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Changing perceptions of palliative care in liver disease

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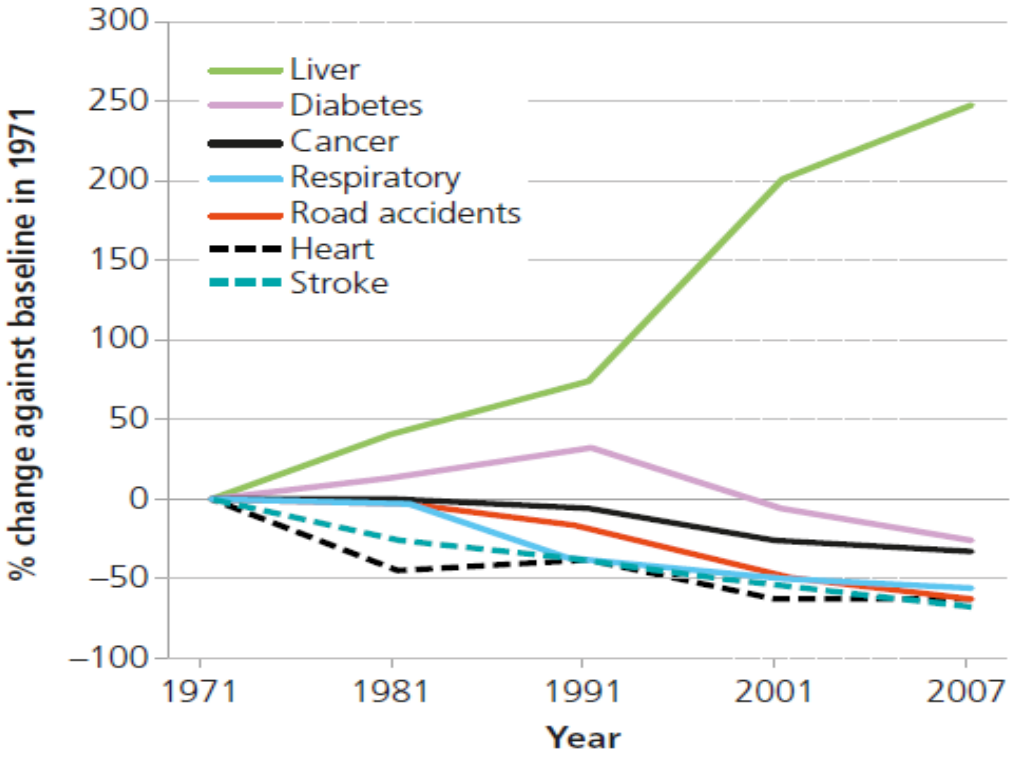
Background

- Deaths from liver disease continues to rise (**400%** rise since 1970)
- These patients access hospital services frequently in the last year of life and **70%** of deaths from liver disease occur in hospital
- Patients experience a high symptom burden
- **90%** of liver related deaths are under 70 years old
- **But referral to palliative care is often late or absent!**

Background – increasing prevalence of liver disease

FIGURE I.3: TREND IN MORTALITY FROM LIVER DISEASE IN RELATION TO TRENDS IN MORTALITY FROM OTHER CAUSES, ENGLAND, 1971–2007



NHS Atlas of Variation in Health Care for People with Liver Disease, 2013
"Deaths from liver disease"
National end of life care intelligence network 2012

