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CLINICAL PRACTICE UPDATE

AGA Clinical Practice Update on Palliative Care Management in Cirrhosis: Expert Review

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Care with palliative care principles (aka Palliative Care, PC) is an approach to care that focuses on improving the quality of life of patients and their caregivers who are facing life-limiting illness. It encompasses the assessment and management of symptoms and changes in functional status, the provision of advance care planning and goals of care discussions, prognostication and caregiver support. PC is applicable across the spectrum of cirrhosis regardless of transplant eligibility. Although a common misconception, PC is not synonymous with hospice care. Unfortunately, despite a high symptom burden and challenges with predicting disease course and mounting evidence to support the benefits of PC in patients with cirrhosis, comprehensive PC and referral to hospice are carried out infrequently and very late in the course of disease. In order to meet the needs of our increasingly prevalent cirrhosis population, it is important that all clinicians who care for these patients are able to work together to deliver PC as a standard of care. To date there are limited guidelines/guidance statements to direct clinicians in the area of PC and cirrhosis. Herein we present an evidence-based review of ten Best Practice Advice statements that address key issues pertaining to PC in patients with cirrhosis.

Keywords: Palliative Care; Hospice; Cirrhosis.

Patients with cirrhosis have a life-limiting chronic illness with a median survival ranging from 2 years in decompensated disease to 12 years in compensated disease.[1] Associated with a high burden of physical and psychological symptoms even in the compensated state, the quality of life of patients with worsening disease severity parallels that of patients with advanced cancer.[2,3] Despite this high symptom burden and chance for acute unexpected deteriorations in their disease course, rates of advance care planning (ACP) and goals of care directives remain low, symptom management is suboptimally addressed, and specialty palliative care (PC) and hospice referrals occur infrequently and late in the course of the disease.[4]

In non-cirrhosis populations, there is established evidence that PC is associated with better quality of life for patients, less aggressive treatments at the end of life, lower costs of care, improved communication between healthcare professionals, and better caregiver outcomes.[5]

During the last decade, there has been an increasing recognition of unmet needs for PC for patients with cirrhosis. This has been associated with a recent surge in funding and publications addressing ACP and the impact of PC on symptoms and health-related quality of life.[4,6] To date however, unlike for cancer and other chronic organ failures (lung, cardiac, renal),[7–10] there remain limited guidelines/guidance statements to direct clinicians in the area of PC and cirrhosis.

This expert review was commissioned and approved by the American Gastroenterological Association (AGA) Institute Clinical Practice Updates Committee and the AGA Governing Board to provide timely guidance on a topic of high clinical importance to the AGA membership and underwent internal peer review by the Clinical Practice Updates Committee and external peer review through standard procedures of *Clinical Gastroenterology and Hepatology*. The authors have reviewed and summarized available data pertinent to the provision of PC in patients with cirrhosis to generate specific practice advice (Best Practice Advice [BPA]) addressing key aspects of clinical management.

BPA 1: Care with palliative care principles should be provided to any patient with advanced serious chronic illness or life-limiting illness such as cirrhosis, irrespective of transplant candidacy; this care should be based on needs assessment instead of prognosis alone, delivered concurrently with curative or life-prolonging treatments, and tailored to stage of disease.

Care with palliative care principles (aka palliative care, PC) is an approach to care that focuses on improving the quality of life of patients and their caregivers who are facing life-limiting illness. At a

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Abbreviations used in this paper: **ACP, advance care planning; AGA, American Gastroenterological Association; BPA, Best Practice Advice; MELD, Model for End-Stage Liver Disease; PC, palliative care.**

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Table 1. Best Practice Advice Statements

Target audience	Hepatologists, gastroenterologists, primary care providers, critical care providers, palliative care specialists, hospitalists
Target population	Patients with compensated cirrhosis, patients with decompensated cirrhosis, patients with cirrhosis awaiting liver transplantation
Setting	Gastroenterology/hepatology clinics, primary care clinics, palliative care clinics, hospital wards
Terminology	Palliative care principles: The early identification and management of physical, psychological, social, and spiritual suffering; excellence in communication for advance care planning, goals of care discussions, and prognostication; screening for caregiver fatigue; and providing needed caregiver support. The incorporation of these principles is meant to optimize quality of life for patients and their families and caregivers. Palliative care: The provision of care inclusive of palliative care principles that may be delivered by healthcare providers from any specialty and within any healthcare setting Specialty palliative care: delivery of care by a palliative care specialist with dedicated training and/or board certification in hospice and palliative medicine. Primary palliative care: delivery of care by a clinician who is not a palliative care specialist.
BPA statements	
1	Care with palliative care principles should be provided to any patient with advanced serious chronic illness or life-limiting illness such as cirrhosis, irrespective of transplant candidacy; this care should be based on needs assessment instead of prognosis alone, delivered concurrently with curative or life-prolonging treatments, and tailored to stage of disease.
2	Care inclusive of palliative care principles may be delivered by healthcare providers from any specialty within any healthcare setting.
3	Providers caring for persons with cirrhosis should assess for the presence and severity of symptoms within physical, psychological, social, and spiritual domains related to their liver disease, its treatment, and prognosis.
4	Across the spectrum of cirrhosis, excellence in communication is integral to high-quality advance care planning, goals of care conversations, and the cultivation of prognostic awareness with patients and caregivers.
5	Routine care for patients with cirrhosis, and particularly those with decompensated disease, should include assessment of caregiver support and screening for caregiver needs.
6	Prognosis should be evaluated by gastroenterology/hepatology providers during routine care visits and at sentinel events.
7	Goals of care discussions in patients with cirrhosis should be repeated at sentinel events including hospital or intensive care admission, before initiation of life-supporting therapies, before surgery, on new onset of cirrhosis-related complications, and after determination of transplant eligibility.
8	Because lack of time is one of the major barriers to administering palliative care, healthcare providers should consider how they can optimize efficiencies in palliative care delivery (identifying local billing codes, prescreening surveys carried out by ancillary staff, development of multidisciplinary teams).
9	Dedicated specialist palliative care services are often a limited resource. As such, healthcare providers should work together with local specialist palliative care teams to establish clear triggers and pathways for referral.
10	Healthcare providers caring for patients with cirrhosis should provide timely referral to hospice for patients who have comfort-oriented goals and prognosis of 6 months or less.

