Palliative Care for End Stage Liver Disease patients

Kat Dobrovolny, MD, MS; VCU HPM Fellow

Palliative Care ECHO, April 2025

I have no financial disclosures to report

Objectives

Define the criteria for palliative medicine involvement in end stage liver disease (ESLD) care

Clarify appropriate triggers for involvement of primary or specialty palliative care

Describe common symptom burden and management in patients with ESLD

Patient case: Mrs. H

62F, PMH notable for ETOH cirrhosis

- hx HAT s/p DDLT (2/2024) c/b hepatic artery pseudoaneurysm s/p coiling, liver infarct, abscess w biliary leak (ongoing)

10/2024

- Admitted with hypercalcemia & concern for sepsis

Mrs. H, continued

Day 16-18

- Primary team schedules oxycodone 2.5mg q6h

Day 18-22

- Dose increased to 5mg q6h scheduled

Day 22

- Palliative care consulted for symptom burden (diffuse pain)

Mrs. H, continued

RASS scores +1/-1

Patient endorses pain "all over"

No palliative care involvement found in EMR prior to liver transplant or current hospitalization

Discontinued scheduled opiates

Allowed for oxycodone 2.5mg q8h PRN in addition to non-opiate therapies

Symptom burden improved as a result

Resource review

PubMed initial search

Current guidelines

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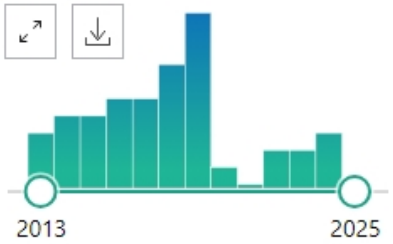

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Palliative care and end stage liver disease: A survey study comparing perspectives of hepatology and palliative care physicians and clinical scenarios that could require palliative care intervention.

Oliveira HM, Ramos JP, Rego F, Nunes R.

Clin Res Hepatol Gastroenterol. 2024 Aug;48(7):102416. doi: 10.1016/j.clinre.2024.102416. Epub 2024 Jul 8.

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When Is the Optimal Time to Refer Patients with End-Stage Liver Disease to Palliative Care Specialists? #481.

Ghoshal A, Marks S, Esteban JP.

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PMID: 38686513 No abstract available.

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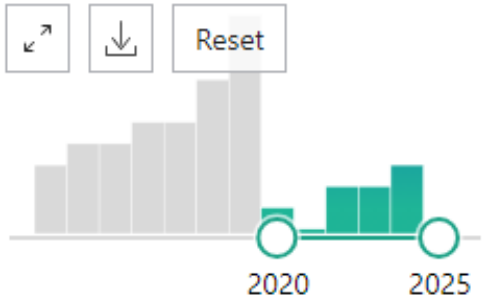

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PRACTICE GUIDANCE

AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis

Rogal, Shari S.[1,2]; Hansen, Lissi[3]; Patel, Arpan[4,5]; Ufere, Nneka N.[6]; Verma, Manisha[7]; Woodrell, Christopher D.[8,9]; Kanwal, Fasiha[*,10,11]

Author Information

Hepatology 76(3):p 819-853, September 2022. | **DOI:** 10.1002/hep.32378

Metrics

Rogal SS, Hansen L, Patel A, Ufere NN, Verma M, Woodrell CD, et al. AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis. Hepatology. 2022;76:819–853. https://doi.org/10.1002/hep.32378RogalSS, HansenL, PatelA, UfereNN, VermaM, WoodrellCD, et al. AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis. Hepatology. 2022;76:819–853. https://doi.org/10.1002/hep.32378

CLINICAL PRACTICE UPDATE · Volume 19, Issue 4, P646-656.E3, April 2021

Download Full Issue

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

Puneeta Tandon [*] · Anne Walling [‡,§] · Heather Patton [‖] · Tamar Taddei [¶]

Affiliations & Notes Article Info

Palliative Care and Cirrhosis

Most current recommendations pertain to decompensated cirrhosis, ESLD

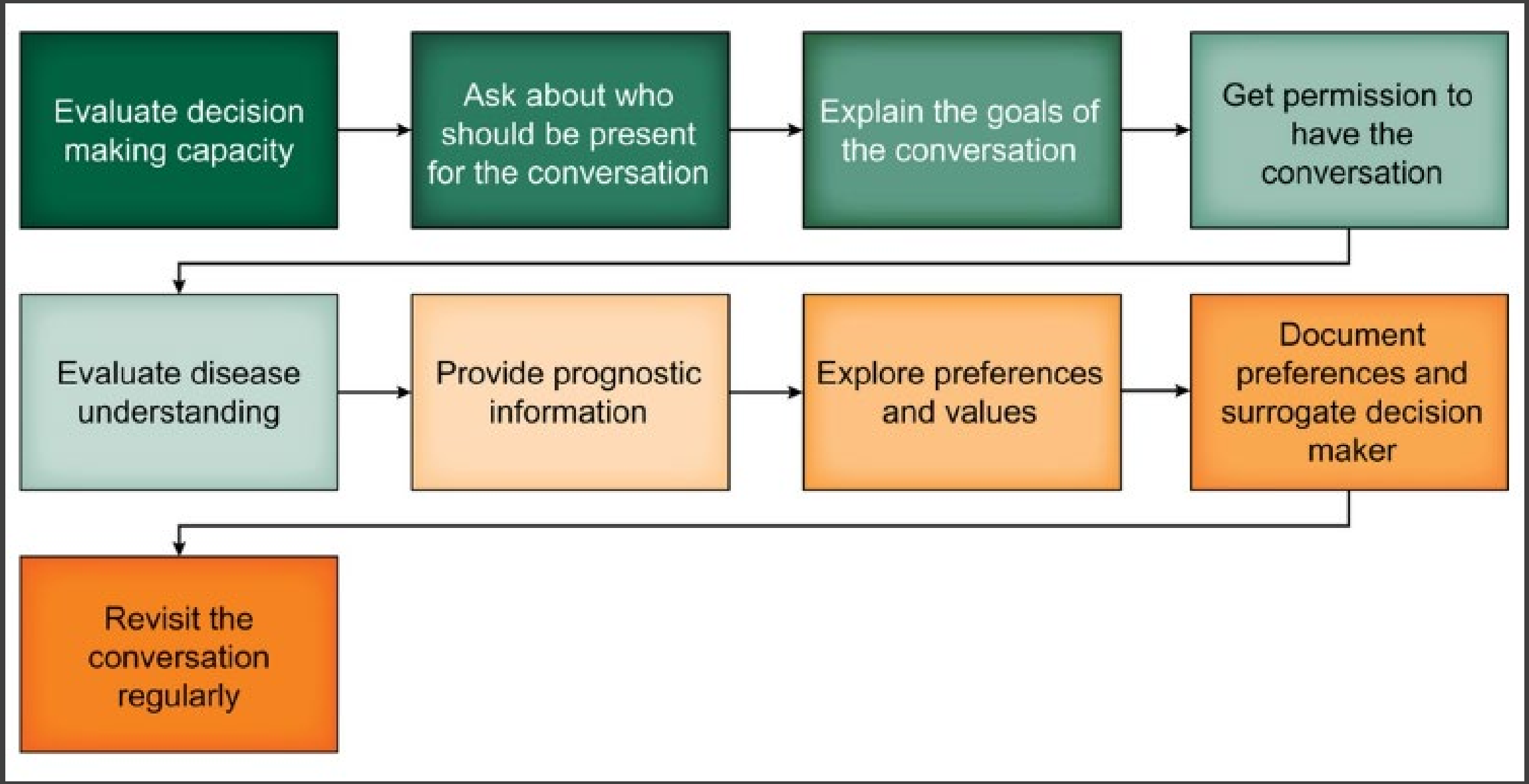
Specific recommendations regarding diagnosis and management of commonly reported symptoms