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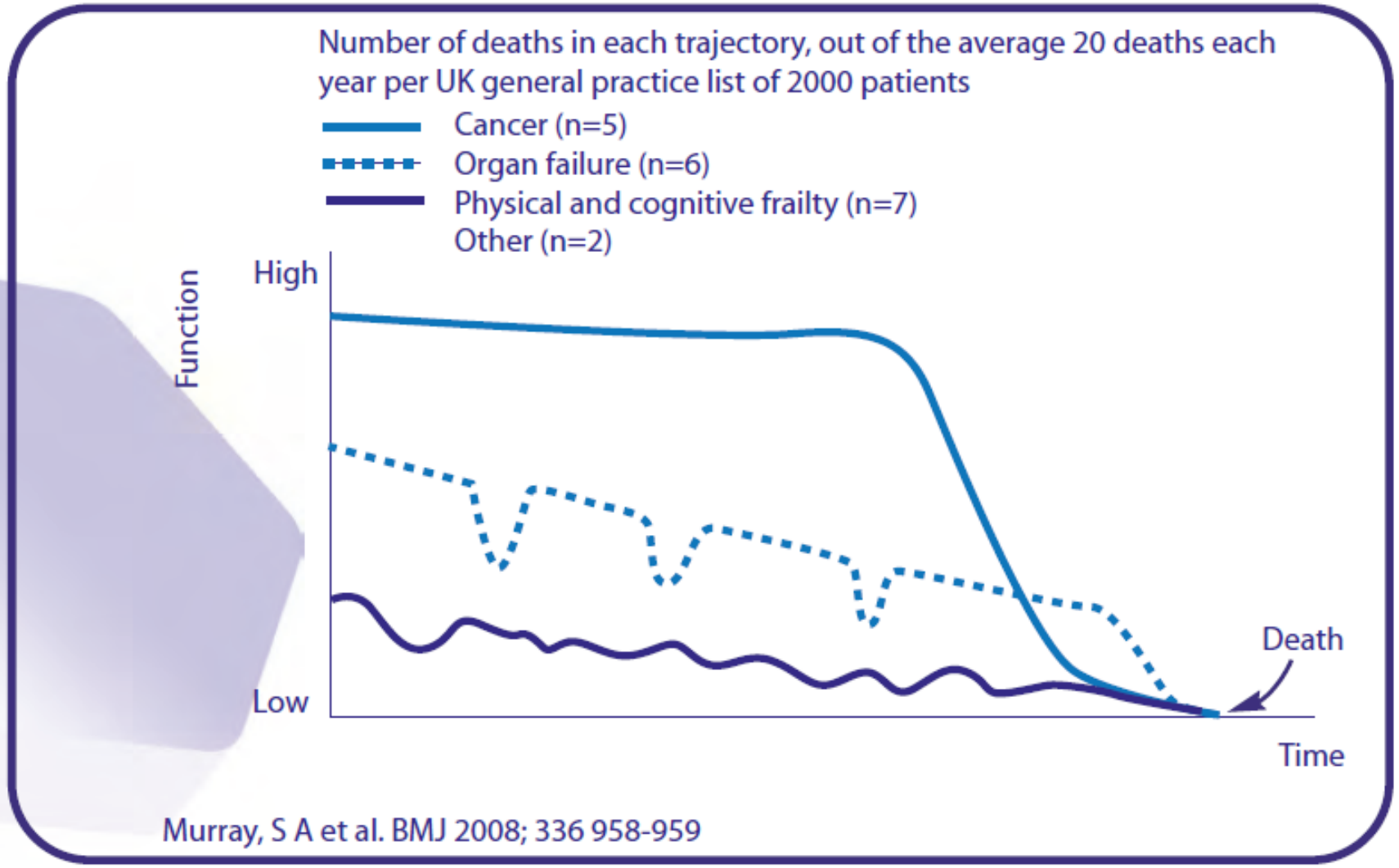
Potential barriers to accessing palliative care