BPA, best practice advice.

fundamental level, PC includes the assessment and management of symptoms and changes in functional status, the provision of ACP and goals of care discussions, prognostication, and caregiver support.[11] Across other life-limiting conditions, the incorporation of PC has been associated with improvements in quality of life, increased patient and caregiver satisfaction, reduced symptom burden, and reduced acute care utilization.[5]

Among others, 3 common misconceptions about the meaning of PC have limited the structured integration of comprehensive PC within cirrhosis care.[12–17] The first is that PC is equivalent to hospice care or end-of-life

Table 2. Moving From Awareness to Execution

Expected (awareness)	Aspirational (execution)
Cirrhosis is life-limiting	Early integration of care with palliative principles
Goals of care discussion	Advanced directive, relevant location-specific goals of care designation on every patient, reviewed at every event
Routine assessment of symptoms	Routine administration of symptom surveys by clinic staff Care coordination that allows continuous management of symptoms
Referral to specialist palliative care when symptoms are beyond scope	Co-management of patients with a multidisciplinary team
Ask about caregiver burden	Systematic assessment of caregiver burden Routine management of caregiver burden
As needed adjustment of clinical schedules to allow time for discussion with use of time-based billing codes	Preemptive scheduling with use of advance care planning codes
Patients have opportunity to receive hospice services at the end of life	Patients understand overall trajectory of illness and are informed with prognosis in line with prognostic awareness and readiness. Timely referral to hospice for patients with a prognosis of 6 months or less to ensure a "comprehensive, socially supportive, pain-reducing, and comforting alternative to technologically elaborate, medically centered interventions.[85]"

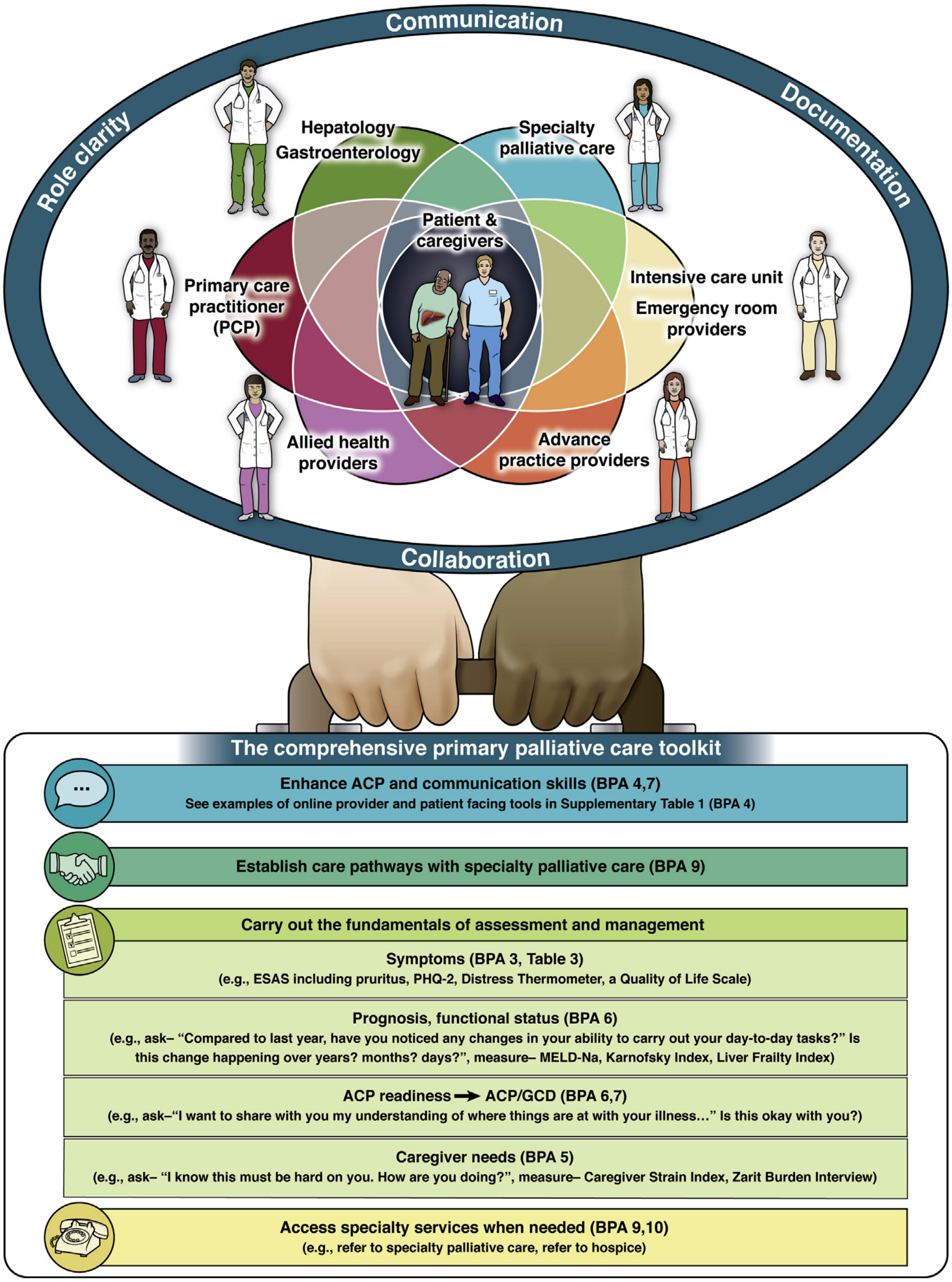
NOTE. The integration of universal palliative care for patients with cirrhosis is a process. This table presents both the current target expectations for palliative care in cirrhosis and targets to aspire to. This information is broken into even more actionable steps in Supplementary Table 1.

