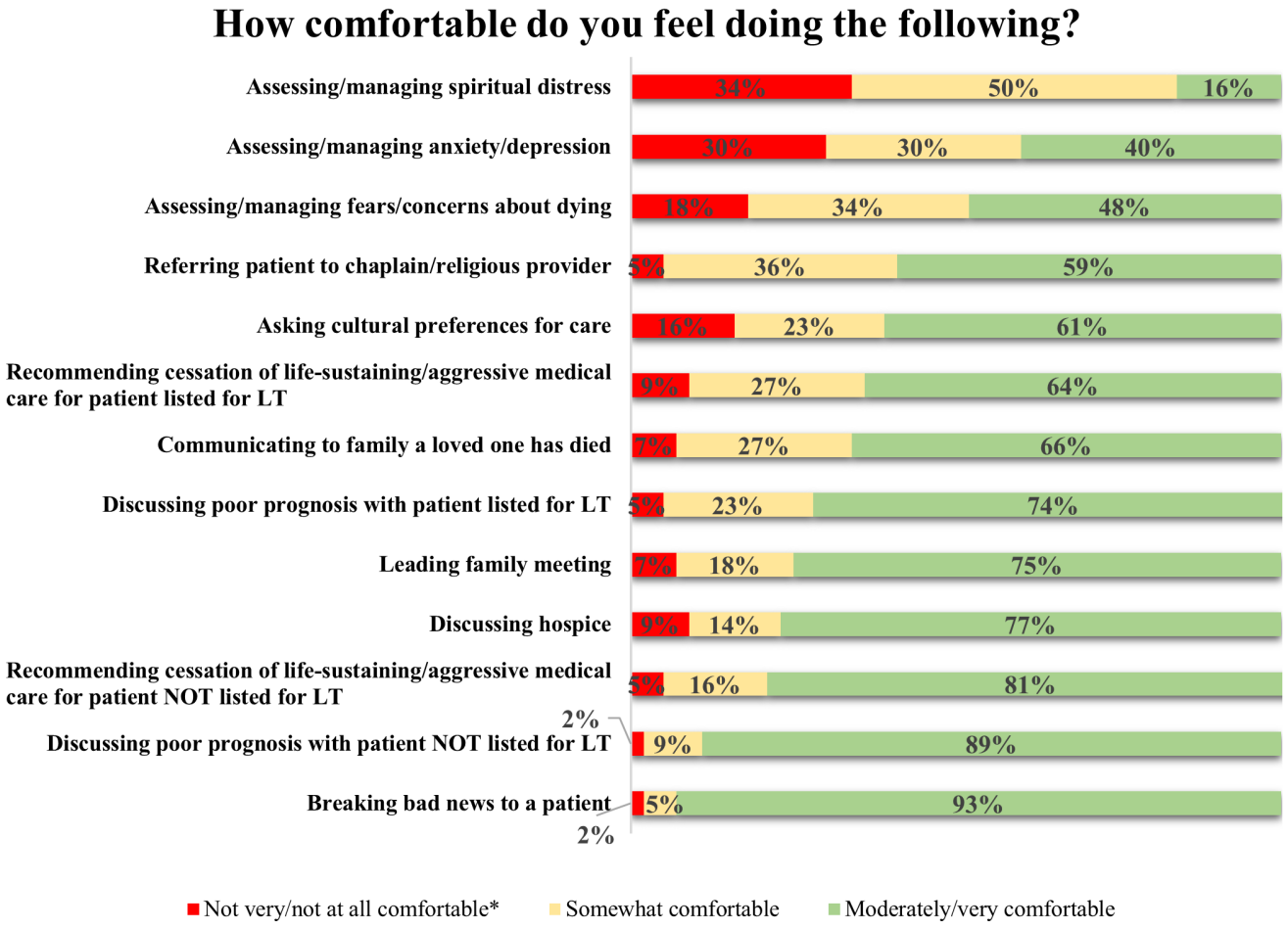


**FIGURE 3** Hepatology fellows' perceived comfort levels with palliative care provision. LT, liver transplantation

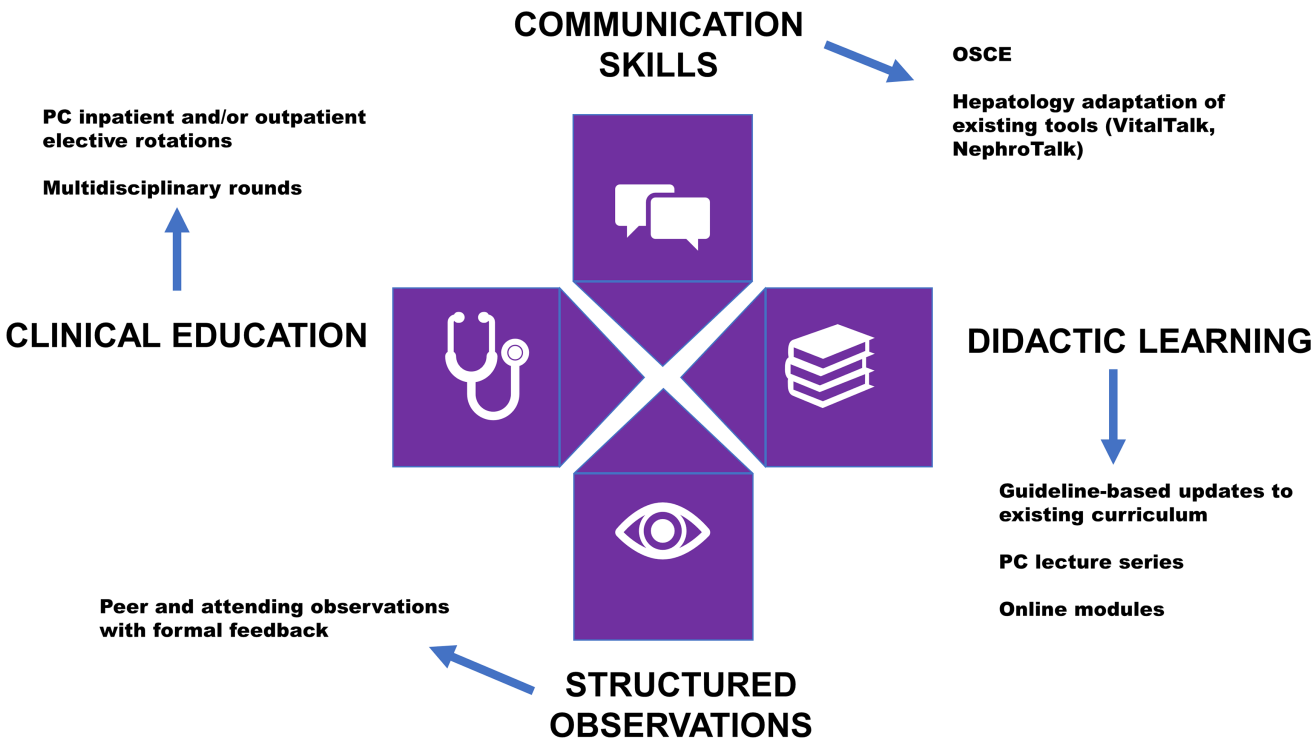


**FIGURE 4** Proposed educational framework for palliative care instruction. OSCE, objective structured clinical examination

n = 30), anxiety and depression (64%, n = 28), and spiritual suffering (59%, n = 26). Greater than a third (36%, n = 16) agreed or strongly agreed that they wished for further communication skills training in fellowship.

## Differences in comfort levels with PC provision by respondent characteristics

We explored differences in comfort with PC provision by gender (male vs. female), any prior PC educational experience versus none, and LT center volume (< 100 LTs per year vs. 100+ LTs per year), and did not find any statistically significant or meaningful differences in responses by these characteristics (Tables S1–S6).

## DISCUSSION

This national survey assesses prior PC experience, comfort, and desire for future training among transplant hepatology fellows. Although most fellows received general PC education during residency, few had specialty-specific training during advanced fellowships or received formal attending observation while breaking bad news, holding family meetings, or discussing prognosis. Despite the lack of hepatology-specific PC instruction, fellows noted adequate experience with serious illness communication and were frequently engaging in GoC conversations, breaking bad news, and leading family meetings. Fellows reported an overall acceptable degree of comfort with communication skills.

