Hepatology Snapshot:

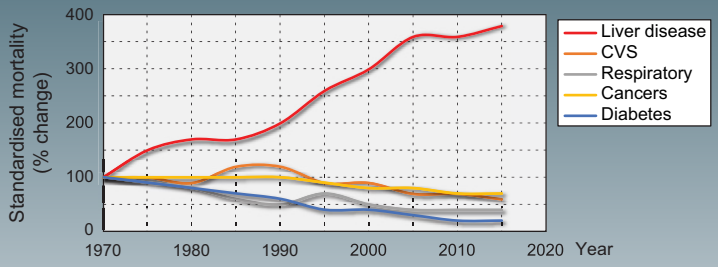
JOURNAL OF HEPATOLOGY

Improving end of life care in liver disease

Philip Berry[1], Sreelakshmi Kotha[1*]

[1]Department of Gastroenterology, Guy's and St Thomas' Foundation Trust, London, United Kingdom
*Corresponding author. Address: Department of Gastroenterology, Guy's and St Thomas' Hospital, London, UK. Tel.: 00447949871727
E-mail address: sreelakshmi_kotha@yahoo.com (Sreelakshmi Kotha).

- Mortality from chronic liver disease has risen significantly by around 400% over the last 3-4 decades (graph)[1]
- In the USA, between 2006 and 2016, prevalence increased by 7.9% in males and 11.4% in females[2]
- Over 70% of the patients with end stage liver disease (ESLD) die in the hospital[3]
- Early palliative care (PC) involvement improves outcomes in patients and care-givers in other chronic diseases[4]
- There is a need to recognise and plan for patients dying from ESLD.



Recognise risk of dying

Markers of poor prognosis:

- Child Pugh C
- ≥2 admissions in last 6 months
- Ongoing alcohol use (in ArLD)
- Diuretic resistant ascites
- Hepatic encephalopathy
- Hepatorenal syndrome
- Bacterial peritonitis
- Recurrent variceal bleeds
- Declined transplant
- NECPAL CCOMS-ICO © [6]

Bristol

SPICT[5]

Honest dialogue

Address:

- Accept uncertainty
- Advance care planning
- Preferred place of death
- Limits of care
- Goals and priorities
- Resuscitation status
- ReSPECT document (UK)
- POLST (US)
- Thinking ahead

Refer to palliative care

Expertise:

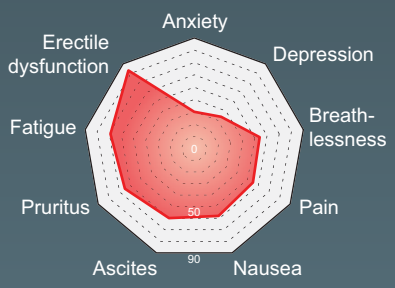
- Pharmacology
- Community engagement
- Communication skills
- End of life care

Review and reassess

Looking for:

- Change of physical status (↑↓)
- New symptoms (CLDQ, LDQOL, ESAS, PHQ-9[7])
- Needs of family unit (*e.g.* financial uncertainty)
- Signposting to assistance
- Confirm priorities

Symptom burden in ESLD[8]



Prescribing and symptom management in ESLD: Tips[10]

Pain

- Paracetamol: 2-3 gm/24 hrs
- Morphine: if eGFR>30
- Hydromorphine: if eGFR<30
- ***Caution***: Buprenorphine patch, gabapentin, pregabalin
- ***Avoid***: NSAIDs, Tramadol, codeine, oxycodone, Amitriptyline

Variceal bleeding

- Endoscopy
- Primary and secondary prophylaxis with non selective beta blockers and endoscopic band ligation

Nausea and vomiting

- Metoclopramide
- Domperidone
- Haloperidol
- Ondansetron
- Levomepromazine
- Cyclizine

Pruritus

- Menthol cream
- Colestyramine
- Antihistamines
- Rifampicin, Naltrexone
- SSRI

Hepatic encephalopathy

- Lactulose/Rifaximin

Ascites

- No added salt and diuretics
- Paracentesis
- TIPSS and indwelling drains (*e.g.* Pleurex)
- Alfapump ®

Malnutrition

- Assess for frailty and sarcopenia
- Dietary input
- Late evening snack

Education

For patients and carers to improve nutrition, manage ascites and control symptoms of hepatic encephalopaty

Barriers to palliative care

Patient

- Uncertain prognosis
- Encephalopathy
- Misconceptions about PC
- Self blame (EtOH, PWID)
- Spiritual factors

Physician

- Over optimism
- Discomfort
- Focus on longevity
- "Transplant imperative"
- Lack of advanced communication skills training
- Misconceptions about PC

Service

- Access
- Capacity

Best practice and innovations

- ACLD MDTs
- Dietetic input
- Engage in R&D
- Parallel working
- Long term ascites drains
- Special interest group (SIG)

Keywords: Palliative hepatology, Cirrhosis, End stage liver disease, Palliative care, Advance care planning
Received 22 June 2021; received in revised form 20 September 2021; accepted 4 October 2021.

Mortality from chronic liver disease has risen significantly in the UK by around 400% over the last 3-4 decades.[1] In the USA between 2006 and 2016, the prevalence of ESLD increased by 7.9% among males and 11.4% among females aged 25-34, accounting for almost 200,000 hospitalisations annually.[2] Over 70% of patients with end-stage liver disease (ESLD) die in hospital, with their treatment costing an estimated 2.1 billion pounds a year in England.[3] The role of palliative care (PC) in ESLD remains poorly researched except in the context of hepatocellular cancer. It is well known early palliative care (PC) involvement improves outcomes in patients and care-givers in other chronic diseases.[4] Though the need for early initiation of PC and advance care planning (ACP) is increasingly recognised, it remains underutilised. The barriers to early referral to PC may be patient, physician or service related.