care.[15,18] Although hospice care falls within the larger umbrella term of PC, hospice and PC are not the same. Hospice care focuses on end-of-life care for patients who have an estimated survival of $<$6 months. On the other hand, PC is applicable at all stages of a life-limiting illness and can be initiated to meet unmet patient and/or caregiver needs throughout the trajectory of a serious illness. A second misconception is that PC cannot be delivered concurrently with curative or life-prolonging treatments such as liver transplantation.[15] This misconception has been challenged by data that support the presence of a high symptom burden and caregiver distress in transplant listed patients as well as data that support significant symptom improvement with PC.[4,19–25] A third is that PC should only be delivered to decompensated patients. Recent data support that distress or depressive symptoms can be identified even in Child-Pugh class A patients, many of whom have quality of life and symptom scores well below population norms.[2,3]

Although PC may seem on the surface to be unfamiliar territory for many health practitioners, the reality is that the majority of us use at least some of these principles in our day-to-day practice. For example, the hepatologist who arranges a paracentesis to treat the abdominal discomfort associated with tense ascites or provides information to a patient about prognosis and the natural history of their disease is providing aspects of PC. The same applies to the primary care practitioner who screens and initiates therapy for depression or sleep disturbance. As summarized in Tables 1 and 2 and Figure 1 and discussed in more detail in the sections below, an eventual goal would be consistent delivery of a comprehensive, needs-based, and stage-of-disease tailored PC toolkit to all patients with cirrhosis regardless of their transplant status. For providers within each patient's circle of care, this will require an understanding of the meaning of and the importance of PC, collaboration, establishing role clarity (ie, who does what), clear documentation, and the development of increased comfort with delivery of elements in the PC toolkit. Certain elements of the PC toolkit will be more naturally championed by certain providers depending on their skillset (eg, prognostication for a hepatologist versus depression management for a primary care practitioner). All providers can incrementally develop comfort with PC skills, and there are multiple resources available to do this. A potential staged approach for hepatologists/gastroenterologists to move from awareness to execution of PC is presented in Supplementary Table 1.

BPA 2: Care inclusive of palliative care principles may be delivered by healthcare providers from any specialty within any healthcare setting.

All healthcare providers should be able to offer patients and their families care inclusive of PC principles across healthcare settings from ambulatory environments to tertiary hospitals.[26–28] The limited workforce of qualified specialist PC providers in comparison with the growing population of patients with cirrhosis underscores the need for primary care and non-PC specialist providers to be well-versed in generalist (primary) PC delivery.[29–31] Current medical and nursing



The comprehensive primary palliative care toolkit

Enhance ACP and communication skills (BPA 4,7)
See examples of online provider and patient facing tools in Supplementary Table 1 (BPA 4)

Establish care pathways with specialty palliative care (BPA 9)

Carry out the fundamentals of assessment and management

Symptoms (BPA 3, Table 3)
(e.g., ESAS including pruritus, PHQ-2, Distress Thermometer, a Quality of Life Scale)

Prognosis, functional status (BPA 6)
(e.g., ask– "Compared to last year, have you noticed any changes in your ability to carry out your day-to-day tasks?" Is this change happening over years? months? days?", measure– MELD-Na, Karnofsky Index, Liver Frailty Index)

ACP readiness → ACP/GCD (BPA 6,7)
(e.g., ask–"I want to share with you my understanding of where things are at with your illness…" Is this okay with you?)