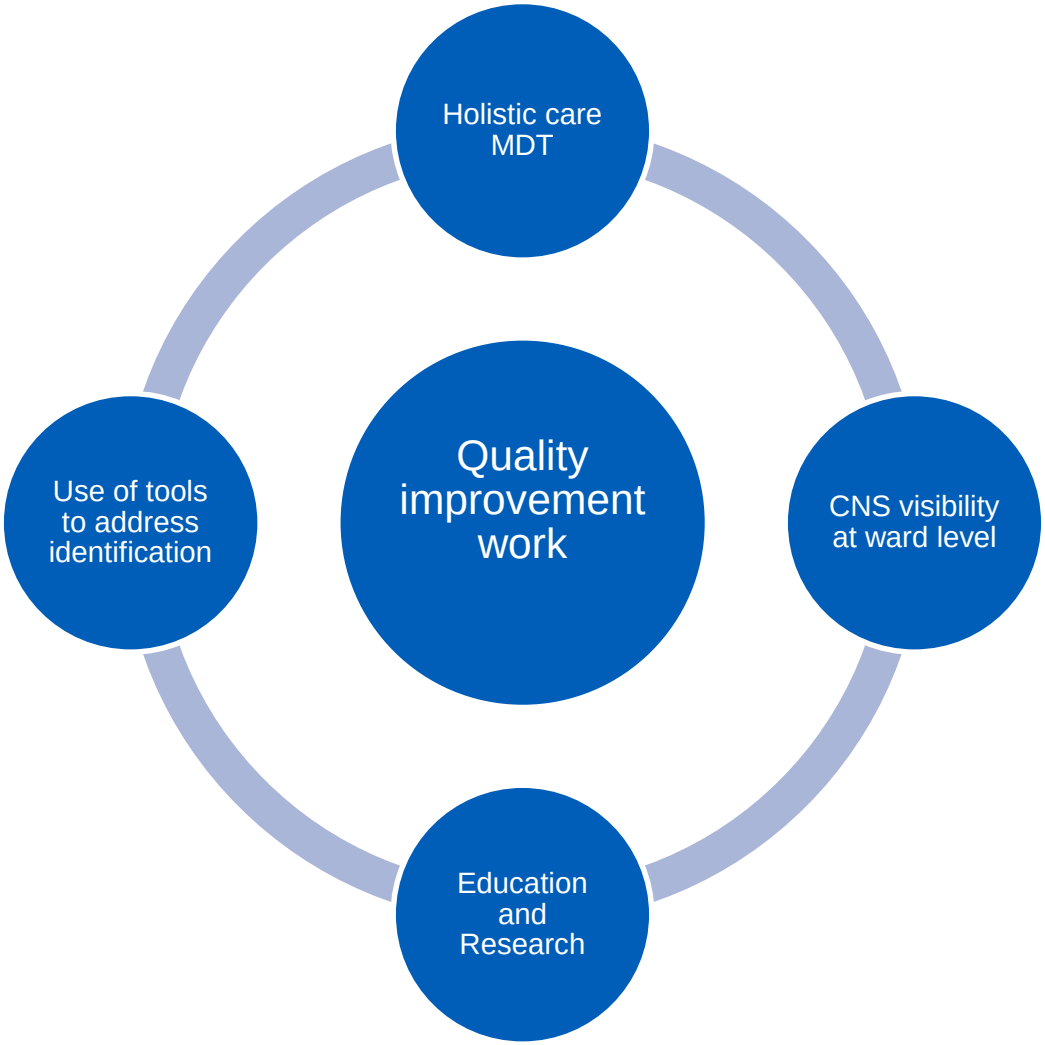
- **Recognition of dying** – uncertain trajectory of disease
- Disease course results in episodes of rapid deterioration
- Social economic – prevalent in more deprived areas
- Challenges relating to the patient group and barriers to accessing care; age, social support, homelessness
- Varied palliative care resources cross the UK – not always familiar with caring for patients with liver disease

Potential barriers – recognition of dying



Murray, S A et al. BMJ 2008; 336 958-959

Addressing the need at the RFH



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Case Study – Mary

40 year old woman

ARLD (conflicting alcohol history)

Previous SBP, previous TIPS, recurrent admissions in last 6 months

Admitted with: UGIB, HE and possible Alc hep, Child pugh C, Frail and cachexic

DNAR, ward based care, OGD and “active management”

Challenge – Identifying palliative care needs?

POOR PROGNOSIS SCREENING CRITERIA FOR INPATIENTS WITH CIRROSIS	
Childs Pugh C	✖
> 2 liver related admissions last 6/12	✖
Ongoing alcohol use in known ArLD	✖
Currently unsuitable for transplantation	✖
WHO performance status 3-4	

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Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s). ✖
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight. ✖
- Persistent symptoms despite optimal treatment of underlying condition(s). ✖
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites ✖
- hepatic encephalopathy ✖
- hepatorenal syndrome
- bacterial peritonitis ✖
- recurrent variceal bleeds ✖

