

# The experiences of people with liver disease of end-of-life care

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## Summary

This poster presents a qualitative study, which is in the early stages, being undertaken as a collaborative project between Bournemouth University and Lewis-Manning Hospice Care. Cathy Beresford is an experienced nurse conducting PhD research with support from the supervisory team. Liver disease is a growing health concern in the UK, causing physical and psychosocial challenges for people living with it, and is a major cause of death. The experiences of people with liver disease of end-of-life care are under-researched, and this study seeks to fill the gap in knowledge through qualitative research methodology.

## Aim

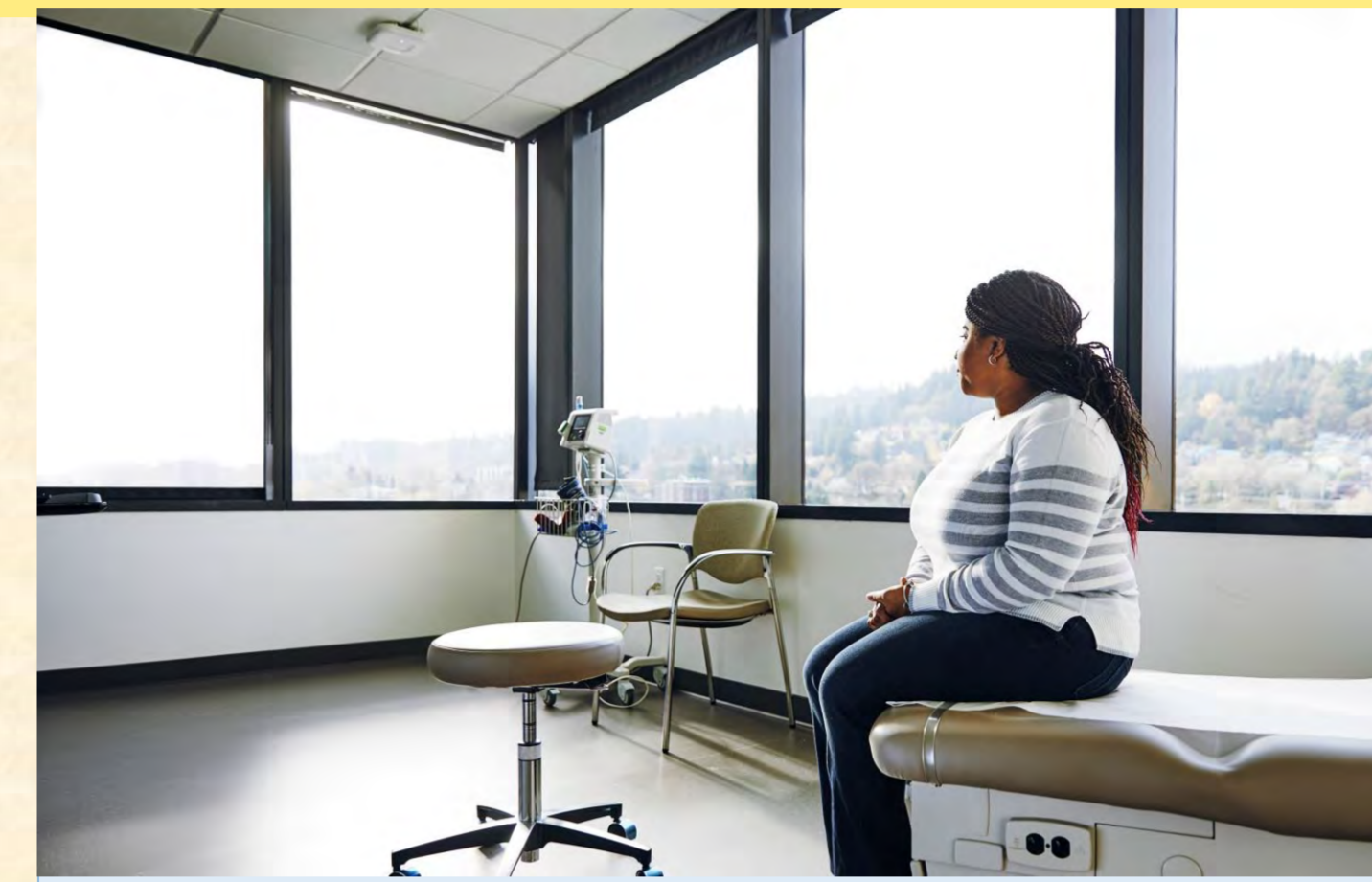
The aim of this research is to describe and explore the experiences of people receiving end-of-life care for liver disease.

## Background

- The liver is the second largest organ in the human body; it has a complex, adaptable and highly specialised role (Nagy et al., 2020).
- Liver disease is usually caused by alcohol use, being overweight, or hepatitis B and C (Office for Health Improvement and Disparities, OHID, 2022).
- Internationally, liver disease causes 2 million deaths every year (Asrani, et al., 2019).
- Incidence of liver disease is increasing in the UK, and it is the fifth most common cause of death (OHID, 2021)
- Younger people are particularly affected - it is the main cause of mortality in people aged between 35-49 (British Liver Trust, 2019).
- Advanced liver disease causes a range of challenging symptoms, as well as psychological and social complications for people with the condition.
- Socioeconomic factors significantly influence liver disease mortality and people living in the most deprived areas are more adversely affected (OHID, 2021).
- Palliative care is a holistic approach that can reduce the impact of symptoms and improve quality of life for people with liver disease.
- A systematic review of qualitative research highlighted 'the need for more research into perspectives of patients with advanced liver disease and their carers regarding palliative and end-of-life care' (Das et al. 2021, p.9).



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## Methods

This research is being undertaken in two phases:

1. A systematic literature review to explore the experiences of people with liver disease of palliative and end-of-life care, which will inform the design of Phase 2.
2. A qualitative study informed by Constructivist Grounded Theory (Charmaz, 2014).

### Data collection

- Recruitment will be with support from Lewis-Manning Hospice Care using purposive sampling
- Participants will include people with liver disease, their families and staff involved in their care.
- In-depth semi-structured interviews will be conducted.

### Data analysis

Data will be analysed using Charmaz's (2014) model incorporating constant comparison, theoretical sampling and seeking to achieve theoretical saturation.

## Ethics

Careful consideration to ethical issues will feature throughout the study, particularly in relation to the recruitment and interview of people who are towards the end of their life. Appropriate ethical approvals will be sought before data collection and all participants will freely give informed consent prior to interviews.

## Public Involvement

Public involvement (PI) is an integral part of this study and is being incorporated through all stages of the research process to ensure that the project is conducted with people with liver disease and not just about them. Lewis-Manning Hospice Care will support PI activities.

## Potential Impact

The study will:

- a) Contribute to knowledge and understanding of care needs for people with end-stage liver disease;
- b) Support the development of future care planning and guidelines;
- c) Provide insight which could help nurses and others working in end-of-life care settings (Griffith & Gelling, 2021).



## References

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## The Study Team

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