Primary vs Specialty Palliative Care

TABLE 1 - Key similarities and differences between primary palliative care, specialty palliative care, hospice, and advance care planning

	Primary palliative care	Specialty palliative care	Hospice	Advance care planning
Primary focus	Quality of life, symptoms, psychosocial and spiritual support	Quality of life, symptoms, psychosocial and spiritual support	Quality of life, symptoms, psychosocial and spiritual support	Longitudinal process of discussing and documenting patient values and preferences around their care (e.g., end of life); identifying surrogate decision makers
Delivered by	Primary or specialist treating teams	Palliative care clinicians/teams, as consultants or embedded within practices	Usually private hospice agencies (or within Veterans Administration system for veterans)	Any clinician; persons can also complete some documents on their own.
Timing	Any time a need is identified	Any time a need is identified	Prognosis ≤6 months	Can be addressed early in the illness course and revisited on a regular basis and when there are major clinical changes
Location	Anywhere under the care of treating team	Inpatient, outpatient, community (home, nursing home)	Home, nursing home, inpatient (limited time for uncontrolled symptoms)	Anywhere
Reimbursement	Routine CMS billing	Routine CMS billing	Capitated payment model through Medicare Part A	Can be reimbursed with ACP billing codes: 99497 (first 30 min) 99498 (additional 30 min)

Rogal, Shari S.1,2; Hansen, Lissi3; Patel, Arpan4,5; Ufere, Nneka N.6; Verma, Manisha7; Woodrell, Christopher D.8,9; Kanwal, Fasiha*,10,11. AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis. Hepatology 76(3):p 819-853, September 2022. | DOI: 10.1002/hep.32378



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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?)

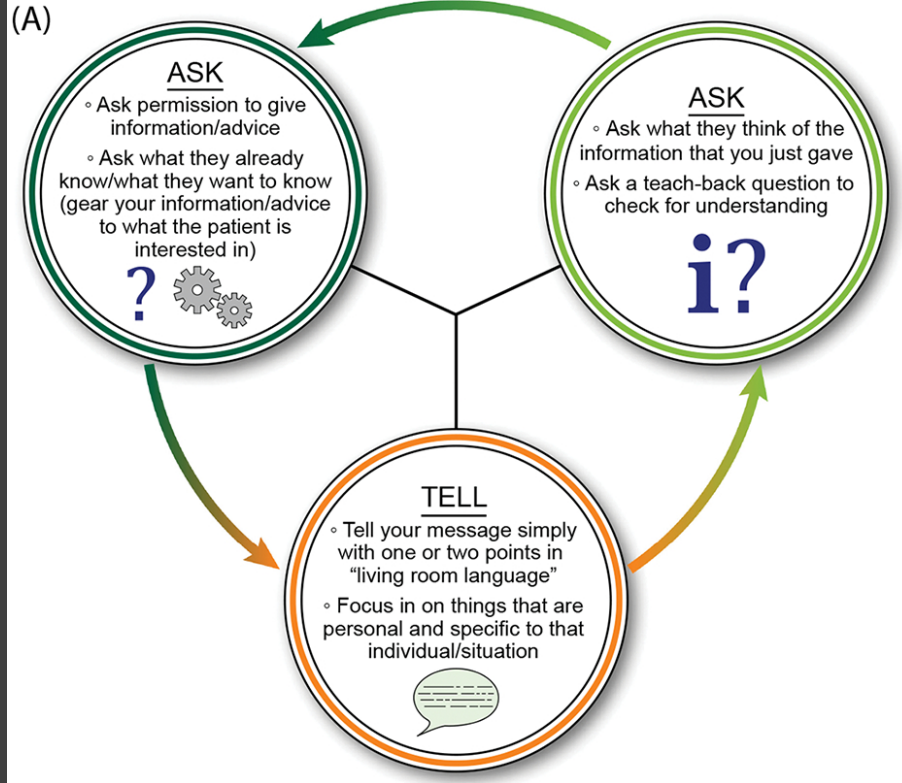
Caregiver needs (BPA 5)

