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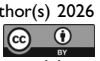
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Empowerment in advanced liver disease: UK experiences of care from the perspectives of people with lived experience, carers and healthcare professionals

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Abstract

Objectives: Liver disease is a leading cause of morbidity and mortality, with alcohol-related liver disease, metabolic-associated steatotic liver disease, and viral hepatitis comprising most cases in the UK. Advanced liver disease presents challenges due to unpredictable disease trajectories, high symptom burden, psychosocial impacts, and stigma. This study aimed to develop an explanatory theory of care experiences in decompensated advanced liver disease from the perspectives of individuals living with the condition, carers, and healthcare professionals, with public involvement embedded throughout.

Methods: Using Charmaz's Constructivist Grounded Theory methodology, semi-structured interviews were conducted across the UK with individuals with advanced liver disease, carers, and healthcare professionals. Data collection and analysis occurred concurrently using constant comparison, focused coding, memoing, and theoretical sampling.

Results: Twenty-four people participated in interviews. Analysis generated the Empowerment Continuum, an explanatory theory conceptualising empowerment as a dynamic, relational process shaped by personal, relational, and systemic factors. Five conceptual categories informed the theory: self-care, navigating healthcare services, healthcare professionals' contributions, carers' involvement and support, and information and communication.

Discussion: The Empowerment Continuum provides a framework for understanding care experiences in advanced liver disease. Supporting empowerment requires collaborative, accessible,

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and person-centred approaches involving people with liver disease, carers, and healthcare professionals.

Keywords
Advanced liver disease, empowerment, constructivist grounded theory, public involvement, qualitative research

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Introduction

Liver disease

Liver disease is a major cause of illness and death.[1] Rates have steadily risen in recent decades, with the primary types being alcohol-related liver disease, metabolic-associated fatty liver disease, and viral hepatitis (Hepatitis B and C), all of which are potentially preventable.[1] According to the Office for Health Improvement and Disparities,[2] in the UK, these account for nine out of ten cases of liver disease; others are related to genetics and autoimmune conditions.

There is increasing interest in research, policy, and services addressing the causes, detection, management, and care for people affected by liver disease.[3] This extends to understanding how best to support those in the advanced stages of the disease, which can be particularly challenging due to the unpredictable disease trajectory, high symptom burden, and associated psychosocial challenges.[4]

Adding to these challenges, liver disease is frequently stigmatised due to its association with so-called 'lifestyle' factors such as alcohol addiction and being overweight.[5] There are inequities in terms of the risk of developing liver diseases and the availability of support.[2–4] Consequently, researchers, healthcare professionals (HCPs), service providers, and policymakers increasingly recognise the need to address liver disease prevention, management, and associated care inequalities.[1–4] Furthermore, those affected by liver disease advocate for improvements through campaigns, networking and sharing information via organisations such as the British Liver Trust and LIVErNORTH.

Care in advanced liver disease

Advanced liver disease may lead to decompensation, where the liver cannot function properly, causing severe symptoms, acute illness, and potentially death.[6] Research indicates that the majority of people are diagnosed when their disease has reached the advanced stages[6–8] by which point, emergency treatment is required, and the condition is life-limiting.

For some, a liver transplant offers a potential cure, but suitability depends on frailty, ongoing alcohol use, and co-morbidities. Decompensated liver disease reduces life expectancy, with a median survival rate of two years.[9]

However, a recent systematic review, conducted as part of a PhD project, identified considerable variation in the reported experiences of palliative and end-of-life care for people living with advanced liver disease and highlighted the absence of an explanatory theory integrating the perspectives of people with lived experience, carers and healthcare professionals (HCPs).[10] Building on these findings, this study used Charmaz's[11] Constructivist Grounded Theory (CGT) methodology. This approach was chosen for its emphasis on understanding lived experiences and generating an explanatory theory grounded in the data through the co-construction of meaning between participants and the researcher.

Aim and research question

Consistent with a CGT approach, the primary research question was intentionally broad to enable theory to emerge inductively from the data:

> What are the experiences of UK care for individuals living with decompensated advanced liver disease, from the perspectives of those individuals, carers and healthcare professionals (HCPs)?

The aim of the study was to develop a grounded theory explaining care experiences in decompensated advanced liver disease. The objectives were to:

1. Explore the subjective experiences and perspectives of:
   (a) individuals with decompensated advanced liver disease receiving care;
   (b) carers (partners, family or close friends) of people with decompensated advanced liver disease; and
   (c) HCPs providing care to people with decompensated advanced liver disease.
2. Embed public involvement (PI) throughout the research project.