Caregiver needs (BPA 5)
(e.g., ask– "I know this must be hard on you. How are you doing?", measure– Caregiver Strain Index, Zarit Burden Interview)

Access specialty services when needed (BPA 9,10)
(e.g., refer to specialty palliative care, refer to hospice)

Figure 1. With a shared understanding of PC, healthcare providers within the patient's circle of care can work together to ensure that a tailored, comprehensive PC toolkit is provided to all patients with cirrhosis. ACP, advanced care planning; BPA, best practice advice; ESAS, Edmonton Symptom Assessment System; GCD, Goals of Care Designation; MELD-NA, Model for End-Stage Liver Disease sodium; PHQ-2, Patient Health Questionnaire-2.

education curricula often lack adequate PC content or formal training[32,33] in PC, resulting in significant variation in both the understanding and practice of PC. Because of shortcomings in medical education pertaining to the delivery of comprehensive PC, providers may need to pursue additional training to support this practice. Professional associations are encouraged to support this practice through the provision of educational resources (eg, continuing medical education meeting or online educational meetings). Ongoing studies seek to improve care delivery models and providers' comfort and clinical acumen with PC delivery in multiple different specialties including hepatology.[23,34,35]

BPA 3: Providers caring for persons with cirrhosis should assess for the presence and severity of symptoms within physical, psychological, social, and spiritual domains related to their liver disease, its treatment, and prognosis.

Provision of PC cannot be accomplished without evaluation and routine reassessment for the presence and severity of symptoms that, individually or collectively, impact quality of life. Symptoms may be influenced by a multitude of variables including underlying severity of cirrhosis, side effects of medications or other therapies used in the management of cirrhosis, the psychological and spiritual impact of life-threatening illness,

Table 3. Instruments Available for Assessment of Symptoms in Cirrhosis

Instrument	Domains	Items, scale
Chronic liver disease questionnaire (CLDQ)[86]	Abdominal symptoms, fatigue, systemic symptoms, activity, emotional function, worry	29 questions scale 1–7
Liver disease quality of life (LDQOL)[87]	Symptoms, effects on activities of daily living, concentration, memory, sexual function, sexual problems, sleep, loneliness, hopelessness, quality of social interaction, health distress, self-perceived stigma of liver disease	75 questions 0–100 scale
Short form liver disease quality of life (SF-LDQOL)[88]	Symptoms, effects of liver disease, memory/concentration, sleep, hopelessness, distress, loneliness, stigma of liver	36 questions 0–100 scale
Liver disease symptom index (LDSI)[89]	Itch, joint pain, abdominal pain, daytime sleepiness, worry about family situation, decreased appetite, depression, fear of complications, jaundice	18 questions Symptoms 1–5 scale Symptom hinderance 0–10 scale
Liver Cirrhosis Patient-reported Outcome Measure (LC-PROM)[90]	Physical, psychological, social, therapeutic	55 items (0–4 scale) within 13 dimensions belonging to 4 domains
Patient-Reported Outcomes Information System (PROMIS-29, PROMIS-CAT)[91]	Anxiety/fear, cognitive function, depression/sadness, fatigue, instrumental support, pain interference, physical function, sleep disturbance, social roles	9 health domains Access to gender- and age-matched normative data
SF-36	Vitality, physical role functioning, bodily pain, general health perception, physical function, social role functioning, emotional role functioning, mental health	36 questions, split into 8 domains with 2 summary scores: the physical component summary (PCS) and the mental component summary (MCS)
Sickness Impact Profile (SIP)[92]	Sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behavior, emotional behavior, communication	136 items in 12 categories
Nottingham Health Profile (NHP)[93]	I: energy, sleep, emotions, pain, mobility, social isolation and II: paid employment, housework, hobbies, family life, social life, sex life, holidays	2 parts Part I: 38 questions in 6 subareas Part II: 7 life areas
Distress Thermometer (DT)[94,95]	Overall assessment of distress plus practical problems, family problems, emotional problems, spiritual/religious concerns, physical problems	Distress: 0 (no distress) to 10 (extreme distress) visual analogue scale resembling a thermometer Problem list: 39 (Yes/No) and 1 open ended (other problems)
Edmonton Symptom Assessment System (ESAS)[19,96]	Pain, fatigue, myalgia, sexual dysfunction, anxiety, sleep disturbance, appetite, well-being, dyspnea, pruritis	10 items 0–10 visual analogue scale Scores: Physical, Emotional, and Total
Patient Health Questionnaire (PHQ-9)[97] (PHQ-2)	Anhedonia, feeling down, sleep, feeling tired, appetite, feeling bad about self, concentration, activity, suicidality Anhedonia, feeling down (first two items of the PHQ-9)	9 items scored 0–3; total score 0–27 used to categorize depression severity as minimal/none, mild, moderate, moderately severe, or severe 2 items. If yes selected for one or both questions, go on to perform the PHQ-9. If no to both questions, screen is negative for depression.

NOTE. Included in the table are selected liver-specific tools as well as instruments that may be applicable to other patient populations. At this point, there are few data to support which tools are best to incorporate into research or clinical practice. These instruments vary in the domains assessed, their length, scoring, and availability in languages other than English. The choice of instrument will vary depending on the clinical need as well as need for expediency.

loss of independence/identity as a result of disability, financial burden, impact of chronic illness on family and other vital relationships, and uncertainty or anxiety pertaining to prognosis. This complex and dynamic milieu is optimally evaluated with the assistance of validated instruments, a multidisciplinary care team, or ancillary training. Importantly, most physical symptoms in cirrhosis are best addressed via optimal management of cirrhosis-related complications (eg, treatment of fluid overload), although some (eg, pruritus) may require additional specific therapies.