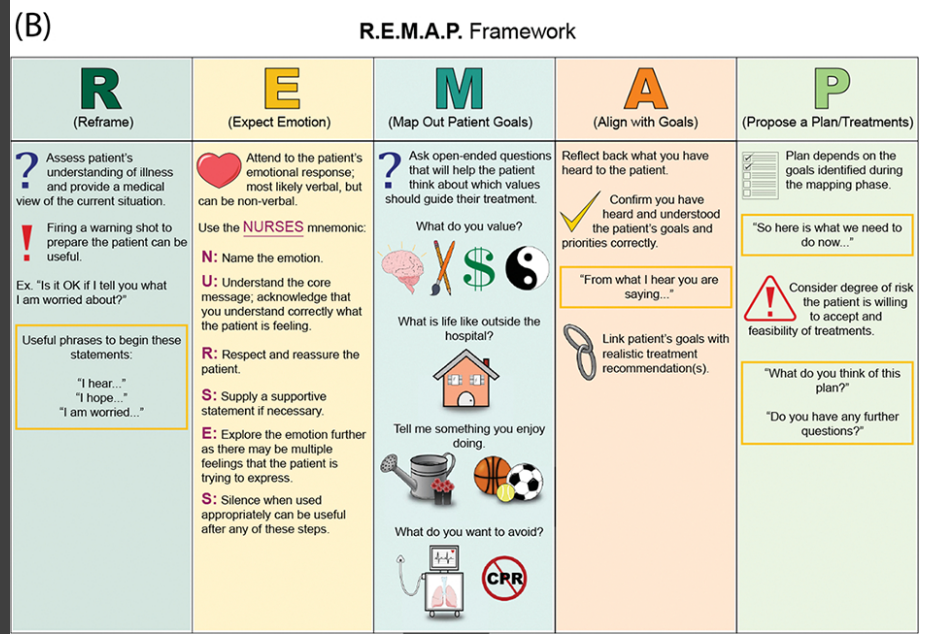
(e.g., ask– "I know this must be hard on you. How are you doing?", measure– Caregiver Strain Index, Zarit Burden Interview)

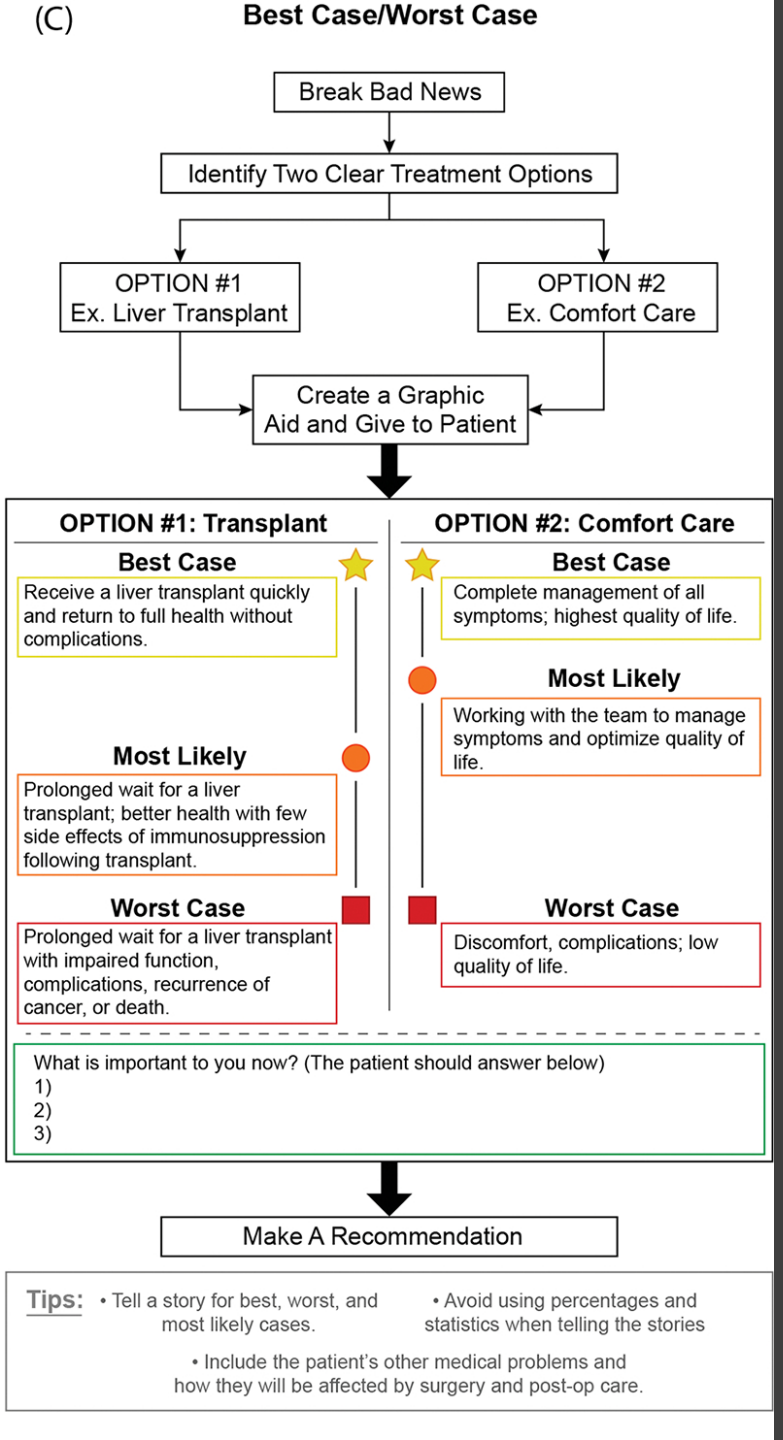
Access specialty services when needed (BPA 9,10)

(e.g., refer to specialty palliative care, refer to hospice)

AGA Clinical Practice Update on Palliative Care Management in Cirrhosis: Expert Review. Tandon, Puneeta et al. Clinical Gastroenterology and Hepatology, Volume 19, Issue 4, 646 - 656.e3







