Improving quality of life in people with advanced cirrhosis

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What is QOL?

- WHO: individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

https://www160.statcan.gc.ca/index-eng.htm

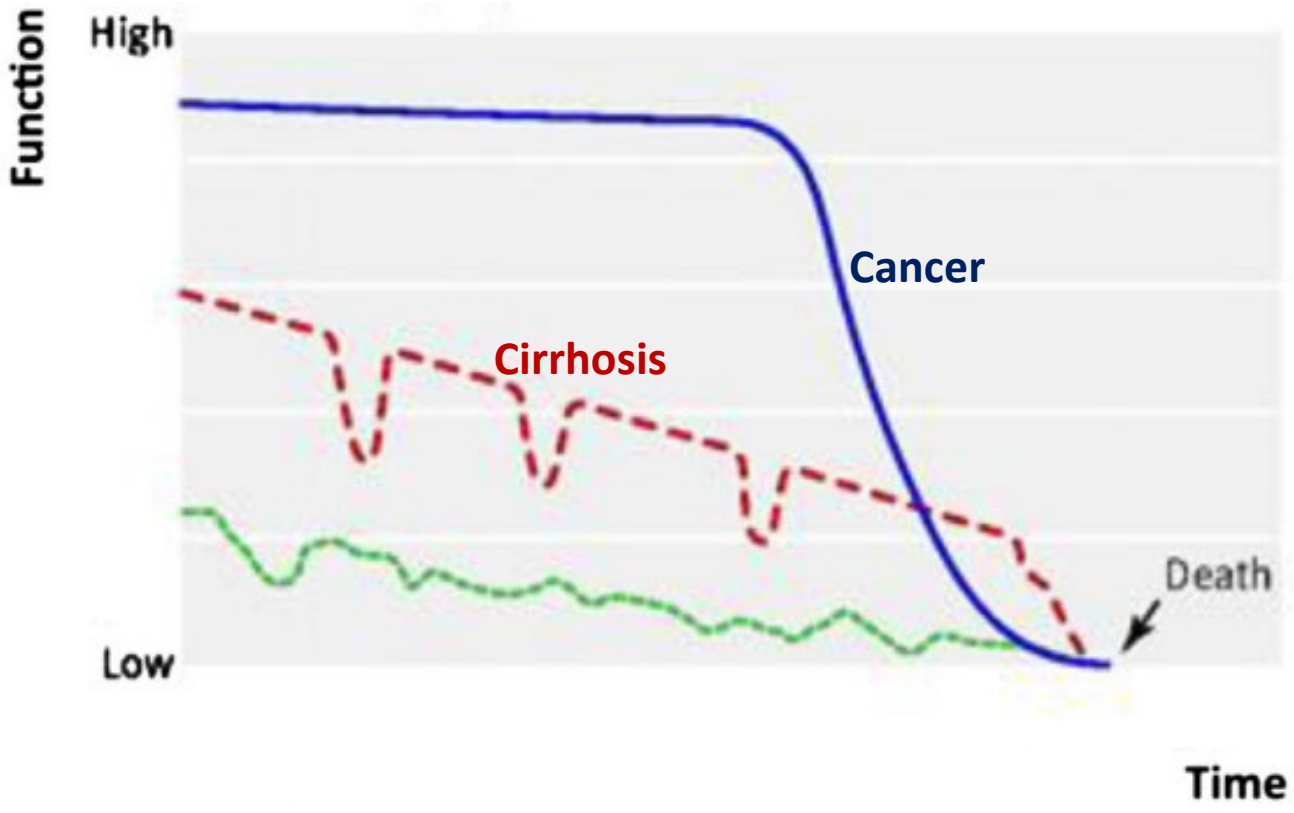
Health-Related QOL

CDC: individual's or group's self-perception of their physical and mental health over time. HRQOL goes beyond the traditionally diagnosable health outcomes to provide a measure of well-being

