Assessing the Feasibility of Netnography in Understanding the Unmet Needs of Individuals with Severe Health Conditions

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Research summary

Unmet needs associated with severe conditions arise in various contexts, from individuals being unaware of their condition due to insufficient screening to challenges in accessing appropriate care due to systemic barriers such as service availability, cost, and quality issues. While traditional metrics assessing unmet needs for specific health services or conditions are valuable, they often do not prioritise these unmet needs, which lack a universally accepted definition and remain difficult to measure.

This study explored the feasibility of netnography—a research method used to study online communities, cultures, and digital interactions—as a tool for identifying unmet needs among individuals with advanced liver disease. Netnography (also referred to as online or digital ethnography) applies the principles of ethnography to the online environment, shifting the focus from geospatial cultural activities to digital discourses and interactions in virtual spaces. While relatively novel and underexplored in healthcare research, we sought to understand the method's substantial potential for capturing real-world patient experiences.

To assess its feasibility, we conducted a netnographic study of discussions from an online health forum where individuals with advanced liver disease shared their concerns, challenges, and lived experiences. To provide a comparative perspective, a scoping review of existing literature on the same topic was also conducted. Comparing the findings from both methods allowed for an evaluation of netnography's effectiveness in identifying and understanding unmet needs.

The findings indicate that netnography can be a valuable and viable method for exploring patient experiences and identifying their unmet needs. By analysing real-time, naturally occurring online discussions, netnography provides insights into both individual and systemic challenges related to the condition. However, the approach comes with ethical and methodological challenges, including concerns around privacy, informed consent, and the representativeness, contextual ambiguity. These factors must be carefully considered when applying netnography in healthcare research.

Background

The growing complexity of society, the rapid pace of social change, and the advent of advanced digital tools have made user-generated content a crucial source of valuable and timely knowledge.[1] In healthcare, the transformative power of digital technologies has led to significant changes in how information is sought and applied. Netnography (also known as online ethnography or digital ethnography) can be broadly outlined as a research method to study online communities, cultures and other computer-mediated social interactions.[2] The principles of netnography share many similarities with those of its predecessor, ethnography, but applies the principles of ethnography to conduct observation in the online environment.[2] However, unlike ethnography, netnography does not limit its study to geospatial cultural activities; instead, it investigates people's discourses within online spaces.[3]

While using netnography in healthcare research is relatively novel and still underexplored, its potential is substantial.[4] Metrics designed to assess unmet needs for specific health services or conditions are valuable for identifying obstacles in the care continuum and informing targeted policies. However, such indicators are insufficient for capturing the broader unmet healthcare needs of an entire population.[5] Current evaluations of health systems often do not focus on unmet health needs, which lack a universally accepted definition and are challenging to measure.[6,7] Social determinants of health significantly affect both the need for and access to services, while individual factors such as values, health literacy, and past experiences also shape whether needs go unmet.[8] Unmet healthcare needs arise in various situations, including when individuals are unaware of their conditions due to insufficient screening, avoid seeking care despite concerns, or receive inappropriate care. Systemic factors like service availability, quality issues, and cost further contribute to these unmet needs.[6] The definition of what constitutes an unmet need is inherently complex, as it encompasses a broad spectrum of healthcare needs that may remain inadequately addressed and is not necessarily confined to specific services or diseases.

Furthermore, Netnography, as a qualitative research method, is inherently influenced by the underlying research paradigms that shape its design, data interpretation, and overall epistemological stance.[9,10] The method has the advantage of using online platforms that are a familiar and safe space for many people. Moreover, the interpretivist paradigm, which is often aligned with netnographic studies, emphasises understanding the subjective experiences and meanings constructed by individuals in their natural digital environments.[11] This orientation is particularly pertinent when examining the concept of unmet need in healthcare, a construct

that is multifaceted, context-dependent, and subject to varying interpretations among different stakeholders.

Nonetheless, a diagnosis of cancer or other advanced and life-threatening diseases can be overwhelming, presenting emotional, mental, and physical challenges. These challenges create deficits that traditional care has not always adequately addressed, potentially leading to overall dissatisfaction with care and a reduced quality of life in some cases.[12] Historically, before the advent of the internet and other communication technologies, patients would typically seek emotional and psychosocial support from local communities, hospital information centres, and condition-specific organisations. While traditional support groups still exist, many patients now turn to online platforms for support and discussion. The anonymity and convenience of online support groups have made them increasingly popular in recent decades.[13] Assessing unmet health needs of cancer patients and those with advanced diseases throughout their treatment journey is critical to informing quality care and improving quality of life. By examining discussions within online forums, netnography offers an innovative approach to identifying unmet health needs. Consequently, it is important to examine this method's potential in helping researchers and healthcare providers to recognise and address gaps in care and support more effectively.

Head and neck cancer (HNC) is a general term used to describe various cancers that originate in the tissues of the head and neck region. These cancers can start in the mouth (including the tongue, palate, gums, and lips), throat (pharynx, divided into the nasopharynx, oropharynx, and hypopharynx), nose and sinuses, salivary glands and middle ear.[14] The morbidity associated with HNCs and their treatment is significant, primarily due to their close proximity to anatomical sites that affect facial appearance and function.[15] HNC is the eighth most common cancer in the UK, accounting for 3% of all new cancer cases (between 2016-2018).[16] There are around 4,100 head and neck cancer deaths in the UK every year, equating to 11 every day (2017-2019). HNC incidence rates are projected to rise by 3% in the UK between 2023-2025 and 2038-2040, to 21 cases per 100,000 people on average each year by 2038-2040.[16] HNC incidence rates in England in females are 64% higher in the most deprived quintile compared with the least, and in males are 101% higher in the most deprived quintile compared with the least (2013-2017).[17]

Advanced liver disease (ALD) refers to chronic conditions that cause progressive damage to the liver over time. ALD progresses through cirrhosis and liver failure. Cirrhosis causes severe

and irreversible scarring of the liver, leading to a decline in function. Although symptoms may not be immediately apparent, the liver's ability to regenerate is compromised. Some symptoms of ALD include: intensely itchy skin; jaundice (yellowing of the whites of the eyes and the skin); oedema (swelling of the legs, ankles, feet); ascites (swelling of the abdomen); extreme fatigue; memory loss; and confusion.[18] Liver failure occurs when the liver can no longer compensate for its decline in function. This stage, also known as decompensated cirrhosis, results in widespread effects throughout the body and is ultimately fatal without intervention such as a liver transplant.[19,20] In the UK, there are more than 10,000 deaths due to liver disease each year; that is more than 27 deaths a day. There has been a four-fold increase in death rates over the last 50 years. [21] Liver disease is closely linked with inequality and deprivation.[21] Mortality due to liver disease deaths is four times higher in deprived areas, driven by alcohol harm, rising obesity and viral hepatitis. Among the worst affected regions are the North East and North West of England, where mortality rates are two to three times higher than the national average.[22] While clinical management addresses the disease course and physical symptoms, it often overlooks patients' experiences and quality of life—both crucial for evaluating overall health and planning liver care.[23]

Considering the prevalence and mortality rates of HNC and ALD, along with the impact of deprivation on these conditions, we selected them as our primary research focus of this project to determine the feasibility of utilising netnography as a research method to identify unmet health needs of individuals with severe health conditions.

Research aims and objectives

Aims

- This project aimed to understand whether netnography can be used to gain rapid insights into healthcare topics, using two health conditions as examples.

- The project also aimed to evaluate the findings of the netnography method by conducting a scoping review to synthesise the current evidence on the unmet health needs of patients with ALD.

Objectives

- To assess if netnography can uncover unmet health needs of individuals with advanced health conditions

- To identify the common themes and patterns related to unmet health needs within online communities for HNC and ALD

- To compare the findings of the netnography research with the existing literature through a scoping review

- To investigate the challenges and limitations associated with conducting netnographic research in the context of health needs assessment for individuals with advanced health conditions

Methods

Ethical approval

Ethical approval for conducting the netnography was obtained by Newcastle University on 23/08/2024 (reference: 2815/49446).

Netnography methods

In this project, we applied an observational netnographic approach. Online social communities can be studied using either participatory (active) or non-participatory (passive) observational methods. In some cases, the researcher's presence may be disruptive or unsuitable, particularly when examining sensitive topics.[2,24] We adopted a non-participatory observational approach to reduce the influence of the researchers' presence, as we believed that a passive role was most appropriate for interpreting data within the context of naturally occurring social interactions. Additionally, we were interested in the use of forum data as an existing data source.

Selecting online forums

An extensive online search was conducted to identify and select UK-based and English speaking online communities related to ALD and HNC on Facebook, Reddit and via Google from May to July 2024. Search terms included phrases such as "advanced/end-stage liver disease," "head and neck cancer," "liver disease community," "cancer support group," "liver patient forum," and "living with cancer" to ensure a broad capture of relevant forums and discussion groups. From the Facebook search results, we excluded groups that were clearly non-UK based and included only groups run by UK based organisations or admins, or those whose targeted locations were unclear. We initially included Facebook groups and subreddits with at least twenty members. A total of sixteen Facebook groups and two subreddits related to HNC and thirty-one Facebook groups and five subreddits related to ALD were identified in the initial search.

While different perspectives and practices exist with regard to how online, publicly available data is viewed, [25] we took a cautious approach and sought consent from administrators or moderators of all online groups that met our criteria for inclusion. We reached out to each group to request consent for data collection from their content. Two researchers (OE and KT)

sent direct messages to the Facebook group moderators and waited two weeks for responses. Additionally, two other researchers (AS and SH) contacted the subreddits moderators and waited 2 weeks for replies. Of the forty-seven Facebook groups related to both conditions that we reached out to, two public groups declined, one private group agreed to participate, and 44 did not respond. However, the private group was excluded from data collection due to low engagement and limited relevant content.

Four additional online communities related to each condition were identified outside of Facebook and Reddit. We successfully connected with administrators of two well-established and UK-based online communities for ALD (British liver trust community) and HNC (Macmillan Cancer). Although Macmillan Cancer met all our data collection criteria, they declined to grant permission for our research, citing their terms and conditions, which specifically exclude the use of user data for research purpose. As written consent from online community administrators was required within our ethics framework, we were unable to collect data from any HNC groups. Ultimately, one UK-based forum focused on ALD granted consent, allowing us to proceed with observation and data collection. Consequently, while our original aim was to gather data on both HNC and ALD online communities, the remainder of the project focused solely on ALD.

Data collection

Four researchers (SG, SH, KT and OE) observed the chat archive of a UK-based forum for adult individuals with liver disease from May to October 2024. The observations were non-interactive, with each researcher assigned to review a specific month's archive.

The focus was on identifying posts and threads related to patients with non-cancerous advanced liver conditions, including alcohol-related liver disease, non-alcoholic fatty liver disease, and cirrhosis. The definition of 'Unmet Need' was broad; discussions were included if they highlighted unmet needs which included unresolved symptoms or side effects, gaps in treatment options or access to healthcare, delays in diagnosis, challenges in accessing emotional, psychological, or social support, insufficient information or guidance on managing the disease, or financial and logistical barriers to treatment. Financial difficulties resulting from serious illness and the inability to work were also considered. Posts that did not explore unmet needs—such as those focused on successful treatment outcomes or general discussions about the disease—were excluded. To ensure consistency and minimise potential bias, a data collection guide was developed prior to the data collection (see Appendix one). We maintained flexibility to capture any unmet health needs not initially covered in the guide.

It was initially intended to use NCapture, a browser add-in that allows instant data capture of online sources which can subsequently be imported into NVivo which is a qualitative data analysis software we used in this study. However, this proved unsuccessful for the selected forum as the data format was difficult to work with, therefore posts and threads related to the unmet health needs of individuals with ALD were manually selected and copied into separate Word documents. These documents were organised by each researcher's name, the number of posts, and the corresponding month. The research team met weekly to discuss any uncertainties or questions about including or excluding specific posts. All usernames and potential details were removed from the collected data and forum users were assigned numbers in place of their usernames prior to the data analysis process.

Data analysis

An iterative analysis of the data was conducted, drawing on both thematic and framework analysis methodologies. An initial coding framework was developed based on our research aims and objectives, guided by a preliminary content evaluation of the selected online forum (British Liver Trust online community). The framework underwent an iterative amendment in a subsequent coding phase to ensure that all relevant data adhered to the inclusion criteria, with any newly identified codes integrated as part of primary code categories or the "other health needs" category. The coding framework can be found in Appendix 3. Employing both a priori and emergent codes enabled the framework to be grounded in our research objective while maintaining the flexibility to incorporate the topics most pertinent to forum participants.[26]

The anonymised data from forum observations were imported into NVivo15 software for qualitative analysis. Data familiarisation was achieved by thoroughly reading and re-reading the transcripts. The primary coding phase was conducted by the lead researcher (SG), who read the posts and applied line-by-line coding to capture data related to unmet health needs in individuals with ALD. In the next phase, the extracted codes were verified against the inclusion criteria and coding framework. Firstly, a second reviewer (MS) checked a random 10% of the coded data to ensure consistency with the coding framework and inclusion criteria, with any discrepancies discussed by the research team. Additionally, a third researcher (MB) reviewed data that had been initially excluded to see if it aligned with any newly identified coding categories. One researcher (MB) also examined 10% of the coded threads in their original context using the codebook to identify any inconsistencies or potential additional codes. MB, MS, and EJ reviewed the codebook extracted from NVivo to validate the hierarchy and categorisation of the codes for accuracy and consistency. Minor additions and code

replacements were suggested and after the team reached an agreement, the codebook was updated accordingly.

Scoping review methods

Insofar as possible, this scoping review was conducted in accordance with the JBI methodology for scoping reviews.[27] .

