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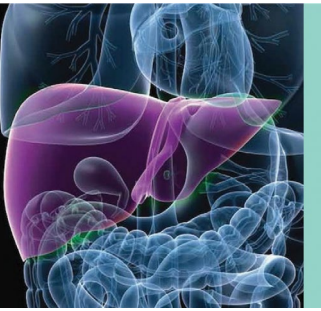
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Integrating Palliative Care in the Management of Patients With Advanced Liver Disease

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Being diagnosed with an advanced liver disease (ALD), such as decompensated cirrhosis or hepatocellular carcinoma, has a dramatic impact on both life expectancy and quality of life for afflicted individuals.^{1,2} Although many scientific achievements in the field of hepatology have led to improved survival in these cohorts of patients, curative options are still unavailable for most.^{3,4} Much less attention has been paid to improving the quality of life for these patients, which is expected to be a growing need. Integrating principles of palliative care in the management of patients with ALD may be one way of solving this issue.

WHAT IS PALLIATIVE CARE?

The National Consensus Project Guidelines define palliative care as a “person- and family-centered approach to care, providing people living with serious illness relief

from the symptoms and stress of an illness”.⁵ The ultimate goal of palliative care is to improve quality of life for the patient and the family. Important dimensions of palliative care include: (1) physical symptom management; (2) mental health management; (3) advance care planning (ACP); (4) addressing social and cultural issues; (5) addressing spiritual, religious, and existential issues; and (6) end-of-life care. Ideally, it is offered across all practice settings, at any stage of a patient’s illness trajectory, and with the involvement of multiple disciplines.⁵ It is thus important to recognize that palliative care is not synonymous with end-of-life care or hospice (Fig. 1A and 1B).

Depending on the resources available in different health care settings, palliative care can be offered by generalists (without specialty training in palliative care) or specialists (have received training).⁶ Interdisciplinary teams include

Abbreviations: ACP, advance care planning; ALD, advanced liver disease; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; ESLD, end-stage liver disease; ESRD, end-stage renal disease; GCD, goals of care discussion; MND, motor neuron disease; MS, multiple sclerosis.

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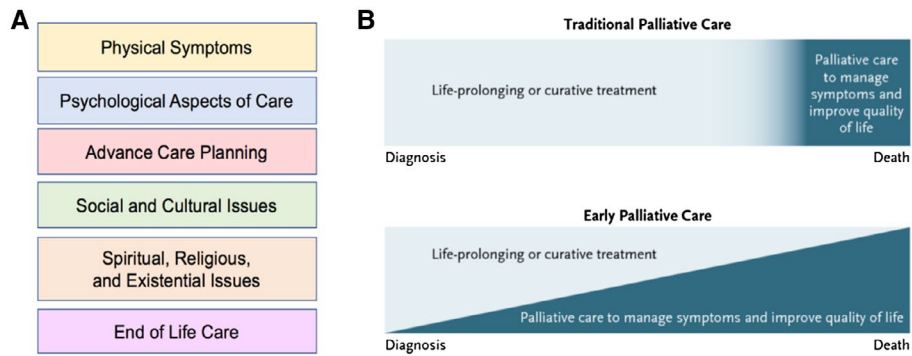


FIG 1 (A) Dimensions of palliative care. Adapted from *Clinical Practice Guidelines for Quality Palliative Care*, 4th ed.⁵ Copyright 2018, National Coalition for Hospice & Palliative Care. (B) Comparison of the traditional versus contemporary model of palliative care. Reprinted with permission from *New England Journal of Medicine*.²⁷ Copyright Massachusetts Medical Society.

not only physicians but also advanced practice registered nurses, physician assistants, nurses, social workers, behavioral health specialists, chaplains, and others based on need.⁵ Early palliative care involvement has been associated with improvements in patient and caregiver satisfaction, as well as lower health care utilization.⁷ In fact, results from a high-quality randomized controlled trial suggest that early palliative care consultation in patients with advanced cancer is associated with better quality of life and mood. The authors of this study hypothesized that this may be due to improvements in coordinated care, self-advocacy, and social support.⁸ Benefits in physical and depressive symptoms have also been seen in a smaller, noncontrolled study of patients with ALD who received palliative care consultation during transplant evaluation.⁹ Multiple subspecialty societies treating patients with advanced cancer, end-stage renal disease (ESRD), heart failure, chronic obstructive pulmonary disease, and other chronic conditions recommend inclusion of early palliative care as part of their management. Despite this, involvement of specialty palliative for patients with ALD is low.^{10,11} In the following paragraphs, we will highlight ACP and symptom management, two particularly unmet needs for palliative care in ALD, and provide strategies for managing these issues in practice or considering specialty referral.