Public involvement

PI is sometimes referred to as patient and public involvement (PPI). In this paper, PI is the preferred term, referring to the input of people with liver disease and their carers, as discussed by Hughes and Duffy.[12] These individuals contributed to the research process *separately* from the research participants. Extensive evidence indicates PI makes research more meaningful, higher quality and acceptable to those it affects.[12–15] Truly meaningful and inclusive PI goes beyond a tick-box exercise and involves genuine co-production, where researchers listen to and act upon PI contributions.[16–18]

The PI group included nine individuals with lived experience of liver disease as patients (n = 6) or carers (n = 3). Their role was crucial in ensuring the research reflected the real-life experiences of people with liver disease and their supporters. This is explored further in Beresford et al.[19] a co-authored paper with PI group members. Several PI group members are also co-authors of this paper, reflecting their substantive contributions to the research process. PI is reported in accordance with the GRIPP2 Short Form (GRIPP2-SF) reporting checklist[20] provided as Appendix 1.

Methods

Study design

Charmaz's CGT provided the underpinning methodological approach. In CGT, findings are grounded in the research data, which is collected and analysed simultaneously. The researcher is not seen as separate from the data, but rather a co-producer of knowledge with the participants, and in this study, with the PI group. Charmaz[11] emphasises a transparent and rigorous approach to the research process to ensure that the findings are credible, original, have resonance and are useful. It was with these principles in mind that the study was designed and undertaken, as illustrated in Figure 1.

Sampling and recruitment

Individuals with advanced liver disease who had experienced decompensation, carers and HCPs were recruited from across the UK. Details of the inclusion and exclusion criteria are provided in Appendix 2. Recruitment was between October 2023 and August 2024 using an initial purposive sampling approach, seeking individuals who met the inclusion criteria. As the study progressed, theoretical sampling guided selection, focusing on those who could provide rich and relevant data to refine the emerging categories and support theory

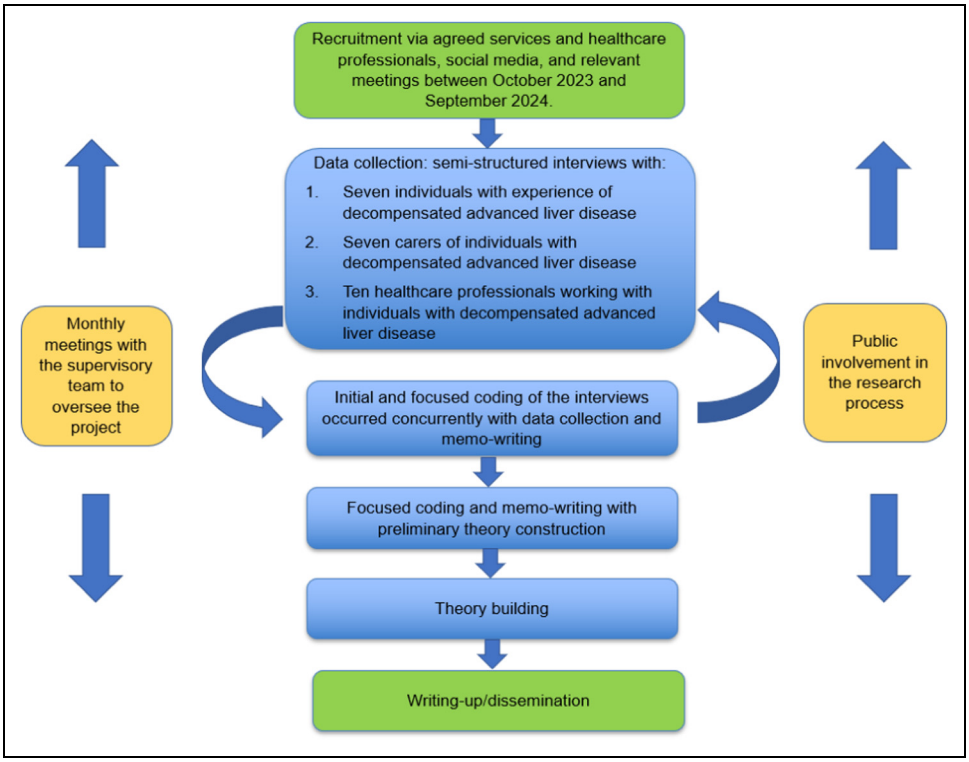


Figure 1. Study design flowchart, informed by Charmaz.[11]

development, consistent with CGT. The protocol set a maximum recruitment limit of twenty participants from each group to allow flexibility; these figures were upper limits rather than recruitment targets. Recruitment continued until the emerging categories were considered sufficiently developed to support theory construction through concurrent data collection and analysis.

