

Palliative/Supportive Care in End Stage Liver Disease

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Objectives

- Scope of the problem
- Definitions
- Factors in ESLD that lead to poor outcomes
- Current management
- Why palliative care needs to be incorporated into the management of ESLD

Scope of the problem

- **Chronic liver disease (CLD) is common**
 - Viral hepatitis C (and B), NASH, Alcohol
 - Increasing prevalence (NASH and Alcohol)
- **Cirrhosis can develop in 20-25% in CLD**
- **Those with cirrhosis can progress to End Stage Liver Disease (ESLD)**
 - Synthetic dysfunction: jaundice, coagulopathy, low albumin
 - Portal Hypertension: Ascites, varices, encephalopathy, SBP
 - Kidney dysfunction: Hyponatremia, AKI, HRS and CKD
 - Hepatocellular carcinoma (HCC)
- Once you develop hepatic decompensation, **prognosis is poor**
- The only long term treatment is liver transplantation

Hepatology consults at VCU: 3/21 to 7/21

- The majority of patients had underlying **alcohol-related liver disease followed by NASH and HCC**.
- The most common liver-related indications for admission were **ascites, HE, AKI, and portal hypertensive bleeding**. Of those admitted with ascites, 13% had SBP.
- The mean MELD at admission was 24.8. Importantly, **52% had a prior admission and of these 69% were re-admitted within 30 days** of the prior discharge supporting the **high burden of decompensated liver disease to our health system**.
- **Palliative care was consulted in only 10%** and was higher in those with HCC (33%) than other diseases (<10%).

Hepatology Inpatient Consults (N=155)	
Age (mean ± SD)	51±13
Gender (male)	50%
Race (White/Black)	75%/14%
Liver Disease	
• Alcohol	64%
• NASH	16%
• HCC	10%
Indication for admission	
• Ascites	71%
• HE	64%
• AKI	52%
• PHT bleeding	30%
Prior admission	52%
Prior admission ≤ 30 days	69%
MELD (mean ± SD)	24.8 ± 6.6
Palliative care consult	10%

Palliative care is underutilized

Hospital readmissions at VCU

Between 2/10/17 and 5/10/20

- **423 re-admissions among 235 patients (range 1-10 readmissions) within 30 days of the initial admission**

Hospital Readmissions	
Age (mean $\pm$ SD)	56 $\pm$ 11
Gender (male)	63%
Race (White/Black)	65%/30%
Non-Hispanic	97%
Disease Etiology	
Alcohol	39%
HCV	14%
NASH	14%
Alcohol + HCV	17%
Comorbid diseases	
CKD	20%
DM	28%
HTN	47%
DL	15%
CAD	13%
HCC	17%
Depression	18%
AUD (current)	21%
MELD	22.8 $\pm$ 7.6

Liver Transplantation at VCU 2017-2020

Liver Transplants at VCU	2017	2018	2019	2020
Number	85	79	87	135
Age (years); median (IQR)	60 (46-67)	60 (46-67)	55 (34-67)	56 (36-67)
Gender (% male)	78	76	63	64
Race (% White/Black/other)	70/22/8	68/19/13	63/27/10	75/18/7
Disease etiology (% AUD/HCV/NASH/AUD+HCV/HCC)	8/3/17/8/30	24/13/19/4/1	24/7/25/6/5	38/6/19/4/5
MELD at transplant; median (IQR)	28 (20-35)	29 (22-26)	26 (19-40)	27 (16-39)

Symptom and care burden often overlooked

- Reduced quality of life (QOL) (almost universal)
- Fatigue (52-86%)
- Depression (10-64%)
- Sleep disturbance (26-77%)
- Chronic pain (30-77%)
- Muscle cramps (56-68%)
- Frailty (17-43%)
- Sarcopenia (30-70%)
- Increased care giver burden

Not captured by MELD and Child class scores

Symptom Assessment

Variable	Patients <i>n</i> (%)		
Pain	89 (94.7)	Numbness/tingling in hands and feet	46 (48.9)
Lack of energy	87 (92.6)	Shortness of breath	44 (46.8)
Feeling drowsy	74 (78.7)	Change in the way food tastes	43 (45.7)
Difficulty sleeping	71 (75.5)	Feeling nervous	43 (45.7)
Difficulty concentrating	66 (70.2)	Dizziness	41 (43.6)
Lack of appetite	63 (67.0)	Cough	40 (42.6)
Feeling irritable	63 (67.0)	Diarrhea	39 (41.5)
Itching	62 (66.0)	Changes in skin	36 (38.3)
Dry mouth	61 (64.9)	I don't look like myself	34 (36.2)
Worrying	56 (59.6)	Constipation	33 (35.1)
Nausea	55 (58.5)	Problems with urination	32 (34.0)
Problems with sexual interest or activity	55 (58.5)	Sweats	32 (34.0)
Swelling of arms or legs	54 (57.5)	Vomiting	30 (31.9)
Feeling bloated	52 (55.3)	Difficulty swallowing	26 (27.7)
Feeling sad	50 (53.2)	Weight loss	25 (26.6)
		Hair loss	13 (13.8)
		Mouth sores	12 (12.8)