Liver transplant is not possible ✖

Hudson BE, Ameneshoa K, Gopfert A, et al. Frontline Gastroenterology Published Online First: 21/12/2017 doi:10.1136/flgastro-2016-100734.

http://www.spict.org.uk/the-spict/

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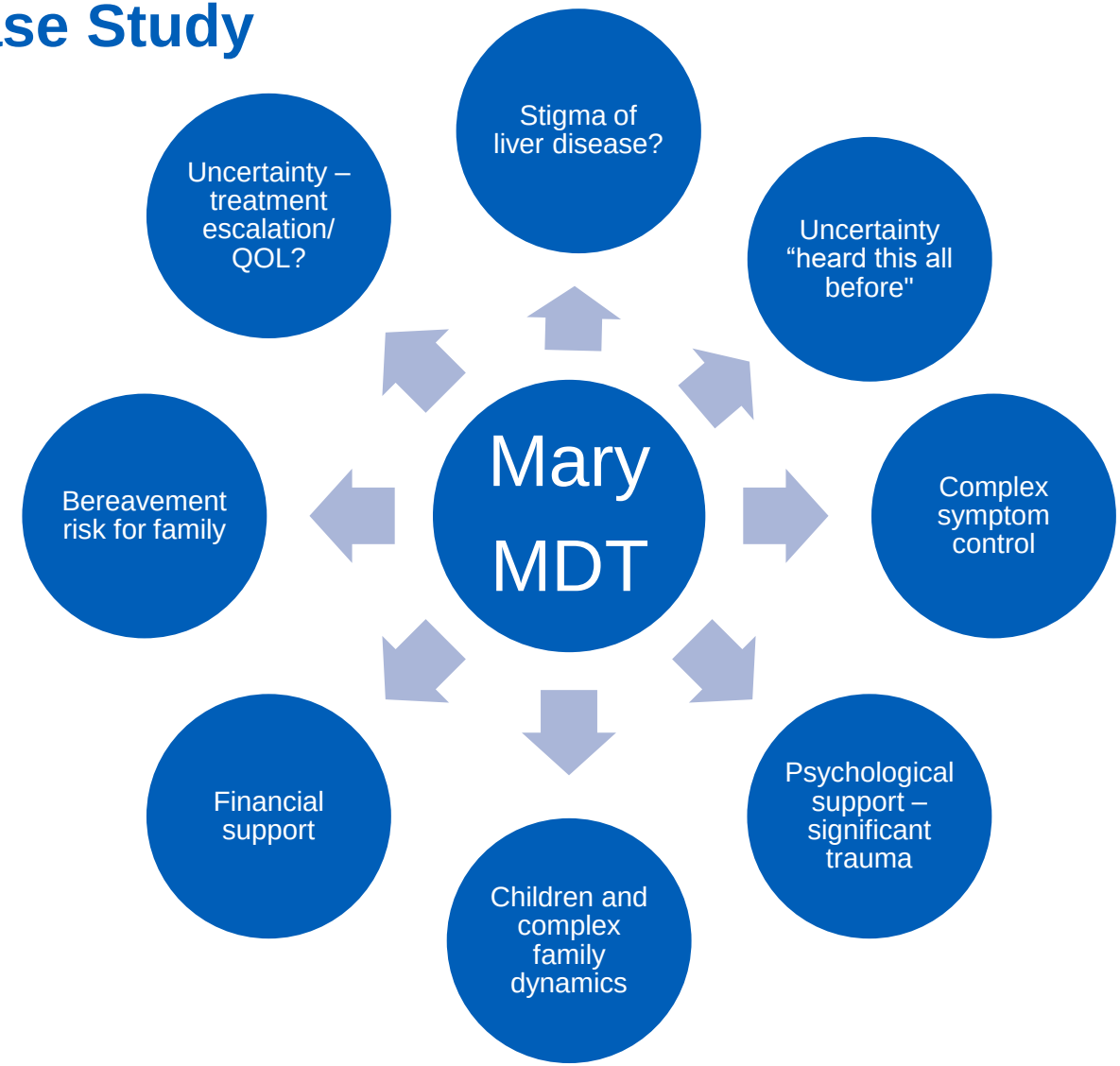
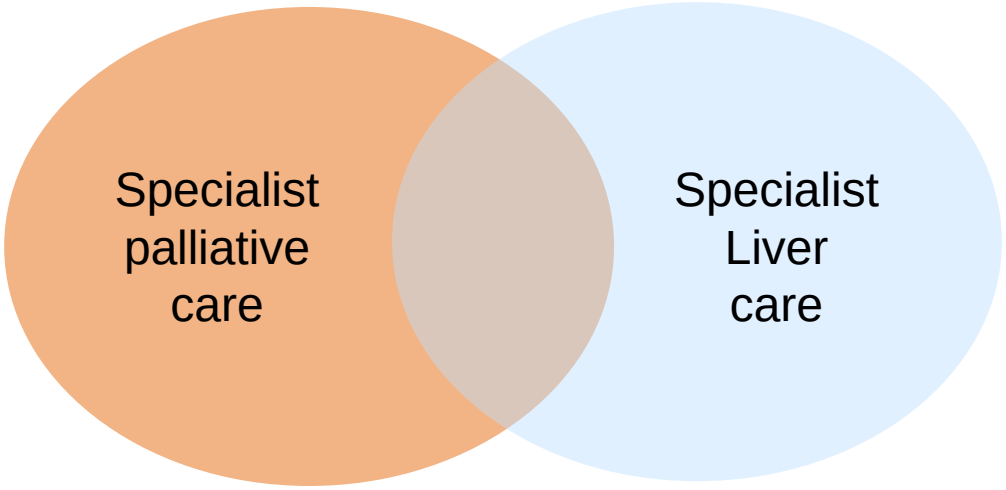
Mary Case Study



