



Cicely Saunders
International
Better care at the end of life

WHO Collaborating Centre for
Palliative Care & Older People

KING'S
College
LONDON



Palliative Care in Alcohol Related Liver Disease

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‘Is life worth living? It all depends on the liver’

William James, American Philosopher,
1842-1910

Overview

- What is palliative care?
- Why alcohol related liver disease?
- Challenges
- The future

Palliative care: a professional's perspective

- ‘An outward manifestation of therapeutic failure...’

Palliative care: a patient's perspective

- 'You took the weight off my shoulders, listened to me, believed in what I needed and helped me to make it happen'
- 'You helped me to make the preparations for dying. Now I'm at home I am living again...'

Palliative care



- ‘Palliative care is an approach that ***improves the quality of life*** of patients and their families facing the problems associated with ***life threatening illness***, through the prevention and relief of suffering by means of ***early identification and impeccable assessment and treatment*** of pain and other problems, physical, psychological and spiritual.’ WHO 2002

What does palliative care have to offer?

- Expertise in dealing with uncertainty
 - ‘Hoping for the best, planning for the worst’
 - Advance care planning
- Complex symptom management
- Complex psychosocial issues
 - Communication skills
- Multi-professional working
- Collaborative working across all settings
- Patient in the context of their specific circumstances

Chronic Liver Disease

- In the UK CLD now the fifth highest cause of mortality after heart, cancer, stroke and respiratory disease; only major cause of death increasing year on year
 - In England 2% all deaths; 4% all deaths if any mention of liver disease included from death certification
 - 9000 deaths /yr England and Wales
- **Disproportionately affects younger age groups**
 - 40-49yr old age group ALD most common cause of death, 1 in 10 all deaths
 - 70% deaths occur in hospital. More likely to be from deprived background.

National End of Life Care Intelligence Network, Deaths from liver disease, implications for end of life care in England. March 2012

Volk ML et al. Hospital readmissions among patients with decompensated cirrhosis. Am J Gastro. 2011 Sept 20.

Verne J, Pring A. Raising the profile of end of life care needs for patients dying from liver disease –using national mortality data.

Public Health England/ www.gov.uk/phe 2013

Symptom prevalence and QOL

Peng et al. Symptom prevalence and quality of life of patients with end-stage liver disease: A systematic review and meta-analysis. *Pall Med* 2019, vol. 33(1)24-36

- Systematic review and meta-analysis
 - 8 electronic databases (Jan 1980-June 2018)
 - 80 studies (30 SP, 41 QOL, 4 both)
 - Pain (30-70%), breathlessness (20-88%), muscle cramps (56-68%), sleep disturbance (insomnia 26-77%), psychological symptoms (depression 4.5-64%, anxiety 14-45%), erectile dysfunction prevalent in men (53-93%)
 - HRQoL patients with ESLD significantly impaired compared with healthy controls or patients with CLD

Role in liver disease

- Poor, but unpredictable prognosis
- Significant physical symptom burden
- Significant social, psychological and financial hardship
- Fluctuating cognition impacting on decision making – role of ACP
- Carer burden
- Cost

Peng JK et al. Symptom prevalence and quality of life of patients with end-stage liver disease: a systematic review and meta-analysis. *Palliat Med* 2019;33:24-36

Proactive approach

- Increasing evidence that early palliative care intervention can improve symptom management and quality of life in many chronic diseases
 - Improved symptom burden and mood
 - Improved survival
 - Less aggressive treatment and less hospitalization
- Temel JS et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N ENGL J Med. 2010;363(8):733-42
- Baumann AJ et al. Benefit of early palliative care intervention in End-Stage Liver Disease Patients awaiting liver transplantation. JPSM 2015;Dec 50(6);882-6 e2
- Walling AM et al. Impact of consideration of transplantation on end-of-life care for patients during a terminal hospitalization. Transplantation. 2013;95(4):641-6
- Haun et al. Early palliative care for adults with advanced cancer (Review) 2017 The Cochrane Collaboration:6:CD011129
- Shinall MC et al. COMPASS: A pilot trial of an early palliative care intervention for patients with end stage liver disease. JPSM 2019;doi:<https://doi.org/10.1016/j.jpainsymman.2019.06.023>

What works

- Early and honest discussions
 - patient focused including goals of care/ACP
 - ‘What you believe depends on who you trust’
- Attention to detail
- Coordination of care:
 - Communication with all
 - Identified key contacts / crossing boundaries
 - MDT discussions and effective sharing of outcomes
 - Guidance documents

Woodland H et al. Palliative care in liver disease: what does good look like? Frontline Gastroenterology 2020;11: 218-227

Advance care planning

- In anticipation of the potential fluctuation in capacity associated with encephalopathy it is vital that clinicians engage patients early in advance care planning
 - Exploration of values and goals
 - Advance care planning documentation
 - Review of experience as disease progresses
- Sharing of information across all care settings
- What do patients really think of this approach and what do they really want?

Advance care planning

Hudson B et al. The incompatibility of healthcare services and end-of-life needs in advanced liver disease: A qualitative interview study of patients and bereaved carers. Pall Med 2018

- Qualitative study – semistructured interviews analysed using thematic analysis; 17 participants
- Described escalating physical, psychological and social needs as disease progressed, disabling symptoms, emotional distress and uncertainty, addiction, financial hardship and social isolation
- End of life care needs were incompatible with the healthcare services available to address them; attitudes towards palliative care were mixed, however participants valued opportunities to express future care preferences and an increased focus on symptom control and logistical aspects of care

Thinking ahead:
Planning for your future with advanced liver disease



Pioneering Liver Health

Challenges for integration

- Misconception that palliative care and end of life care are synonymous
- Professional 'fear'
- Unpredictable trajectory
- Lack of confidence amongst 'non-specialists' regarding prognostication and management
 - Lack of confidence in some palliative care teams
- Fear of prescribing
- Lack of time and resources

Challenges and opportunities

- Incidence and prevalence of chronic liver disease is set to increase
- Patients often have a high symptom burden requiring complex and often acute management
- Poor understanding regarding what palliative care can offer, so few patients are referred
 - Improved understanding of what offered is needed
- Paradox of potentially life saving options for treatment in the context of a fatal disease
- Collaboration is key