Areas in which fellows expressed discomfort were assessment and management of pain and distressing symptoms such as fatigue and insomnia as well as evaluation and treatment of psychological distress. Nearly 25% of fellows had not screened a single patient for depression or anxiety during their transplant hepatology fellowship, and those who do screen regularly refer patients to mental health providers for further treatment. Given the high physical and psychological symptom burden, disease uncertainty, and poor QoL in advanced liver disease and the inherent challenges in treating symptoms and mental illness in this patient population, these self-identified gaps are concerning and suggest the need to enhance liver disease–specific PC instruction during training.[3] Certainly more complex mental health cases and somatic symptom cases would require input from a specialized professional, but having the knowledge of which therapies and drug classes are safe to prescribe for more straightforward cases of depression, anxiety, or uncontrolled pain could potentially be a useful skill to have. Transplant hepatology fellows recognized training gaps in physical and psychological symptom management and expressed the desire to obtain more PC education in these domains. Future studies could use semistructured interviews to obtain a more in-depth perspective of fellows' perceived deficits and barriers to PC provision during fellowship and independent practice.

Results of our survey are aligned with what has been noted in other fields such as gynecologic oncology, hepatobiliary surgery, and cardiology in that a significant proportion of fellows in our study had prior clinical education in the form of a PC or hospice rotation before their transplant hepatology fellowship.[13,15,16] This prior training experience, which may have included communication skills instruction, may potentially provide some explanation for fellows' high degree of comfort in certain areas of PC provision, such as in breaking bad news or holding family meetings. However, even if internal medicine residency provides a foundational knowledge of the tenets of PC provision, certain aspects of hepatology-related care—including managing prognostic uncertainty for those awaiting LT, the complexity of pharmacologic symptom management in patients with liver dysfunction, and psychological distress and substance use disorders—merit more nuanced, hepatology-specific PC instruction.

Despite not having significant training in communication skills during transplant hepatology fellowship, transplant hepatology fellows report high degrees of comfort with serious illness communication including GoC clarification, discussing poor prognosis, hospice, and de-escalation of disease-focused care. It is certainly possible that fellows expressed increased comfort with GoC discussion due to prior experiences during residency in communication skills training or prior PC rotation experience. Yet, comfort with these aspects of clinical care does not necessarily guarantee that care is delivered in a competent, patient-centered manner. A study by Chaudhary et al. highlighted the discrepancy between confidence and perceived competence of trainees and objective measurements of competence during a GI-specific OSCE examination. After a liver-focused OSCE, fellows tended to perceive their performance more highly, whereas standardized patients felt that less than half of fellows adequately explained and summarized information during an EoL discussion case.[20] Differences between objective skills and confidence is a known challenge in medical education.[24] Respondents noted deficits in elements of advance care planning (ACP) such as a low rate of completion or documentation; this suggests they may have perceived GoC conversations as only those at the end of life, rather than those that can occur throughout a patient's illness trajectory. Recent studies have shown deficits in such communication at transplant centers, and if such a broad definition was applied, trainees may report more discomfort.[25] Ensuring that fellows demonstrate competency in these domains is important and could be feasibly piloted in a standardized hepatology-specific OSCE delivered at the end of a PC rotation or educational lecture series.

The need for earlier PC in advanced liver disease is increasingly recognized. Although practicing hepatologists acknowledge the importance of being able to address patients' physical and psychological symptoms and engage in advance care planning, the burden of PC provision may fall solely onto PC providers.[26,27] Given the known, anticipated shortages in the supply of PC clinicians, greater effort should be placed on building primary PC skills among non-PC clinicians.[28,29] Initial efforts to accomplish this primary PC skill development have been documented. Patel et al. sought to improve rates of advance directive and GoC completion by implementing a multifaceted educational initiative geared toward hepatology providers. Following the intervention, which included regular small group educational sessions regarding the value and importance of ACP and proper documentation of GoC discussions, the rate of ACP documentation rose from 8% to over 30%.[30] To allow for reimbursement for time spent integrating ACP into visits, Medicare released several CPT codes (99497, 99498) for billing purposes, something that could potentially encourage providers to be more active in engaging in ACP discussions.[31] Through the delivery of another PC educational training program, the ongoing multicenter PAL-LIVER study aims to evaluate how receipt of PC training impacts hepatologists' ability to effectively deliver PC-related services.[32] Transplant hepatology fellowship could be leveraged to deliver hepatology-specific PC education, enhance PC training through direct observation and feedback, and learn how to better work with PC clinicians as part of a multidisciplinary team.