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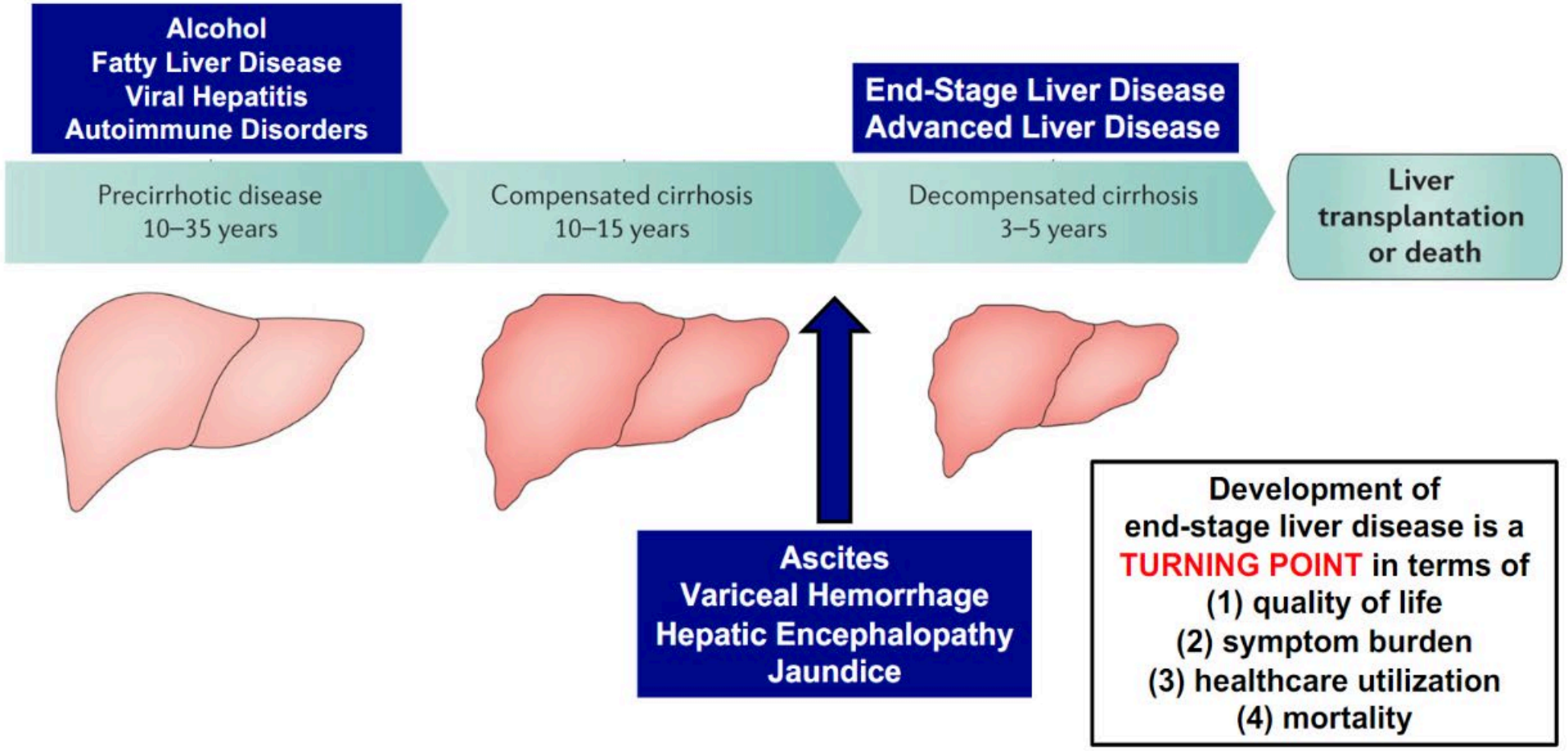
Decompensated liver cirrhosis

Objective measures



Arroyo et al., Nature Reviews Disease Primers, 2016; Garcia-Tsao et al., Hepatology, 2017

Defining ESLD

MELD-Na	90-day mortality estimates
• Need for dialysis • Creatinine • Bilirubin • INR • Na	• >32: 65-66% mortality