Factors that affect the clinical picture in ESLD

Cirrhosis related	Physical inactivity	Organizational	Other
• Synthetic dysfunction • Portal hypertension • Fluid retention • Ascites • Cognitive dysfunction • Encephalopathy • Increased ammonia • Anabolic resistance • Etiology of liver disease • HCC • Edema • Overall catabolic state • Oxidative stress	• Muscle disuse • Cardiovascular deconditioning • Frailty • Sarcopenia • Weakness	• Delayed diagnosis • Social determinants of health • Lack of resources • Confusion of responsibility • Distance to liver center • Insurance coverage • Financial • Care giver burden	• Systemic inflammation • Metabolic dysregulation • Insulin resistance • Endocrine dysfunction • Age-related conditions • Reduced testosterone • Malnutrition • Microbiome

Definitions

- **Malnutrition**

- Imbalance (deficiency or excess) of nutrients and affect tissue body/form or function

- **Frailty**

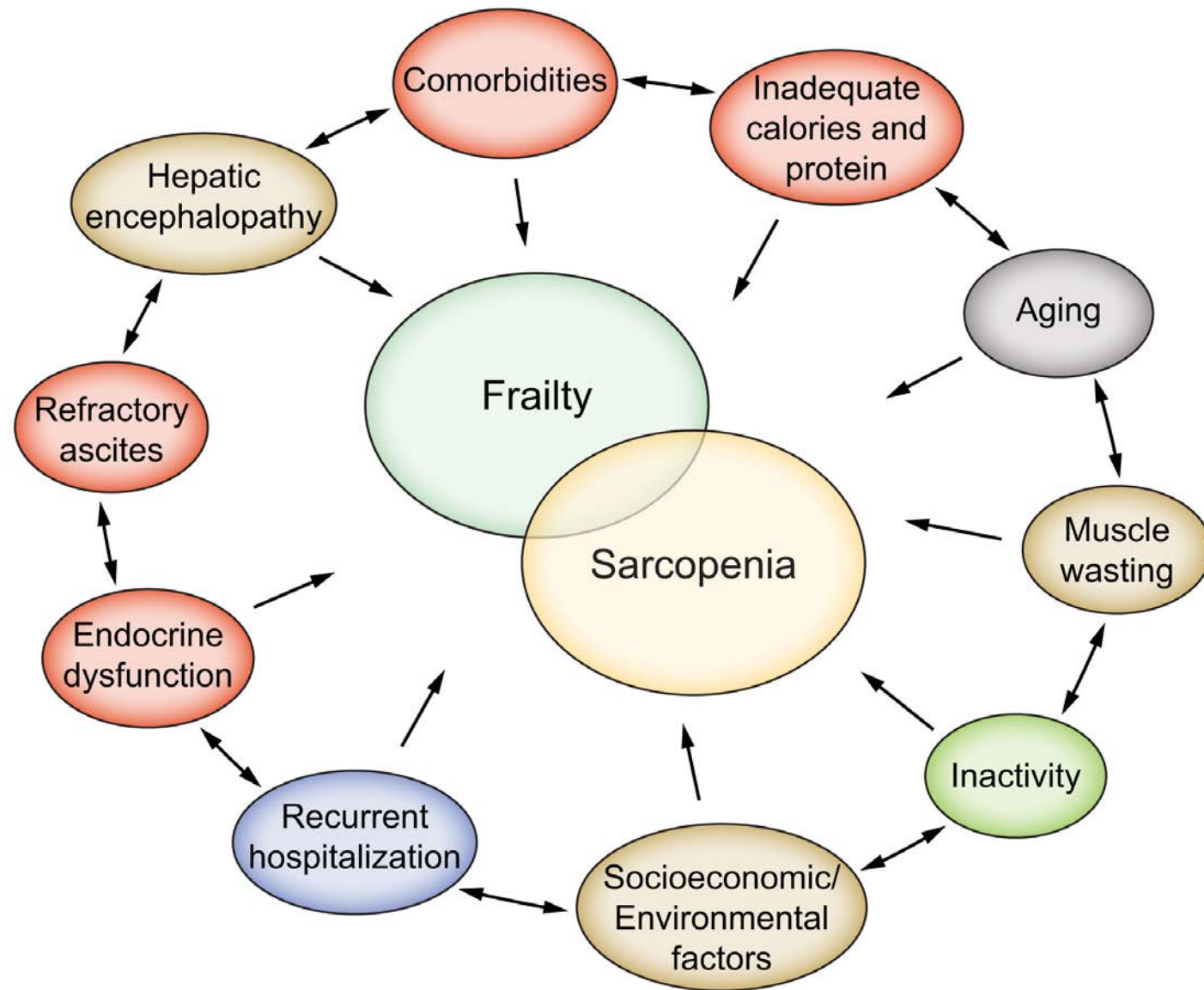
- Clinical state of decreased physiologic reserve
- Physical frailty: impaired muscle contractile function that leads to decreased physical function, performance, and disability