The study was advertised via social media platforms (Facebook, WhatsApp, X), through hospices, and voluntary sector organisations, including the national liver charity LIVErNORTH. It was promoted through professional networks and research platforms such as VOICE Global,[21] supporting the inclusion of carers. Two individuals with advanced liver disease became aware of the study opportunity during routine clinical care. The nurse involved in their care signposted them to the publicly available study information but was not involved in the recruitment process, consent procedures or data collection. Some HCPs were recruited through existing professional contacts. This approach enabled the recruitment of people with lived experience, carers, and HCPs across a range of settings.

The number of individuals who viewed the study information but chose not to contact the research team was unknown; therefore, non-participation could not be quantified.

Data collection

A flexible interview guide was developed based on Charmaz,[11] informed by the systematic review, the study aims and in discussion with the PI group. Questions explored participants' experiences of care in relation to the research question and were deliberately broad because

of the CGT methodology, with prompts evolving through constant comparison and concurrent data analysis. Semi-structured interviews were conducted by the lead researcher by telephone, in-person, or video call (Microsoft Teams), depending on each individual's preference. Seven individuals with advanced liver disease, seven carers and 10 HCPs took part. Table 1 provides the demographics of the people who participated. Two carers were connected to people who also to1ok part: Sidney (PWLD02) and Rose (Carer02); Colin (PWLD07) and Louise (Carer05).

Each interview was between 16 to 60 min, with a mean of 40.1 min across all 23 interviews. The total cumulative interview time was 913 min. Sidney (PWLD02) and Rose (Carer02) were interviewed together at their request.

Data analysis

CGT informed the data analysis. NVivo 20 supported coding, organisation, and access to data, enhancing auditability, transparency and scientific rigour.[22] As Bazeley[23] notes, qualitative software supports but does not replace in-depth, interpretive analysis.

The rigorous process involved:

- Field notes during each interview.
- Transcription via Microsoft Teams and Word, with manual checking for accuracy, familiarisation, and reflection.
- Participant transcript review, enabling clarifications and additional reflections to enhance credibility.
- Line-by-line coding of anonymised transcripts in NVivo 20, followed by focused coding, discussed with the supervisory team.
- Constant comparison and manual sorting of focused codes supported the development of conceptual categories, which were integrated through the core category (Empowerment Continuum).
- Mind-mapping to explore relationships between categories and support theory development.
- Memoing recorded in NVivo 20 as part of the CGT process.
- Core category development, with empowerment emerging as central to the theory.

The lead researcher is a registered nurse with clinical experience in supporting people with long-term conditions, which informed her interest in this topic. This professional background may have influenced interactions with participants and interpretation of the data; therefore, reflexive memoing and discussion with the supervisory team and PI group were used to critically examine assumptions and emerging interpretations. This approach is consistent with Charmaz's CGT.[11]

PI further enhanced scientific rigour. During data analysis, four PI meetings (March 2024 - January 2025) explored category development and interpretation, contributing to core category refinement, with empowerment emerging as central to the theory.

Ethical considerations

Ethical issues were a priority throughout this project, protecting people's dignity and safety.[24] This was particularly important in the process of recruitment and interview of individuals living with advanced liver disease and carers. Approval was obtained from:

- Proportionate Review Sub-committee of the West of Scotland Research Ethics Committee (REC 4; IRAS project ID: 331914; REC reference 23/WS/0150)
- Bournemouth University (Ethics ID: 52129)

Participants were given an information leaflet and able to ask questions before signing the consent form. Data was kept securely in the university's password-protected platform.

Table 1. Demographics of the people who participated in an interview.

Category	Male	Female	Age	Ethnicity	Type of liver disease	Type of carer	Occupation of HCP	Total
Individual with advanced liver disease	6	1	40–49 years n = 2 50–59 years n = 2 60–69 years n = 2 70–79 years n = 1	White British n = 7	Alcohol related n = 6 MASLD n = 1	Not applicable (N/A)	N/A	7
Carer	1	6	30–39 years n = 1 50–59 years n = 3 60–69 years n = 2 70–79 years n = 1	White British n = 5 Mixed Asian-African n = 1 White English-Irish n = 1	Alcohol related n = 3 MASLD n = 3 Other n = 1	Partner/ spouse n = 3 Parent / step- parent has liver disease n = 3 Other relative n = 1	N/A	7
HCP	1	9	30–39 years n = 2 40–49 years n = 4 50–59 years n = 3 60–69 years n = 1	White British n = 8 White Irish n = 2	N/A	N/A	Nurse specialising in hepatology n = 5 Nurse specialising in palliative care n = 2 Dietitian specialising in hepatology n = 1 GP n = 1 Psychologist n = 1	10