Differences between protocol and review are documented in Appendix 7.

Search strategy

The search strategy aimed to locate both published and unpublished studies. A three-step search strategy was utilized following JBI recommendations. Firstly, an initial limited search of MEDLINE (Ovid), PsycInfo (EBSCO) and CINAHL (EBSCO) was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were then used to develop a full search strategy for the sources listed below. Following peer review by another information specialist, the strategy was then adapted for each included information source. Finally, the reference list of identified reviews were screened for additional studies of relevance.

Studies were limited to those published in English only to aligns with our focus on the UK health context. Studies published between January 2019 and October 2024 were included. Given the rapid pace of change in healthcare contexts, any older studies were unlikely to still be relevant to current practice. Example searches can be seen in Appendix 11.

Types of sources

- Medline (Ovid)
- Embase
- CINAHL (Cumulative Index to Nursing and Allied Health Literature)
- Cochrane Library
- PsycINFO (OVID)

Grey Literature Sources

- ProQuest Dissertations and Theses
- Epistemonikos

Eligibility criteria

Population

We included studies of adult patients with ALD and associated conditions; we included the following diagnoses based on published definitions. [28,29]

- Alcohol-related liver disease

- Non-alcoholic fatty liver disease (NAFLD)
- Viral hepatitis (e.g. hepatitis B, hepatitis C)
- Primary biliary cholangitis, sometimes called primary biliary cirrhosis
- Primary sclerosing cholangitis
- Autoimmune hepatitis
- Cirrhosis
- Steatotic liver disease (SLD)
- Metabolic dysfunction-associated steatotic liver disease (MASLD)
- Metabolic-associated steatohepatitis (MASH), the more serious form of NAFLD; previously termed as NAS)
- Met-ALD – the term for people who have MASLD but who also drink alcohol
- Cryptogenic SLD –fatty liver disease where the cause is unknown, as people do not have any of the metabolic risk factors

We did not include studies focused on other primary liver diseases not classified as advanced (e.g., acute hepatitis, fatty liver disease without cirrhosis); studies focused on secondary liver disease (e.g. in HIV); or advanced liver cancers (e.g. hepatocellular carcinoma).

Concept

We included various categories of unmet health needs. These comprised the ongoing assessment and management of physical symptoms, such as pain, fatigue, jaundice, ascites (fluid buildup in the abdomen), pruritus (itching), and gastrointestinal issues. We also considered treatment gaps, including access to liver transplantation, as well as support with psychological needs like managing low mood, anxiety, and fear of disease progression. Social and caregiving support needs were included, along with barriers to accessing healthcare services, such as palliative and specialist care, which may involve long waiting times, delayed diagnosis, and challenges in coordinating treatment.

Context

We included studies focusing on the unmet health needs of adults with ALD in various UK based health settings, including clinical settings (hospital, outpatient, primary care), home-based care and palliative care environments. Studies published outside of the UK or not published in English were excluded to align with the focus of the UK health context.

Study selection

Following the search, all identified citations were collated into EndNote x21.0.1 (2024, Clarivate Analytics, PA USA) and were deduplicated before being imported into Rayyan for screening. A pilot screen then was conducted, where 10% of titles and abstracts were independently screened by three reviewers (SH, OE, and KT) to assess the level of agreement.

Following this step, three reviewers (SH, OE, and KT) independently assessed the remaining titles and abstracts against the eligibility criteria. Any potentially relevant sources were retrieved in full and assessed against the eligibility criteria by the same reviewers. Discrepancies have been resolved through discussion or by consulting another reviewer (SG), when required. Reasons for excluding sources at the full-text stage were documented and reported in Appendix 10. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA flow diagram.[30] Prior to data charting, multiple reports of a single study will be combined into a single unit of analysis.

Data charting

We created a standardised data charting form within Microsoft Excel. Four independent reviewers (OE, KT, SG and SH) piloted the form on 10% of included records to test agreement of individual extractions and to identify any potentially redundant or that needs refining. Following piloting, we modified and revised the draft data charting tool. The final data charting form contained items on bibliographic details, methodology, context, population, sample size, type of ALD, specific unmet health needs, main findings, and limitations of the studies. The final data charting form can be found in Appendix 8.

Following piloting, four reviewers (KT, SH, SG and OE) charted the remaining records. Two reviewers (EEJ and SG) checked the charted data for accuracy. Any disagreements between the reviewers were resolved through discussion and reviewing the citations. If appropriate and required, we would have contacted the authors of papers to request missing or additional data.

Data analysis and presentation

Following data charting, Four researchers (KT, OE,SH and SG) analysed the extracted data and presented results in either a tabular or graphical form with an accompanying narrative synthesis. We reported the review in accordance with the PRISMA extension for scoping reviews (PRISMA-Scr; see Appendix 9).

Findings

As the study aimed to evaluate the feasibility of netnography, data from the netnography was synthesised and interpreted before analysing the scoping review findings. This approach was taken to minimise potential influences from the scoping review on the netnography results. To ensure consistency and comparability between the two methods, the same approach was applied to categorise the findings from both. However, we remained flexible in identifying any unmet needs or domains in the scoping review that were not captured by the netnography method.

Netnography findings

535 posts and 4250 replies from May to September 2024 were reviewed from the archive of a UK-based online forum for patients with liver disease. Of these, 155 posts and replies met the inclusion criteria for relevance to ALD and unmet health needs. Line-by-line coding of the extracted data identified three primary domains of unmet needs: medical and clinical; emotional and psychological; and financial. Each domain encompassed several specific needs (see Appendix 4 for the codebook and appendix 6: Coding Hierarchy). The analysis also highlighted overlaps and interconnections among the identified needs, where certain data excerpts were applicable to multiple domains.

1. Medical and clinical needs

This domain broadly categorised the various medical and clinical health needs of patients with ALD from their own perspectives or those of their caregivers. Analysis of the data related to this domain revealed five sub-domains, as detailed below.

1.2 Access to comprehensive treatment options and healthcare support

This sub-domain includes data highlighting patients' unresolved symptoms, such as fatigue, ascites, jaundice and hepatic encephalopathy, as well as expressing dissatisfaction with symptom management strategies provided by the healthcare system. For instance, one forum user posted:

> *"The specialist nurses don't seem to have any solution for managing oedema in someone who can't take diuretics. His disease in itself tends to limit movement, and this swelling has made things worse. Life has become so very small for us. Does anyone have suggestions for easing this difficulty?"*

Prolonged waiting times for treatments and medical procedures emerged as a recurring concern among users. For instance, a forum user wrote:

> "*The fluid is gradually increasing though, so he's been trying to see his GP the last 4 weeks… More than 30 in the queue as soon as phone lines open. I tried for him, and receptionist went to speak to a doc and said tell your bro to present himself at A&E and say referred by GP. He did, got*

examined, Xray, bloods done then they said, sorry, no one here qualified to do drain. Go home and ring your gastro doctor's secretary and make an appt to see him instead at his hospital. That was Weds. He's tried to ring secretary but he's in a queue again of over 30, so he hung up, 'sod it' attitude has kicked in. Frankly I despair…"

There were some discussions regarding liver transplantation, in which forum participants described frustration, disappointment, and the emotional burden of being unable to qualify for or maintain eligibility on the transplant list. These posts also underlined the long-term need for medical support, monitoring, and guidance, even after transplantation. The prolonged waiting times were highlighted as a recurring concern. For example:

"…We too had a long and bumpy ride to transplant - I won't bore you with detail of how my husband was on and off the list, false alarms etc but now on this side of it all I can see more clearly. The process of transplant and recovery is equally tough, and the hardships you go through whilst waiting prepare you for this…"

1.2 Clear diagnosis and assessment

The included references in this category highlighted patients' efforts to obtain clarity regarding their diagnosis and care plans alongside other challenges, such as conflicting test results and delays in receiving results. For instance, a forum user wrote:

"*I haven't been given a prognosis, but I am so scared. I am an alcoholic and morbidly obese. I have been given brief guidance around diets and abstaining from alcohol, but I don't know where to start. Is there hope for my condition?"*

The findings underscored the importance of transparent communication and guidance from healthcare providers to reduce stress and confusion, allowing patients and their families to feel more confident and supported in managing the condition. For instance, one user posted:

"After being given the fibroscan result, I saw a specialist gastro dietician. She put me on a high calorie, high fat diet, to compensate for some recent weight loss. However, I do have cardiac issues, for which that diet is not good and really, should be avoided. Does anyone know what the next step might be? since one test tells me I have cirrhosis and the other says I don't."

Another user wrote:

"…I joined recently with a recent diagnosis of decompensated cirrhosis: so many questions going round my head, fear, not sure what I should be doing help myself. Stuck in limbo between consultant and GP."

1.3 Addressing comorbidities and complications

The included references in this sub-domain contained patient or caregivers' narratives on complications or comorbidities associated with ALD that may or may not be addressed in their treatment plans. The most frequently mentioned comorbidities in the coded references were obesity and type 2 diabetes, as well as neuropathy and its associated symptoms (including burning pain, numbness, muscle twitching, and pins and needles), often linked by forum participants to alcohol use or B12 deficiency. Kidney dysfunction, such as hepatorenal syndrome and complications from immunosuppressant medications, was also reported, which led to confusion, drowsiness, and the need for medication adjustments. Weight loss and muscle loss, attributed to liver dysfunction and insufficient protein intake, were highlighted alongside anaemia, often requiring blood transfusions. nFor instance, one user mentioned:

*"…I think I could sleep all day, no energy, worse than ever the last 6 months… I am super obese and in my 60s. Diabetic type 2. Lonely. I don't drink. My tum is getting very large - but I am sure it is fat not fluid. I think diabetes may be causing that"*nAnother user also posted:

"…sounds very much like neuropathy… I didn't get any problems when I first quit drinking, but around 3 months later then different things started to happen, my arms and legs would randomly move around, and then the pains appeared, they were exactly how you explained, it was like red hot pokers being shoved into my knees and going down to my toes."

Post-transplant complications, including persistent diarrhoea, eczema, and infections, were also reported , reflecting the complexity of post-transplant care. Recurrent infections (e.g., gallbladder infections, abscesses, or urinary tract infections) and systemic symptoms like fatigue, light headedness, and nausea were frequently described.

1.4 Dietary needs

This sub-domain includes references emphasising the perceived importance of adapted dietary guidance for individuals with ALD. The data reflected uncertainty among patients regarding dietary choices, for example the recommended intake of eggs and the balance between protein and carbohydrate consumption. Some patients reported being advised to increase protein intake to prevent muscle loss, while others reported conflicting guidance about foods that could strain liver function, underscoring the need for personalised professional support.

Many patients described a lack of access to dieticians or nutritionists and expressed a need for professional guidance to navigate complex dietary requirements. For instance, one user posted:

"*Released from hospital with no advice about diet or what medication I can and can't take such as painkillers, have had one brief meeting with a registrar who said possible cirrhosis on the report mild ascites, again no advice about what was wrong with me and what to do or expect, was asked if I had any questions, but as for me newly diagnosed, everything was still in a spin and I had no idea what I needed to know*"

Another user posted:

"*Just wondering if there are any vegetarians on this forum who could help me out regarding the cirrhosis diet if you're a vegetarian. I just want to make sure I get enough protein [from what I've read, I need a lot of this? My specialist has not discussed with me what I should be eating/drinking.*"

1.5 Disease-related knowledge

This category includes references focusing on the extent to which patients with ALD or their caregivers could understand and use relevant health information to manage their condition. This included challenges in interpreting medical terminology, treatment plans, and care instructions. The additional references further highlighted how reliance on online sources frequently led to confusion and anxiety. The findings sometimes showed the delay in receiving results or follow-up appointments caused anxiety, leading individuals to search for answers online. For example, waiting weeks for a FibroScan or biopsy results often prompted patients to use the internet to fill the information gap. Moreover, they reported conflicting information on specific conditions and test outcomes, struggled to decipher acronyms and biomarker values, and worried about the risks of certain recommended procedures after reading alarming accounts online.

For example, one user wrote:

"My consultant said my liver function was remarkable, so I was upset when FB was 33. My main question is, is a fibrscan accurate in obese patients? I've googled it big mistake freaked me out. Back on diet now."

Some patients or their caregivers often turned to search engines (referred to as *"Dr Google"*) for guidance on interpreting test results, biopsy findings, or the severity of certain diagnoses when their ultrasound, CT, or MRI findings seemed unclear or contradictory. Another user shared:

"We were in shock when told and therefore feel we didn't get all the information we needed at the time. I knew I was being silly but decided to use Google and now I don't know what to think."

2. Emotional and psychological needs

This domain encompassed a broad spectrum of emotional challenges experienced by patients with ALD, their families, and caregivers, including concerns about the future, uncertainty regarding clinical outcomes, and confusion surrounding palliative care options. The domain contains some primary categories as follows.

2.1 Emotional impacts of ALD on patients

The references included in this category illustrate the need for emotional reassurance, understanding, and guidance for individuals dealing with ALD. This appeared to be strongly linked to some of the medical and clinical needs described. For some, the lack of clear guidance from healthcare providers left them feeling lost, seeking answers and comfort from online communities and forums. As previously mentioned, the emotional toll was further amplified by the overwhelming and often alarming information found online. Some forum users frequently described how searching on platforms like Google left them feeling anxious or devastated, particularly when the information painted a bleak picture of their prognosis.