- **Sarcopenia**

- Progressive skeletal muscle

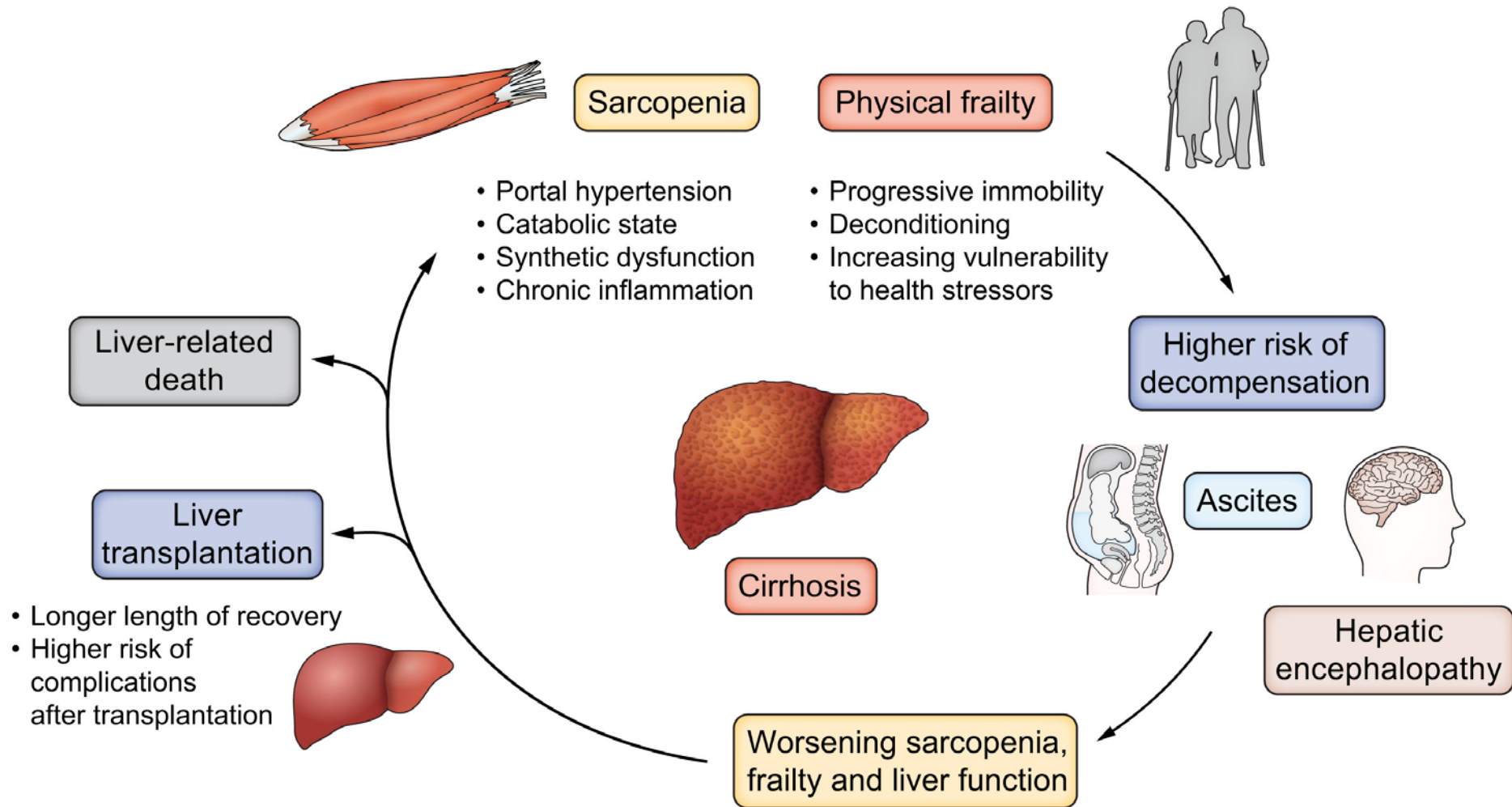
Malnutrition in ESLD

- **Poor po intake**
 - Early satiety
 - Nausea and vomiting
 - Dysgeusia
 - Unpalatable diet (low Na)
 - Water restriction
- **Defects in absorption/increased loss**
 - Fat soluble vitamins, fatty acids, zinc
 - Bacterial overgrowth
 - Na/K/Mg loss with diuretics
- **NPO** for procedures