A systematic review of symptom prevalence in adult patients with end-stage liver disease summarized the following as most commonly reported: pain (30%–77%), breathlessness (20%–88%), muscle cramps (56%–68%), sexual dysfunction (53%–93%), insomnia (26%–77%), daytime sleepiness (30%–71%), fatigue (52%–86%), pruritus (47%–64%), anxiety (14%–45%), and depression (10%–64).[3] Another integrative review including 26 quantitative studies found the most commonly reported symptoms across chronic liver disease populations were fatigue, depression, sleep disturbance, pain, cognitive impairment, and dizziness.[36] There are many tools available to facilitate the evaluation of symptoms that occur across multiple domains as well as an overall estimate of symptom severity on quality of life. These tools vary in their length, content, applicability to clinical care versus research, inclusion of liver-specific variables, and availability in languages other than English (Table 3). There is evolving expert opinion-based literature to guide the selection of tools in cirrhosis.[37] As highlighted by Verma et al,[38] the routine integration of these assessment metrics in real-world hepatology care will require several steps focused on implementation methodology including local buy-in and action plans that are tied to the results.

Although the primary objective for symptom assessment in patients with cirrhosis is to guide interventions that may alleviate suffering, there is also utility in symptom assessment in determining prognosis (Supplementary Table 2).

BPA 4: Across the spectrum of cirrhosis, excellence in communication is integral to high-quality advance care planning, goals of care conversations, and the cultivation of prognostic awareness with patients and caregivers.

Studies suggest that patients with cirrhosis often have preferences for care that are not in accordance with fully aggressive care. For example, the SUPPORT study surveyed patients with at least 2 features of advanced disease (serum albumin $\leq$3.0 mg/dL, uncontrolled ascites, hepatic encephalopathy, cachexia, upper gastrointestinal bleed) and showed that 43% would rather die than receive care in a nursing home, and most reported wanting to die rather than live in a coma or with a ventilator or feeding tube.[39] To ensure that patients' preferences for care are followed, ACP and goals of care conversations should be addressed early in the course of disease.[40,41] A recent systematic review in support of the National Consensus Project clinical practice guidelines concluded that there was moderate quality evidence for ACP (both advance directives and care planning conversations) having a positive impact on preference documentation and the receipt of preference-concordant care.[42] More research is needed to establish best practices specifically in cirrhosis, with at least one study underway to evaluate different approaches to inform best practices.[23] Current clinical practice can be informed by research from other serious illnesses and general ACP tools and/or provider-focused communication skills training courses.

Much of the data supporting high-quality communication regarding prognosis and care planning is from the cancer literature. A multi-site U.S. cohort study of patients with advanced cancer and their caregivers showed that timely ACP and goals of care conversations were associated with improved quality of life, less intensive treatments at the end of life, earlier hospice enrollment, and better bereavement adjustment in family members.[43] In oncology, early integration of PC is supported by professional society guidelines and models that integrate assessing prognostic awareness throughout the disease trajectory.[7,44,45] Although more research is needed in this area to inform practice, a number of groups have made courses and resources available to improve communication skills when working with patients with serious illness, such as Vital Talk, Respecting Choices, and Ariadne Lab's Serious Illness Conversation guide.[46–49] Patient facing tools such as PREPARE for your Care have also been shown to be beneficial.[50]

BPA 5: Routine care for patients with cirrhosis, and particularly those with decompensated disease, should include assessment of caregiver support and screening for caregiver needs.

Within the PC literature, the term *caregiver burden* is identified through the following attributes: perception of physical symptoms, psychological distress, impaired social relationships, spiritual distress, financial crisis, role strain, disruption of daily life, and uncertainty.[51] Downstream consequences of caregiver burden may include impaired physical health status, psychiatric illness, and poor quality of life. There are several instruments available for the evaluation of caregiver burden including the Zarit Burden Interview,[52] the Caregiver Reaction Assessment,[53] Family Strain Questionnaire-Short Form (FSQ-SF),[54] the Caregiver Strain Index (CSI),[55] and measures offered through PROMIS (accessible through the HealthMeasures website[56]). Quality of life domains including limitation in functioning due to emotional health, vitality, mental health, and social functioning are impaired among primary caregivers of people with cirrhosis relative to national norms.[57]

Among patients with cirrhosis who have previously experienced hepatic encephalopathy, cognitive performance and Model for End-Stage Liver Disease (MELD) score are correlated with caregiver burden.[58] Caregivers of individuals with alcohol-related liver disease may face additional strain, potentially related to variance in available social networks, and caregivers of patients awaiting liver transplant frequently feel unprepared to adequately perform their roles.[21,59] A recent cross-sectional study of 100 patients with cirrhosis and their caregivers identified that caregiver burden scores were significantly increased among patients with either previous overt hepatic encephalopathy or minimal hepatic encephalopathy and inversely correlated with liver disease severity scores.[60] Repeated hospital admissions, alcohol as etiology, and lower socioeconomic status were independent predictors of caregiver burden.[60] Caregiver strain before and after liver transplant from a single center study appears to predominantly impair mental, rather than physical, quality of life.[61] Higher caregiving strain (measured via the Caregiver Strain Index) was significantly correlated with lower mental quality of life, lower life satisfaction, and more mood disturbance.