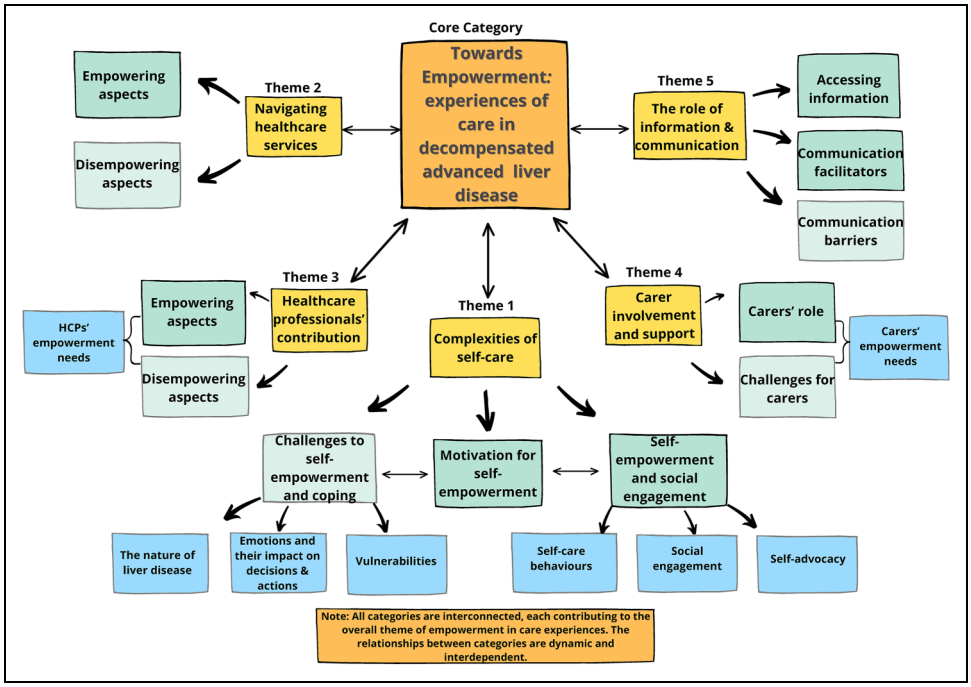


Figure 2. Infographic produced during data analysis.

Pseudonyms are used throughout this paper. If anyone became distressed or experienced difficulties during interviews, they could pause or stop and were signposted to support. The interviewer is a registered nurse with experience in discussing sensitive topics and managing difficult conversations.

Findings

Seven individuals with advanced liver disease, seven carers and ten HCPs participated; Table 1 provides participant demographics. Analysis generated an explanatory theory of care experiences in decompensated advanced liver disease, conceptualised as the Empowerment Continuum. Empowerment emerged as the core category, integrating five interrelated categories and explaining how interactions between individuals with advanced liver disease, carers, HCPs and healthcare systems shaped experiences of care. Within this theory, empowerment is conceptualised as a dynamic process that is strengthened or diminished through these interactions, influencing individuals' ability to navigate, participate in and manage their care. The five interrelated categories underpinning the Empowerment Continuum were:

- The complexities of self-care
- Navigating healthcare services
- HCPs contributions
- Carers' involvement and support
- Information and communication

Figure 2 illustrates the core category of empowerment and its relationship with the interconnected categories. It shows how empowering and disempowering experiences shaped care.

The complexities of self-care

In the context of advanced liver disease, self-care refers to how individuals manage their

health and well-being. For example, diet, activity, medication, abstaining from alcohol, attending appointments, seeking information, support and self-advocating. There was a strong desire to look after oneself; however, several factors hindered individuals' ability to do so.

Challenges

The nature of liver disease. People expressed that late diagnosis, challenging symptoms and unpredictable prognosis presented challenges to self-care and empowerment. For example, severe illness could be a significant barrier:

> "I was suffering from liver failure and encephalopathy in the brain and that. So, I was seriously hallucinating for ages…I was just off my head really. But not through drink or drugs, just through that like, you know, encephalopathy." (Dan, PWLD05)

Vulnerabilities. Physical, emotional and social factors impacted empowerment and self-care. HCPs recognised the many challenges faced by individuals with liver disease and acknowledged that services often fell short of meeting their complex needs:

> "There's huge issues with mental health and access to mental health services… a lot of them struggle with addiction… the things that you hear from the patients, you know things are - domestic violence, childhood abuse and trauma ongoing. You know, loneliness is a huge issue. Social isolation…" (Angela, HCP06)

Motivation. Although people were living with advanced illness, difficult symptoms, and personal challenges, motivation was present in those with liver disease:

> "You've got to actually help yourself. Instead of laying there, and feeling sorry for yourself, you can't expect them to just basically, how can I put it, them to come and help you 24/7. You gotta help yourself." (Lennie, PWLD04)

Despite difficulties, self-advocacy and social engagement were fundamental aspects of individuals' care experiences. Even with advanced disease and variable support, people demonstrated empowerment by self-advocating, accessing information, and connecting with others.