The data highlighted that, for those awaiting medical results or grappling with unexpected diagnoses, the emotional impact was profound. Some users expressed shock and confusion, highlighting the absence of adequate communication or support from their healthcare teams. There were some patients who expressed profound disappointment as they came to terms with their end-stage condition. For instance, a forum user wrote:

"…The consultant again said I might not live long still. I'm active a healthy weight yes I've had too much alcohol in the past and am sorry for that. I feel like what's the point and may as well go sooner so it makes my loved ones feel better and get over me sooner…"

The psychological impact of physical decline, prolonged recovery, and lifestyle restrictions was evident in some users' posts, as one forum user expressed their frustration and despair:

"This is just bloody unfair. "I am in pain at the moment with osteoporosis arthritis plus all the other added agonies cirrhosis brings. I am very depressed ,trying not to cry. I do the best I can & really can't do more.

"I am now living in a home with care, and I appear to be getting worse! I sleep all the time, I have no energy, no strength, I don't mix with people because I am almost stone deaf!! My mind sometimes

feels like a big black cloud!!! Sometimes I think I'm ready to go although I have an adult son who relies on me!!"

2.2 Emotional impacts of ALD on caregivers

This sub-domain includes coded references highlighting the emotional support needed for caregivers and families of patients with ALD. Some caregivers (mostly wives, but some parents and children of patients with ALD) reported intense emotional strain, with feelings of frustration, sadness and despair being common. These emotions were often tied to the challenging behaviours and personality changes exhibited by patients, particularly those stemming from complications such as hepatic encephalopathy. Some caregivers found themselves in the role of advocates, persistently pushing for their loved ones' needs to be addressed within healthcare systems. This often involved overcoming barriers, delays and gaps in communication, which only heightened their stress and frustration.

The data showed that some caregivers had to manage a range of responsibilities, including attending medical appointments, handling financial concerns, and providing day-to-day support. These demands frequently forced them to restructure their own lives, such as reducing work hours or juggling additional caregiving tasks at home. Despite their efforts, many caregivers felt isolated and unsupported, with little assistance from family, friends or professional services to share the load. Some caregivers described irritability, non-compliance with medical advice, and personality shifts in patients that made caregiving particularly difficult. Many expressed disappointment and frustration at health systems that they felt were unresponsive or lacked sufficient support, leaving them to navigate the complexities of care on their own. As two forum users stated: "*But now I'm struggling not so much with his illness but his behaviour it is becoming a living nightmare he's narky horrible argumentative most days (I think he's had a drink on these days but he lies to my face) he's very rarely 'my husband' anymore and I'm struggling to cope with it. "I want to cry every day, even writing this I'm crying I'm at my wits end, I'm embarrassed about his behaviour when he's like this, we were in a and e last night for 10 hours as his heart rate was 165, he's been sent home as he's already being treated for the pneumonia but he stunk of vodka it was mortifying."*

2.3 Alcohol-related challenges

This sub-domain includes data highlighting the ongoing challenges and experiences of individuals with ALD related to alcohol use and addiction. Some users discussed the challenges of dealing with ongoing or relapsed drinking habits, both for those personally struggling with alcohol use and for their loved ones who bear witness to its consequences. Some caregivers and family members expressed frustration and helplessness in coping with the behaviour of

those struggling with addiction, which in some cases had become destructive or alienating. Several patients shared personal accounts of their own battles with alcohol. Some reflected on the physical burdens, including sweating, tremors, muscle ache, neurological damage, as well as severe liver damage. Others described the psychological difficulties of quitting, such as anxiety, depression, having nightmares, a loss of confidence and social withdrawal, but also noted a sense of happiness and relief after overcoming their addiction. For some users, relapses were a significant source of fear and shame, with some users recounting the triggers and emotional turmoil that led them to resume drinking. For instance, two forum users noted:

"I have lost some confidence since I've quit drinking, well a lot really, I'm not as outgoing as I once was, I'm more reserved and withdrawn and I'd probably find myself boring in my company."

"I'm so scared as I had a relapse. We had some family issues at home which I didn't deal with very well [this is no excuse of course....I'm just an idiot]. I'd been doing so well, no alcohol at all for 6 weeks, and I guess I thought I was invincible. Then I drank wine 3 times this week."

Family dynamics were often strained, with caregivers and relatives expressing concern about secretive or non-compliant behaviours, such as hiding drinking or refusing to follow medical advice. This secrecy and denial created barriers to effective support and intervention. Some users noted how addiction had profound life-altering consequences, including loss of jobs, relationships, and access to their children. The stigma and lack of comprehensive support systems to build self-acceptance in individuals further complicated recovery efforts. As one user wrote:

"I was asked about units of alcohol I consume, I said none. I haven't touched a drop since 28th November 2022. I just flicked a switch and stopped. I found I was explaining myself to her, I asked what the screen said. I feel ashamed and judged. The way she looked at me. It was written all over her face. This is what I fear."

Others recounted being warned by medical professionals about the life-threatening risks of continued drinking but found it difficult to stop due to the addictive nature of alcohol and the varying levels of support available.

2.4 Quality of life consideration and end of life planning and counselling

This sub-domain captures references discussing the emotional strain of managing a progressive condition, some of which were present in previous codes. Concerns included those regarding the future, prognosis, and end-of-life care, including confusion surrounding palliative care and advance care planning. They also reflected conversations about deteriorating quality of life and the emotional and physical strain experienced by both individuals and their caregivers.

Some patients and caregivers highlighted the importance of discussing end-of-life wishes and planning during moments of disease stability, emphasising the value of communicating patients' preferences before their health deteriorates further. Symptoms such as confusion, irritability, fatigue and speech difficulties caused significant concern, with caregivers often uncertain about when to seek medical intervention. Some caregivers reported feeling stuck between respecting the individual's reluctance to seek help and their own desire to ensure proper care, particularly during crises.

As a forum user wrote:

"…but this will be down to your dad's wishes. You could also ask him if he wants this as this journey is a tough one for the patient and the family carers around him. It's good to talk about the serious stuff when he is in a good place, then you as a family will know his wishes"

Declining quality of life was mentioned by some users, which included a loss of independence, physical limitations and emotional challenges. Some users also revealed challenges in accessing consistent healthcare support. Some noted limited engagement with medical professionals, with specialists and general practitioners providing minimal input until end-of-life care was initiated. As a forum user noted:

"*…He's doing good with abstaining from it but really tired, restless legs, not being able to do much he's not got a great quality of life at the moment. I'm* just so worried he will give up as he has been so down and deflated since that appointment."

Others expressed feelings of abandonment by the healthcare system, particularly when symptoms such as oedema, fatigue or pain went unaddressed due to a lack of effective management strategies.

3. Financial needs

This domain highlights the financial challenges reported by some individuals with ALD and their families, encompassing issues related to healthcare costs, employment, and access to support systems. The domain includes two primary categories as follow.

3.1 Employment and Financial Adjustments

Some forum users highlighted the impact of ALD on their employment, with some having to leave their jobs due to the severity of their condition, including extreme fatigue, mobility issues, or cognitive impairments. Some patients shared ongoing struggles to balance their health with

work, persevering through symptoms to retain employment despite considerable physical and emotional strain. For some caregivers, the need to reduce work hours or leave their jobs to provide care added to the financial burden. As a forum user wrote:

"My story is I've been in quite a stressful role for nearly 24 years and was diagnosed with cirrhosis about 18 months ago. I am feeling increasingly tired with considerable joint pain although I do have thinning of the bones. My employers are not aware of my diagnosis but realise I am being monitored for something with 6 monthly scans and appointments. I recently had a week off work and had my first back to work meeting ever which I found uncomfortable. I feel I am pushing myself every day and have also noticed changes in my memory although that could be an age thing"

Accessing financial support was also an issue highlighted by some forum users. Some users shared their difficulties in navigating complex benefits systems, sometimes facing long delays or being denied assistance despite severe illness. For instance, one individual reported being deemed ineligible for financial aid despite needing taxis to attend medical appointments due to mobility limitations. There were some forum participants who described the mental and physical toll of applying for and appealing such decisions, which then discouraged further attempts to seek support.

"*I had no choice… after 15years working for the NHS, I had my contract terminated as the d.w.p. class me as terminally ill and they informed me I couldn't work there as I could fit within their insurance policy. Unfortunately, though as I meet all critical physically for higher pip. I can't claim as I'm mentally sound*"

The broader financial strain was reflected in decisions around major life choices, such as taking out loans or managing household priorities. Participants expressed fear and uncertainty about the future, with concerns about declining health impacting their ability to sustain financial stability.

3.2 Seeking treatment beyond the NHS

A smaller number of forum users discussed the burden of navigating long waiting times within the NHS, with some opting for private healthcare to access diagnostic tests, treatments, or consultations more quickly. One user shared their concerns, writing:

" I am afraid the fibro scan date won't be early given long waiting time in NHS. Please advise, if I can go for a private scan worth it? Anyone knows a better option near London. Please help!"

The discussions also revealed concerns about the affordability of private care, with some questioning how to cover the costs of essential services or whether health insurance would include such expenses. For example, another user wrote:

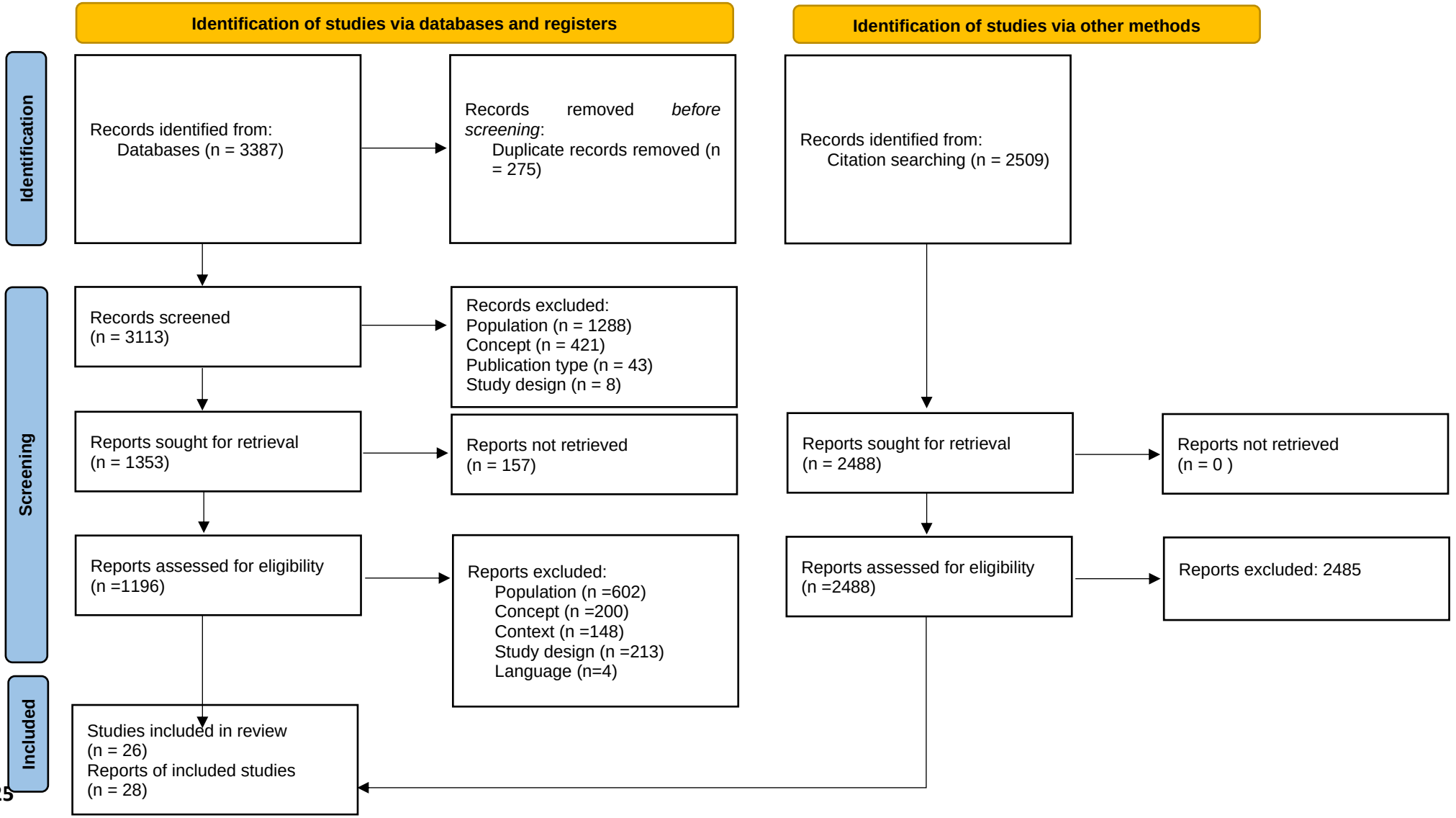
> "*There is new medication, which can stop progression and reverse the condition back - Rezdiffra, isn't it? But I am concerned how people can afford it in the UK? Why is NHS not buying it to prescribe? If I buy health insurance, will it cover the cost of this medication?*

Scoping review findings

Results of the search

The PRISMA flow diagram for the scoping review can be seen in Figure 1. Initially, we included twenty-eight reports corresponding to 26 unique studies in this scoping review. We recorded reasons for exclusion of sources at full text and report these within the appendices of the scoping review (see Appendix 10).

Figure 1. PRISMA flow diagram



Characteristics of the included studies

Characteristics of the included studies are presented in table 1. Of the 26 studies, 23 were published as research articles, two as conference abstracts, and one as an abstract. Fourteen studies employed quantitative methods,[31-41] [42-45] seven were qualitative[46-51] and five used a mixed-methods approach.[52-56] Figure x below shows the specific numbers of each type of study included in the citations. The data collection methods of the included citations mostly involved the use of questionnaires,[31,33,34,36-38,40,44,45,52,56]semi-structured interviews,[46,48-51,53,54] systematic screening,[32,41-43] and surveys.[31,35,38,54] Notably, none of the included studies utilised a netnographic approach for data collection.