The unpredictable course of ESLD, especially in younger patients, makes it challenging to prognosticate and initiate PC. In the minds of both patients and doctors, PC is often associated with end-of-life care and cessation of active treatment. However, ESLD provides an opportunity to introduce parallel planning with ongoing active management of the underlying condition while preparing patients and families for sudden deterioration and encouraging ACP. Experience in individual centres has demonstrated that 15% of patients on the transplant list will either die or be delisted; therefore PC, including hospice admission, is not incompatible with selection for liver transplantation. Liver specific models such as Child-Pugh, model for end-stage liver disease (MELD) and Chronic Liver Failure Consortium (CLIF-C) acute-on-chronic liver failure score can be used to identify patients approaching end of life. Screening tools like SPICT[5] and Bristol can be used to identify patients with poor prognosis who may benefit from PC input, but this should not prevent discussions around ACP in earlier stages of disease. The NECPAL CCOMS-ICO© and Surprise questionnaire explores functional and psychological symptoms and has been validated in large cohorts of patients with chronic disease in Spain; it identifies patients with high mortality over next 24 months who would benefit from PC.[6]

ESLD has a significant symptom burden. Numerous tools are available to assess symptoms such as chronic liver disease questionnaire (CLDQ), liver disease quality of life (LDQOL), short form liver disease quality of life (SF-LDQOL), liver disease symptom index (LDSI), liver cirrhosis patient-reported outcome measure (LC-PROM), sickness impact profile (SIP), Edmonton symptom assessment system (ESAS), and patient health questionnaire (PHQ-9).[7] However, there is significant variability in the domains assessed, leading to a lack of standardisation. A meta-analysis by Peng *et al.*[8] showed a significant symptom burden in ESLD with the most frequent symptoms being pain (30-79%), breathlessness (20-88%), erectile dysfunction (53-93%), anxiety (14-45%) and depression (4.5-64%). Symptoms are poorly managed in this cohort due to concerns about drug metabolism. Pain has a dramatic impact on quality of life (QOL), but less than half report adequate control despite polypharmacy with opiates.[8,9] Recognition and management of overt and covert encephalopathy, frailty and sarcopenia also have profound impacts on QOL. The British Association for the Study of Liver disease (BASL) special interest group (SIG) has published guidelines for prescriptions for common symptoms in ESLD.[10]

Ultimately, PC should not be the sole responsibility of palliative care teams; primary care physicians, gastroenterologists and hepatologists should be trained to recognise and initiate early conversations regarding PC and APC with patients and carers.

Recent developments likely to improve patient experience include regular multi-disciplinary meetings focussed on patients with advanced liver disease, insertion of long term ascitic drains with reduced frequency of emergency admissions, and training of hepatologists in advanced communication techniques and PC skills. Clinical trials in this area, although challenging in terms of recruitment, are to be encouraged, with an emphasis on gathering patient reported outcomes.

Financial support

The authors received no financial support to produce this manuscript.

Conflict of interest

The authors declare no conflicts of interest that pertain to this work.

Please refer to the accompanying ICMJE disclosure forms for further details.

Authors' contributions

PB - Writing, creating the infographic and reviewing the manuscript. SK - Writing the manuscript and creating the infographic.

Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jhep.2021.10.001.

References

[1] Williams R, Aspinall R, Bellis M, Camps-Walsh G, Cramp M, Dhawan A, et al. Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis. Lancet 2014;384:1953–1997. https://doi.org/10.1016/S0140-6736(14)61838-9. 2014/12/01.

[2] U.S. Department of Health and Human Services; Centers for Disease Control; National Center for Health Statistics. Health, United States, 2017, With Special Feature on Mortality. National Center for Health Statistics; 2018. https://www.cdc.gov/nchs/data/hus/hus17.pdf. [Accessed 4 December 2019].

[3] National End of Life Intelligence Network - Deaths from liver disease: implications for end of life care in England. 2012.

[4] National Institute for Clinical Excellence (NICE). Chronic obstructive pulmonary disease. National clinical guideline for management of chronic obstructive pulmonary disease in adults in primary and secondary care. Thorax 2004;59(Suppl. 1):1–232.

[5] Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the supportive and palliative care indicators tool (SPICT): a mixed-methods study. BMJ Support Palliat Care 2014;4:285–290.

[6] Gomez-Batiste X, Mart_ınez-Mu∼noz M, Blay C, Ambl_as J, Vila L, Costa X, et al. Utility of the NECPAL CCOMS-ICOVC tool and the Surprise Question as screening tools for early palliative care and to predict mortality in patients with advanced chronic conditions: a cohort study. Palliat Med 2017;31:754–763.

[7] Tandon P, Walling A, Patton H, Taddei T. AGA clinical practice update on palliative care management in cirrhosis: expert review. Clin Gastroenterol Hepatol 2021 Apr;19(4):646–656.e3. https://doi.org/10.1016/j.cgh.2020.11.027. Epub 2020 Nov 19. PMID: 33221550.

[8] Peng JK, Hepgul N, Higginson IJ, Gao W. Symptom prevalence and quality of life of patients with end-stage liver disease: a systematic review and meta-analysis. Palliat Med 2019 Jan;33(1):24–36.

[9] Chiang JK, Kao YH. Predictors of high healthcare costs in elderly patients with liver cancer in end of-life: a longitudinal population-based study. BMC Cancer 2017;17:568.

[10] https://www.basl.org.uk/index.cfm/content/page/cid/33.