Tools to assess frailty and sarcopenia

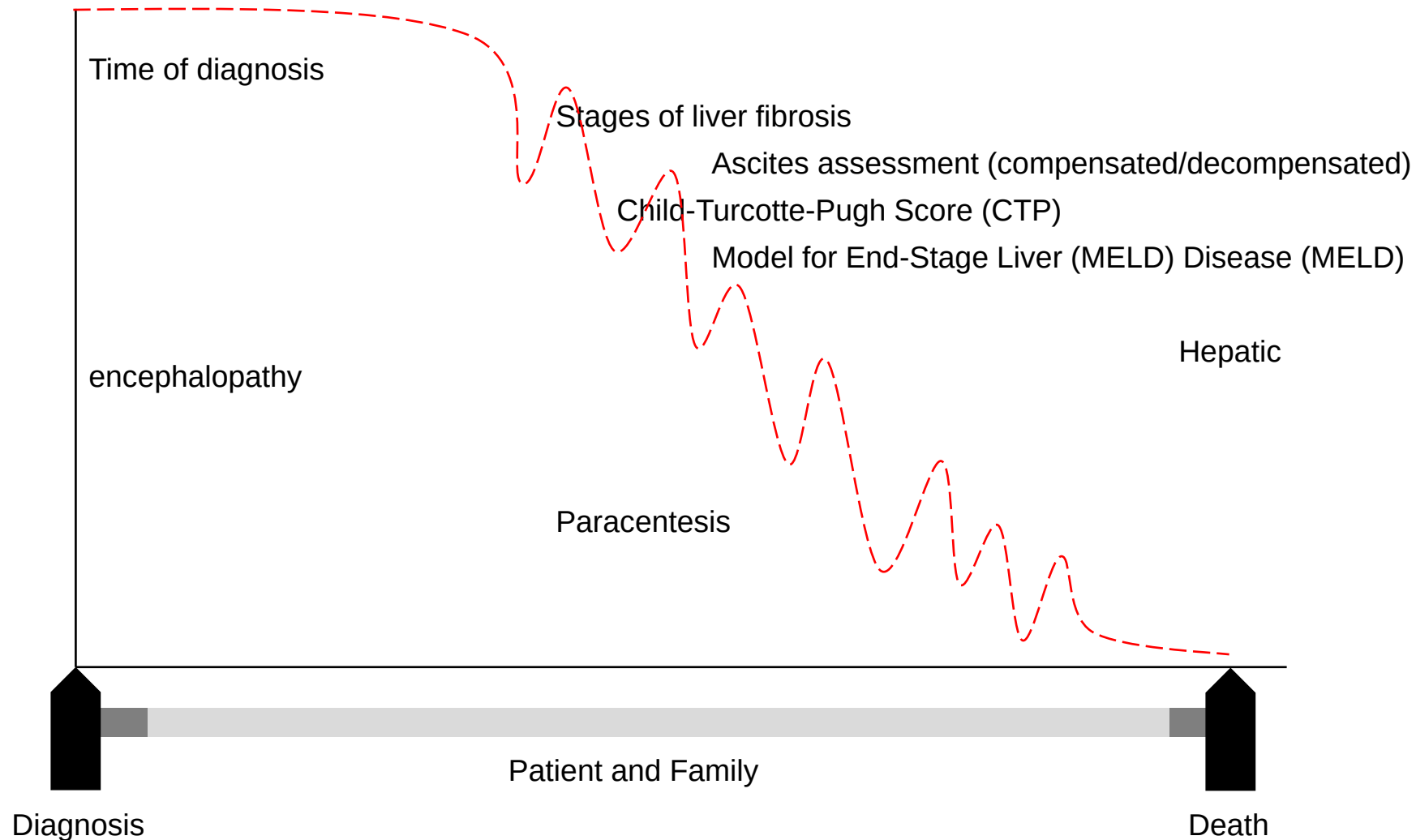
Frailty	Sarcopenia
Clinical frailty score (1-9)	Total skeletal muscle area at L3 normalized to height (Skeletal muscle index, SMI)
Karnofsky Performance Status (0-100)	DEXA
Liver Frailty Index (0-5)	Psoas muscle index
6 minute walk	Bioelectrical impedance analysis (BEI)
Grip strength	Anthropomorphic (mid-arm circumference, triceps skin fold thickness)



Current management of ESLD

- PCP → local GI → Hepatology/Transplant center
- Hepatology manages complications of liver disease
- Some get evaluated for transplant (and some don't)
- Care of other symptoms get referred back to PCP

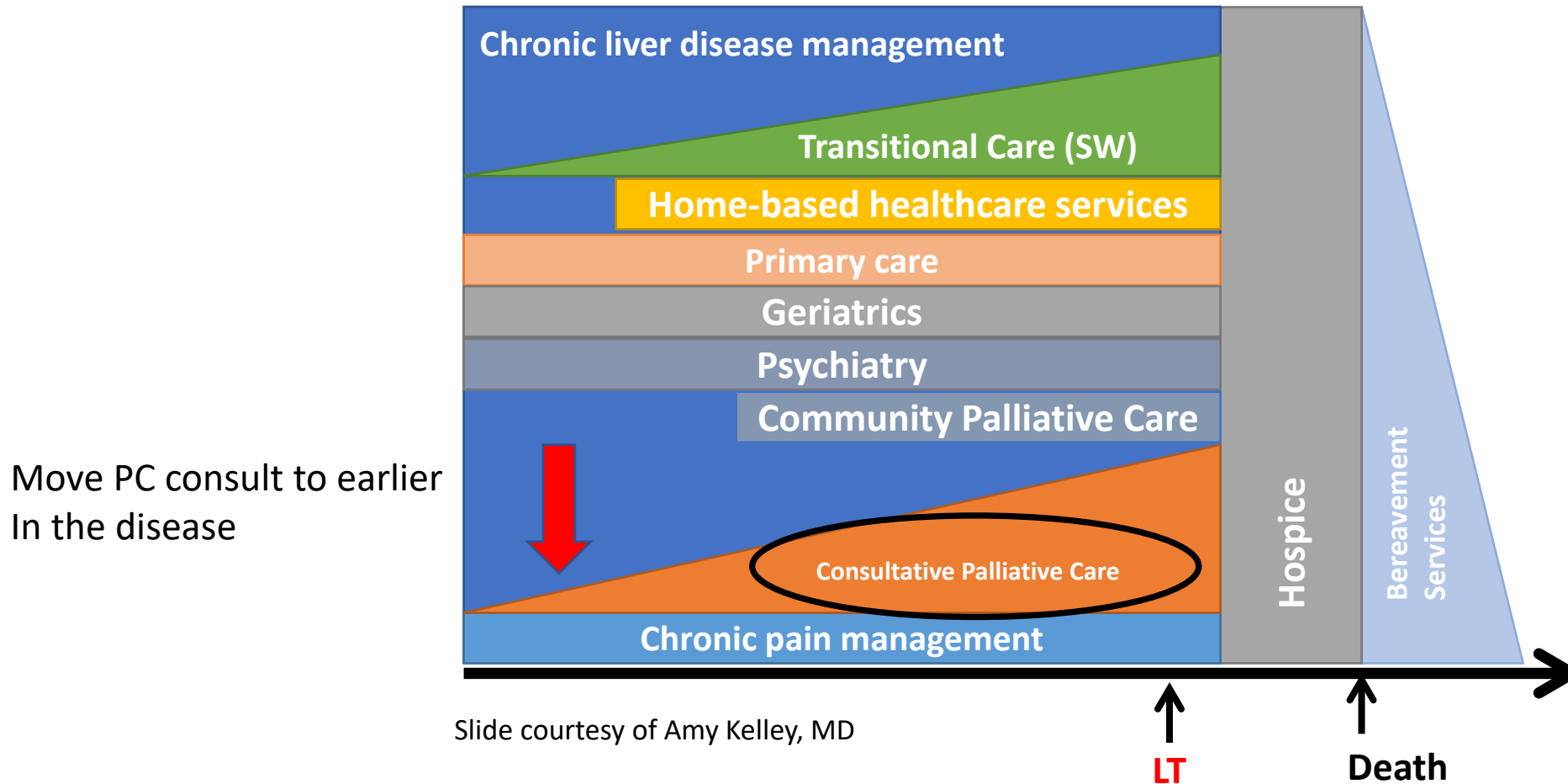
Across the Trajectory of Liver Disease:



Palliative (Supportive) Care in ESLD

- An **approach that improves the quality of life** of patients and their families who are facing problems associated with life-threatening illness
- **Ideally suited** to help assess and care for those with systemic illness such as **ESLD**
- Provide **holistic care** to both patients and caregivers
- **Focus on symptom management**, goals of care discussions, advanced care planning, care giver burden
- **Improve QOL, lower health care costs** by preventing ER visits and readmissions, improve communications

Spectrum of Services for People with Advanced Liver Disease



Slide courtesy of Amy Kelley, MD

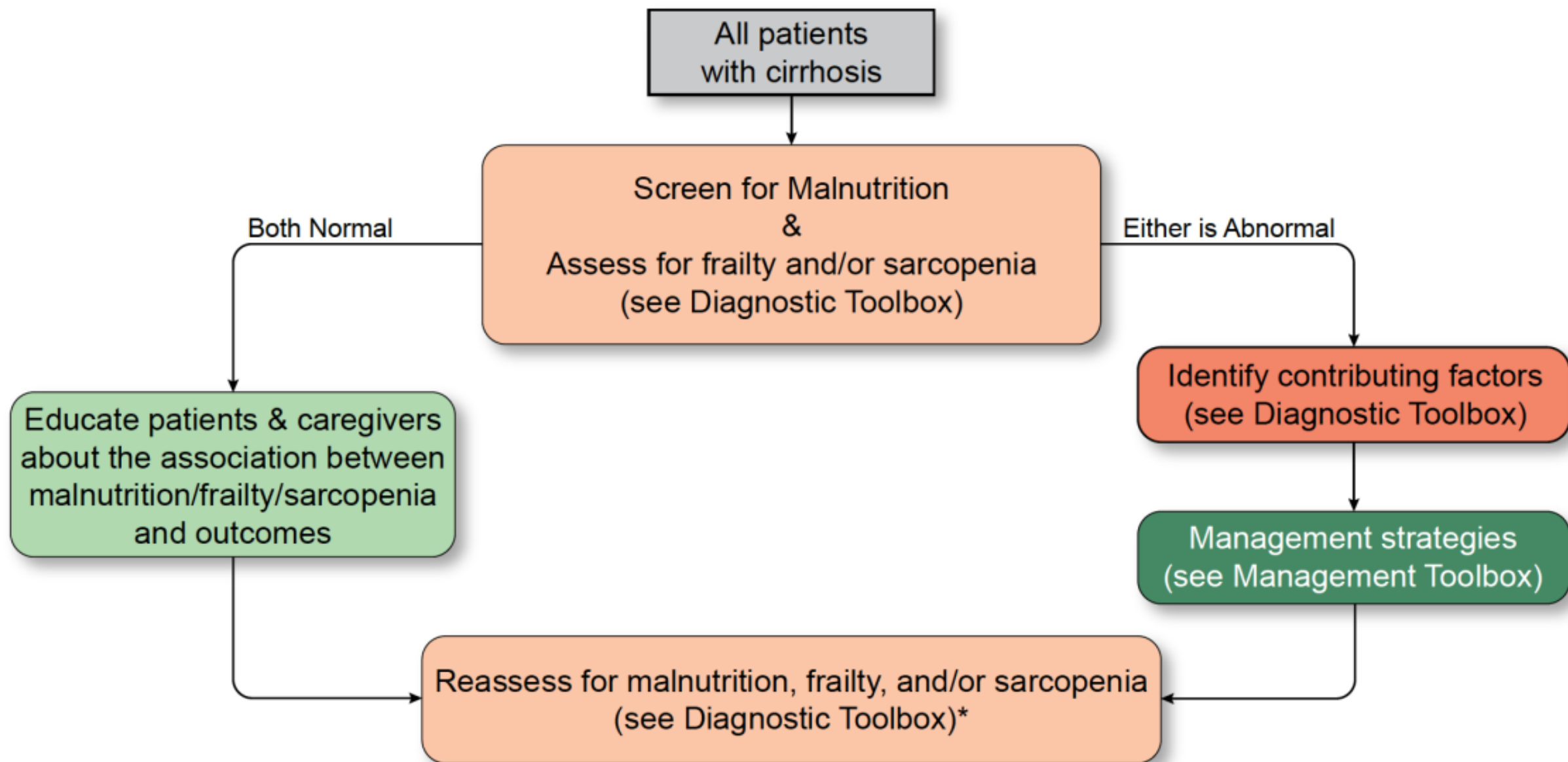
Palliative Care vs. Hospice