Physical	Mental

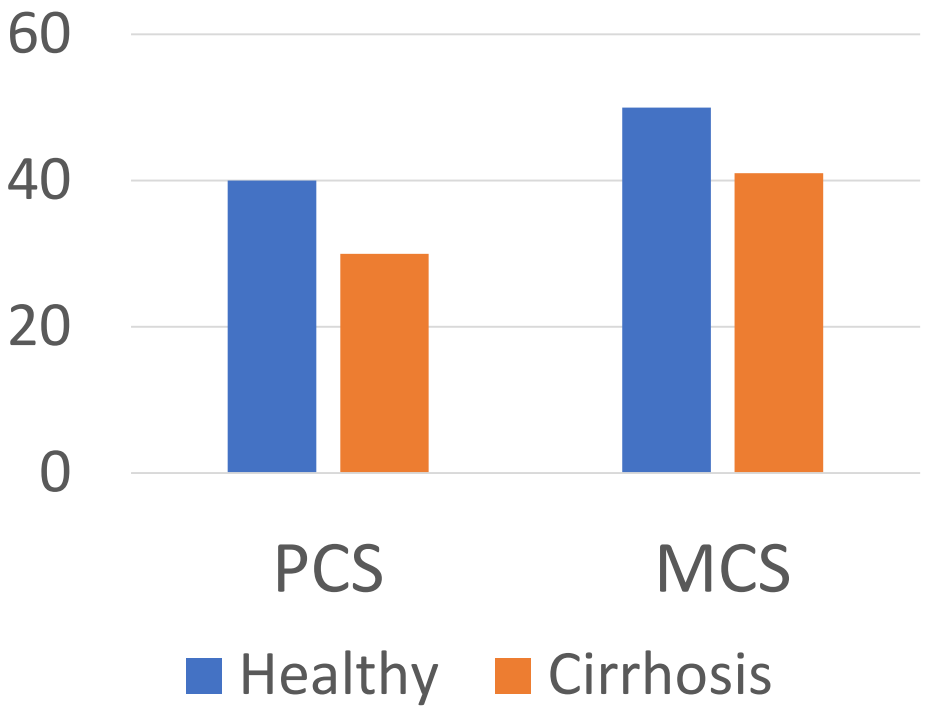
Cirrhosis Disease Trajectory

- 5M in the US have cirrhosis
- Five-year mortality of 50%
- Cirrhosis is unique



Murray SA, and Sheikh A BMJ 2008:336:958-959

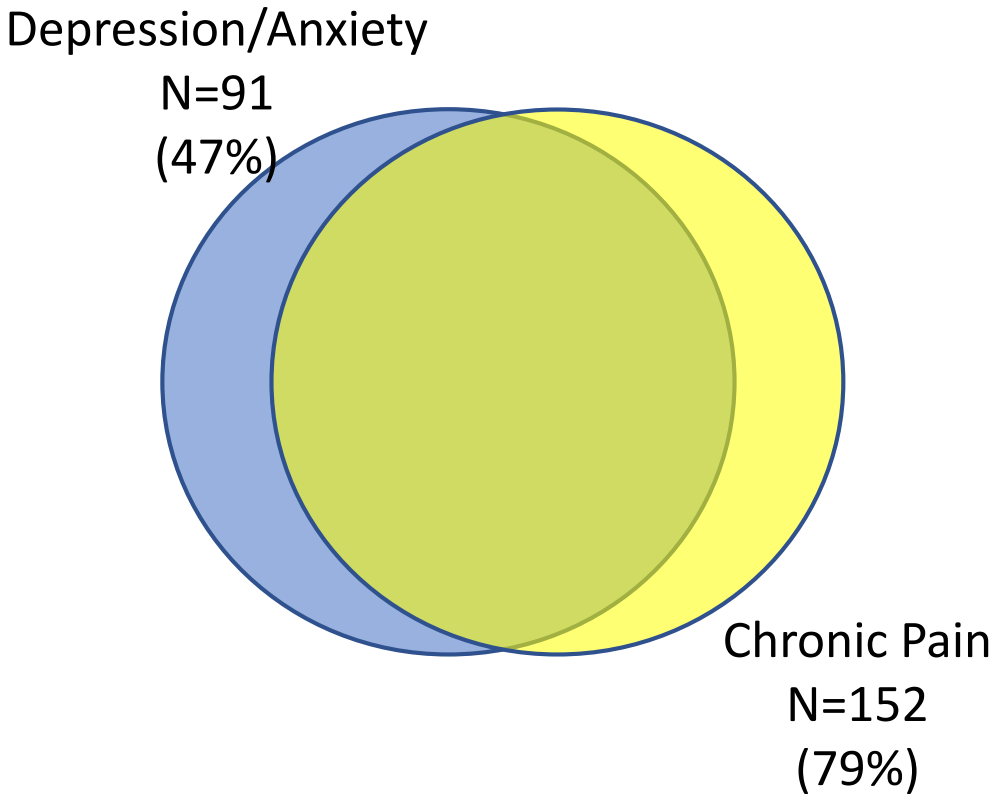
HR-QOL in Cirrhosis

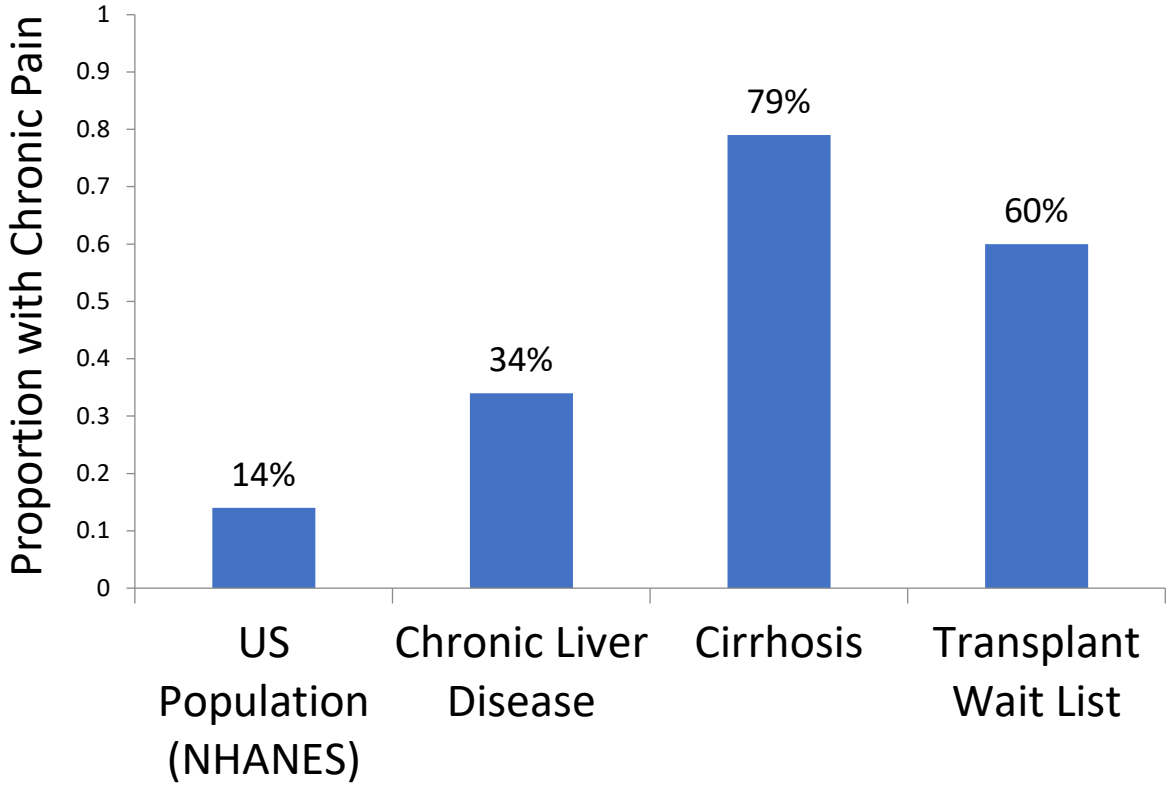


Covariates	Full PCS Model β(SE)	Reduced PCS β(SE)	Full MCS Model β(SE)	Reduced MCS β(SE)
Age	**0.11 (0.05)**	**0.13 (0.05)**	**0.21 (0.06)**	**0.21 (0.06)**
Male Gender	2.21 (2.84)		-1.06 (3.08)	
Race (vs. white)				
Black	1.92 (1.37)		2.22 (1.49)	2.24 (1.48)
Other	-0.43 (1.89)		**-4.76 (2.04)**	**-4.60 (2.01)**
Hispanic/Latinx Ethnicity	-0.07 (0.87)		-0.35 (0.94)	
Region (vs. Midwest)				
Northeast	1.94 (1.48)		**4.37 (1.61)**	**4.36 (1.61)**
South	0.57 (1.20)		0.97 (1.31)	0.98 (1.30)
West	1.15 (1.28)		2.02 (1.40)	2.01 (1.39)
Comorbidities	**-2.07 (0.23)**	**-2.04 (0.23)**	**-1.72 (0.25)**	**-1.71 (0.25)**
Decompensation yes/no	**-3.66 (0.91)**	**-3.81 (0.89)**	**-2.20 (0.98)**	**-2.22 (0.97)**
Unsure of Decompensation	-1.84 (0.96)	**-1.87 (0.95)**	**-3.28 (1.05)**	**-3.25 (1.04)**
Satisfaction	0.53 (0.29)	**0.57 (0.28)**	**1.55 (0.31)**	**1.55 (0.31)**