Navigating healthcare services

Individuals in this study accessed a wide range of services, including primary care, Accident and Emergency, inpatient care, specialist hepatology or gastroenterology, and other services. Availability of hospice and palliative care varied, and most people reported limited access to such support. The desire to avoid hospitalisation was apparent throughout, with hospital admission associated with deterioration in health and reduced autonomy:

> "I was desperate to keep him out of hospital because he didn't… want to be in hospital… That was absolutely clear… not to spend weeks in hospital, he would have just gone absolutely crazy… he was so independent." (Belinda, Carer01)

Individuals and carers navigated their way through both empowering and disempowering experiences of care.

Empowering aspects. Care was found to be empowering when person-centred, holistic and accessible. For example, Robert had been severely unwell as an inpatient when he was first diagnosed with liver disease and spoke highly of the care he received, which he largely attributed to HCPs:

> "I've got to be honest, the care I received it well, the nurses and the doctors there, they saved my life. I can't have thanked them enough for what they what they for me. I still go and see them now." (Robert, PWLD03)

Robert expressed that this care had been a motivating factor in his subsequent abstinence

from alcohol and his determination to improve his health.

Similarly, Rose, who cared for her husband Sidney, reflected on the care they received from their hospice:

> "I think it's because they don't see Sidney as just a liver. Yes. And you know, sort of you don't feel like you're a specimen in a bed and that you're a real human being and there's other things going on and age and everything else, but they treat you… as a human being." (Rose, Carer02)

Originally given a six-month prognosis, Sidney was interviewed two years later. He and his wife, Rose, attributed this to the hospice care they had received.

People valued accessible support, joined-up services, and care which addressed their needs. When this was unavailable or inadequate, there was frustration, anxiety and declining health.

Disempowering aspects. Barriers to care, lack of access to services and disparity in service provision were disempowering to people with liver disease and their carers. HCPs also reported dissatisfaction and frustration when there were shortcomings in service provision. For example, disjointed care pathways, inadequate relationships between different services, or inadequate service provision:

> "I think this this cohort of patients are really poorly cared for and let down." (Bella, HCP09)

Inequities in service provision were a major theme:

> "… care can be good if they've got the right team, the right GP, the right hospital. I think when they don't have those things, typical postcode lotteries, they end up in A&E a lot. They end up in the GP a lot, and there's not much they can do or there's lots of people involved, but not actually getting anything done, which is a real challenge for them as patients." (Iris, HCP02)

There was a strong theme of services being under immense pressure, impacting the care experiences of individuals with liver disease and their carers, as well as the HCPs delivering care.

Services under pressure. Service pressures were especially problematic for those individuals who were more vulnerable and less able to assert themselves:

> "… the NHS is not a place for old people. It really isn't. And I don't know what anybody would do about that because he couldn't even, no way could he advocate for himself." (Belinda, Carer01)

HCPs also recognised the limitations in providing care, emphasising the impact of systemic pressures:

> "I'm just really aware of all the challenges at the moment as well, and you know, the pressures on the teams and the impact that that can have on patient care and obviously the well-being of staff as well." (Dawn, HCP01)

Despite challenges, HCPs were involved in quality improvement projects and networked to enhancing care for people with liver disease. Furthermore, individuals and carers self-advocated by seeking advice and information, asking questions, and joining organisations including the British Liver Trust and LIVErNORTH. For example:

> "… the [British] Liver Trust was really helpful. I would say that was probably the most helpful thing, to be honest… Speaking to other people, they were in the same position, similar positions to yourself." (Kevin, PWLD06)

Healthcare professionals' contributions

HCPs are fundamental to care provision. Consequently, their skills, behaviour and actions were instrumental to people's care experiences. People in this research frequently

referenced the positive and negative aspects of HCPs' contributions and their profound impact.

Empowering contributions. Individuals and carers encountered extremely challenging circumstances due to liver disease. For example, Mabel had cared for her husband until his death, describing it as one of the hardest things she had experienced. However, she reflected that the doctor made the situation more bearable:

> "I mean the doctor was absolutely fantastic. She was so caring." (Mabel, Carer04)

A key finding was that, despite difficulties such as uncertain prognoses, ill health and life-limiting illness, HCPs often contributed to a more positive, empowering experience. They did this by supporting disease management, encouraging changes to health behaviour, facilitating advanced care planning and providing emotional support. For example, reflecting on the care her family had received from their specialist nurse, Lucy highlighted that it had been helpful:

> "…not to shy away from the reality of the situation, because the more information people have, the better situational awareness they have, the better position they're in to actually make plans as much as they can, and you know, for whatever [time] they have left." (Lucy, Carer07)