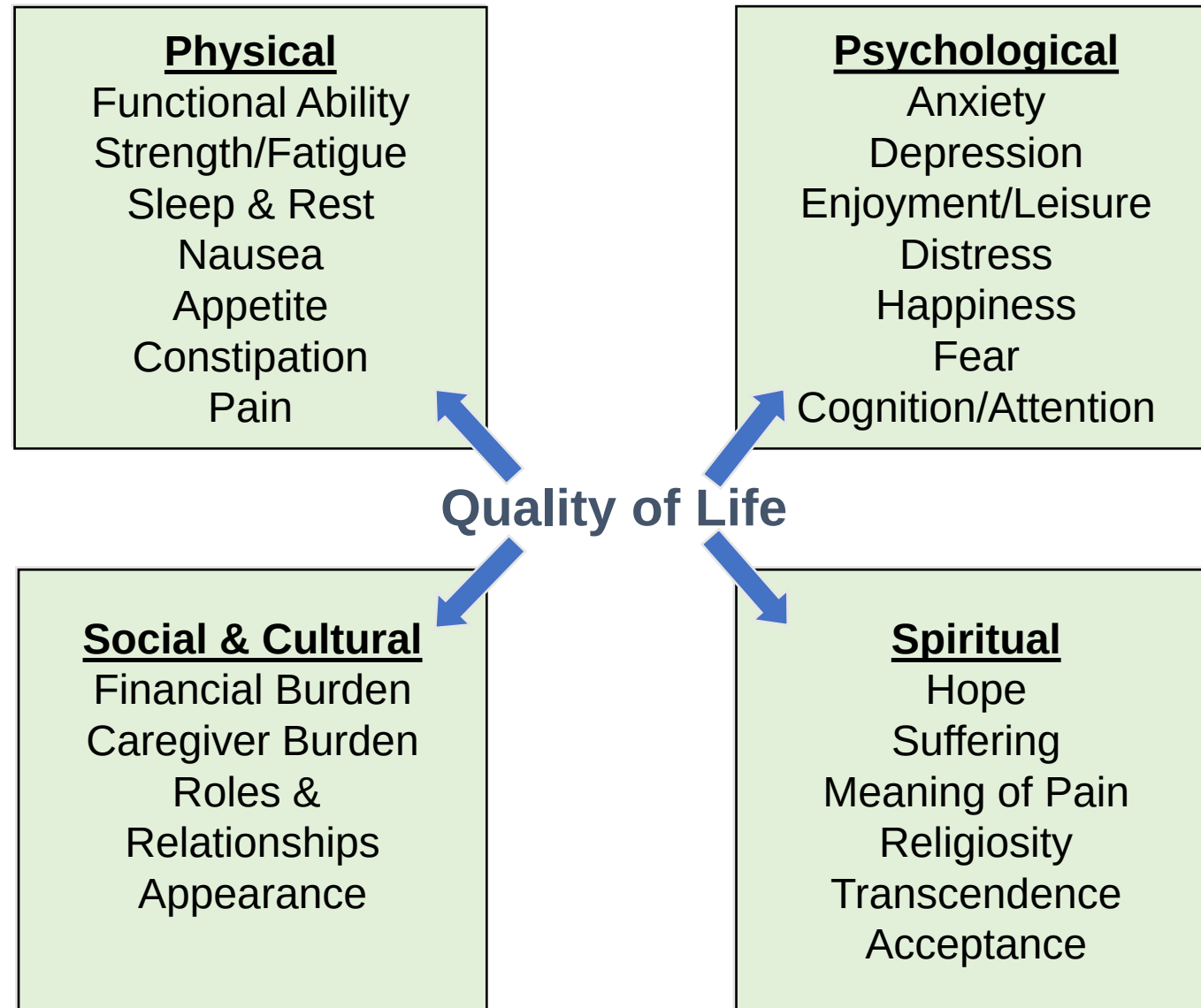
Palliative Care



Hospice

- o Receive medical treatment & palliative care concurrently
 - o Delivery of appropriate supportive interventions and consultations
 - o Coordination of care
 - o Collaboration with referring physician
 - o Goals of care/care preferences
 - o Help in navigating the healthcare system
 - o Facilitate transition to alternative care settings
- o Life expectancy of six months or less
 - o Prepares the patient and the patient's family for his/her death
 - o Help with practical tasks like bathing
 - o Usually delivered at home or in nursing home
 - o Primarily nurse led (is interdisciplinary)
 - o Symptom management