Rogal et al (2020) PlosOne

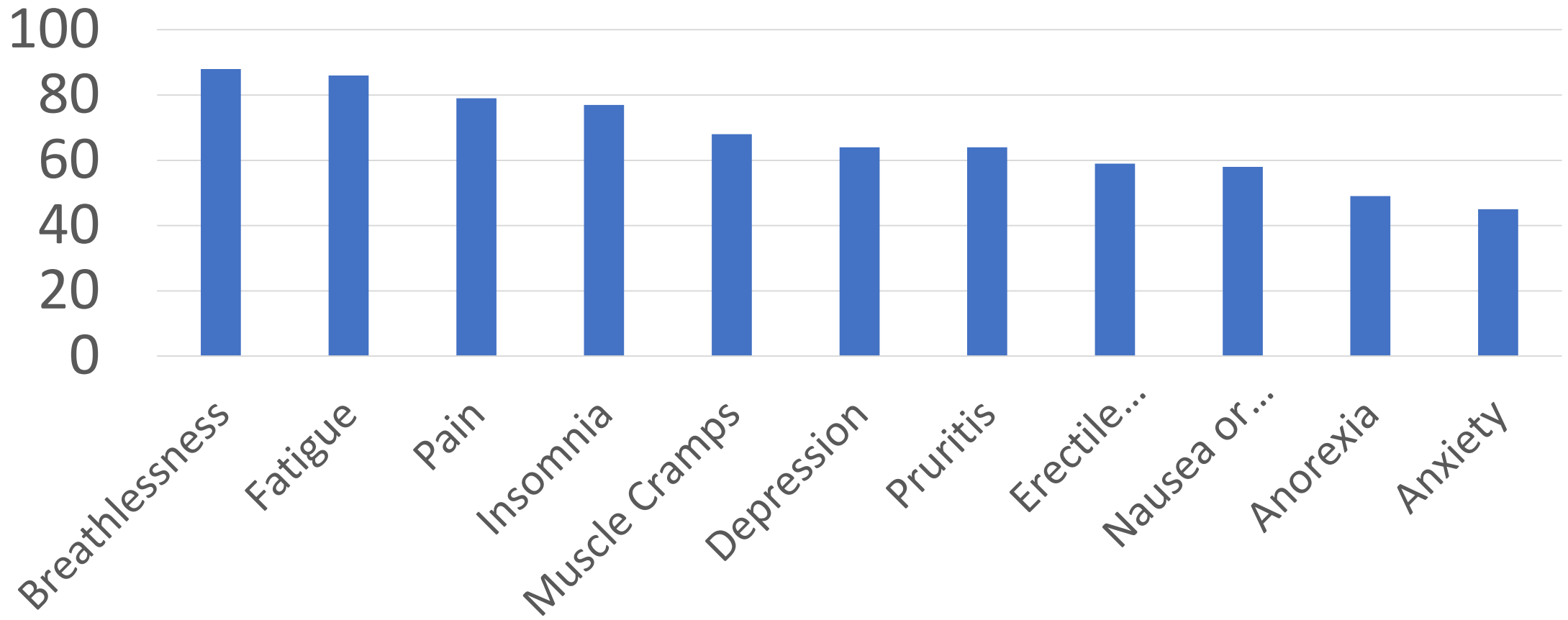
Chronic Pain and Cirrhosis





Hardt *et al.* (2008) Pain Med.
Rogal *et al.* (2013) Dig. Dis. Sci.
Rogal *et al.* (2015) CGH

Other Symptoms



Peng et al. (2019) *Palliat Med*

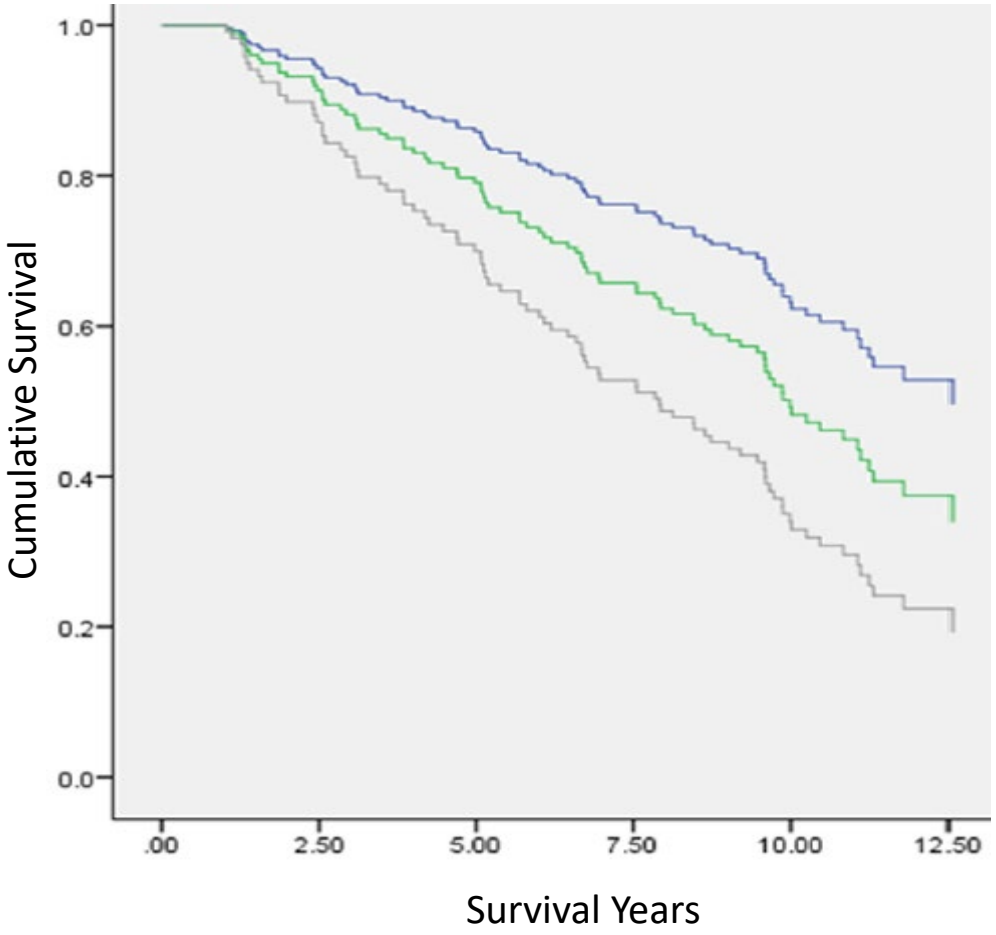
Consequence of poor HR-QoL in cirrhosis

Importance of Pre-Transplant Depression

- n=1,115 UPMC liver transplant recipients
- Longer hospitalization
  - 19 vs. 14 days, IRR = 1.3 (1.1,1.4)
- Discharge to a facility
  - 36% vs. 25%
  - OR = 1.7 (1.2,2.5)
- Decreased survival
  - HR = 1.5 (1.1,2.1)