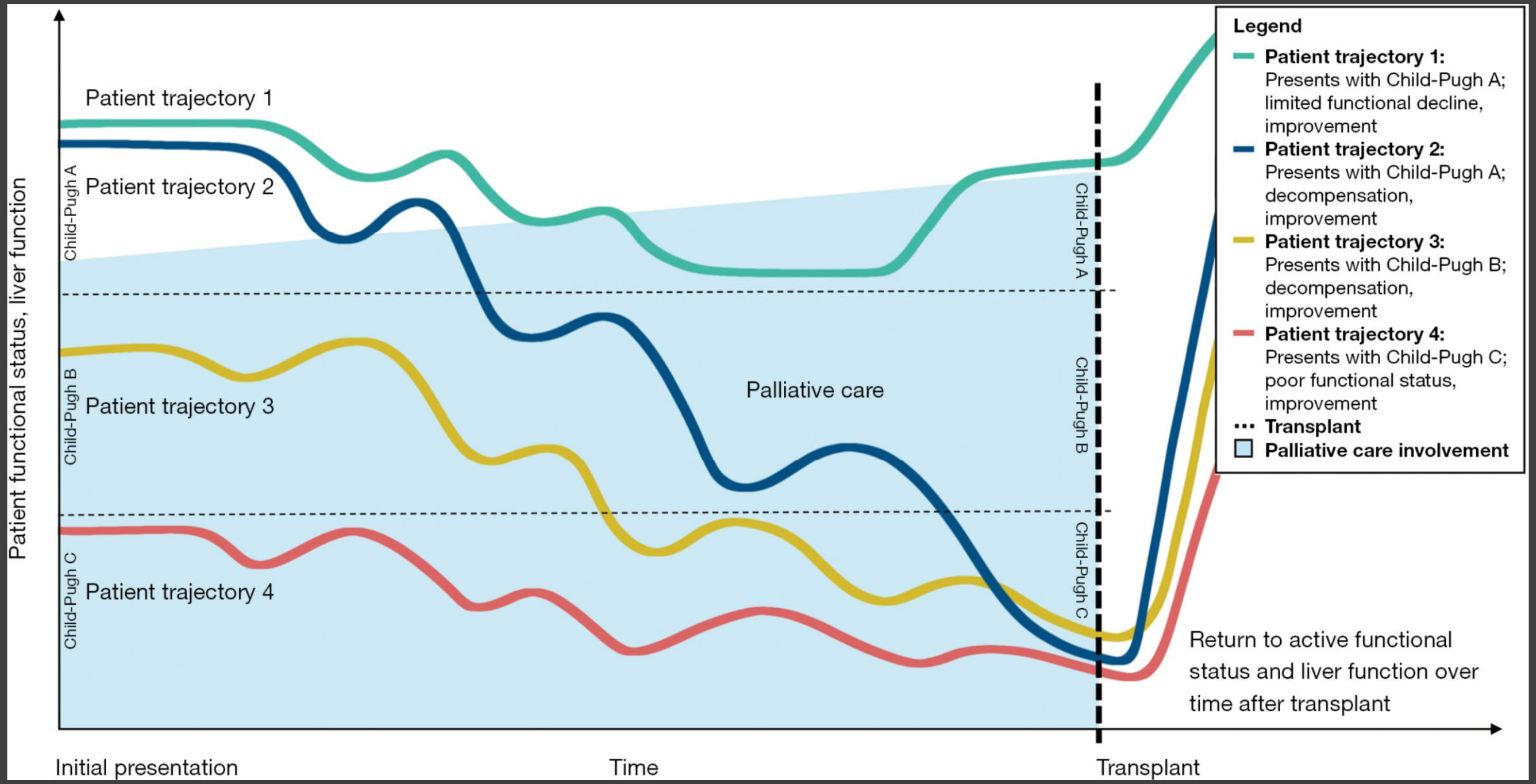
Defining ESLD

Child-Pugh

- Bilirubin
- Albumin
- INR
- Ascites
- Presence/severity of encephalopathy

Class A, B, C

- A: life expectancy >15 years
- B: indication for transplant evaluation
- C: life expectancy 1-3 years



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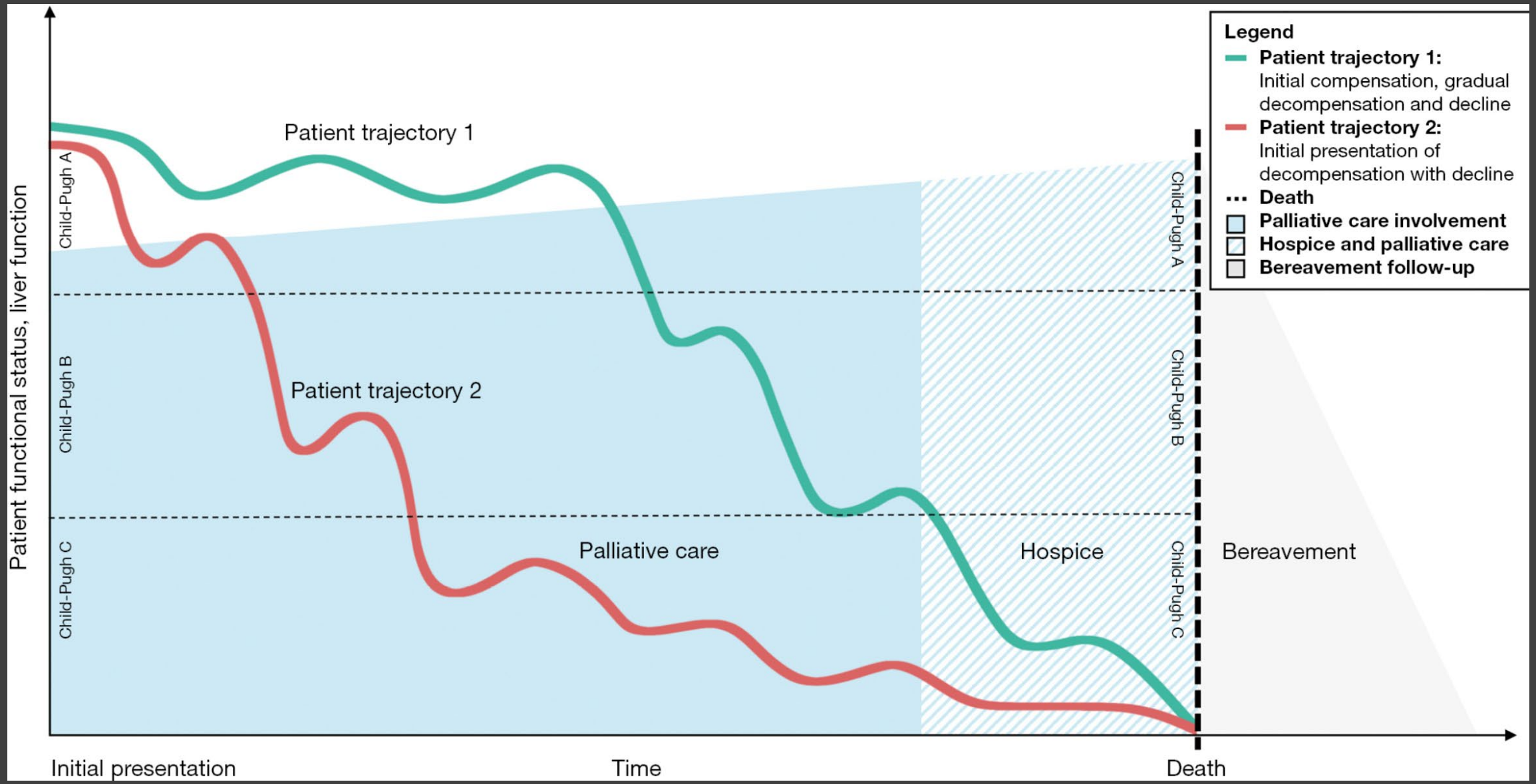

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HEPATOLOGY

AASLD
AMERICAN ASSOCIATION FOR THE STUDY OF LIVER DISEASES

Original Article | Free Access

Development of a novel frailty index to predict mortality in patients with end-stage liver disease

Jennifer C. Lai, Kenneth E. Covinsky, Jennifer L. Dodge, W. John Boscardin, Dorry L. Segev, John P. Roberts, Sandy Feng

First published: 19 April 2017 | https://doi.org/10.1002/hep.29219 | Citations: 250

Liver Frailty Index®

Inputs: For instructions, see ⓘ below.