ACP

ACP is the iterative process by which patients and their caregivers clarify, establish, and document their illness and prognostic understanding, personal values and health goals, and preferences for medical care throughout the course of their illness.¹² Timely ACP has been associated

with a number of positive outcomes for patients, including improved quality of life and satisfaction with care, as well as reduced health care utilization at end of life.¹³ Unfortunately, ACP occurs infrequently. In a prospective study of outpatients with cirrhosis, only 14% of patients had completed a goals of care designation, and only 33% had identified a surrogate decision-maker.¹⁴ Surveys of clinicians providing care to patients with ALD have identified insufficient clinician communication skills training and limited reimbursement as important barriers to ACP.^{15,16}

Timely ACP is critically important for patients with ALD. Documenting preferences for medical care (through a health care proxy form, a physician or medical order for life-sustaining treatment, or a living will) and establishing a surrogate decision-maker for patients with ALD should occur early in the disease course. Special attention should be given to: (1) patients who are being considered for liver transplant and noncandidates, (2) patients with hepatic encephalopathy, and (3) patients who were previously treated in the intensive care unit or received life-sustaining treatments.¹⁷ Given that acute deteriorations such as variceal bleeding, sepsis, and acute kidney injury are often unpredictable, prior knowledge of patients' preferences regarding the intensity of care they would like to receive allows clinicians to provide goal-concordant care.

A number of conceptual frameworks can be used to help guide discussions with patients with ALD. The SPIKES framework, initially developed in the oncology setting, provides a stepwise approach for disclosing difficult news¹⁸ (Table 1). Brisebois et al.¹⁹ have also published suggested conversation starters for ACP discussions

TABLE 1. THE SPIKES FRAMEWORK FOR DELIVERING BAD NEWS¹⁸

6-Step SPIKES Framework

Setting	<p>Setting up the interview</p> <ul style="list-style-type: none"> • Arrange for some privacy. • Involve significant others if the patient chooses. • Invite other relevant parties: interpreter, social worker, surgeon, palliative care physician. • Sit down with the patient. • Make a connection and establish rapport with the patient. • Manage time constraints and interruptions.
Perception	<p>Assessing the patient's perception</p> <ul style="list-style-type: none"> • Use open-ended questions to determine the patient's level of comprehension about his or her medical condition (i.e., "What have you been told about your medical situation so far?").
Invitation	<p>Obtaining the patient's invitation</p> <ul style="list-style-type: none"> • Assess the patient's readiness to receive information. • Discuss information disclosure at the time of ordering studies (i.e., "I have some updates on your condition to discuss. Would it be all right if I shared these with you now?"). • If the patient does not want to know details, offer to answer any questions he or she may have in the future or to talk to a caregiver.
Knowledge	<p>Giving knowledge and information to the patient</p> <ul style="list-style-type: none"> • Consider a warning prior to disclosing bad news to the patient (i.e., "Unfortunately, I do not have good news" or "I'm sorry to tell you that..."). • Start at the level of comprehension and vocabulary of the patient. • Try to use nontechnical words and avoid medical jargon. • Avoid excessive bluntness. • Give information in small chunks, and periodically reassess the patient's understanding. • When the prognosis is poor, avoid using phrases such as "There is nothing more we can do for you," because patients may have other important therapeutic goals outside of curative therapy, such as good symptom relief.
Emotion	<p>Addressing the patient's emotions with empathic responses</p> <ul style="list-style-type: none"> • Observe for any emotion on the part of the patient. • Identify the emotion experienced by the patient by naming it to oneself: use open-ended questions to query the patient as to what he or she is feeling. • Identify the reason for the emotion—if you are not sure, ask the patient. • After you have given the patient time to express his or her feelings, show the patient that you recognize and empathize with his or her emotional response.
Strategy and summary	<p>Presenting a clear plan for the future with the patient</p> <ul style="list-style-type: none"> • Assess whether the patient needs clarification on what has been discussed. • Ask the patient if he or she is ready for a discussion regarding next steps in management. • Set out a medical plan of action.

(Table 2). Starting in 2015, Medicare adopted new billing codes to provide reimbursement to clinicians for ACP using Current Procedure Terminology (CPT) codes 99497 and 99498. These provide some incentive for physicians to help integrate ACP into their practice.²⁰ Involvement of specialty palliative care services has also been associated with more frequent goals of care discussions in the intensive care unit setting and greater completion of advance directives in outpatients undergoing liver transplant evaluation, so considering expertise of these teams should strongly be considered.^{9,21}

PHYSICAL AND PSYCHOLOGICAL SYMPTOM MANAGEMENT

Patients with ALD experience a great deal of physical and emotional suffering throughout the course of their

illness and at the end of life.²² Although certain physical symptoms may be well managed by gastroenterologists and hepatologists, pain and mental health issues are often underrecognized.²³ Peng et al.²⁴ described the prevalence of physical and mental health symptoms in a recent systematic review (Table 3). Caregivers also report declines in their physical and mental health; this burden often increases steadily throughout a patient's illness trajectory and is often unaddressed.²⁵ A previous publication from *Clinical Liver Disease* contains a comprehensive review of pharmacological options and highlights challenges involved in pain management for patients with cirrhosis.²⁶ Greater recognition of symptoms and caregiver issues in patients with ALD and their caregivers is needed, and referral to specialty palliative care services may be warranted in patients with complex pain management issues, history of opioid addiction, and management of spiritual and caregiver issues.