Rogal *et al.* (2016) *PlosOne*

Untreated depression is the strongest predictor of post-transplant mortality



No depression (n=95)

Treated depression (n=31)

AHR 1.66 (p=0.11)

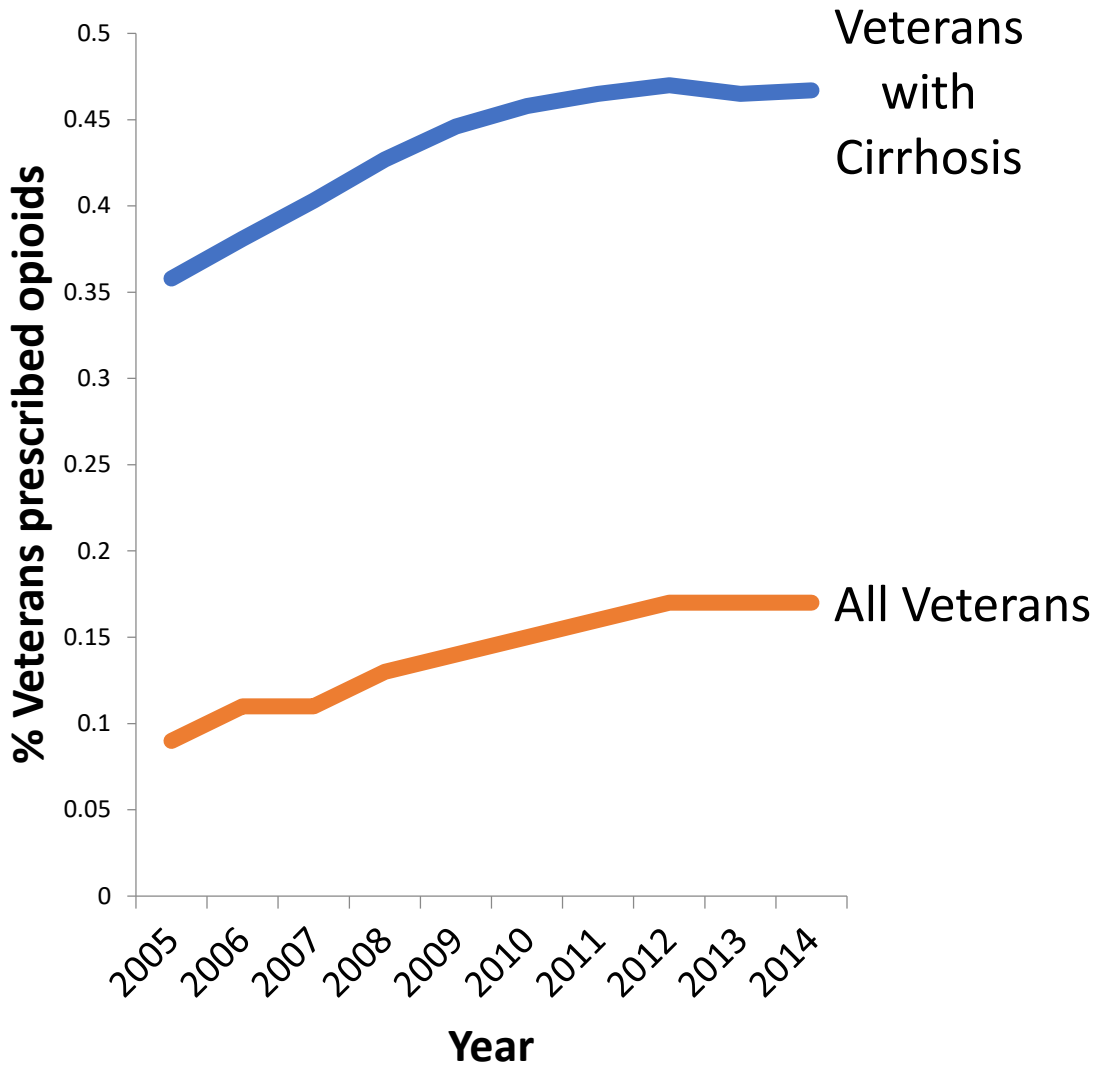
Untreated depression (n=41)

AHR 2.44 (p=0.001)