Table 1. Characteristics of included studies

Study ID	Source Type	Specific design cleaned	Data Analysis Approach	Country	Participants' sex/ gender	Participants' ethnic group	Age Range	Type of ALD
Asquith 2023[31]	Journal Article	Questionnaire	Statistical	UK	Mixed	Not Reported	19-78	Non-alcoholic fatty liver disease, Hepatitis B or Primary biliary cirrhosis
Chang 2022[32]	Journal Article	Cross-sectional study	Statistical	England	Mixed	Not Reported	30 years and older	Alcoholic liver disease, Autoimmune liver disease, Chronic hepatitis B infection, Chronic hepatitis C infection and Non-alcoholic fatty liver disease
Cooper 2021[52]	Journal Article	RCT, structured interview, questionnaire	Descriptive statistical and thematic analysis	England	Mixed	Mixed (White/Asian)	42-80 years	Cirrhosis and End-stage liver disease
Davis 2023[46]	Journal Article	Semi-structured interview	Framework analysis	England	Mixed	90% White British	Mean age:	Cirrhosis

							59 years.	
Gray-Renfrew 2020[47]	Journal Article	Structured interview	Thematic analysis	Scotland	Mixed	Not Reported	35-84 years	Alcoholic liver disease, Hepatitis C, Autoimmune hepatitis, non-alcoholic fatty liver disease, hepatocellular carcinoma
Haigh 2019[53]	Journal Article	Semi-structured interview	Statistical, thematic analysis	UK	Mixed	Not Reported	18-75 years	Non-alcoholic fatty liver disease
Hallsworth 2020[48]	Journal Article	Semi-structured interview	Theoretical Domains Framework (TDF)	UK	Mixed	Not Reported	58.9 years [range 44–72 years]	Non-alcoholic fatty liver disease
Hussain 2024[33]	Conference abstract	Observational study	Statistical	UK	Mixed	Not Reported	Median age 60 years	Metabolic dysfunction-associated steatotic liver disease
Jarvis 2022[49]	Journal Article	Semi-structured interview	Thematic analysis	England	Mixed	Not Reported	Not Reported	Chronic liver disease in general
Knight 2020[50]	Journal Article	Semi-structured interview	Thematic analysis	UK	Mixed	Not Reported	Mean age: 57.9 years	Chronic liver disease in general
Krzeczkowska 2021[51]	Journal Article	Semi-structured interview	Interpretative Phenomenological Analysis (IPA)	Scotland	Male	Not Reported	18 years and older	Patient with chronic Hepatitis C
Lloyd 2023[54]	Journal Article	Survey, semi-structured interview	Descriptive statistical and thematic analysis	UK	Mixed	White British	Median age: 55 years	Autoimmune hepatitis
McPherson 2020[34]	Journal Article	Cross-sectional study	Statistical analysis	England	Mixed	93% White British	Median age: 52 years	Hepatitis C
Mehta 2024[55]	Journal Article	Interventional study, focus groups	Exploratory statistical and	England	mixed	Mixed	Median age: 46 years	Alcohol-related liver disease

			descriptive analysis					
Mitchell-Thain 2023[35]	Conference abstract	Survey	Not Reported	UK	Mixed	Not Reported	65% aged over 50 years	Primary biliary cholangitis
Nayagam 2024[36]	Journal Article	Questionnaire	Statistical	UK	Mixed	Not Reported	Median age: 43.2	Sclerosing cholangitis
Papatheodoridi 2023[37]	Journal Article	Questionnaire	Statistical	UK	Mixed	Not Reported	59 ± 13 years	Non-alcoholic fatty liver disease
Poon 2023[38]	Abstract	Survey, questionnaire	Statistical	UK	Mixed	Not Reported	Median age: 58 (range 48–75)	Advanced cirrhosis (half with alcoholic liver disease and half with non-alcoholic steatohepatitis)
Rahim 2023[56]	Journal Article	Questionnaire	Statistical	UK	Female	Mixed	Median age: 32	Chronic liver disease in general
Ranieri 2020[39]	Journal Article	Focus groups	Thematic analysis with features of narrative analysis	UK	Mixed	Not Reported	Mean range: 28-74 years	Primary Sclerosing Cholangitis
Rice 2021[40]	Journal Article	Questionnaire	Statistical	UK	Mixed	Not specified	Median ae: 67-69	Primary biliary cholangitis
Swain 2019[41]	Journal Article	Cohort study	Statistical, cox regression	UK	Mixed	Not Reported	Mean age: 37-41 (2 groups)	Hepatitis B and C
Vijayaratnam 2024[42]	Journal Article	Cohort study	statistical	UK	Mixed	Not Reported	Not Reported	Chronic liver disease
Ward 2022[43]	Journal Article	Cohort study	statistical	UK	Mixed	Not Reported	Not Reported	End-stage liver disease
Wu 2023[44]	Journal Article	Cohort study	statistical	UK	Mixed	Not Reported	40-69	Non-alcoholic Fatty Liver Disease

Zoe 2020[45]	Journal Article	Cohort study	Statistical	UK	Mixed	Not Reported	Mean age: 55.7	Chronic liver disease

The number of each of the data collection methods used in the included studies are shown in Figure 2. below.

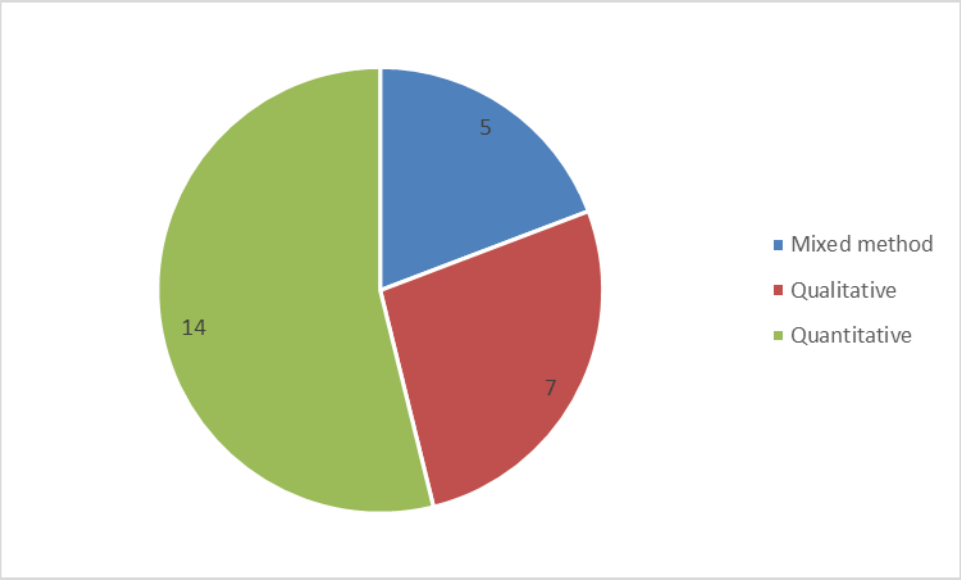


Fig 2. Types of research methods used in included studies

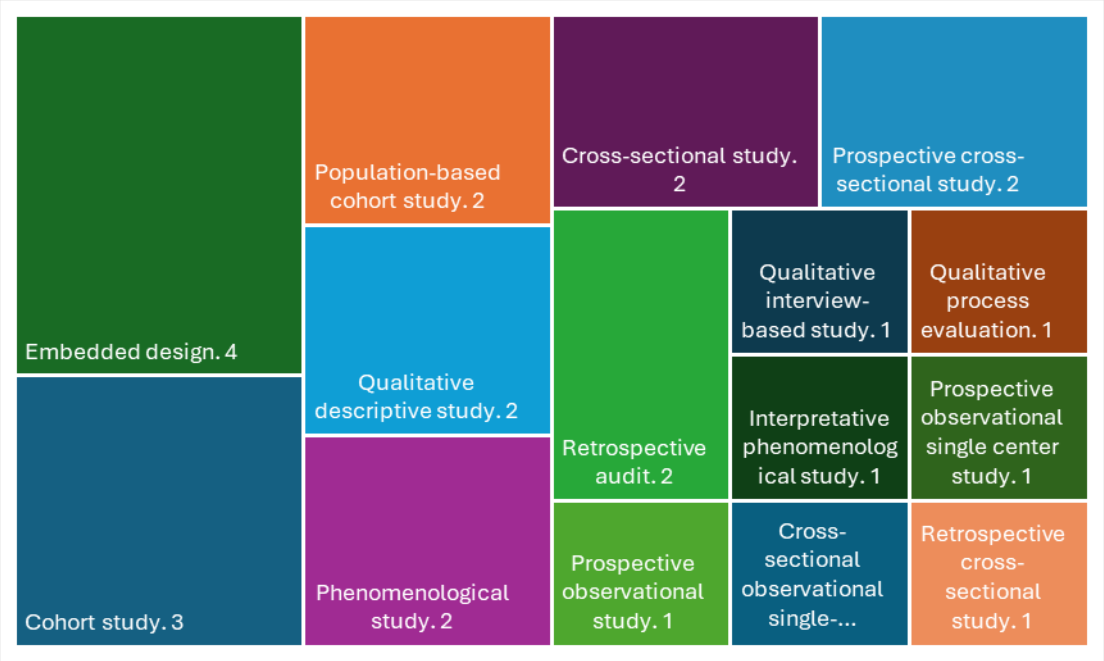


Fig3. Types of study designs used in included citations

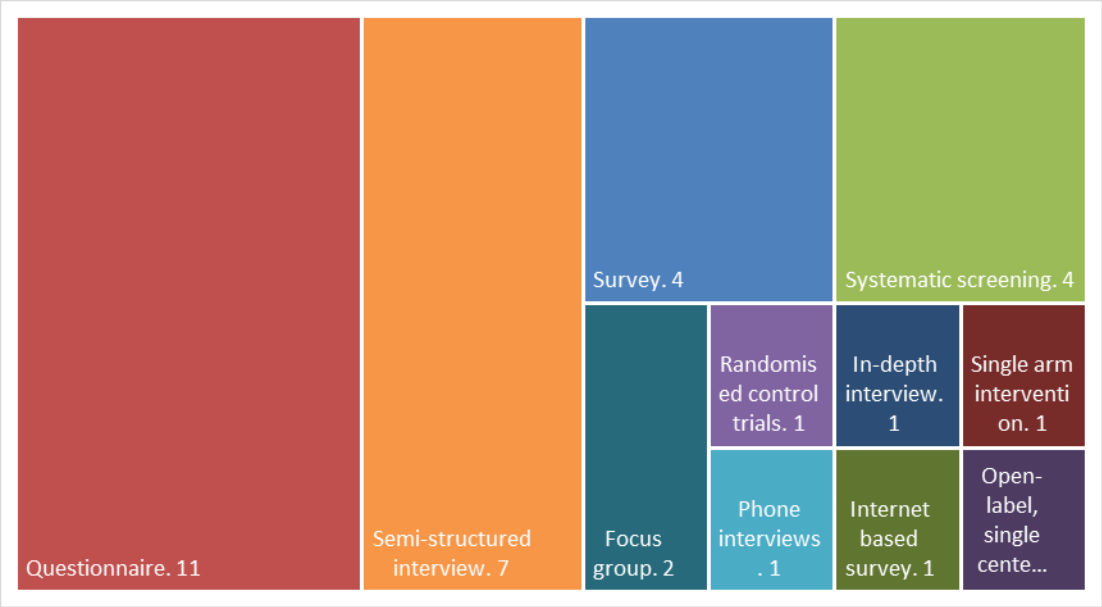


Fig 4. Data collection methods used in included studies

The median average sample size across all studies was 59 with an inter-quartile range (IQR) of 239.75. All participants were over the age of 18 years and the method of reporting age differed between mean average age, median average age, average range and range (Figure 5).