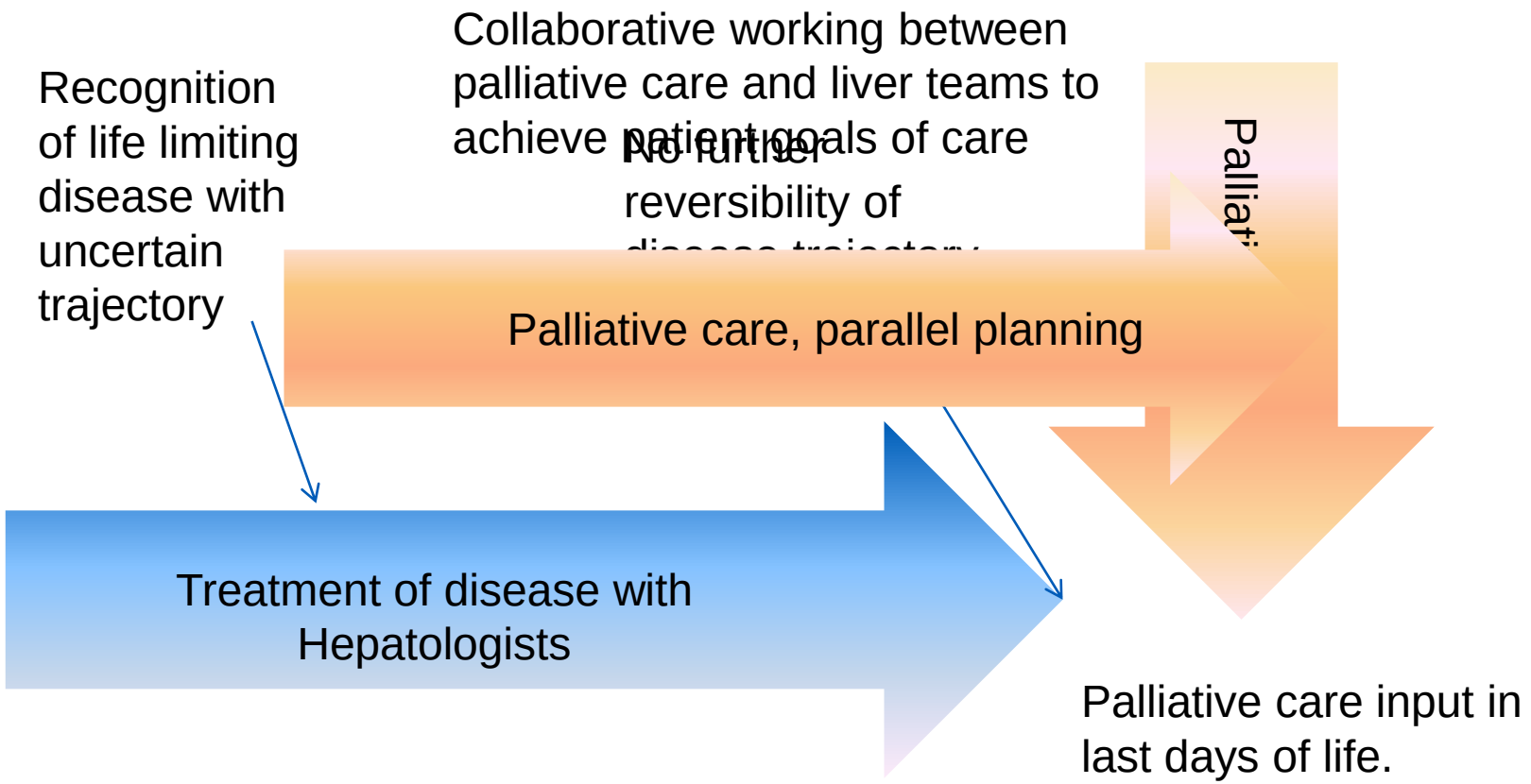
Palliative care CNS input

- Provides specialist advice for liver team, palliative care and community teams



- Parallel planning – Navigating uncertainty with patients
- Symptom control – liver specific knowledge
- Carer support – including bereavement support
- Holistic assessment of patients needs

Parallel planning



Mary Case Study

- **Physical**: Pain – Abdominal, usually on MST
- **Psychological**: coming to terms with uncertain prognosis, previous trauma linked to alcohol use
- **Social**: lives between Wales and London? Homeless?
- **Family**: Has a son (12) limited access, fractured relationship with ex partner, mum and sisters in Wales. Mary's son is very important to her and she wishes to spend quality time with him.
- **Spiritual**: Catholic faith, not practicing but important to her mum
- **Information**: weighing up quality of life vs quantity, hospice vs hospital

A new role – pushing boundaries

- Challenging services to ask:
- "What is palliative care?" "When is it offered?" "Who gets palliative care?"

"Too young: they aren't palliative yet"

"We're not their yet"

"No palliative care needs"

"It's a bit early"

"Social issues not palliative care issues"

"Patient wants to return to hospital - No advanced care plan needs"