Rogal *et al.* (2013) *AJT*

Opioid Prescribing in Cirrhosis

- Rogal *et al.* (2018) *CGH*



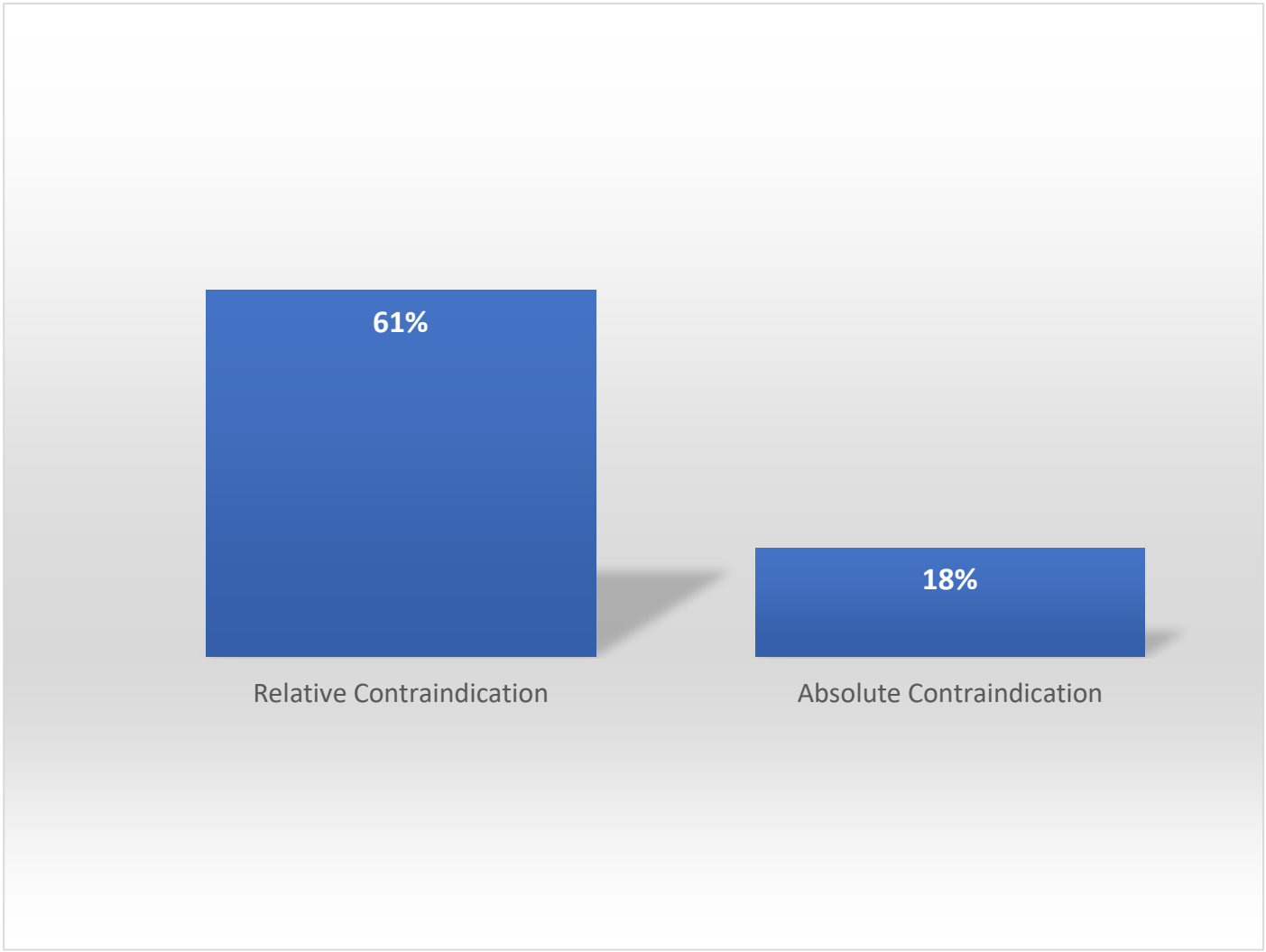
Opioids and Healthcare Utilization

Outcome	AOR/AIIR	95% CI
Hospitalization	2.72	1.72,4.29
Hepatology Clinic Visits	1.16	1.05,1.28
PCP Visits	1.80	1.22,2.68
Phone Calls	1.42	1.21,1.68