Adapted from Ferrell et al., 1991; Ferrell et al., 1996

Advance Care Planning (ACP)

Awareness of Prognosis and
Future Health Events

Clarification of Values
and Health Goals

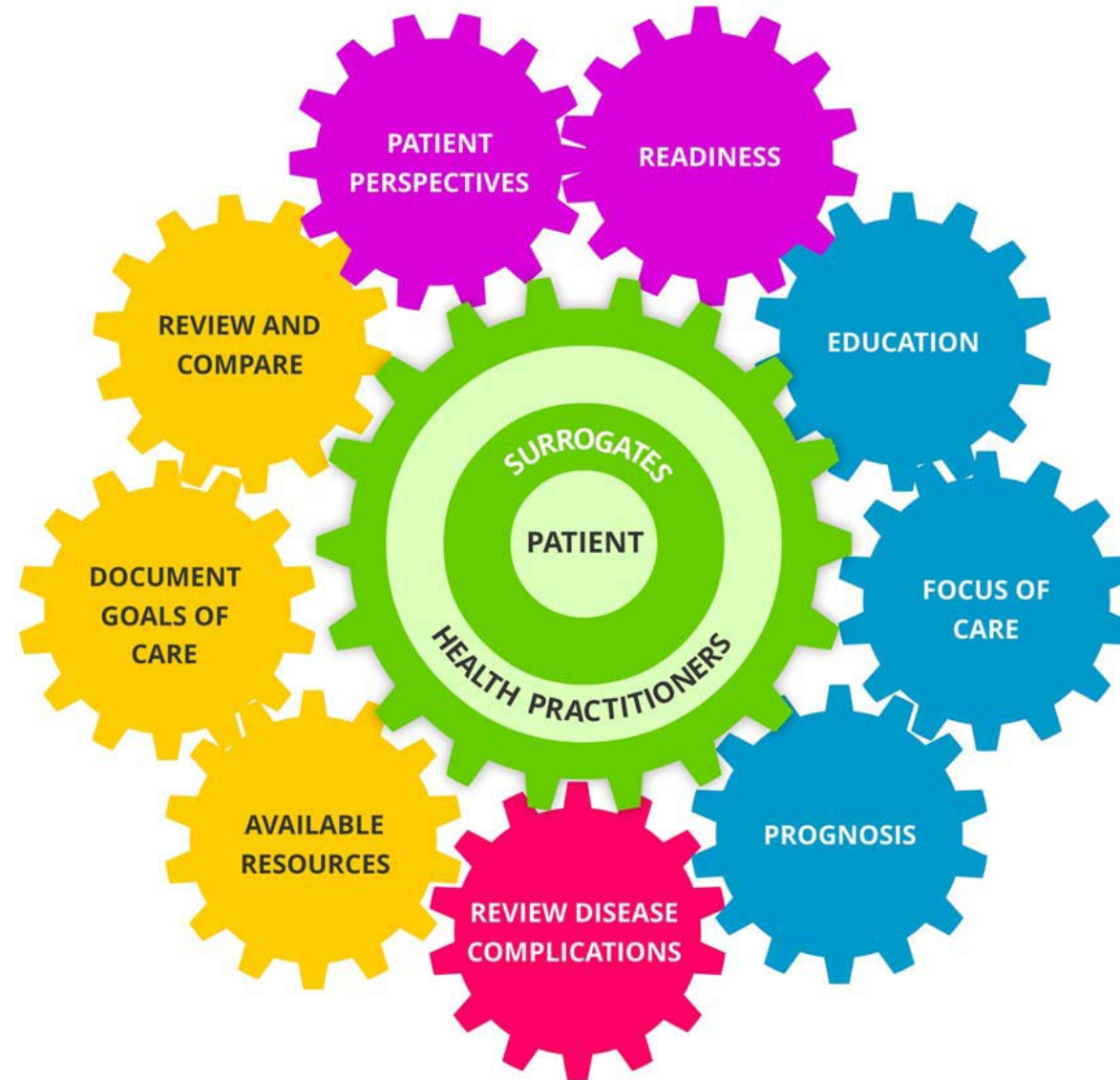
Establishing Care
Preferences

Establishing a Surrogate
Decision Maker**

Documentation

Hastings Center Guidelines for End of Life Care
Billings et al. JAMA Int Med 2014