The financial implications of caregivers of patients with cirrhosis are profound if evaluated in a comprehensive fashion. In a prospective assessment of older adults with cirrhosis included in the Health and Retirement Study, nearly 30% of patients with cirrhosis demonstrated functional decline over a median of 2 years, and 18% of individuals with cirrhosis had severe functional decline.[62] On the basis of the median national wage for a home health aide, the annual costs of provision of care to older adults with cirrhosis in this study were estimated to be more than double those for an age-matched comparison group (for 2009, $4700 per person with cirrhosis compared with $2100 without cirrhosis).

In addition to assessing caregiver burden, it is important to consider practice and locale-specific pathways to provide resources to caregivers in need. A small prospective trial of 20 patients with cirrhosis/caregiver dyads has shown that a short (4-week) intervention of mindfulness and supportive group therapy resulted in improved measures of caregiver burden, mental health, and sleep.[63] More research is needed to understand the optimal provision and impact of this support.[64–66]

BPA 6: Prognosis should be evaluated by gastroenterology/hepatology providers during routine care visits and at sentinel events.

As a cornerstone of PC, prognostication should be carried out at all routine care visits and reevaluated during sentinel events such as hospitalization or intensive care unit admission, on the development of liver-related complications including hepatocellular carcinoma, after the determination of transplant eligibility, and before the initiation of life-supporting therapies or surgery.

Population-based prognostic scores such as MELD, the MELD sodium, the Child-Pugh classification, and liver-specific critical care scores for acute-on-chronic liver failure such as the CLIF-C Acute-on-Chronic Liver Failure score[67] have recognized limitations when applied to individual patients. A more complete understanding of prognosis can be gained by considering data around comorbidities, functional status/frailty, the rapidity of functional decline, and other factors such as the potential for improvement with etiological therapy.[68–71] The data suggest that clinicians remain overly optimistic when it comes to their individual patients' prognoses.[72] In a large multi-center study evaluating end-of-life care comparing physician-estimated and modeled prognoses, both physicians and models failed in predicting mortality in cirrhosis, underscoring the difficulties inherent in predicting the clinical course of this disease.[73]

Alongside the estimation of prognosis, it is important that practitioners are familiar with how to assess an individual patient's desire to hear this information and how to present it to them within their context of prognostic awareness and readiness to hear this information. Various statements can be used to initiate these conversations including a statement from the Serious Illness Conversation Guide[49] such as, "I want to share with you my understanding of where things are with your illness…", "Is this ok with you?", or from a recent review on ACP in cirrhosis,[74] "To make sure that both you and your family are prepared, I like to address both the best- and worst-case scenarios regarding how your cirrhosis may progress. Can we talk about these now?". In patients with prognostic ambivalence and worsening disease that make prognostic conversations even more time sensitive, "what if" scenarios can be useful to elicit preferred healthcare decisions.[45]

BPA 7: Goals of care discussions in patients with cirrhosis should be repeated at sentinel events including hospital or intensive care admission, before initiation of life-supporting therapies, before surgery, on new onset of cirrhosis-related complications, and after determination of transplant eligibility.

Despite the benefit of ACP and goals of care conversations, some small studies show that these are underused among patients with cirrhosis. In a recent publication from Alberta where there is a public awareness campaign to promote ACP, one third or less had documented directives or goals of care.[75] The lack of documented ACP and late initiation of PC in this population were also observed for patients in a recent study from Yale.[76] In a recent survey study of hepatology and gastroenterology cirrhosis providers by Ufere et al,[77] most respondents (81%) thought that ACP discussions occurred too late in the illness trajectory. This may be due to a number of barriers such as insufficient communication between clinicians and families about goals of care and lack of training.

Using the RAND/UCLA modified Delphi method, a 9-member, multidisciplinary expert panel has identified 13 quality indicators for information and care planning for patients with "end stage liver disease".[78] Sentinel events for initiating goals of care discussions include diagnosis of decompensated cirrhosis, consideration of liver transplant, admission to an intensive care unit, admission to a hospital, use of a mechanical ventilator, and initiation of hemodialysis.[78] These measures were recently pilot tested and should be tested in larger populations to inform quality improvement for patients with cirrhosis.[79]

BPA 8: Because lack of time is one of the major barriers to administering palliative care, healthcare providers should consider how they can optimize efficiencies in palliative care delivery (identifying local billing codes, prescreening surveys carried out by ancillary staff, development of multidisciplinary teams).

In the survey study by Ufere et al,[77] 91% of cirrhosis providers noted competing demands for time as a significant barrier to engaging in PC; another 76% cited insufficient reimbursement as a limitation to PC delivery.[77] Healthcare policy suggests that the value of PC is significant, and trends in reimbursement are beginning to reflect this with codes for chronic care management, ACP, and transitional care management.[80] Validated screening surveys (BPA 3, Table 3) can be administered by ancillary clinic staff to alert providers of symptoms requiring attention. Where feasible, advanced practice providers with PC training can be embedded in practices for multidisciplinary care, allowing PC to be shouldered by a group rather than an individual.[42] A randomized control trial suggests integration of multidisciplinary PC early in the course of advanced cancer treatment is more beneficial than PC consultation[42]; these types of studies should be assessed in patients with cirrhosis.[81]

BPA 9: Dedicated specialist palliative care services are often a limited resource. As such, healthcare providers should work together with local specialist palliative care teams to establish clear triggers and pathways for referral.