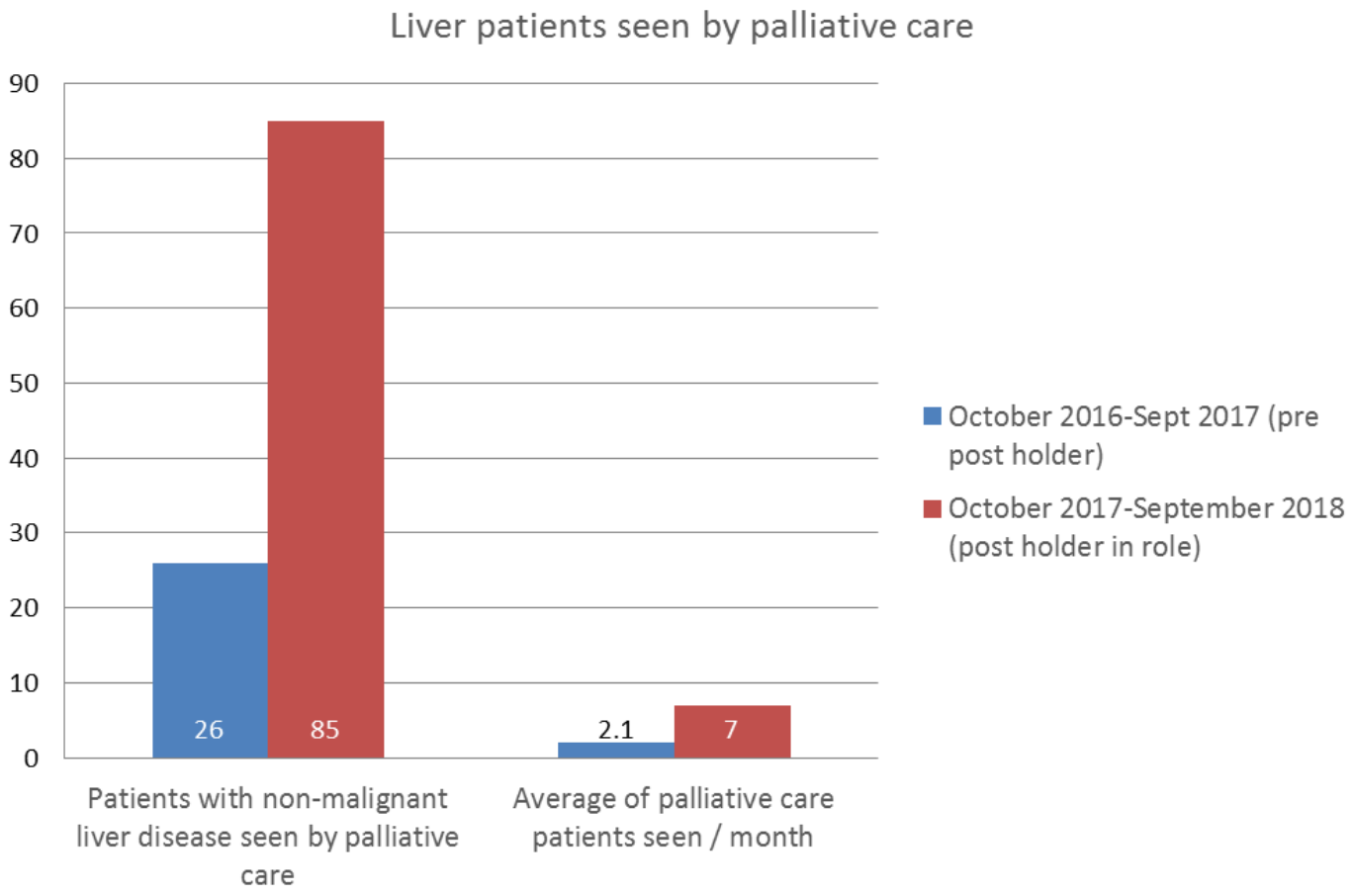
Uncertainty – patients "don't fit" regular service provisions

Limited charitable support compared to other diseases e.g. cancer

Case Study Outcomes, Mary

- Preferred place of care and death is hospice
- Mary opts to go to the hospice for QOL vs staying in hospital
- Transferred to local hospice where she spends time with her family.
- Dies within 2 weeks of hospice admission
- Family receive ongoing bereavement support from hospice service

Impact on palliative care referrals in RFH



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Feedback

"You babysat me throughout my dad's death, I will never forget you. I believe having you there things are easier for me now my dad has passed than they would have been without you." Relative

"This is the first ward I have ever worked on with a dedicated palliative clinical nurse specialist, and it has made such a positive difference. Hepatology is unfortunately a field with a considerably high morbidity and mortality, and it really helps having the palliative team pick these patients up early on to help manage their symptoms both as inpatients and as outpatients in the community." Junior Clinical fellow

"I wished we could measure this – I thought that the person that was dying was receiving amazing care. I really believe that this is due to all your hard work." Macmillan CNS Community Palliative Care Team

References and further reading

- Atlas of variation for palliative care and end of life care in England, October 2018
- Peng, JK et al (2019) Symptom prevalence and quality of life of patients with end stage liver disease: a systematic review and meta analysis. Palliative medicine 33 (1) 24-36
- https://publichealthmatters.blog.gov.uk/2014/09/29/liver-disease-a-preventable-killer-of-young-adults/
- Office of national statistics 2019: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2018#leading-causes-of-death
- Williams R, Aspinall R, Bellis M, *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;384:1953–97.
- Poonja Z, Brisebois A, van Zanten SV, Tandon P, Meeberg G, Karvellas CJ. Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management. Clin Gastroenterol Hepatol 2014; 12(4): 692-8.

Thank you and Questions?

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"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die" - Cicely Saunders

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