Advance Care Planning



Domains of Palliative Care: A perfect fit for ESLD

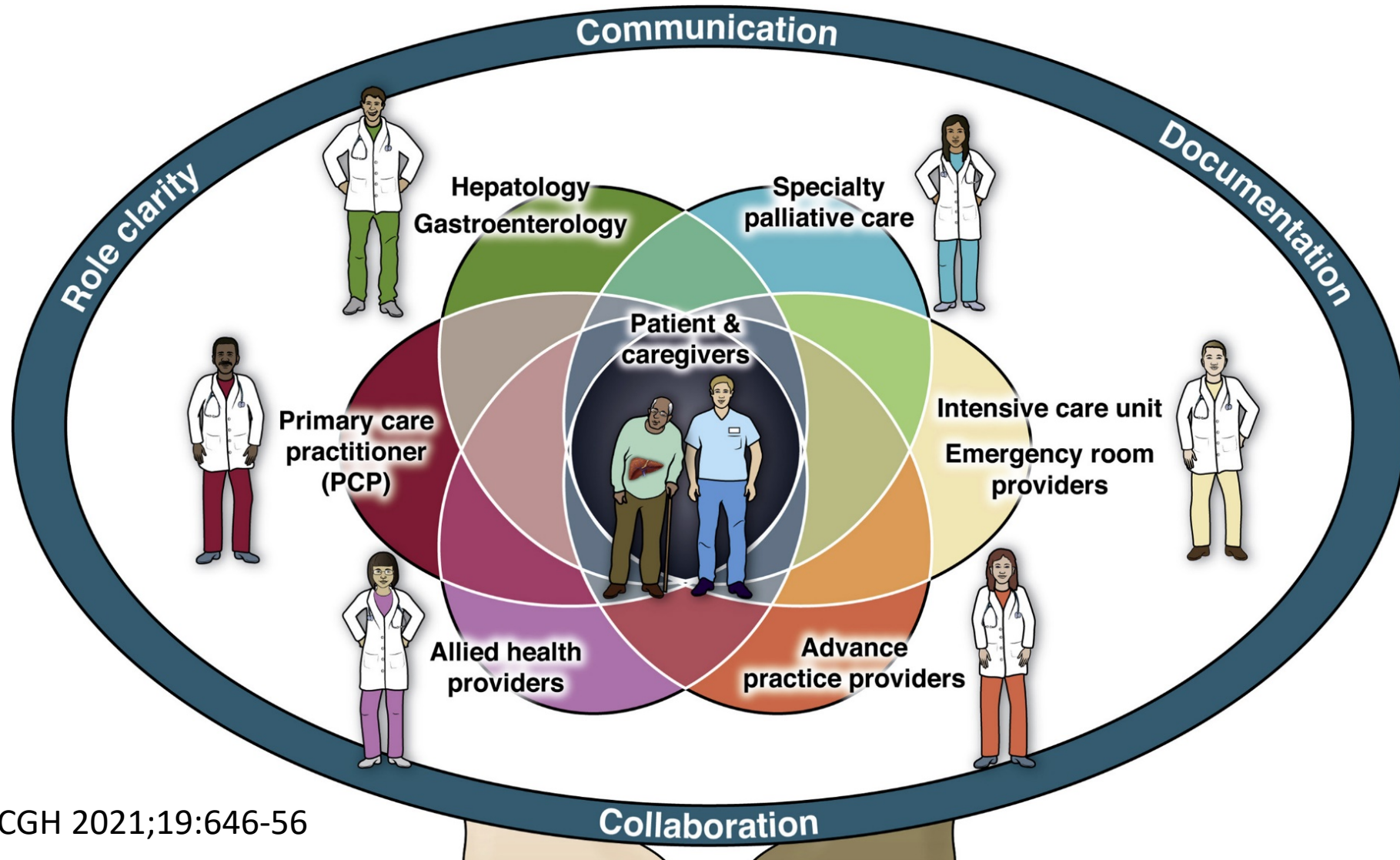


Adapted from National Consensus Project, 2018

Palliative Care in ESLD: AGA Best Practice

Table 1: AGA Best Practice Advice on PC in ESLD (adapted from Tandon et al)	
1	Care with PC principles should be provided to any patient with ESLD, irrespective of LT candidacy and based on needs instead of prognosis.
2	PC may be provided by health care providers from any specialty within any healthcare setting.
3	Providers caring for those with ESLD should assess for the severity of symptoms within physical, psychosocial, social, and spiritual domains.
4	Excellence in communications in goals of care, advanced care planning, and cultivating prognostic awareness with patients and caregivers.
5	Care in those with ESLD should include assessment of caregiver support and needs.
6	Prognosis should be evaluated during both routine visits and during sentinel events.
7	Goals of care discussions should be repeated at hospital admissions, when new complications develop, before the initiation of life saving therapies, before surgeries, and after LT eligibility.
8	Providers should optimize efficiencies in PC delivery including billing codes for services provided, surveys performed by ancillary staff, and multidisciplinary teams.
9	Healthcare teams should develop triggers and pathways for PC referrals in those with ESLD.
10	Timely referral to hospice for those with comfort-oriented goals and prognosis less than 6 months.

Integrating palliative care into ESLD management



Integrated team approach to palliative/supportive care in ESLD



Conclusions

- Liver disease is **common**.
- 20-30% will progress to **cirrhosis and many progress to ESLD**.
- In addition to complications of cirrhosis (synthetic and PHT), ESLD has **frailty, sarcopenia** and significant **symptoms that impact QOL and care giver burden**.
- Current care models (hepatologists) are ill equipped (and trained) to deal with these issues.
- This lead to **frequent ER visits and hospitalization**, increased \$\$.
- **Palliative/supportive care is an ideal solution** to improve patient care and QOL, care giver burden, and reduce health care costs.

Discovery Comes to the Prepared Mind



Thank you for your attention



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