Depending on practice and locale, the integration between specialist PC teams and non-PC providers (primary care physicians, advance practice providers, gastroenterologists, hepatologists, transplant surgeons, emergency department and intensive care unit physicians) ranges from complete integration within inpatient or outpatient hepatology/transplant services to a distinct specialty PC consultation service.[24]

Primary PC (ie, symptom screening, basic symptom management, ACP, prognosis discussions) should be provided by non-PC providers (Figure 1). This allows specialist PC services to be reserved for inpatients and outpatients with more complex needs. For example, these needs include assistance with difficult ACP and goals of care discussions, the management of refractory symptoms, complex care coordination, challenging family and treatment team dynamics, and referrals to hospice that involve conflict.

Across all sites, collaborations between specialist palliative teams and non-PC providers are encouraged so that consensus can be reached regarding pathways for specialist referral including local referral triggers and so that lines of support can be established for any questions that may arise. Although there is limited evidence on this in cirrhosis, tools including the Supportive and Palliative Care Indicators Tool can be used to guide referral.[82,83] Similarly, in a setting where primary PC is being provided, it is essential that primary care physicians and hepatologists/gastroenterologists are aware of indications for specialist referral and that role clarity is established around "who does what" for primary PC.

BPA 10: Healthcare providers caring for patients with cirrhosis should provide timely referral to hospice for patients who have comfort-oriented goals and prognosis of 6 months or less.

Accurate prognostication is essential to optimal PC delivery and hospice referral. Understanding the limitations of accurate prognostication in cirrhosis (BPA 6), hospice referral should be made in a timely fashion and, ideally, in the context of preceding ACP and goals of care discussions. It is important to note that patients are appropriate for hospice benefits if prognosis is estimated to be less than 6 months. Insurance coverage of hospice benefits usually requires comfort-focused care without pursuit of further curative treatments. Referral to hospice should not come within days of death or as a surprise to patients. Hospice care should instead be an expected eventuality for patients who have been well-informed along the continuum of care of the natural history of cirrhosis.

Unfortunately, many studies have shown late or no referral to PC/hospice in patients with cirrhosis. Although studies have shown an increase in national trends of PC/hospice referral over time as well as benefits of lower costs and procedure burden among those who are receiving PC/hospice care, in patients with cirrhosis there are still substantial barriers to receiving this care relating to ethnicity, geography, and comorbid medical and psychiatric conditions.[12,84]

Supplementary Material

Note: To access the supplementary material accompanying this article, visit the online version of *Clinical Gastroenterology and Hepatology* at www.cghjournal.org, and at https://doi.org/10.1016/j.cgh.2020.11.027.

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Conflicts of interest
The authors disclose no conflicts.

Supplementary Table 1. Potential Steps for Moving to Awareness and Then to Execution

	Awareness of the tenets of palliative care (PC) in cirrhosis according to BPA statements	Suggested steps for non-PC specialist providers to introduce BPAs into practice	Opportunities for non-PC specialist providers to expand on implementation of BPAs in practice	Mature practice targets for non-PC specialist providers to implement BPAs in practice
BPA-1	• PC ≠ hospice • PC can and should be offered alongside “curative” therapies • PC can also be relevant for compensated patients	Teach your learners about PC principles and the broad applicability of PC across the range of patients with cirrhosis.	Pick a week to actively identify opportunities where you could initiate PC in your outpatients and your inpatients with cirrhosis.	Early integration of care with palliative principles in all patients with cirrhosis.
BPA-2	Providers involved in the care of patients with cirrhosis should strive to contribute to care with palliative principles.	Identify which PC principles you have gaps in your comfort or knowledge level: Symptom screen and basic management Prognostication, prognostic readiness assessment ACP and GCD Function screen Caregiver needs screen and management	From BPAs 3–10 choose an area you wish to begin to integrate into your practice.	A systematic approach to early integration of care with palliative principles in all patients with cirrhosis by all providers involved in their care.
BPA-3	The symptom burden of patients with cirrhosis is tremendous.	Set up a collaborative brainstorming session between local primary care physicians and specialty PC colleagues to determine who would manage symptoms when they are flagged on routine screening.	Initiate routine screening of symptoms and distress in your liver clinic using the ESAS and the Distress Thermometer (or other such tools). Ancillary staff can initiate these.	Evidence-based symptom scales and guidelines are readily available to all providers to support universal symptom screening and management. Role clarity discussions between gastroenterology/hepatology and primary care as to who initiates these screens and who acts on them.
BPA-4	Early advance care planning and goals of care designations are infrequent but important to ensure value aligned medical care. This requires practice with high-quality communication.	Explore ACP tools and communication courses about to support high-quality ACP and GCD conversations Examples of provider facing resources: (Vital Talk or Respecting Choices/ Center to Advance Palliative Care Courses or Serious Illness Conversation Guide) Examples of patient facing resources: can be found at the American Society on Aging website	Block off separate clinic visits to initiate ACP and GCD conversations, initially in your decompensated patients and then moving to tailored conversations in the compensated patients.	Advanced directive, relevant locale-specific goals of care designation on every patient.