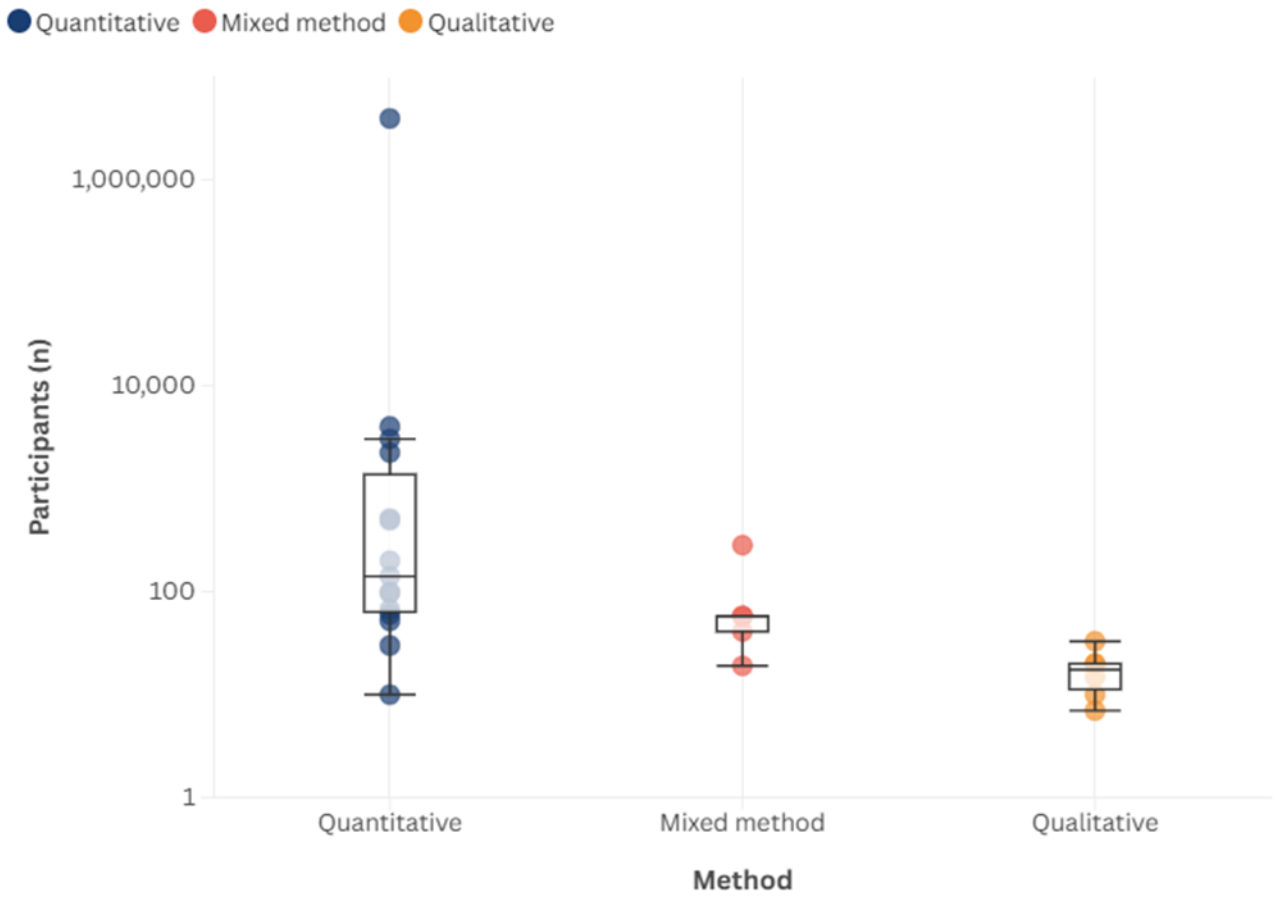


Fig 5. Boxplots of the distribution of sample sizes across quantitative, mixed methods and qualitative studies.

Data analysis approaches used by included studies

The included qualitative studies were analysed using framework analysis,[46] thematic analysis[39,47,49,50], the Theoretical Domains Framework,[48] and interpretative phenomenological analysis.[51] The quantitative studies were mainly analysed using statistical methods (N=13).[31-34,36-38,40-45] .One study did not report on the methods it used for analysis[35]. The mixed methods studies were analysed using a combination of statistical [52-56](N=5), and thematic analyses[52-55] (N=4).The total number of each of the data analysis approaches used in the included studies are represented in the figure below.

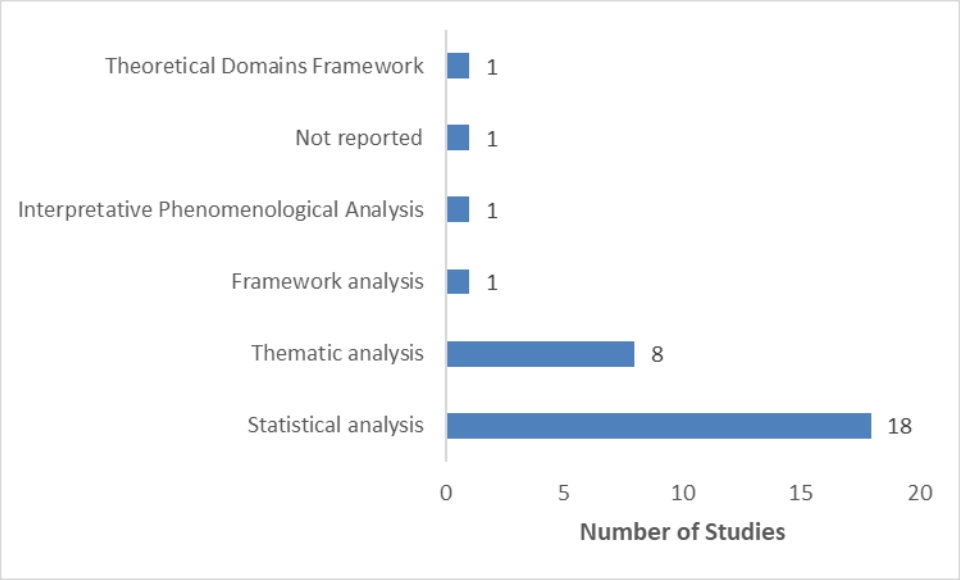


Fig 6. Data analysis approaches used in included studies

Study location and setting

Of the twenty-six studies included, all were carried out in the UK, with six specifying they were conducted in England,[32,34,46,49,52,55] with two carried out in Scotland.[47,51] The studies were conducted across various settings, including community[39], primary[32,40,41,45,48-50,52,54], secondary[32,34,36,38,42-44,48,51,55], and tertiary care settings[31,33,37,46-48,52,53,56]. The highest number of studies were conducted in secondary care settings (N=10). One of the studies did not report where it was carried out[35]. Figure 7 below represents the number of studies in each care setting:

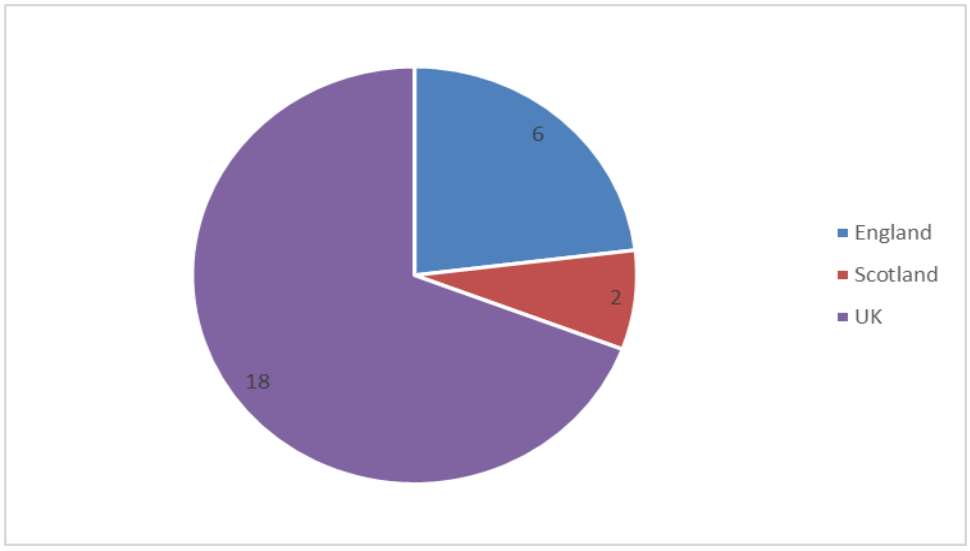


Fig.7 Study locations of included citations

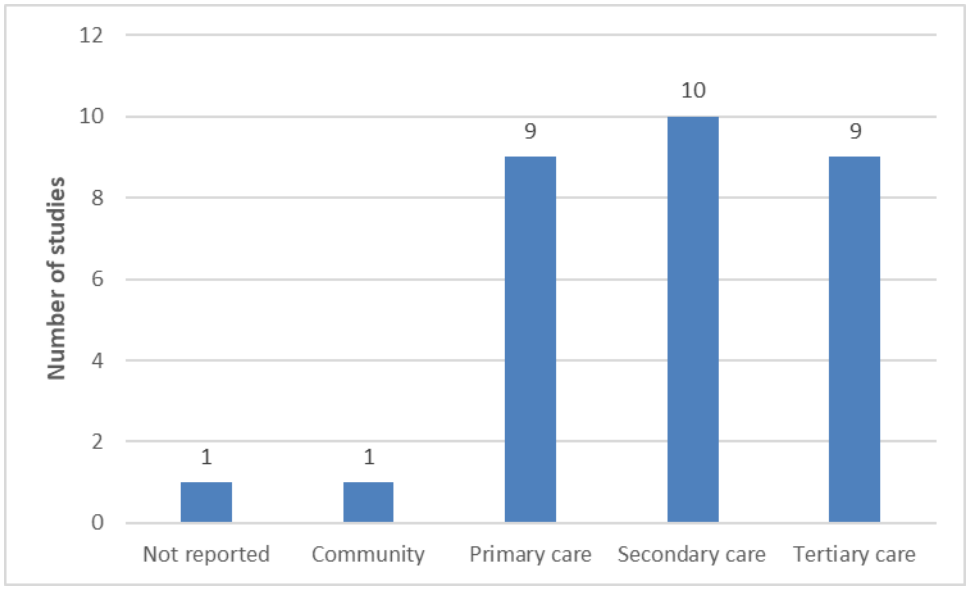


Fig. Study settings of included citations

Participant characteristics

Thirteen different conditions were represented across the 26 studies, with 20 studies involving participants with only one specific condition[33-37,39,40,42-46,48-51,53-56] and six involving up to five conditions.[31,32,38,41,47,52] NAFLD was the most frequently included condition, in seven studies,[31,32,37,44,47,48,53] followed by chronic liver disease in general[42,45,49,50,56] and chronic hepatitis C,[32,34,41,47,51] which were both discussed in five studies. Four studies included people with some form of cirrhosis.[31,38,46,52] One study involved participants with advanced cirrhosis (half with alcoholic liver disease and half with non-alcoholic steatohepatitis).[38] Autoimmune liver disease/hepatitis,[32,47,54] alcoholic liver disease,[32,47,55] and chronic hepatitis B[31,32,41] were each assessed in three studies. Two studies each involved participants with sclerosing cholangitis,[36,39], PBC,[35,40] or end-stage liver disease.[43,52] One study involved participants with metabolic dysfunction-associated steatotic liver disease (MASLD).[33] The specific conditions included across the reported studies can be seen in figure 9.

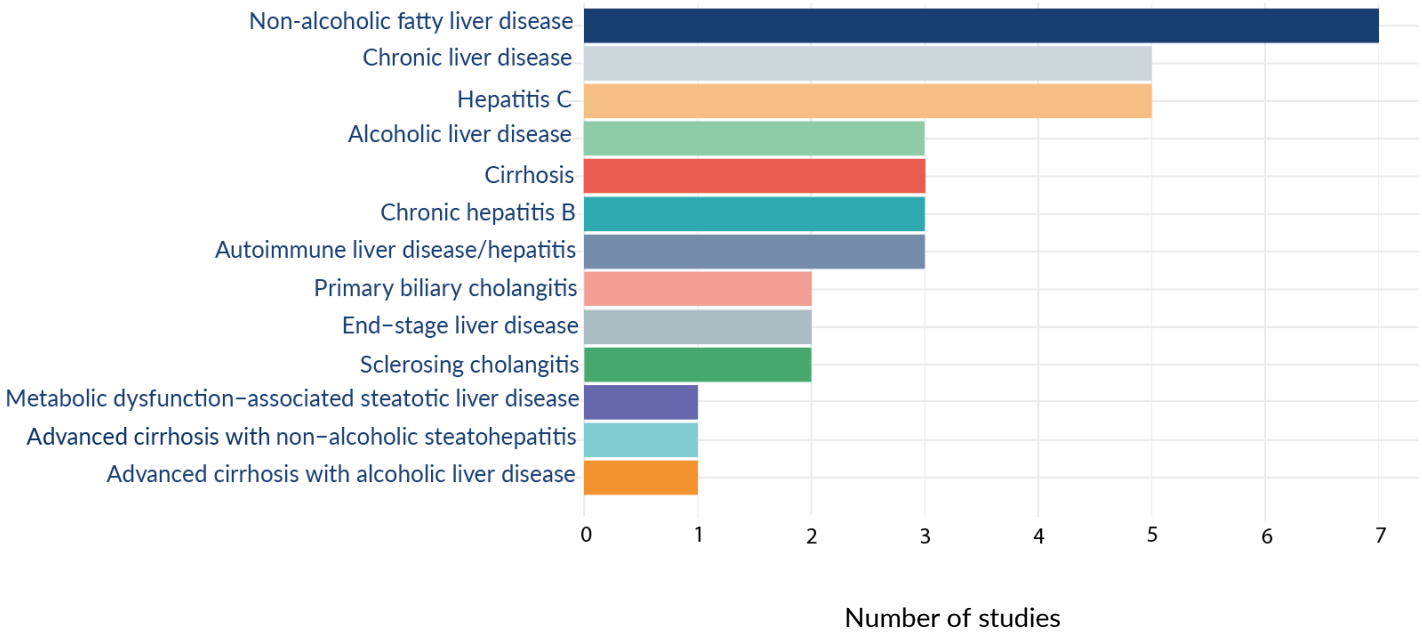


Fig 9. The specific conditions reported by the included studies

The included studies involved sample sizes that varied significantly, from 7 participants to 3,929,596. Figure 10.

