



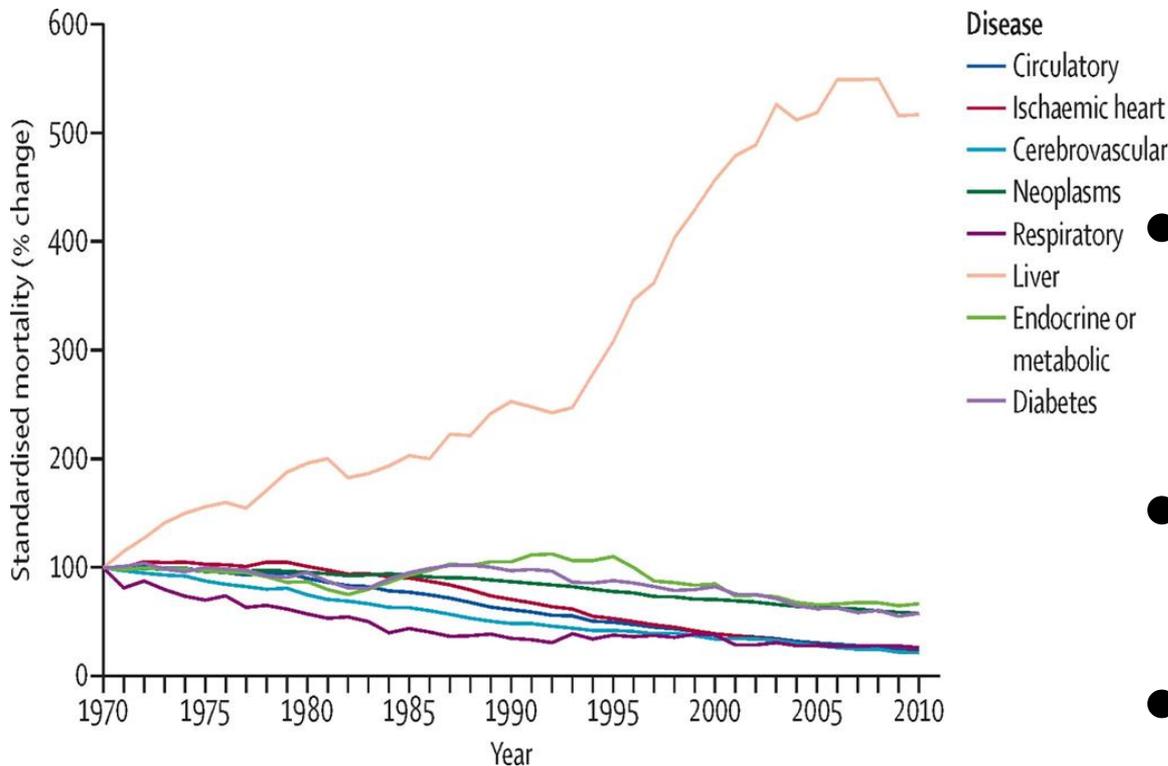
Nurse-Led Supportive Care Intervention for patients with Advanced Liver Disease: Feasibility Study

Research Team:

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Background



The Lancet 2014 384, 1953-1997

- Mortality rates for Liver Disease up 400% since 1970
- 3rd commonest cause of premature death in UK
- Average age of death 59
- Erratic and unpredictable
- Liver transplantation unavailable for many



Patient experience



- High physical and emotional burden
- A lack of understanding and explanation of the illness
- No emotional support
- Poor continuity of care in health and social services
- Little or no anticipatory care planning or identification for a palliative care approach





Project overview



- **Project aim:** To test the feasibility of an intervention delivered by a supportive care liver nurse specialist to:
 - **Co-ordinate** care and improve quality of life
 - **Support** patients and carers
 - **Provide advice** to professionals in the community
 - Facilitate **anticipatory care planning**, through the use of KIS (Key Information Summary)
- **Evaluation** using mixed methods



The Study Population



- Patients with advanced liver disease

Inclusion criteria

- 1 or more unplanned admission due to decompensated cirrhosis
- liver transplantation not appropriate

Exclusion criteria

- Expected survival <1 month
- Non-hepatic condition likely to cause death within 12 months
- Persistent cognitive impairment



Recruitment



Participants	
Patients recruited	47
M/F	31/16
Age	31-87 (<i>mean 60.5</i>)
Alcohol-related aetiology	31
Family carers	27



The Intervention



- “Thinking Ahead” booklet
- Face-to-face care review meeting
- Review letter to patient, GP and lead consultant
- Key Information Summary (KIS)
- Monthly follow-up calls for six months
- Final review letter and updated KIS to patient, GP and lead consultant



The role of supportive liver nurse specialist



- Act as case manager and co-ordinator
- Support patients and carers to live as well as possible
- Support care delivered by professionals in the community



Outcomes



- Supportive care liver nurse role, specialist advice and continuity of care welcomed by all
- Intervention and methods of evaluation feasible and acceptable
- Improved care experience
- Some reduced amount of contact with GPs
- 85% of participating patients had a KIS created or updated.
- Information gained will guide recruitment in future



- “Its nice to have somebody to talk it through with...” (Patient)
- “She was very helpful, she put my mind at rest, she answered questions that I hadn’t thought about, you know, and she gave me more confidence to be able to deal with what I’m doing” (Carer)
- “To me she was like the missing link that could explain everything to everybody and certainly was a great support to [patient] and his family” (Social Worker)
- “[Study Nurse]’s name appears in the notes on 6 different dates, referring to discussions I had with her to do with symptom management or arranging admission” (GP)



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