Rogal *et al.* (2013) *Liver Int.*

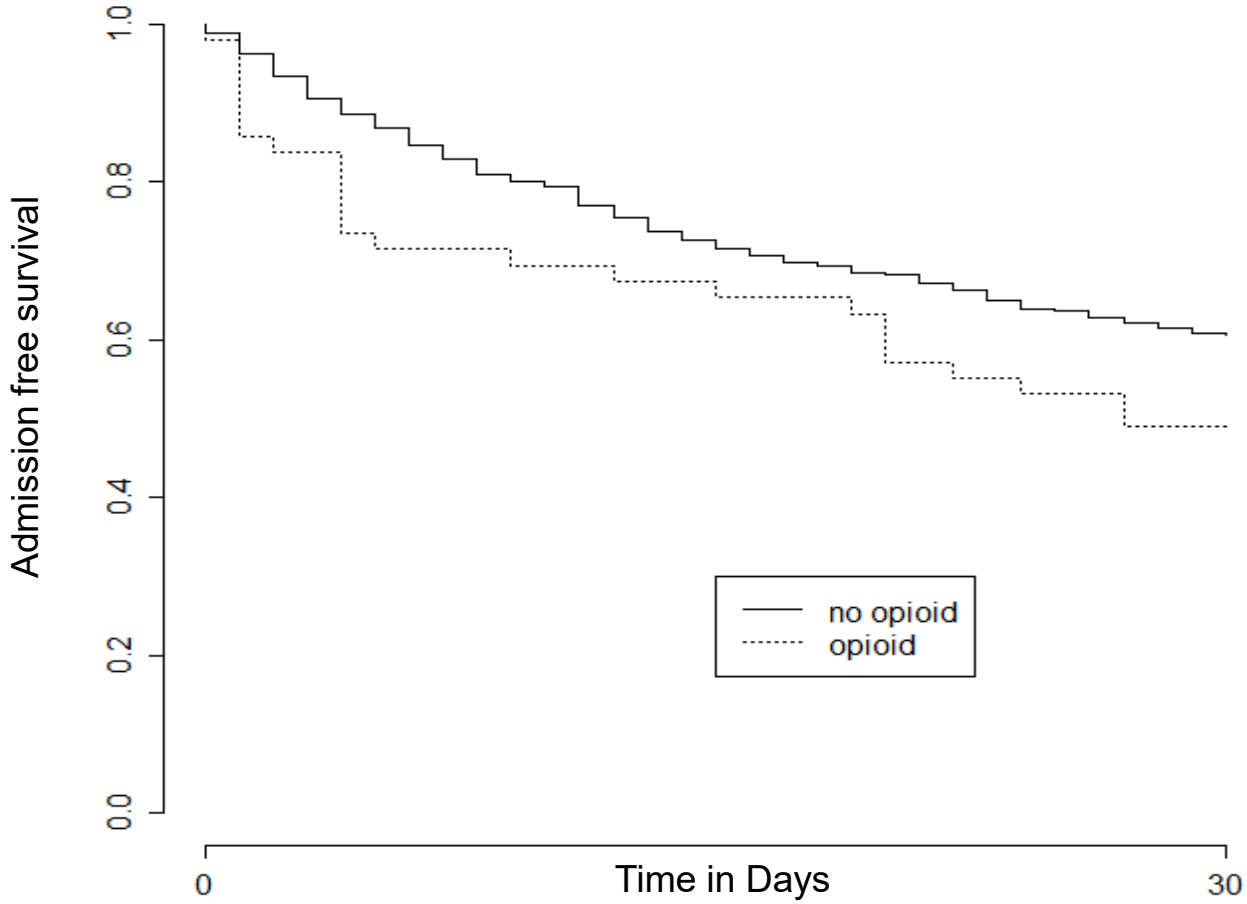
Opioids Decrease Transplant Access

% of Liver Transplant Centers



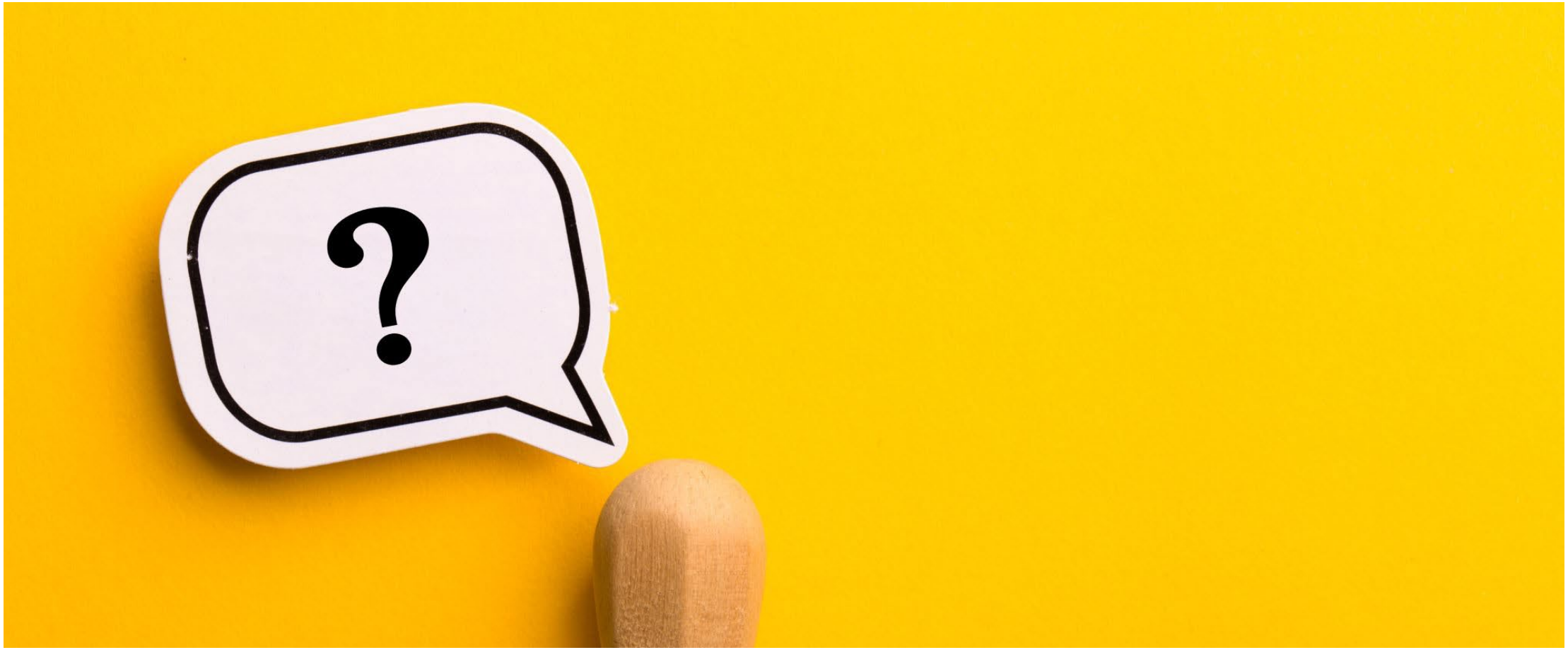
Fleming…Rogal (2017) *Clin. Transplant*

Opioids are Associated with Post- Transplant Readmission



Rogal *et al.* (2016) *Clin. Transplantation*

What can we do?



Palliative care in cirrhosis is received by <20% of eligible patients despite evidence for improving….

Physical symptoms	Care coordination	QOL
Psychological symptoms, coping	Resource use & readmission	Goal-concordant care at the end of life

Baumann et al. 2015; Kimbell et al. 2018; Lamba et al. 2012; Shinall et al. 2019;Bailey et al. 2017; Bajaj et al. 2017; Ufere et al. 2021

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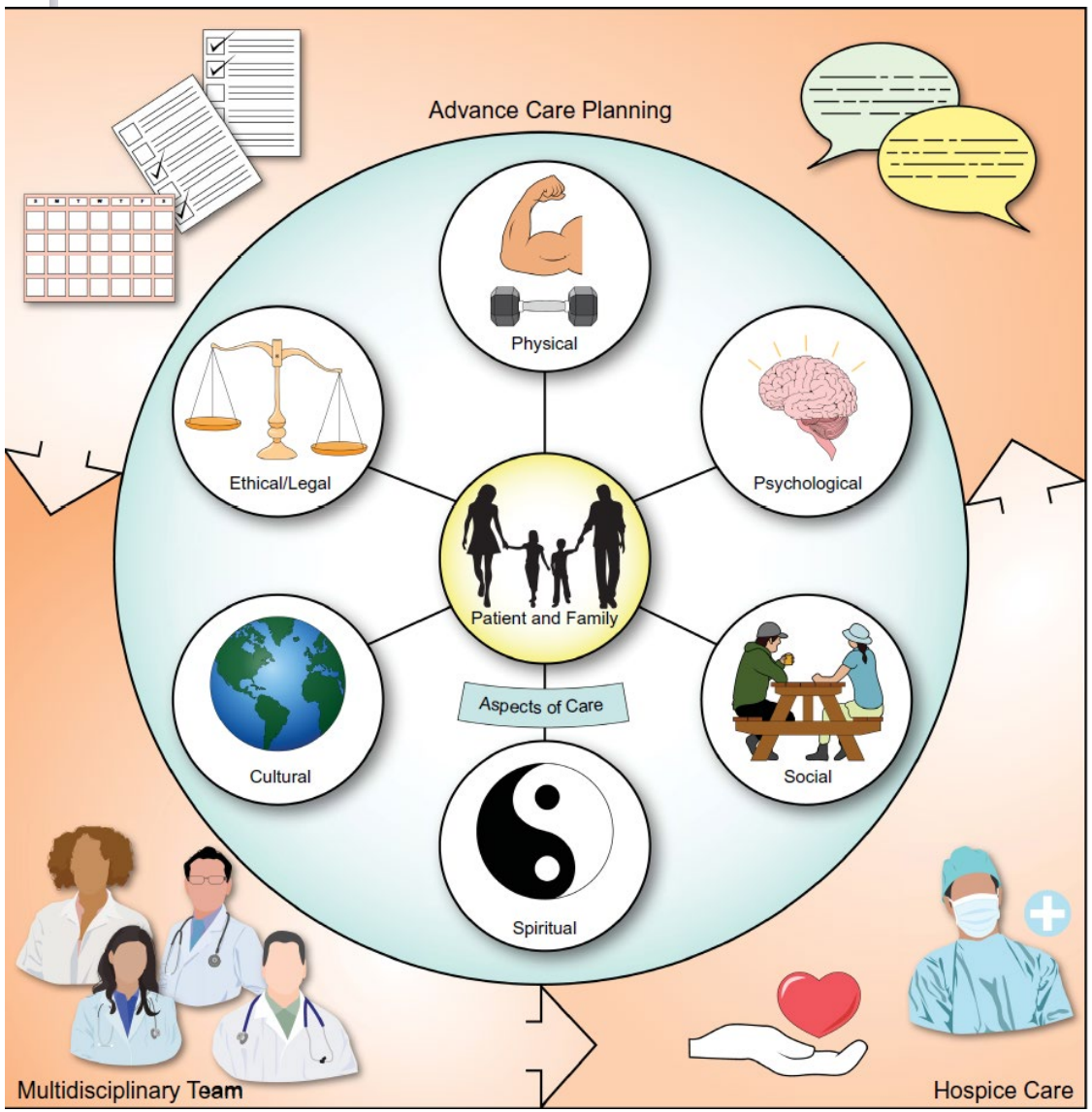
PRACTICE GUIDANCE

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

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



Guidance

- Disease-directed care, such as transplant evaluation and listing, **does not preclude palliative care** delivery or consultation