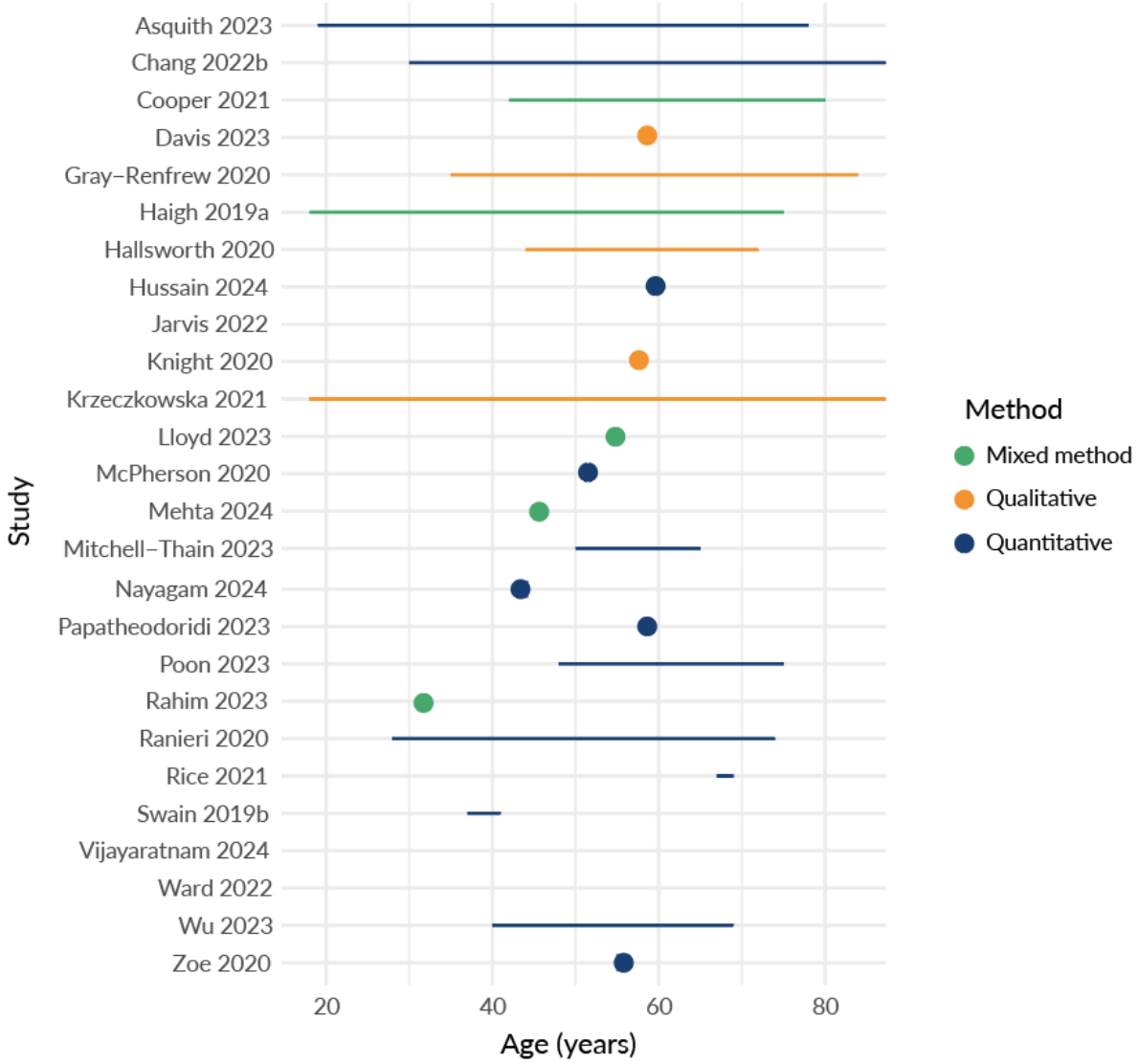


Fig 10. Age of participants (range/average/average range) across studies by method type

Twenty studies did not report on the ethnic group of participants. However, available data in six studies reported that the cohorts were white British,[34,46,54] or mixed range of ethnicities.[52,55,56] Twenty-four of the studies included both men and women, with one study only including men,[51] and one only including women[56].

The main findings of the included studies

Types of unmet needs

In total, 31 specific medical and clinical unmet needs were identified from 21 studies,[32-35,37-40,42-50,52-54,56] 26 different emotional and psychological unmet needs related to patients and caregivers from 17 studies,[31,34-37,39,41,45-48,50-54,56] four financial unmet needs from two studies,[52,54] six unmet needs were related to behavioural and lifestyle regulations from four studies,[31,44,48,55] and four unmet needs related to social and cultural issues were identified from two studies.[39,53] The identified unmet needs are presented and briefly summarised in tabular form in Table 2 below . Similar to the netnography findings, overlaps and interconnections were evident between the identified domains, with some citations addressing multiple unmet needs, making them relevant to more than one domain.

Table 2. Types of identified unmet needs from the included studies

Domain	Subdomain	Number of unmet needs	Studies	Specific unmet needs
Medical and clinical needs	**Comorbidities, symptoms, side effects and complications**	16	11 studies[32-35,37,40,42,44,45,52,54]	• Increased risk of cardiovascular disease/events; comorbidities (hypertension, type 2 diabetes, obesity, metabolic syndrome) • Symptoms (including ascites, pruritus, fatigue, cognitive problems, bone ache/disease, mobility limitations, pain/discomfort) • Medication side effects • Life years lost
	Quality of life considerations	3	5 studies[33,35,37,40,45]	• HRQoL reduced due to symptoms (unmanaged puritis; fatigue, bone ache, memory/concentration problems, ascites; pain/discomfort and mobility limitations) • Comorbidities (hypertension, type 2 diabetes, obesity, cardiovascular disease) further reduce HRQoL • General QoL impact noted in one study.

Domain	Subdomain	Number of unmet needs	Studies	Specific unmet needs
	Barriers in care delivery	8	5 studies[39,46,47,49,52]	• Long waiting times (hospital, transplant, administrative delays) • Difficulties in accessing healthcare (GP referrals, specialist access) • Issues with assessment • Lack of transparency in care hierarchy (e.g., MDTs) • Lack of integration in multimorbidity care • Unclear roles for GPs • Need for better training and continuity in care
	Disease-related knowledge	3	8 studies [39,46-48,53,54,56]	• Unmet needs in receiving/accessing information (insufficient/reliable info, lack of basic NAFLD diagnosis/management details, need for clear screening communication) • Unmet needs in understanding information (limited understanding of disease, diagnostic process, treatment, risk factors) • Need for pre-pregnancy counselling in CLD.
	Comprehensive support and palliative care planning	3	3 studies [38,43,52]	• Lack of advance care planning in end-stage cirrhosis • Need to improve quality of palliative care in end-stage liver disease • Need to improve overall care delivery to reduce the burden on hospitals.

Domain	Subdomain	Number of unmet needs	Studies	Specific unmet needs
Emotional and psychological needs	**Emotional impacts of ALD on patients**	21	17 studies[34,36,37,39,41,45-48,50-52,54,56]	• High anxiety (linked to prognosis, diagnosis, treatment intervention, social exposure, transplant/cancer concerns) • Depression (complicating alcohol addiction, low mood, higher prevalence in HCV) • Worry (about disease progression, family impact) • Fear (of sudden death, waiting for transplant) • Feelings of guilt, shame, helplessness, Surprise caused by treatment intervention • Shock due to diagnosis • Sense of helplessness • Lack of control over one's body and diagnosis • Uncertainty surrounding diagnosis • Feelings of distress or upset related to: • Diagnosis • Leakage problems • Fatigue and its impact on daily life • Frustration and anger due to loss of physical ability • Feeling overwhelmed due to disease complexity • Lack of confidence to ask questions of healthcare professionals • Need for psychological support from healthcare professionals • Stress caused by long waiting times and extra costs • Disrupted sleep and its impact on mental health • Low intrinsic motivation to change diet
	Emotional impacts of ALD on caregivers	2	2 studies[39,52]	Psychological impact on caregivers, including • stress and • frustration—especially related to referral processes and managing the condition (e.g., living with PSC)

Domain	Subdomain	Number of unmet needs	Studies	Specific unmet needs
	QoL considerations	3	5 studies[34,35,37,45,56]	• Reduced HRQoL in emotional domains due to high anxiety, depression, and worry • Additional challenges noted in younger patients, females, and those with unmanaged symptoms.
	Building self-acceptance in patients	2	2 studies[51,54]	• Issues include feelings of stigmatisation (due to HCV, alcohol, drugs, or sexual transmission) and difficulty disclosing the condition.
Financial needs	**Financial needs**	4	2 studies[47,52]	• Cost issues related to hospital parking and long waiting times • Financial insecurities and career loss due to disease • Potential financial burden on caregivers (e.g., needing to ring a son for support while also needing to earn a living)
Behavioural and lifestyle regulations	**Behavioural and lifestyle regulations**	6	4 studies[31,44,48,55]	• Need for behavioural interventions (e.g., smart apps for reducing alcohol intake) • Need for lifestyle interventions (dietary improvements, increased physical activity) • Lack of information/support for behaviour change • Addressing eating disorders before initiating diet and exercise interventions in NAFLD.
Social and cultural factors	**Social and cultural factors**	4	2 studies[39,53]	• Change in social life and feelings of isolation due to disease rarity • Impact of an obesogenic environment (high-calorie foods, sedentary lifestyles) as a barrier to healthier diets • Family support identified as a facilitator for positive changes

1.Medical and clinical needs

The studies indicated medical and clinical issues in patients with ALD were characterised into three subdomains as follows.

1.1 Comorbidities, symptoms, side effects and complications

Issues related to complications, symptoms and comorbidities in individuals with ALD were reported in 11 studies.[32-35,37,40,42,44,45,52,54] A population-based cohort study analysing the health records of nearly four million individuals with five different types of liver disease reported an increased burden of cardiovascular disease (CVD) in people with alcoholic liver disease, NAFLD (MASLD), hepatitis B (HBV), hepatitis C (HCV) and autoimmune liver disease. Findings of the study suggested that patients who also had non-liver comorbidities (including diabetes, hypertension, chronic kidney disease, diverticular disease and gastro-oesophageal reflex disorders) had a higher risk of CVD.[32] A cross-sectional, single-centre study with 100 participants with HCV also reported higher risk of CVD associated with high prevalence of hypertension, diabetes and metabolic syndrome among individuals with HCV.[34] A cohort study using UK Biobank data from more than 130,000 participants also reported that male participants with NAFLD (MASLD) had a higher prevalence of obesity, hypertension, diabetes and statin use, along with other characteristics, and were at an increased risk of CVD.[44]

In a mixed-method study including an RCT, interviews and a questionnaire, severe complications such as refractory ascites in end-stage liver disease were investigated, with the study emphasising the importance of palliative approaches, such as large-volume paracentesis, in enhancing the quality of care at home.[52] Additionally, pruritus associated with ALD was reported in another two studies. A prospective observational study of 200 patients with MASLD reported that one in three patients with MASLD experienced moderate to severe itching, with anti-cholestatic agents showing efficacy. The study indicated that higher pruritus severity was associated with advanced fibrosis, female gender, higher body mass index, and elevated serum autotaxin levels. Factors contributing to the persistence of pruritus were reported as ongoing.[33] A cross-sectional survey-based study with 141 participants further reported that pruritus in primary biliary cholangitis (PBC) has an impact on patients' quality of life and is often under-prioritised by clinical specialists, highlighting a gap in addressing this symptom effectively.[35] In a mixed-methods study with 283 participants including survey and interviews with individuals with autoimmune hepatitis, participants reported medication side-effects, including negative experience of corticosteroids, and unmanaged symptoms such as fatigue as main issues that are significant burden.[54] A cohort study with 493 participants reported symptoms such as pain, discomfort and mobility limitations in individuals with high risk of chronic liver disease which could impact HRQoL.[45] One study based on a retrospective

audit investigated bone disease as a medical complication in individuals with cirrhosis and reported that current practices for its assessment and management are inadequate.[42] Another cross-sectional study based on survey and questionnaires reported fatigue, bone ache, memory and concentration problems, ascites and medication side effects as further reducing HRQoL in individuals with PBC[40] In a prospective cross-sectional study with 513 participants, a high level of non-liver related comorbidities in NAFLD patients was reported, such as hypertension, type 2 diabetes, obesity and CVD.[37]

1.2 Quality of life considerations

Five studies examined HRQoL, highlighting how symptoms, complications, and comorbidities contribute to its reduction, as previously mentioned.[33,35,37,40,45] Papstheodoridi et al., in their study on individuals with NAFLD (MASLD), reported the impact of non-liver comorbidities on reducing HRQoL.[37] Tildesley et al also reported decrements in HRQoL score in the pain, discomfort and mobility limitations domains in patients with chronic liver disease.[45] Additionally, the results of Mitchell-Thain et al.'s study focused on the effects of PBC on quality of life and health care costs, suggesting that most major symptoms of PBC significantly reduce HRQoL, except for itching, which had a minimal effect.[35] Rice et al also reported reduced HRQoL in individuals with PBC associated with symptoms, side effects and comorbidities.[40] Hussain et al. also reported the impact of pruritus on quality of life in individuals with ALD.[33]

1.3 Barriers in care delivery

Five studies suggested that structural barriers in primary and secondary care are likely to hinder the effective management of ALD.[39,46,47,49,52,53] A qualitative phenomenological study with 30 participants including focus groups of patients with PSC suggested there are issues related to timely access to care, access to an appropriate specialist, lack of continuity in care and the need for better training for doctors.[39] A qualitative, interview-based study including 20 participants on liver disease management in primary care suggested barriers such as lack of integration of liver disease into multimorbidity care and unclear roles for GPs in managing lifestyle interventions.[49] Another study reported challenges in accessing timely care, navigating healthcare systems, and inadequate support systems that further impact patients' ability to manage conditions, such as ascites. These issues also impacted upon caregivers.[52] A mixed methods study focussing on barriers and facilitators to adopting a Mediterranean diet by patients with NAFLD (MASLD) also highlighted the importance of joint development of intervention tools by patients and clinicians to optimise the adoption and maintenance of dietary interventions for patients.[53] A qualitative descriptive study, based on semi-structured interviews with 10 participants, focused on healthcare encounters of people with cirrhosis, and suggested a lack of transparency in the hierarchy of healthcare delivery.[46] A qualitative study

based on in-depth interviews with 15 participants suggested delays in access to care, such as liver transplantation, delays in arranging social workers and hospital-based processes for patients with ALD.[47]