1. Gender:

○ Male ○ Female

2. ⓘ Dominant hand grip strength (kg):

attempt 1:	attempt 2:	attempt 3:	Avg:	
				kg

3. ⓘ Time to do 5 chair stands:

sec

4. ⓘ Seconds holding 3 position balance:

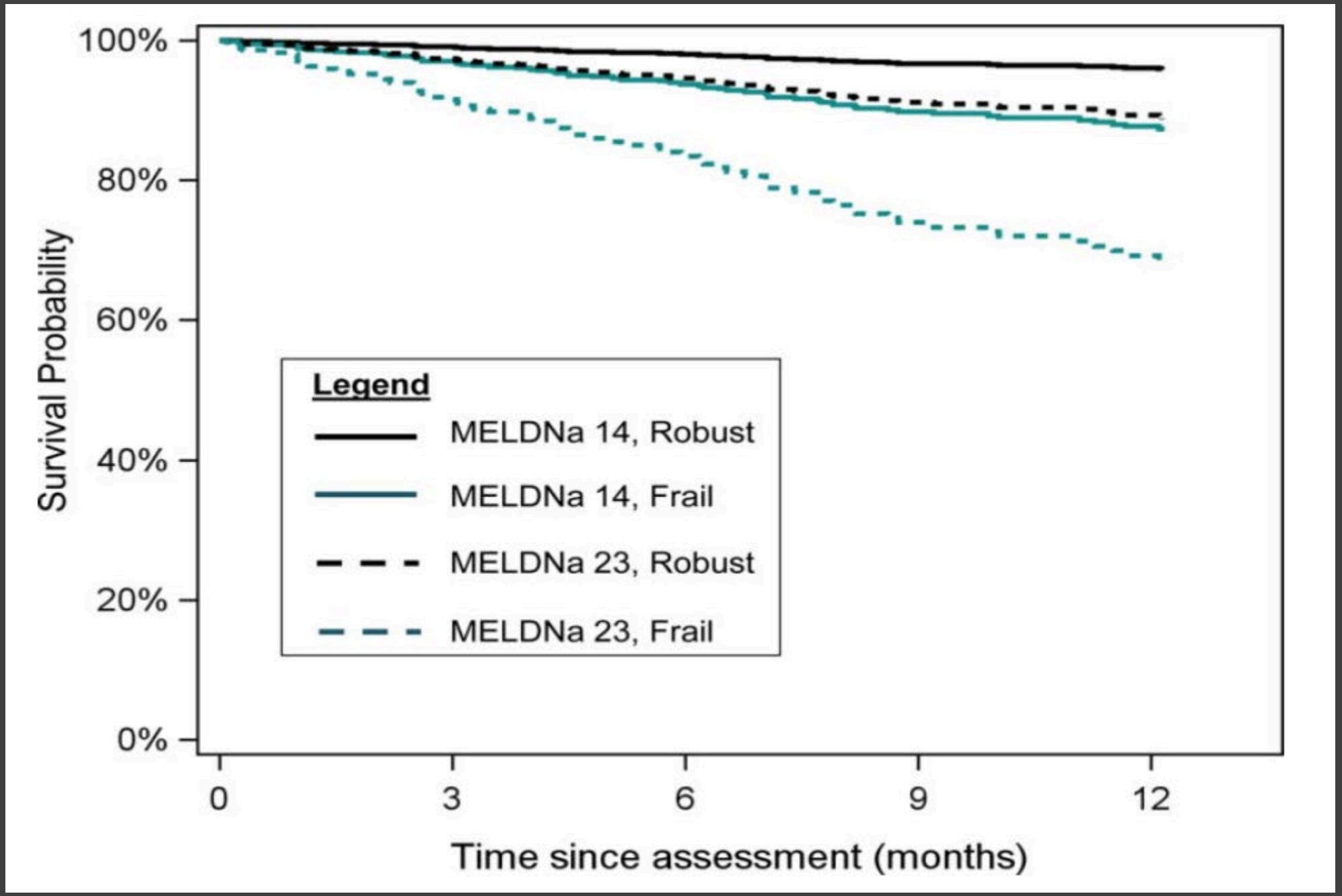
Side:	SemiTandem:	Tandem:	Total:	
				sec

Results: refresh results

The Liver Frailty Index® is ____

Decimal precision:

2



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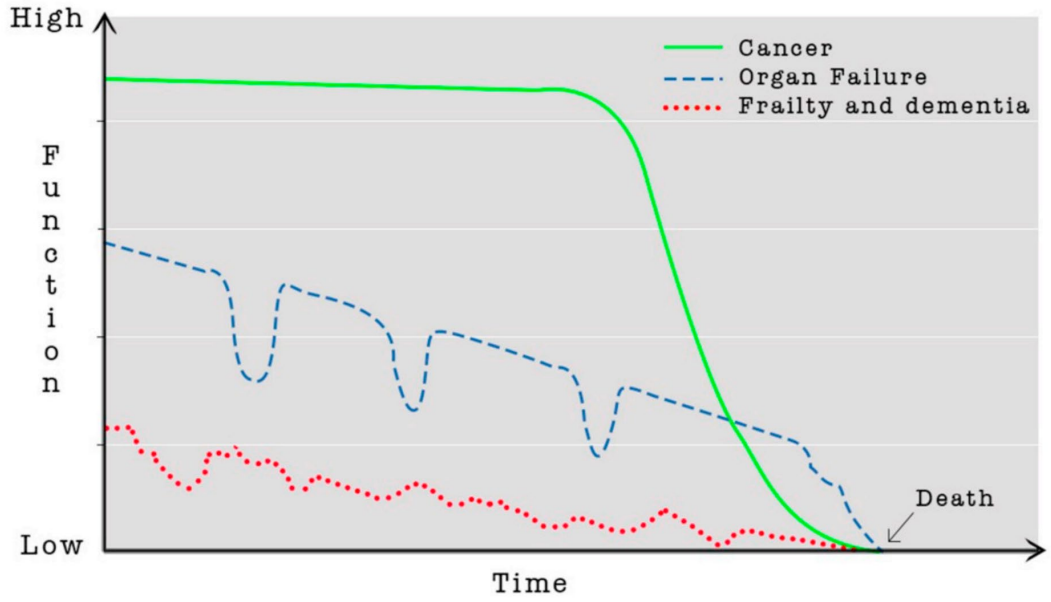
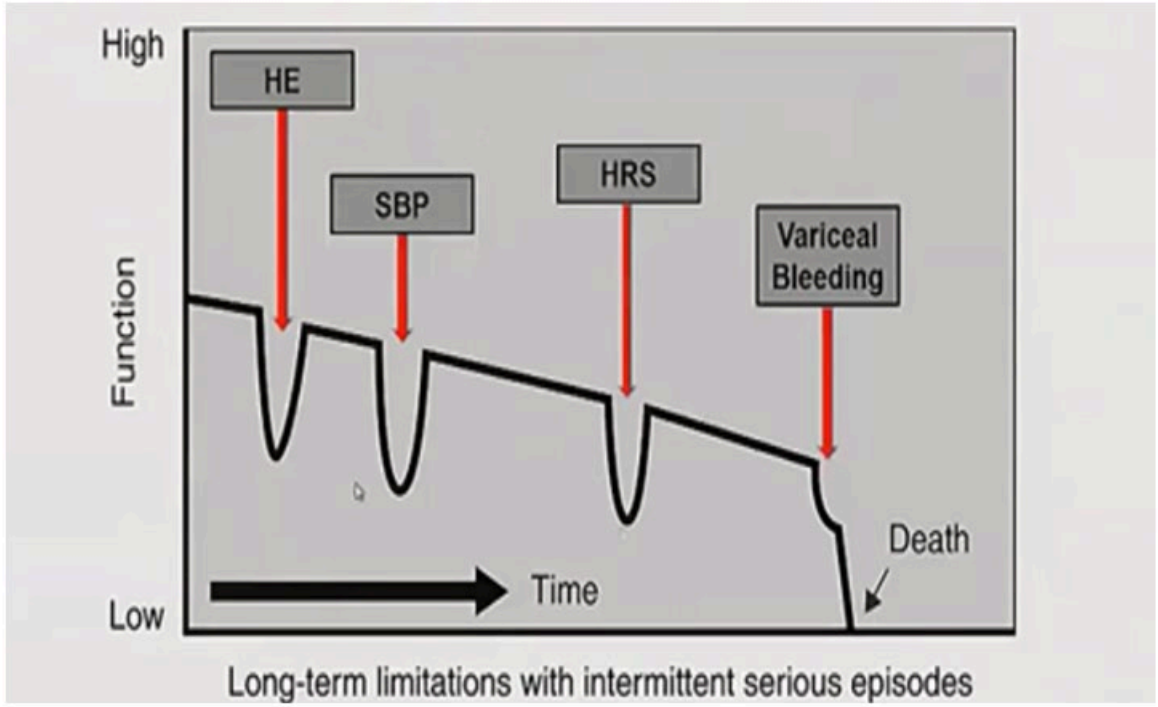


Fig. 3. The three typical end-of-life trajectories (adapted from Murray and McLoughlin, 2012, Fig. 3.1 cited Murray and Sheikh, 2008).

(left) image source: Teggi, Diana. (2018). Unexpected death in ill old age: An analysis of disadvantaged dying in the English old population. Social Science & Medicine. 217. 10.1016/j.socscimed.2018.09.048.



Lynn and adamson RAND Health 2003

Decompensated liver cirrhosis

Subjective measures

PHQ-9	ESAS	PROMIS-29, PROMIS-CAT	LDSI	CLDQ	SF-LDQOL
Anhedonia, feeling down, sleep, feeling tired, appetite, feeling bad about self, concentration, activity, suicidality	Pain, fatigue, myalgia, sexual dysfunction, anxiety, sleep disturbance, appetite, well-being, dyspnea, pruritis	Anxiety/fear, cognitive function, depression/sadness, fatigue, instrumental support, pain interference, physical function, sleep disturbance, social roles	Itch, joint pain, abdominal pain, daytime sleepiness, worry about family situation, decreased appetite, depression, fear of complications, jaundice	Abdominal symptoms, fatigue, systemic symptoms, activity, emotional function, worry	Symptoms, effects of liver disease, memory/concentration, sleep, hopelessness, distress, loneliness, stigma of liver

SF-36	Distress Thermometer (DT)	NHP	LC-PROM	LDQOL	SIP
Vitality, physical role functioning, bodily pain, general health perception, physical function, social role functioning, emotional role functioning, mental health	Overall assessment of distress plus practical problems, family problems, emotional problems, spiritual/religious concerns, physical problems	I: energy, sleep, emotions, pain, mobility, social isolation II: paid employment, housework, hobbies, family life, social life, sex life, holidays	Physical, psychological, social, therapeutic	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	Sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behavior, emotional behavior, communication

Common Symptoms in ESLD

Pain

Liver-associated mechanical pain, Inflammatory pain

- Ex: splenomegaly, ascites, and hepatic capsular stretch or indirectly because of elevation of proinflammatory cytokines

Non-liver-associated pain

- Common ex: neuropathic, musculoskeletal

Pain Management

Multidisciplinary approach	Evaluate for, and treat reversible causes	Medications
• Palliative care, psychiatry, pain management, pharmacy, physical and occupational therapy, or social work • Mindfulness/meditation, CBT, nerve block when appropriate	• Ascites • Local infection • MSK injury	• Nociceptive vs neuropathic regimen • Lowest effective dose