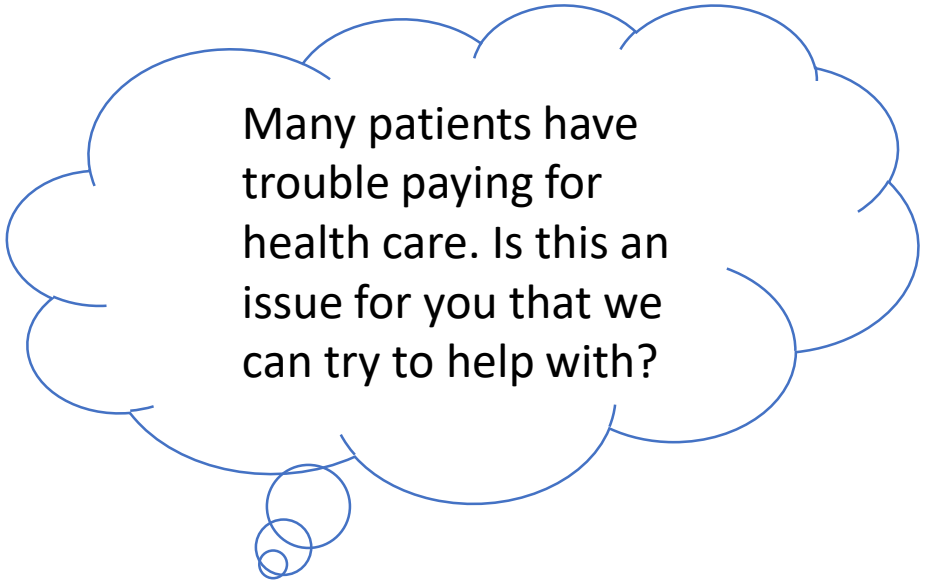
- Evaluation for unmet palliative care needs and specialty palliative care consultation should be considered for all patients with decompensated cirrhosis and their caregivers

- Hepatology clinicians should play a central role in offering primary palliative care services to patients with cirrhosis

Social Aspects of PC

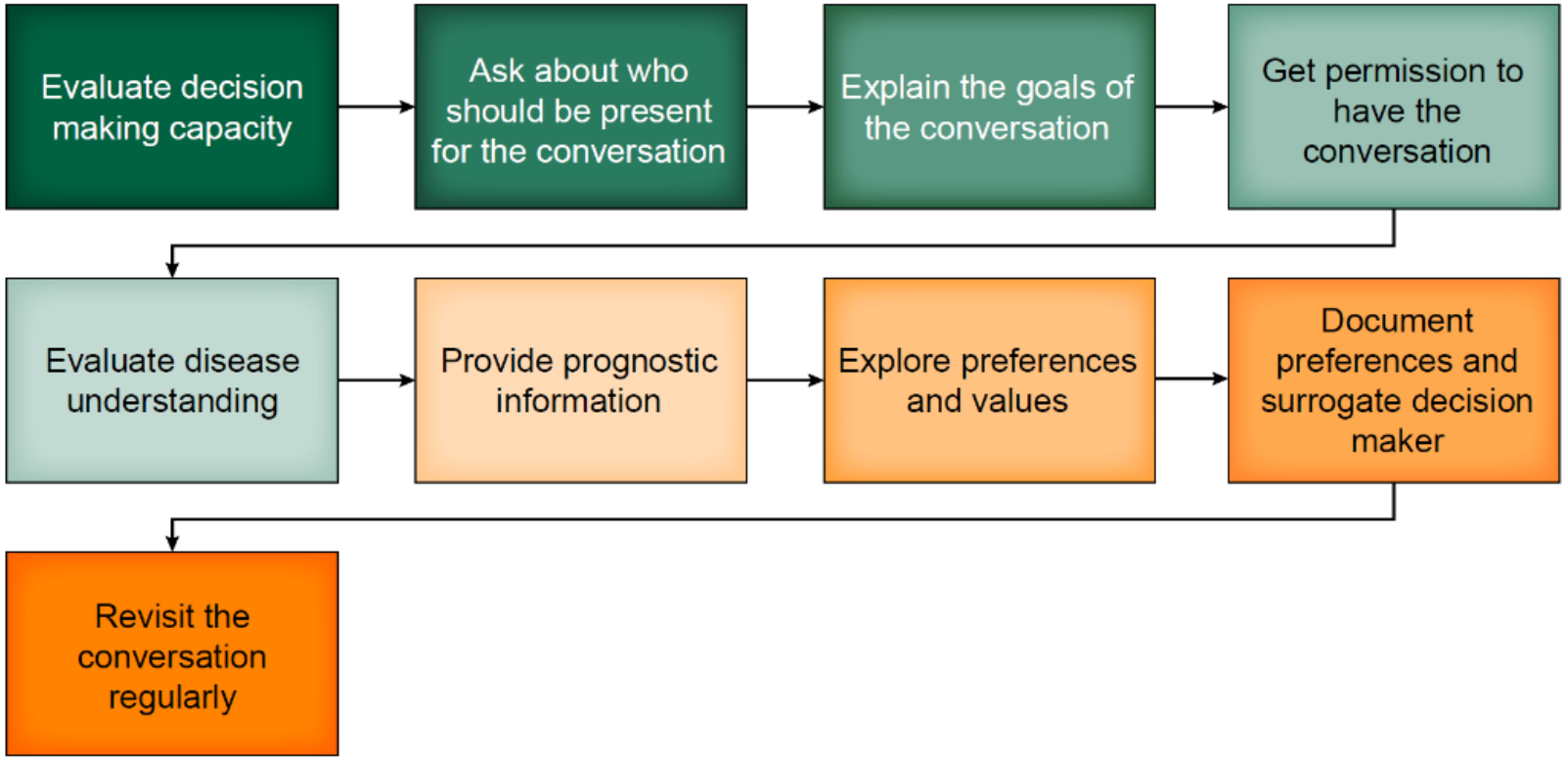
Caregiver support should be provided across the trajectory of liver disease, at the end of life, and after the patient's death

- Financial assessment
- Living situation
- Equipment needs
- Food insecurity



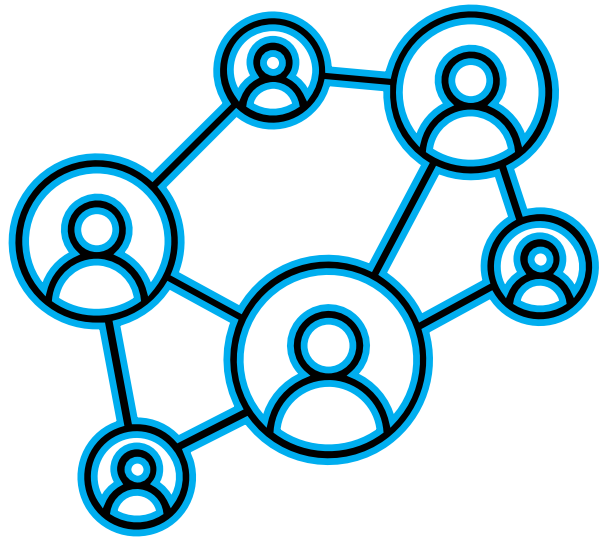
Ethical/Legal Aspects of PC

- Advance care planning
- Communicate about prognosis
- Identify a surrogate decision-maker