1.4 Disease-related knowledge

Eight included studies stated the importance of disease-related knowledge in treatment and management of ALD.[39,46-48,50,53,54,56] In one study, patients' concerns about conflicting information on their prognosis and their lack of medical information were highlighted.[47] A qualitative study based on semi-structured interviews with 33 patients and healthcare professionals reported a lack of basic information surrounding NAFLD diagnosis and management and the need for clear information about the diagnostic process, as well as NAFLD and comorbid conditions such as type 2 diabetes.[48] Another study also reported a poor understanding of NAFLD (MASLD), which potentially affected the priority placed on adherence to dietary advice.[53] A further study reported on a lack of understanding regarding the aetiology of autoimmune hepatitis and the disease itself.[54]

Furthermore, one study highlighted the need to signpost patients to reliable and accurate information and sources of support at the time of diagnosis to help families familiarise themselves with the illness and feel less isolated.[39] A retrospective cross-sectional study with 58 participants reported concerns among females with chronic liver disease regarding health deterioration, maternal death, pregnancy loss, medication effects and disease transmission, emphasising the importance of pre-pregnancy counselling to improve patient experiences.[56] Davis et al reported that patients felt poorly informed about their condition and its likely progression and were unable to seek information and plan for future care. This study suggested dynamic issues of power during healthcare encounters, illustrated by participants' reluctance to voice concerns and express themselves, challenge decisions, or seek information.[46] Additionally, a qualitative evaluation-based study including 20 participants focusing on the acceptability of chronic liver disease screening (transient elastography; TE) in a UK primary care setting suggested that none of the participants were aware of metabolic risk factors prior to the intervention. While TE enhanced understanding of personal risk factors and encouraged reflection on potential lifestyle changes across all TE stratifications; participants' perceptions of risk were influenced by how healthcare providers communicated the TE scores.[50]

1.5 Comprehensive support and palliative care planning

Alongside Cooper et al.'s study on palliative long-term abdominal drainage, which was reported to be well-accepted by patients and nurses, improving care delivery for those with ALD and reducing the burden on hospitals,[52] two other studies reported inadequate palliative care input

received by patients with end-stage liver disease. A retrospective audit study on patients with end-stage liver disease highlighted interventions such as systematic supporting and palliative care indicators tool (SPICT) screening and multidisciplinary reviews, which are reported to have improved palliative care delivery.[43] Another quantitative study focused on advance care planning in end-stage cirrhosis in a UK district general hospital highlighted a lack of awareness and implementation of advanced care planning among patients with a poor prognosis.[38] Hallsworth et al indicated patients' need for support during monitoring for their disease progression and lifestyle change.[48]

2. Psychological and emotional needs

The included studies highlighted the psychological and emotional impacts of ALD on patients and were characterised into three subdomains as follows.

2.1 Emotional impacts of ALD on patients

The findings of 17 studies reported emotional impacts of ALD on patients.[31,35,36,39,41,46-48,50-52,54,56] In a quantitative cohort study with 96 participants focusing on the role of mental health in NAFLD, patients reported a higher prevalence of personality disorder and uncontrolled eating disorders.[31] A population-based cohort study with more than 3000 participants reported that the prevalence of major depressive disorder among HCV patients was higher compared with HBV patients. The study also suggested that HCV patients were more likely to use antidepressants compared with HBV patients. The study indicated the association between using anti-depressants and decompensated cirrhosis.[41] A prospective observational study with 52 participants focusing on assessing mental wellbeing in patients with sclerosing cholangitis reported a high level of anxiety and depression among advanced and chronic liver disease patients, with worry and fear surrounding progression, as well as common concerns about possible treatment including transplant needs.[36] Cooper et al. also reported stress caused by long waiting times and extra costs, as well as feelings such as embarrassment and distress caused by leakage in patients with ALD who require palliative drainage.[52] Anxiety associated with diagnosis was also reported by participants in Hallsworth et al study.[48]Surprise and anxiety caused by treatment intervention were reported in Knight et al.'s study.[50]

Davis et al. reported patients' struggle to articulate their concerns or challenge decisions regarding their care and treatment, as well as their fear and worry about receiving information and feelings of being overwhelmed as a result of disease complexity.[46] Gray-Renfrew et al. also reported that participants' feelings of fear, anger, sadness and guilt featured in patient's experience of advanced liver disease. Specific factors that provoked these emotional responses were suggested, including the shock of diagnosis, uncertainty concerning illness, a lack of

coordinated care, worrying symptoms and sudden death.[47] Rahim et al.'s study also reported the concerns of female patients with chronic liver disease surrounding pregnancy, including fears around a deterioration in health, maternal death, pregnancy loss, medication effects and disease transmission, as well as highlighting the importance of counselling in reducing those concerns.[56] An interpretative phenomenological study on seven male participants with HCV reported distress, uncertainty and loss of control surrounding diagnosis, as well as feelings of guilt, shame, regret, and anxiety around their condition being "exposed".[51] In Lloyd et al.'s study, participants expressed their feelings of frustration and lack of control of their bodies and concerns about passing their condition to their children.[54] Issues such as disrupted sleep and mental health problems reported in the study by Mitchell-Thain et al. were associated with unmanaged symptoms.[35] Ranieri et al. also reported anxiety, fear, and low mood following diagnosis and during the transplant process; their participants highlighted post-transplant challenges, including changes to life, work and well-being, as well as a lack of access to helpful information and guidance.[39]

2.2 Emotional Impact of ALD on caregivers

Two studies indicated the psychological impact of ALD on caregivers. Cooper et al. reported caregivers' frustration with the referral process from GPs to hospital for asities drainage in patients with cirrhosis,[52] while Ranieri et al. reported on psychological distress in caregivers of individuals living with PSC.[39]

2.3 Quality of life considerations

Lower scores of HRQoL were reported to be related to emotional function, worry and anxiety domains in Papatheodoridi et al.'s study.[37] HRQoL scores in anxiety and depression domains were also reported to be lower in patients with high risk of chronic liver disease, which was reduced as age increased.[45] Individuals with HCV were also reported by another study to experience reduced HRQoL in all domains of the SF36v2 compared with the general population, which was associated with the presence of cirrhosis, HCV viraemia, metabolic syndrome, history of mental health disorders and sedentary behaviour.[34] Mitchell-Thain et al. found that symptoms such as pruritus in patients with PBC were linked to negative emotional impacts, including sleep, mental health damage and quality of life.[35]

2.4 Issues related to stigma and self-acceptance

Issues related to stigma were found to affect male patients with HCV in Krzeczkowska et al.'s study, leading to difficulties in disclosing their condition and impacting their self-identity and interpersonal relationships.[51] In Lloyd et al.'s study, participants reported stigma and a perceived loss of control over their condition as significant challenges. Participants also reported feelings

of frustration and powerlessness, particularly in relation to stigma, including experiencing stigmatising remarks from healthcare professionals and colleagues.[54]

3. Financial impacts of ALD

Issues related to the financial burden of the disease were briefly mentioned in two studies. Cooper et al. reported that patients experienced stress due to costs associated with hospital parking fees and prolonged waiting times for accessing care. Discussions around financial burden were highlighted by one patient, who noted that they needed to call their son for support but recognised their need to maintain their livelihood.[52] Financial insecurities and loss of career associated with alcohol misuse and ALD were highlighted in Gray-Renfrew et al.'s study.[47]

4. Social and Cultural needs

Some social and cultural impacts were discussed by two studies, including Haigh et al. who highlighted the concept of an obesogenic environment, which reflects the social and cultural context in which high-calorie, readily available foods and sedentary lifestyles are prevalent. This environment was identified as a barrier to adopting healthier diets such as the Mediterranean diet. However, family support was identified as a facilitator in the study, indicating that social networks may play a key role in motivating and sustaining dietary changes.[53] Ranieri et al. also reported changes in social life, feeling isolated due to rarity of the disease or tiredness in individuals with PSC, as well as observing family members and friends working and functioning as 'normal' leading to feelings of loneliness in those individuals.[39]

5. Behavioural regulations

Asquith et al. reported that patients with NAFLD (MASLD) were more likely to exhibit uncontrolled eating disorders (associated with personality disorders) than non-NAFLD liver disease patients.[31] The study suggested that NAFLD (MASLD) patients should be screened for personality disorders and, if identified, treated prior to the commencement of diet, exercise and locus of control management. Hallsworth et al. also indicated healthcare professionals' perspectives towards behavioural regulations, including diet and exercise in patients with NFLD. The study highlighted that patients were only told about potential lifestyle changes as a management option, and they reported a lack of support surrounding behaviour change to undertake lifestyle interventions.[48] While the above-mentioned studies reported the psychological aspects of lifestyle changes, one study reported on the association between unhealthy lifestyles and major adverse cardiovascular events in patients with NAFLD (MASLD).[44] In a mixed methods study, other behavioural changes, such as alcohol reduction

facilitated by technology-based interventions, such as alcohol reduction applications, were suggested to substantially reduce alcohol consumption and hospital readmissions among compliant patients.[55]

Comparing study limitations identified in the scoping review with netnography perspective

Beyond presenting our findings, we also undertook a comparative analysis of the methodological limitations identified in the included studies and our own experiences with a netnographic approach. This comparison offers a critical examination of how netnography corresponds with or diverges from traditional research methodologies in the context of online health discussions. Table 3 outlines the principal limitations reported in the studies included in our scoping review and contrasts them with the challenges and considerations specific to netnographic research

Table 3. Comparing studies limitations

Main limitations identified in included studies	Netnography perspective
Reliance on self-report measures[31]	Relies on user-generated content, which can be biased but reduces reliance on traditional self-report measures
Use of secondary data restricted to text analysis, lacking contextual and behavioural cues[47]	Text-based data collection may restrict contextual cues
Limited generalisability due to single-centre studies or studies conducted in specific regions[32,46,49]	Our Findings are specific to one online community, may limiting generalisability
Small sample sizes, reducing statistical power and limiting the range of experiences captured [38,46,52]	Considering the number of posts and the level of users' engagement, our selected online community may represent larger populations; however, demographic information about the online forum was not available at the time of study.
High dropout rates and incomplete data sets[55]	Dropout rates were not an issue in this study as archived chat data from an online forum was used.
Use of telephone interviews, which reduced spontaneity and engagement[52,54]	Does not involve telephone interviews but lacks interactivity
short duration of interviews, potentially limiting depth of insights [48]	No interaction between observers and forum users
Low participation rates and potential selection bias [39]	No participant recruitment was needed. With permission from forum administrators, researchers were able to access as much data as they wished.
Lack of follow-up or longitudinal data in many studies [33,36]	Often lacks longitudinal data unless forums are studied an extended period.
Questionnaire response rates often below 60%, with severely ill patients unable to participate [40,56]	Non-participation of certain groups can result in limited insights, such as severely ill patients, people not using

	the forum, or those lacking internet access or knowledge.
Participants recruited from specific clinical settings, limiting broader applicability [34,51]	Forum demographics are not explicitly available; however, the forum is publicly accessible in the UK.
Exclusion of diverse ethnic backgrounds and caregivers, restricting representativeness[39,46]	Ethnicity information of forum users was unavailable. Some groups may be underrepresented in online discussions due to digital literacy or access issues.
Predominance of certain demographic groups [51,54]	While the forum is publicly available across the UK, certain groups of patients may have greater access to online platforms due to familiarity with technology or internet availability.
Recruitment confined to specific geographical areas, affecting generalisability[32,49]	Data collection was limited to one online platform, which can affect broader applicability.
Lack of detailed assessments for specific conditions or outcomes[37,53]	Our Netnography study did not include condition-specific assessments
Use of outdated or less specific evaluation tools[41,44]	Evaluation tools are not a feature of netnography, so this limitation doesn't directly apply
Limited use of newly developed, disease-specific scoring systems[37]	Scoring systems are not relevant to netnography
Studies conducted during the COVID-19 pandemic, potentially skewing findings[36]	External influences like COVID-19 can affect online behaviours, indirectly influencing findings
External factors influencing healthcare experiences[45]	External factors such as online forum's policies can shape experiences captured
Focus primarily on patient perspectives, with limited insights into clinicians' viewpoints[46]	No clinicians' insights were captured
Insufficient exploration of caregivers' accounts[39]	Caregiver perspectives were included, as some forum users were caregivers of patients with ALD.
Narrow scope, focusing on specific subpopulations or diseases without broader context[38,53]	The scope was kept broad, including any type of ALD defined by the inclusion criteria.
Missing data on individuals who declined participation[50]	Missing data from non-users remains an issue, similar to other methods
Self-selection bias due to recruitment through advertisements or targeted outreach[39]	Self-selection bias is a known issue in online research
Influence of the interviewer's presence on participant responses[50]	No interviewer was conducted, and no interaction occurred between observers and forum users
Clinician-led studies reflecting trends within healthcare[35]	Did not rely on clinician-led studies
Reported interim results, with longitudinal follow-up pending[33]	Although data was collected from a five-month archive, the findings may be limited by the lack of comprehensive or longitudinal data

Discussion

Summary of key findings

This study sought to understand whether netnography can be applied as a rapid qualitative method for capturing the unmet needs of individuals with severe conditions, such as ALD, within the context of healthcare research. Employing a complementary method — a scoping review — addressing the same topic enabled us to assess whether the insights gained from the netnography were broadly comparable to the published literature and the wider feasibility of the method.

Comparing the netnography findings with those from the scoping review underscored the method's effectiveness in identifying the unmet needs of individuals with ALD. Notably, many of these needs were also captured by the studies included in the scoping review. For instance, both methods identified multiple unmet needs related to medical and clinical issues, emotional and psychological challenges and financial burdens faced by individuals with ALD. Additionally, the scoping review identified some social impacts highlighted by some studies that were briefly captured by the netnography with more emphasis on the emotional and psychological impact of these issues. However, it also highlighted the need for behavioural regulation, including diet and lifestyle changes, although the need for dietary advice was also identified by the netnography method.