HCPs frequently spoke of multi-disciplinary collaborative working and educating non-specialist staff as part of improving liver disease care:

> "… it's all about looking at joined-up working and on-the-spot education to give the non-specialist teams the right kind of guidance as to how to manage those patients so that it was a bit more equality across the hospital as to how these patients were managing." (Ivy, HCP04)

Mixed experiences of HCPs' contributions were reported. Belinda described overall failings in the care provided to her stepdad, who had died from liver disease. However, she described a positive encounter with a specialist nurse:

> "… the [liver] nurse had good caring skills and… spoke to my stepdad, you know, because sometimes – how do I put it - if somebody's a deaf old man, there's all sorts of different ways that that old, older people get treated in the hospital, and sometimes they're kind of semi-ignored or laughed at… and sometimes they're actually addressed as human beings that they really are… she spoke to him, explained things to him and treated him like the sort of human being that he was." (Belinda, Carer01)

Disempowering contributions. Negative experiences were frequently attributed to poor communication skills from HCPs. For example, Sidney reflected on the care he received from a GP:

> "I mean one of them. He stands eight foot away. He's still wearing COVID stuff, masks, though, the lot, you know? And he's like 'Stay back there' and you know he won't touch you; he won't communicate with you. What's the point of going to see him? There is none." (Sidney, PWLD02)

However, there was recognition that HCPs were under enormous pressure and struggling to deliver care to the standard they would like, with staff often doing the best they could under difficult circumstances.

Carers' involvement and support

Carers' role. Friends, family and partners played a vital role in supporting people with advanced liver disease. This was described by carers, HCPs and individuals themselves, including Kim (PWLD01), who described her dad as "amazing" for the support he provided, and Dan (PWLD05), who referred to his partner as a "diamond." Belinda explained the practical aspects of being a carer:

> "… there was so much to do with ferrying him about… doing the shopping and keeping the flat clean because he was starting to become incontinent, you see. So, I was having to go to the flat and wash carpets where he couldn't get to the toilet in time. So, physically there was masses to do so. It just felt like a massive caseload…" (Belinda, Carer01)

Challenges for carers. Although carers expressed a strong desire to look after their loved ones, their role placed immense responsibility and challenges on them. For example, when asked who she could go to for support or advice, Louise explained:

> "Nobody. There's nobody. There's absolutely nobody. It's a very lonely thing." (Louise, Carer05)

This contrasted with the hospice support Rose had received while caring for her husband, Sidney. Her account highlighted variations in what services were available, with some carers feeling unsupported and others having access to comprehensive care. Rose's experience also demonstrated the value of appropriate support, not only for people with liver disease but also for their families.

> "I know with the hospice that you are totally covered every which way. Night, day I can just phone and say something's wrong and they can advise me… Which is very - as a carer, is very, very supportive, because otherwise you're just running around in circles." (Rose, Carer02)

Support for carers. A key finding was that carers wanted to look after their loved ones, but they needed support, to feel valued and included in discussions. Access to appropriate support and advice was crucial to their well-being and that of the person with liver disease:

> "All the family needs is someone to be able to talk to, to say, 'What do I do? I can see this symptom.' And that, having that reassuring voice that they can speak to - a call centre person, an actual specialist associated with that disease. Then the patient will feel, or their loved ones will feel, reassured." (Vikram, Carer06)

Information and communication

A crucial, interweaving theme throughout the findings was the value of honest and understandable information, communicated in a timely, sensitive and accessible manner. When lacking, there were difficulties for individuals with advanced disease and their carers:

> "We weren't given the level of information that I expected that I should have been on what to expect, you know, what happens to a dying person." (Mabel, Carer04)

There was frustration when access to information and support was inadequate:

> "…for me there needs to be more of an approach or a central point of contact…Because I find a lot of that just kind of gets forgotten about. I'm not kept in the loop about anything." (Kevin, PWLD06)

Many sought to educate themselves, which could be empowering. However, the initial lack of clear information added stress to an already difficult situation. Furthermore, some individuals had difficulty self-advocating, contributing to the challenges and additional carer responsibilities.

Overall, there was a desire from individuals and carers for positive communication and accessible information:

> "Because all a patient and their loved one wants is that understanding of what is happening to them, what is going to be done to help them. So, communication is the first thing. Access to the people [HCPs] you talk to, to get that reassurance" (Vikram, Carer06)

Discussion

Empowerment

Empowerment as a concept has gained prominence since the civil rights movement of the 1960s and has been a key theme in healthcare discussions for decades.[25] In healthcare, it has been highlighted that empowerment is frequently framed as a helping process of making patients act differently, rather than the redistribution of power or a co-constructed process.[26] In this study, empowerment is conceptualised as a continuum, experienced variably across different interactions and influenced by personal, relational, and systemic factors.