Spiritual, Religious, and Existential Aspects of PC

- Important to patients and families
  - 2 qualitative studies identified spirituality as a key determinant of HRQoL and perceptions of medical care for people with cirrhosis
- Know about chaplaincy services
- Ask if/when to include a spiritual leader/community member



Shabanloei et al. 2017; Abdi et al. 2015

Cultural Aspects of PC

- Ask about traditions, customs around death and dying, beliefs, sources of strength

- Use the preferred language of patients and caregivers and a medical translator

Psychological Aspects of PC

1. Ask! PHQ-2 or other screeners
2. Evaluate underlying contributors (e.g., vitamin D)
3. Prioritize non-pharmacotherapies
4. Consider medication safety
5. Low threshold for referral

	Not at all	Several days	More than half the days	Nearly every day
Lost interest or had little pleasure in doing things	0	1	2	3
Felt down, depressed, or hopeless	0	1	2	3

Total score = sum of two items.
PHQ-2 score ≥ 3 is suggestive of elevated symptoms of depression.
*The PHQ-2 was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues, with an educational grant from Pfizer Inc.

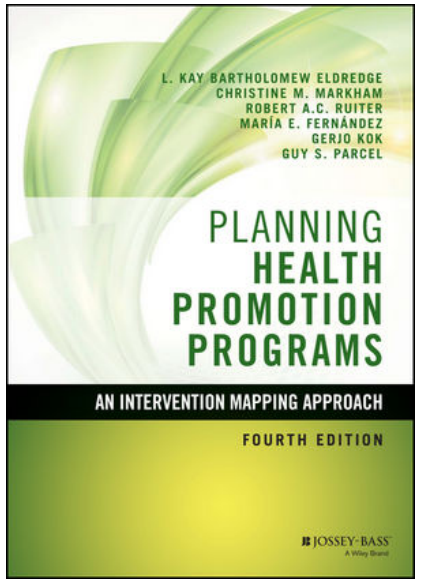
Pain

Treat contributing symptoms (e.g., sleep disorders)
Nonpharmacological options
Hot/cold
Physical therapy
Mindfulness/meditation
Other behavioral pain self-management strategies (e.g., cognitive behavioral therapy)
Acupuncture (caution if platelets <50,000)
Other complementary options based on preferences (e.g., transcutaneous nerve stimulation)

Pharmacological options
Topical/injection treatments
Lidocaine patches
Capsaicin cream or patch
Topical nonsteroidal anti-inflammatory medications (e.g., diclofenac sodium 1% gel)
Injections by pain specialists (e.g., osteoarthritis of knee)
Systemic therapies—with CAVEATS
Acetaminophen 500 mg q6h for a maximum of 2 g/d
Gabapentin 300 mg daily (starting dose) or pregabalin 50 mg b.i.d. (starting dose) (for neuropathic pain)
Fentanyl patch 12-µg starting dose (typically not recommended as the initial agent; avoid in sarcopenia/cachexia)
Hydromorphone 1-mg q6h prn starting dose
Oxycodone 2.5-mg p.o q6-8h prn starting dose

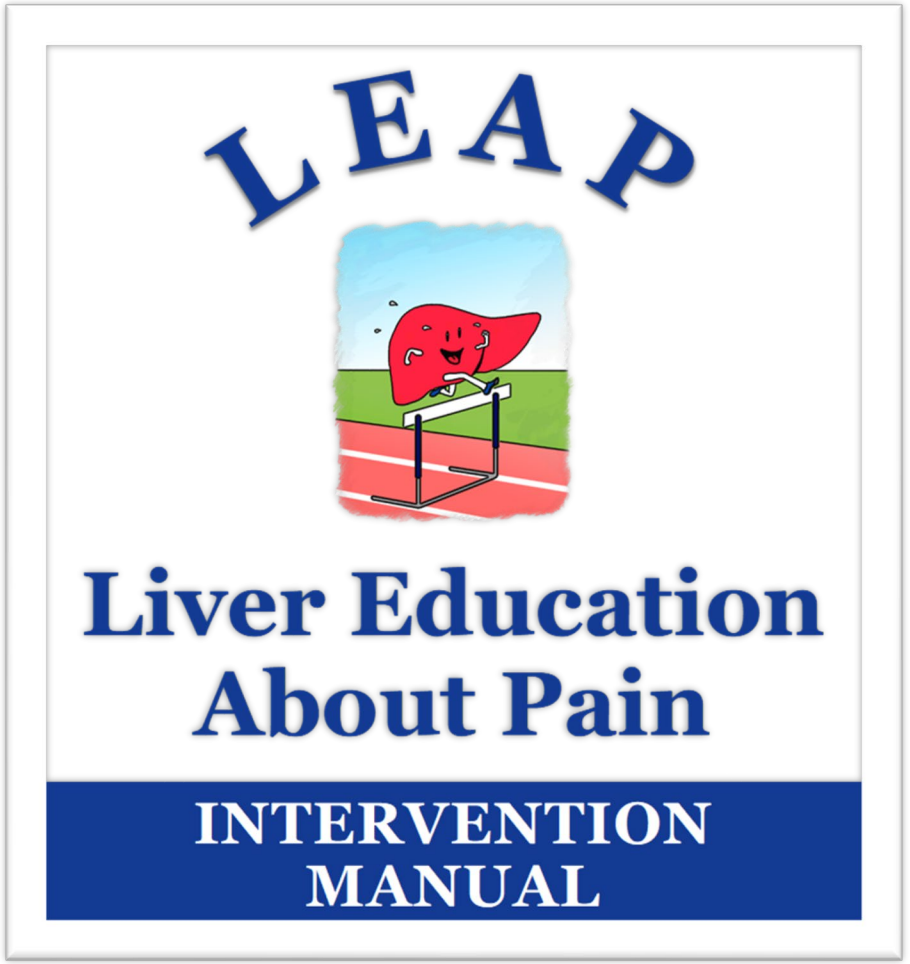
Intervention Mapping

1. Logic Model of the Problem
2. Logic Model of Change
3. Program Design
4. Program Production
5. Implementation
6. Evaluation



Innovation Development: Designing for Implementation

- Simple, adaptable, modular
- Run outside of clinic by health coach
- Evidence-based components
- Used patient quotes in the manual
- Anticipatory implementation barriers addressed in design
- Telephone option (low tech, low literacy)



What can I do right now?

Ask about symptoms

Consider PC early

Investigate what is available in your center

Elicit preferences early and often

Conclusion

QOL and HR-QOL are poor in cirrhosis

Small steps can help: ask, validate, address

Thank you

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