Supplementary Table 1. Continued

	Awareness of the tenets of palliative care (PC) in cirrhosis according to BPA statements	Suggested steps for non-PC specialist providers to introduce BPAs into practice	Opportunities for non-PC specialist providers to expand on implementation of BPAs in practice	Mature practice targets for non-PC specialist providers to implement BPAs in practice
BPA-5	Caregiver burden is common, especially in patients with decompensated disease. It has physical, mental, and financial consequences.	Become familiar with one of the caregiver burden indices (eg, the Caregiver Strain Index).	Talk to your local primary care and specialty PC colleagues about the types of resources that are available to caregivers once caregiver burden is identified.	Initiate routine screening of caregiver burden. These can be carried out by ancillary staff. Locale-specific resources provided to the patient/caregiver.
BPA-6	Prognostication can be challenging in cirrhosis, and healthcare providers may avoid these discussions because of prognostic uncertainty and challenges with initiating the prognosis conversation.	Become familiar with prognostication tools in addition to the MELD and Child-Pugh (eg, functional assessment such as frailty, changes in function over time).	See BPA-4: sign up for a short course that goes through how to have high-quality ACP and GCD conversations (eg, Serious Illness Conversation Guide). These courses all go through how to discuss prognostication.	Prognostic readiness should be assessed on every patient and carried out during routine care visits and sentinel events.
BPA-7	Goals of care discussions should be repeated at sentinel events to ensure value aligned medical care.	Become familiar with your locally accepted GCD documentation forms and associated resources.	See BPA-4: use online resources that support high-quality ACP and GCD conversations (eg, Serious Illness Conversation Guide).	Advance directive, relevant locale-specific goals of care designation on every patient, reviewed at every event
BPA-8	There are strategies available to optimize efficiencies in PC delivery by all members of the healthcare team.	Find out your local billing numbers for chronic care management, ACP, and transitional care management.	Adjust clinic schedules to allow time for discussion with use of time-based billing codes.	Preemptive scheduling of patients for ACP discussions with the use of ACP codes.
BPA-9	It is useful for liver specialists and primary care physicians to work together with local specialist PC teams to establish clear triggers and pathways for referral.	Make contact with a member of your local specialist PC team to determine the process for accepting referrals on cirrhosis patients.	Referral to specialist PC when symptoms are beyond scope	Referral to specialist PC when symptoms are beyond scope. Eventually building toward integrated PC management with a multidisciplinary team of providers.
BPA-10	Existing hospice referrals are often made late. These should ideally be made in a timely fashion.	Find out your local referral criteria for hospice and what would be required to refer a cirrhosis patient there.	If consistent with patient's values, patients have the opportunity to receive hospice services at end of life.	Patients understand overall trajectory of illness and are informed with prognosis in line with prognostic awareness and readiness. Timely referral to hospice for patients with a prognosis of 6 months or less.

NOTE. Meant for delivery of PC by clinicians who are not PC specialists and do not have routine integration of specialist PC within their outpatient or inpatient system. This approach may also be applied to graduate medical education in gastroenterology and hepatology fellowship training. Consider exploring the Center to Advance Palliative Care website, the Shiley Institute for Palliative Care website, and the B.C. Inter-Professional Palliative Symptom Management Guidelines for additional resources and available online modules.

ACP, advanced care planning; BPA, best practice advice; ESAS, Edmonton Symptom Assessment System; GCD, Goals of Care Designation; MELD, Model for End-Stage Liver Disease; PC, palliative care.

Supplementary Table 2. Summary of Data Demonstrating Relationship Between Quality of Life and Prognosis in Patients with Cirrhosis

Study population	Population size	Instrument	Key findings
Retrospective analysis of patients with cirrhosis and severe ascites included in clinical trial for salvaptan	405	SF-36	After confounder adjustment, the hazard ratio for a 10-point increase in the physical component score was 0.83 (95% confidence interval, 0.72–0.97) for all-cause mortality and 0.84 (95% confidence interval, 0.71–0.99) for cirrhosis-related deaths.[94]
Multicenter, prospective study of patients with cirrhosis with mean MELD 12	402	Chronic Liver Disease Questionnaire (CLDQ) and EuroQoL Group-visual analogue scale (EQ-VAS)	Health-related quality of life (HRQoL) was independently associated with the primary outcome of short-term unplanned hospitalization/mortality.[2] Every 1-point increase in the CLDQ and every 10-point increase in the EQ-VAS reduced the risk of reaching this outcome by 30% and 13%, respectively
Single-center prospective study of patients awaiting liver transplant.	156	Short Form Liver Disease Quality of Life	Higher baseline HRQOL predicted lower mortality (hazard ratio, 0.96; 95% confidence interval, 0.94–0.99), independent of MELD.[95]
Multicenter prospective study of patients in the Pulmonary Vascular Complications of Liver Disease study	252	SF-36	Lower baseline Physical Component Summary scores were associated with increased mortality rate despite adjustments for age, gender, MELD score, and liver transplantation (*P* for the trend = .0001).[96]

MELD, Model for End-Stage Liver Disease.