Across the data, empowering experiences were those that made people feel strong, capable, and supported, offering a sense of control, hope, or motivation. In contrast, similar to the findings of others,[27] disempowering experiences left individuals or carers feeling uncertain, helpless or overlooked. Importantly, not everyone wanted or was able to be "empowered" at all times. Serious illness, cognitive changes, or emotional exhaustion often meant carers or HCPs acted on the person's behalf. This aligns with the ideas that empowerment is not a fixed outcome, but a dynamic and context-sensitive process.[28,29]

The findings illustrate how individuals and carers move along this empowerment continuum. For example, those experiencing hepatic encephalopathy or in intensive care were often unable to participate in decisions. Consequently, carers or HCPs stepped in. As an individual recovered, they were able to regain control. How this was done mattered, as argued by Williams et al.,[30] when care was person-centred and responsive to individual needs (e.g., explaining clearly, adjusting communication, involving family), it supported dignity and preserved agency. When perceived as dismissive or there was a lack of reasonable adjustments, such as in the case where a carer had to explain a terminal prognosis to her stepfather due to poor communication, it became disempowering and distressing.

Self-care was both a potential source of empowerment and a challenge. Managing symptoms, attending appointments, or seeking support could enhance confidence and control, but delayed diagnoses, fluctuating health, stigma, guilt (e.g., related to alcohol use), or inadequate access to services could undermine this. As noted by Gray-Renfrew et al.[31] such factors affect emotional well-being. Despite challenges, people showed acts of empowerment, including seeking information and support, or switching GPs, even in the face of system failings.

Navigating services emerged as a key determinant of empowerment. Services that were accessible, joined up, and flexible supported people to feel heard and involved. This aligns with the findings of other researchers in liver disease care.[4,32–35] In contrast, like the findings of Wakefield et al.[36] fragmented or unresponsive systems, with poor HCP communication or inequitable access to specialist care, created barriers and deepened disempowerment.

HCPs played a dual role. Many advocated for better services, worked holistically, and supported people through person-centred care, as described by McCormack et al..[37] However, others were associated with disempowering experiences through poor communication, gatekeeping, or limited time, shaped by wider system pressures, also described elsewhere.[38,39] Communication, empathy, trust and access were crucial in determining whether HCP interactions supported empowerment.

Carers, too, navigated their own empowerment journeys. While they advocated on behalf of their loved one by asking questions, managing appointments, or seeking information, they also needed recognition, information, and support, as argued by Abrahamson et al..[40] Feeling ignored or unsupported made their role more stressful and less sustainable.

Finally, like the findings of others[4,33] information and communication were central. Timely, accessible, and tailored information

enhanced informed decision-making and managing life with advanced illness, aligning with the arguments of Spiers et al.[41] in their research focusing on what is important to people with multiple long-term conditions and their carers. In the absence of adequate information provision, people turned to charities or online sources, which were helpful but reflected gaps in service provision.

In summary, these findings show that empowerment is not an inherent quality or outcome, but a relational, dynamic process shaped by interactions between people, HCPs, and systems. Supporting empowerment is not simply about promoting self-management. It involves joined-up, person-centred care, with access to services and support for the people living with liver disease, as well as for families and HCPs who support them. Creating structures that facilitate relationships and communication practices that acknowledge the realities of serious illness can help people to be empowered in ways that they want to.

Limitations and suggested areas for future research

This small-scale qualitative study provides valuable insights into the UK care experiences of individuals with liver disease, carers and HCPs. However, most individuals with lived experience were White British men with alcohol-related liver disease; therefore, the findings may not fully reflect the experiences of women or those with other liver disease aetiologies. Although the HCP sample included professionals from several disciplines, nurses were more highly represented than other professional groups.

Despite following guidance to make the research as inclusive as possible,[42,43] using multiple recruitment methods and opening the research to people across the UK, we were unable to achieve the ethnic diversity we had hoped for. This underrepresentation means that the experiences and perspectives of some ethnic groups may not have been fully captured.

We recommend that future research include a broader range of ethnicities, as cultural backgrounds and practices can influence healthcare experiences and interactions.[44] As one member of the PI group stated:

> "Cultural norms, cultural expectations, and cultural ways can also be a huge factor in providing healthcare." (PI group member)

While ethnicity and culture are distinct, they are often interrelated in shaping individuals' experiences of care.[45] To address this gap, collaborative partnerships between universities and community organisations may be key, as they can facilitate involvement with underrepresented groups and ensure culturally sensitive recruitment strategies. Inclusive research is high on the agenda for funding bodies such as the National Institute for Health and Care Research (NIHR),[46] and Hughes et al.[47] advocate for new and adaptive approaches to achieve genuine inclusivity. Ensuring diverse research involvement supports a more comprehensive understanding of healthcare experiences and helps shape more effective, equitable care.