TABLE 2. RECOMMENDED CONVERSATION STARTERS FOR PRACTITIONERS DURING ACP DISCUSSIONS

Topics	Conversation Starters
Patient perspectives	<ul style="list-style-type: none"> Level of detail <ul style="list-style-type: none"> • Are you a detail-oriented learner or do you prefer a general overview and plan? Learning style <ul style="list-style-type: none"> • Some people are visual learners while others process conversations best. Which learning approach suits you the best? Values and fears <ul style="list-style-type: none"> • What is most important to you in life? • What aspect of health would need to be taken from you, for you to feel that living was worse than dying?
Education	<ul style="list-style-type: none"> • Meeting for the first time about a new illness that you have been diagnosed with can be overwhelming. • We have created educational pamphlets we can provide for you, which can help guide our future discussions. • Our clinic communicates with your other health providers, so that we all know your wishes and details regarding your health.
Readiness	<ul style="list-style-type: none"> Readiness to discuss ACP and GCD <ul style="list-style-type: none"> • Very ill patients with cirrhosis cannot always make their own health care decisions. We like to talk about these things early on to understand what you value in case such a situation arises. How would you feel discussing how cirrhosis may affect you in the future? Readiness to choose a surrogate <ul style="list-style-type: none"> • If you were to get very sick, is there anyone you trust to make medical decisions for you? Does this person know what is important to you?
Focus of care	<ul style="list-style-type: none"> • Recently, you had a complication of cirrhosis and were quite unwell. I would like to explain how cirrhosis may affect you in the future. • It is important to understand how disease-modifying treatments and symptom-control therapies are used together during an illness.
Prognosis	<ul style="list-style-type: none"> Discuss in general terms <ul style="list-style-type: none"> • 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? • Some patients ask me how their cirrhosis will affect how long they live. Are you interested in this type of information?
Review cirrhosis	<ul style="list-style-type: none"> Disease complications <ul style="list-style-type: none"> • The investigations that we have done show that your disease has worsened. I would like to discuss how that affects what treatments and therapies are going to help you live the best-quality life possible. End-of-life wishes <ul style="list-style-type: none"> • What would be important to you in your last months of life? • Where would you prefer to die?
Resources	<ul style="list-style-type: none"> • Many communities have additional supports for patients with medical, social, psychological, and spiritual needs. Would you be interested in learning about some of these resources?
Documentation	<ul style="list-style-type: none"> • This depends on where the patient is located. Various websites describe local and regional Goals of Care Medical Orders.
Review and compare	<ul style="list-style-type: none"> • Please tell me what you understand of your decisions with respect to your GCD. What impact do they have on your life? I want to ensure that the designation properly reflects your values and wishes. • Since we last met, have you had any experiences that may change your view about living with cirrhosis? • Are your wishes outlined anywhere else, such as in a Will or legal document? If so, we should look at it to ensure your wishes are consistent with your medical documents.

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TABLE 3. SYMPTOM PREVALENCE IN PATIENTS WITH ESLD COMPARED WITH OTHER CHRONIC CONDITIONS²⁴

Symptom	ESLD	Cancer*	COPD*	CHF*	ESRD*	Dementia*	MND*	MS*
Pain	30-79	30-97	21-77	14-78	11-83	14-63	52-76	68
Breathlessness	20-88	16-77	56-98	18-88	11-82	12-52	81-88	26
Insomnia	26-77	3-67	15-77	36-48	1-83	14	24-33	
Fatigue	52-86	23-100	32-96	42-82	13-100	22		80
Anorexia	49	76-95	64-67		38-64			
Nausea or vomiting	58	2-78	4	2-48	8-52	8		26
Depression	4.5-64	4-80	17-77	6-59	2-61	46	23	15
Anxiety	14-45	3-74	23-53	2-49	7-52	8-72	19	24

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*Data on prevalence of symptoms. The values are given in percentage.

SUMMARY

The following are tips for including palliative care in practice:

- Ensure that physical symptoms, including pain, and mental health issues are being recognized and addressed.

- Consider developing skill in performing ACP. This includes encouraging completion of advance directives.
- Recognize caregiver burden and spiritual distress.
- Invest in building relationships with specialty palliative care teams so that all dimensions of palliative care can be addressed.

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