Our study has several strengths and limitations. Important strengths include the 79% response rate, diverse demographics, and national representation. With respect to limitations, it was difficult to determine the true denominator of transplant hepatology fellows in training, as some programs had unfilled fellowship spots for that academic year and some programs did not respond to email inquiries for contact information. As with any self-reported survey, there is the potential of recall bias with respect to type and frequency of training and practical experiences. Additionally, fellows more interested in this topic were more likely to respond. We assessed self-reported trainee comfort; however, it is unknown how self-reported comfort correlates with competency. Additionally, it is not known how many times a trainee must perform a certain task before feeling comfortable or competent. This could be further elucidated through future prospective studies. There may be potential lack of clarity with respect to fellows' answers on observed educational interactions. For example, a fellow responding that they have never held a supervised family meeting may mean that this fellow has never held a family meeting at all (not that they lacked supervisor oversight throughout training). Additionally, a fellow reporting a low number of times that they have been supervised may mean that they

had been observed only a few times (< 5) and deemed competent enough to conduct meetings alone without an attending present. Finally, the survey may not have fully captured PC-related education and experiences, given that it was administered 2–3 months before completion of training, although survey administration during training mitigates recall bias.

## FUTURE DIRECTIONS

Although it is not yet a requirement for transplant hepatology training, PC instruction is already being performed, as 40% of hepatology fellows report having had some PC education during training. The development of competency in PC provision may be feasible through the delivery of multifaceted educational initiatives, which could be didactic instruction, clinical education, and communication skills training that includes modeling and skills practice. A proposed multifaceted framework for PC education is shown in Figure 4. A feasible approach to PC education would be through the introduction of a pilot program aimed at improving PC provision competency. Didactic instruction could be delivered by PC specialists through clinically relevant lectures and multidisciplinary conferences. A brief inpatient and outpatient rotation with dedicated PC specialists could provide invaluable clinical experience as well as opportunities for attendings to provide structured feedback to fellows during clinical encounters. This educational experience could culminate in a hepatology-specific OSCE that includes opportunities for fellows to discuss and navigate difficult palliative topics with standardized patient actors. Additional educational interventions could be devised to address fellows' expressed desire for further training in symptom management and mental illness in patients with liver disease. Collaboration with content experts in the field of psychiatry or PC could allow for the creation of a symptom checklist or screening tool that could identify patients in need of further attention for somatic symptoms and/or mental health issues. For those who want to learn more about how to manage these symptoms, an educational tool such as a mobile app could provide safe treatment recommendations based on the input of certain values such as renal function and degree of liver disease.

Given the multiple demands on hepatologists' time, feasible, sustainable, and financially viable strategies to deliver timely and integrated PC care will need to be investigated. Enhanced coordination and communication between hepatologists and PC specialists, and training of advanced practice providers or nurses in PC delivery should be considered. Improving hepatologist training, comfort, and competency in PC principles can foster such collaborations and improve care delivery.

## CONCLUSIONS

Transplant hepatology fellows have a variety of prior PC educational backgrounds, yet they do not uniformly receive formal hepatology-specific PC instruction in their transplant hepatology training year. Although most fellows feel comfortable with their communication skills, there remain deficiencies in comfort levels managing mental health, pain, non-pain symptoms, and spiritual distress. Fellows are open to receiving further training during their transplant hepatology year to further develop their PC skills. We believe the gaps in PC training and the need for PC and EoL education identified in this survey can be used to inform and develop educational opportunities specifically tailored to trainees caring for those with advanced liver disease.

### ACKNOWLEDGMENTS

We would like to thank Dr. Jennifer Kogan for her input on survey design.

### CONFLICT OF INTEREST

Nothing to report.

### ORCID

*Arpan Patel* https://orcid.org/0000-0002-6548-4531
*Oren K. Fix* https://orcid.org/0000-0002-8570-9646
*Marina Serper* https://orcid.org/0000-0003-4899-2160

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## SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

**How to cite this article:** Whitsett MP, Ufere NN, Patel A, Shea JA, Jones CA, Fix OK, et al. Palliative care experience and perceived gaps in training among transplant hepatology fellows: A national survey. Hepatol Commun. 2022;6:1680–1688. doi:10.1002/hep4.1939