Recommendations

This study offers insight into the care experiences of people with liver disease, carers, and HCPs, with practical recommendations drawn from their voices, informed by the Empowerment Continuum and co-developed with the PI group. These are presented in Table 2 and are not prescriptive but reflect how people find ways to manage and act, even when illness or systems feel overwhelming.

Conclusion

This study generated the Empowerment Continuum, an explanatory grounded theory demonstrating how care experiences in decompensated advanced liver disease are shaped by dynamic interactions between individuals, carers, HCPs and healthcare systems. The

Table 2. Overview of study recommendations.

For People with Liver Disease and Carers
Support is crucial. Living with advanced liver disease is often exhausting, and it's okay to need help. Small actions, such as asking questions, seeking information and bringing someone to appointments, may strengthen empowerment by increasing confidence and involvement in care. Recognising your personal strengths matters too.
For Healthcare Professionals and Services
Person-centred, holistic care that strengthens empowerment should underpin practice. Clear communication, collaborative working, and joined-up care are central to this. Reducing variation in service provision and ensuring timely access to specialist and supportive care may enhance empowerment by reducing barriers to appropriate care and support. HCPs should be supported with training, time, and resources to deliver high-quality care, maintain their own well-being and network with others to share good practice.
For Researchers
Future studies should continue to prioritise inclusion of ethnically and socially diverse voices. While this study aimed to engage a broad range of people, greater diversity may be supported through collaboration with community partners. PI enhanced the relevance of this study and should be embedded in future research.
For Carers
Recognising carers as partners in care may strengthen empowerment for both carers and people living with liver disease. Carers must be recognised, included in decision-making (with consent), and supported emotionally, practically, and financially. Their knowledge is vital, and flexible support should be available throughout the illness journey.
On Empowerment
The Empowerment Continuum suggests that empowerment happens through everyday interactions, accessible care and collaborative working. It is relational and systemic. When people feel involved, respected, and supported, they are more able to act, participate, and influence care. Empowerment is about creating conditions where all involved feel able to make informed decisions and contribute to care processes.

findings highlight how empowerment is strengthened or diminished through experiences of self-care, navigating healthcare services, relationships with HCPs, carer support, and information and communication.

The findings also reveal significant variation in service provision for people with decompensated advanced liver disease. Overall, people with the condition emphasised their own role in managing their health through diet, activity, medication, abstaining from alcohol, and attending appointments. However, despite their desire to manage their liver disease, there were challenges and inconsistencies in access to care.

Carers were invaluable in providing a range of practical and emotional support to people with liver disease. While they wanted to provide such care, they faced immense challenges often without sufficient support or recognition. HCPs also demonstrated a commitment to delivering high-quality care, but this was often against a backdrop of immense pressure due to service constraints, workload stresses and the challenging nature of advanced liver disease.

Adequate information provision, which was clear, honest and understandable, was crucial to people with liver disease and their families. This was best communicated in an honest and empathetic way. When this did not happen, it was disempowering for people affected by liver disease and their families. Despite difficulties, people found ways to advocate for better care, showing that empowerment is possible even in the most challenging circumstances. The Empowerment Continuum provides a framework for understanding these care experiences and highlights opportunities to strengthen

empowerment through more coordinated, person-centred models of care.

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Ethical approval and informed consent statements

Ethical approval was obtained from the Proportionate Review Sub-committee of the West of Scotland Research Ethics Committee (REC 4; IRAS project ID: 331914; REC reference: 23/WS/0150) and Bournemouth University (Ethics ID: 52129). All individuals provided informed consent to participate, and pseudonyms have been used throughout to protect confidentiality.

Author contributions

Author CB: Conceptualisation, Methodology, Investigation, Data Curation, Formal Analysis, Writing – Original Draft, Visualisation, Project Administration.

Authors SB, JD & LG (Supervisors): Supervision, Writing – Review & Editing.

Authors YG, CO, MR, SR & WW (Public involvement contributors): Conceptualisation, Validation, Writing – Review & Editing.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability statement

The data that support the findings of this study are openly available in anonymised form in Bournemouth University data repository at: https://doi.org/10.18746/bmth.data.00000519. Anonymised excerpts are included within the article.

Any other identifying information related to the authors and/or their institutions, funders, approval committees, etc, that might compromise anonymity.

No additional identifying information related to the authors, institutions, funders, or approval committees is included that could compromise anonymity.

Supplemental material

Supplemental material for this article is available online.

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