Ascites

Renal sodium retention

Worsens with disease progression

Often associated with pain, cramping, dyspnea

Management

- Diet and medication optimization
- Large volume paracentesis (LVP)
- TIPS
- Abdominal drains

Hepatic Encephalopathy (HE)

Range of neuropsychiatric abnormalities resulting from the accumulation of neurotoxic substances in the bloodstream of patients with liver dysfunction

Diagnosis of exclusion

Severe impacts on caregiving burden, patient quality of life

HE: Management

Lactulose

- Promotes excretion of ammonia via an osmotic effect
- Titrate to 2-3 bowel movements per day
- Associated with bloating, abdominal pain, diarrhea

Rifaximin

- Antibiotic that reduces ammonia production by targeting and eliminating ammonia-producing bacteria in the colon

Dyspnea: Etiology

Patient report of shortness of breath in ~47-88% of cirrhotic patients

- Ascites, volume overload (refractory to diuretics), hepatopulmonary syndrome, portopulmonary syndrome, infection, anxiety

Subjective markers:

- Difficulty pulling in a breath, increased effort of breathing, increased rate of breathing, overall distress

Objective markers:

- Hypoxia, tachypnea, use of accessory muscles

Dyspnea: Management

Pharmacologic treatment limited to end-of-life care	Non-pharmacologic treatments
• Opiates • Benzos	• Fan for stimulation of trigeminal nerve • Use of supplemental oxygen • Mindfulness exercises

Muscle Cramps: Etiology

Present in ~50% of patients

Common causes:

- Ascites complicated by spontaneous bacterial peritonitis (SBP) or electrolyte disturbances

Muscle Cramps: Management

Treat underlying etiology	Vitamins	Low dose baclofen
• SBP with antibiotics • Electrolyte abnormalities with repletion, adjustment of diet	• Vitamin E, taurine, L-carnitine	• Refractory cases

Pruritus

Multiple causes	• Ranging from topical irritants and dry skin to biliary stasis
Non-pharmacological therapy	• Topical emollients and creams
Lifestyle modifications	• Avoiding hot showers/baths, harsh soaps and detergents, wearing loose clothing
Pharmacological therapy	• Cholestyramine • Antihistamines are typically avoided due to side effect profile

Nausea, Vomiting: Etiology

Multifactorial

- Physical distention/discomfort from ascites
- Electrolyte imbalances
- Adrenal insufficiency
- Pharmacological causes
- Underlying gastrointestinal disorders (i.e. GERD)

Nausea, Vomiting: Management

Behavioral	Pharmacological
• Small, frequent meals • Aromatherapy, peppermint or alcohol wipes	• Ondansetron, haloperidol/olanzapine, metoclopramide, etc. • Treat underlying etiology

Sleep Disturbances

Non-pharmacological therapy	Pharmacological therapy
• Sleep hygiene, daily exercise • Cognitive behavioral therapy	• Melatonin • Hydroxyzine • Trazodone • Avoid benzodiazepines or hypnotics

Fatigue: Etiology

Evaluate for underlying factors

- Hypothyroidism
- Adrenal insufficiency
- Depression
- Sleep disorders

Fatigue: Management

Non-pharmacological

- Daily exercise; physical therapy assessment
- Evaluate for underlying etiology (if hypothyroid, adrenal, etc.)

Pharmacological

- Insufficient evidence for stimulants in cirrhotic patients
- Ex: modafinil, methylphenidate

Depression, Anxiety: Etiology

Multifactorial

- Underlying mood disorder
- Existential suffering
- Vitamin deficiencies
- Encephalopathy
- Sleep disturbances
- Hormonal
- Housing, food insecurity
- Financial instability

Depression, Anxiety: Management

Non-pharmacological

- Psychosocial support
- Multidisciplinary teams including psychiatry, counseling, social work, chaplain, palliative care providers

Pharmacological

- Selective norepinephrine reuptake inhibitors (SNRIs)
- Selective serotonin reuptake inhibitors (SSRIs)
- Benzos

Sexual Dysfunction

Screen for comorbidities

Decreasing use of alcohol, tobacco

Limited data for female patients

Erectile dysfunction

- Tadalafil

Criteria for hospice

In patients with decompensated cirrhosis

Patients should show both:

Prothrombin time prolonged >5s over control or INR >1.5

Serum albumin <2.5g/dL

In addition to supporting evidence from the following:

- Ascites, refractory to treatment or patient noncompliant
- SBP
- Hepatorenal syndrome
- Elevated Cr and BUN with oliguria
- HE, refractory to treatment or patient noncompliant
- Recurrent variceal bleeding, despite intensive therapy

Documentation of the following to support eligibility for hospice care:

- Progressive malnutrition
- Muscle wasting with reduced strength and endurance
- Continued active alcohol use
- HCC
- HBsAg positive
- Hepatitis C refractory to treatment
- MELD score >21
- Child-Pugh score >12

Back to our patient case, Mrs. H

Patient without specialty palliative care until time of hospitalization

Is this due to…

Patient preference?	Provider preference?	Lack of specialist availability?	Not knowing resources available to ESLD patients?	Initially low symptom burden?

Moving forward

Optimizing Palliative Care Involvement

Identifying local billing codes

Prescreening surveys completed by ancillary staff

Development of multidisciplinary teams

Timely referrals to hospice based on aforementioned criteria

Resources

- Rogal, Shari S.1,2; Hansen, Lissi3; Patel, Arpan4,5; Ufere, Nneka N.6; Verma, Manisha7; Woodrell, Christopher D.8,9; Kanwal, Fasiha*,10,11. AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis. Hepatology 76(3):p 819-853, September 2022. | DOI: 10.1002/hep.32378
- AGA Clinical Practice Update on Palliative Care Management in Cirrhosis: Expert Review. Tandon, Puneeta et al. Clinical Gastroenterology and Hepatology, Volume 19, Issue 4, 646 - 656.e3
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Questions?