Medical and clinical needs

The netnography method highlighted various medical and clinical needs in individuals with ALD through the lens of lived experiences. The study captured patients and caregivers' frustrations with long waiting times, miscommunication, unmanaged or poorly managed symptoms, lack of sufficient attention to their dietary needs, clarity in diagnosis and inconsistent guidance regarding treatment. These unmet needs were also identified by the scoping review. Issues related to complications and comorbidities were also identified in both methods. Specific complications, such as refractory ascites, bone disease, pruritus, and comorbidities such as cardiovascular disease were identified by the scoping review.[32,33,35,54] Importantly, both the netnography and the scoping review drew attention to a higher prevalence of non-liver comorbidities, such as obesity, hypertension and type 2 diabetes and cardiovascular events, which impact health-related quality of life.[34,37,44] The netnography also identified issues related to neuropathy and post-transplant complications.

The findings of the scoping review also included data on structural barriers, such as poor integration of liver disease management into primary care and need for timely access to palliative care for end-stage liver disease.[43,48,49,52] The netnography findings also highlighted the need for clear discussion about palliative and end of life care plan with patients with end-

stage liver disease. Moreover, while the netnography captured emotional narratives of individuals with ALD experiencing a compromised quality of life, some studies within the scoping review provided quantified measurements of HRQoL domains and their variations based on disease type, progression, and patient characteristics.[37,45]

The scoping review also identified knowledge gaps across multiple studies, emphasising that patients with different types of ALD frequently lack clear information on disease prognosis, diagnosis and management. Studies highlighted confusion regarding diagnostic procedures, comorbid conditions (e.g. type 2 diabetes), and conflicting information from healthcare professionals.[47,48,54] Moreover, a lack of understanding about the disease impacted patients' adherence to treatment recommendations.[53] Conversely, the netnography revealed how patients and caregivers navigate these knowledge gaps in real-time. It highlighted challenges in interpreting medical terminology, treatment plans and test results. The reliance on online sources, such as search engines and forums, exacerbated confusion and anxiety, particularly when official communication was delayed or unclear. Patients frequently sought online guidance to interpret test results (e.g., FibroScan or biopsy outcomes), often encountering conflicting or alarming information that increased distress.

Although the netnography method provided insight into certain medical and clinical needs relevant to ALD, it had limitations in identifying unmet needs specific to individual liver conditions. Due to the nature of the study, access to participants' clinical diagnoses and disease stages was not available, and displaying test results was not permitted on the forum. Some forum users were also uncertain about their diagnosis, further limiting the specificity of the information shared. This lack of diagnostic detail can constrain the applicability of findings to distinct ALD subtypes and made it challenging to fully align the narratives with the data from the scoping review. Moreover, the absence of demographic information in the netnographic data can restrict the ability to contextualise certain unmet needs within specific population groups, thereby reducing the precision and generalisability of these insights for targeted interventions.

Emotional and psychological needs

Both the scoping review and netnography identified emotional and psychological challenges for individuals with ALD. The emotional burden of ALD on caregivers was also identified by both methods. However, the netnography provided more nuanced narratives of caregivers' difficulties by capturing the subtleties of their emotional struggles, including feelings of isolation, frustration with healthcare systems, and the complexities of balancing caregiving responsibilities with personal wellbeing. These rich, unfiltered narratives offered deeper insight

into the lived experiences of caregivers, which may not have been as comprehensively captured by the scoping review.

While uncertainty about the future and emotional burden of diagnosis and disease progression were identified by both methods, some studies included in the scoping review quantified these issues, demonstrating a measurable impact on HRQoL. Despair and psychological burden from disease progression and declining quality of life were also captured by both methods. The scoping review highlighted the higher prevalence of mental health disorders, including anxiety and depression, in individuals with various types of ALD. This comparison could not be made using the netnography method.

Issues related to stigma in individuals with alcohol-related liver disease were identified by both methods. However, the scoping review specifically highlighted certain populations, such as men with HBV and HCV, as being particularly vulnerable to experiencing stigma.[46,51,54]The netnography also highlighted alcohol-related challenges, including difficulties in quitting and relapse drinking behaviours. These issues were identified in the scoping review, which included studies examining interventions, such as a smart application designed for patients with alcohol-related liver disease.[55] Additionally, the scoping review highlighted the association between depressive disorders and alcohol addiction, as well as the fear and sense of guilt experienced by individuals with alcohol-related liver disease. Furthermore, it addressed how individuals with high levels of alcohol consumption may be overlooked in screening programmes.[47,50]

However, as with the identified medical and clinical needs, the netnographic data were broadly categorised, and the psychological impacts were not tied to specific types of advanced liver disease or particular characteristics such as gender and age. While the narratives offered valuable insights into the shared psychological burden of living with ALD, they lacked the granularity required to address condition-specific challenges. This limitation highlights the need for additional approaches to gain more detailed insights of psychological needs in the context of distinct liver conditions, as well as for specific gender and age subgroups.

Financial needs

The netnography highlighted financial burden as a considerable unmet need. Forum participants shared challenges such as affording private healthcare due to delays in NHS care, navigating complex benefits systems, and dealing with income loss caused by illness or caregiving responsibilities. These narratives illustrate the link between financial hardship and access to timely, effective care, which can exacerbate both medical and psychological outcomes. In contrast, financial issues were only briefly discussed in two studies within the scoping review, which mentioned the financial impact of long waiting times and high hospital

parking fees, as well as the potential financial burden on caregivers.[47,52] However, no included study emphasised the significance of these financial challenges. This absence underscores a possible gap in recent UK-based literature, which tends to focus more on the clinical and psychological aspects of disease management rather than financial challenges such as indirect and out-of-pocket costs.

Behavioural regulation and social and cultural needs

While social issues such as feeling isolated or importance of family supports were categorised amongst psychological needs in the netnography findings, behavioural change topics like the need for dietary modifications were viewed as medical needs, based on the nature of the conversations. On the other hand, some studies within the scoping review highlighted social and cultural influences on lifestyle behaviours in liver disease. For instance, environmental issues such as "obesogenic environments" were identified as barriers to adopting healthier diets like the Mediterranean diet; this underscored the complex interplay between psychological factors, lifestyle behaviours, and disease progression in patients with ALD.[53] Additionally, issues such as higher rates of uncontrolled eating disorders associated with personality disorders in patients with NAFLD,[31] or the association between unhealthy lifestyle behaviours and major cardiovascular events,[44] were identified by the scoping review. The scoping review also highlighted the potential role of digital interventions in supporting alcohol reduction and promoting healthier lifestyles.[55] These specific issues were not captured by the netnography method.

Implications for further research

The way patients and their caregivers share information on various online platforms—ranging from health topics to personal experiences with specific diseases—creates promising new opportunities for healthcare research.[57] As more individuals turn to online communities for sharing their experiences, the application of netnographic methods to uncover the unmet needs of those with severe conditions is becoming increasingly relevant. The results of this study broadly aligns with existing literature, suggesting that observational netnographic methods can provide a more rapid and pragmatic method for capturing insights from within online communities.[24] However, for netnography to be widely accepted as a legitimate research method within traditional healthcare studies, it is essential to establish a comprehensive understanding of its benefits, limitations and constraints when applied to diverse topics and online environments. Future studies could extend this understanding by

employing netnographic methods across a broader range of healthcare-related subjects, by allocating additional time and resources.

In this study, ethical considerations significantly extended the research process, making it less expedient. To ensure ethical integrity, this study adopted the precautionary ethical approach for netnography outlined by Robert Kozinets.[11] This meant that no data were collected, even from publicly accessible online communities, without first obtaining consent from forum administrators. While this approach was considered important by our research team, this is not the approach taken by all researchers. For example, a 2019 study used data from Macmillan Cancer Support and, while obtaining University ethics, considered that data in the public domain required no explicit consent for use .[58] Taking this approach to a netnographic study would be potentially transformative with regard to the number of sources available for data collection. However, debate remains regarding the appropriateness of seeking permissions to use forum data.[59,60]

Our more cautious approach sought to ensure a high ethical standard. Additionally, safeguarding the anonymity and confidentiality of forum participants was paramount, despite the public nature of the data and it was essential to respect the original context and intent behind users' shared experiences. By contrast, the scoping review synthesised secondary data from a range of relevant studies and did not require ethical approval. As such, it will be crucial for future netnographic studies to address practical ethical considerations, which in turn could broaden the spectrum of online platforms from which reliable data may be collected.

Furthermore, integrating other data collection methods—such as interviews, surveys and questionnaires—could complement netnographic approaches by gathering demographic information and enhancing the robustness of the overall analysis. Further research could work towards combining these methodologies, which in turn may provide deeper insights into the digital health landscape and contribute more effectively to patient-centred healthcare research. Additionally, netnographic methods may be useful across the research life-cycle, for example as an initial step to inform subsequent study processes such as recruitment, data collection or the refinement of research questions or topics. While it was beyond the scope of our study, *participatory* ethnography methods, in which a researcher engages with an online community, may offer a different set of opportunities than the passive approach taken in this study.

Strength and limitations of the study

A key strength of applying a netnography method was the ability to collect data from an online setting where participants could share their experiences without the influence of a researcher's

presence, resulting in detailed narratives that highlighted unmet needs and barriers for those with experience of ALD. Another advantage of using the netnography method was its ability to capture a diverse range of perspectives by obtaining consent from forum administrators, thereby eliminating the need for individual consent from each forum member. Additionally, the use of archived forum discussions allowed us to gather a substantial amount of data in a relatively short period, reducing some of the logistical challenges common in traditional qualitative methods. As such, this study was able to capture lived experiences and direct insights surrounding the unmet needs of over 150 patients and caregivers in the UK affected by ALD from a five-month archive of a single UK-based online forum. Obtaining this depth of information through traditional qualitative methods, such as interviews and focus groups, would have required significantly more time and resource. The approach used in this study enabled the rapid identification of key concerns and priorities, facilitating a more efficient understanding of patient and caregiver experiences.

A limitation of this study was its reliance on a single online platform. Although the British Liver Trust forum is well-known in the UK with high-level of user engagements, using additional platforms such as Reddit or Facebook might have reached a more diverse group of individuals with ALD. Permission to conduct the netnography using online communities relating to HNC, which was initially considered as another area of interest for the work, was not received. This limited the netnography to a single clinical topic area from a single source.

Using a single researcher for the qualitative analysis may introduce bias, although a portion of the data was subsequently sense-checked by two additional researchers. Furthermore, while this approach reduced time-consuming logistical challenges commonly associated with traditional qualitative methods, the forum's anonymity policy restricted the collection of demographic data, including participants' gender, age, and ethnicity. Lack of access to definitive diagnoses, and the inability to ask follow-up questions due to lack of direct engagement between the researchers and the forum users or gather information about their health backgrounds, limited the specificity and contextual applicability of the findings. These limitations could hinder the translation of insights into targeted interventions, highlighting the need for a multifaceted approach to address the complex healthcare needs of individuals with ALD.

For the scoping review, a notable strength was the prospective publication of the protocol on the Open Science Framework, along with transparent reporting of any deviations.[61] The review was guided by recommendations from the JBI and informed by recent guidance from the Cochrane Rapid Reviews Methods Group, which helped ensure a thorough process and

conducting comprehensive searches within a short timeframe.[27,62] However, the scoping review also had limitations. Deviations from the pre-published protocol may have introduced some bias, and limiting the search to studies published between 2019 and 2024 might have excluded relevant literature. Additionally, while a single reviewer conducted the initial screening and data charting, only a portion of the work was checked by a second reviewer, which may affect the overall accuracy of the findings.

Conclusions

The findings of this study suggest that netnography can be considered a feasible method for capturing the unmet needs of individuals with severe conditions when applied with careful consideration of its methodological and ethical challenges. The method's ability to access naturally occurring online data offers insights that complement traditional research approaches. However, issues such as representativeness, contextual ambiguity and ethical uncertainties should be addressed through rigorous research design and data analysis practices. Integrating netnography findings with other methodological approaches may enhance the overall understanding of unmet needs in this population while maintaining a balanced perspective on the limitations inherent in online data collection.

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Appendices

Appendix 1: Inclusion Guidance for Observing and Extracting Data from Online Forums

- **Observing Posts and discussions**: The content must explicitly mention advanced liver disease, including discussions of diagnosis, treatment, side effects, and patient experiences.
- Posts discussing other types of cancer or unrelated health conditions should be excluded unless the primary focus is on a type of head and neck cancer or advanced liver disease.

Diseases that may lead to end-stage (advanced) liver disease include:

- Alcohol-related liver disease
- Non-alcoholic fatty liver disease
- Viral hepatitis (e.g. hepatitis B, hepatitis C)
- Primary biliary cholangitis, sometimes called primary biliary cirrhosis
- Primary sclerosing cholangitis
- Autoimmune hepatitis
- Primary hepatocellular carcinoma (HCC) on a background of chronic liver disease
- Autoimmune hepatitis
- Primary hepatocellular carcinoma (HCC) on a background of chronic liver disease
- Cirrhosis
- Patients awaiting liver transplantation
- Steatotic liver disease or SLD
- Metabolic dysfunction-associated steatotic liver disease (MASLD)
- NASH the more serious form of NAFLD will now be called Metabolic-associated steatohepatitis (MASH)
- Met-ALD – this is a new name that has been created for people who have MASLD but who also drink alcohol
- Cryptogenic SLD – this is the name doctors will use for fatty liver disease where the cause is unknown as people do not have any of the metabolic risk factors
- Occasionally the cause of end-stage liver disease is unknown

- **Focus on Unmet Health Needs (Please note: These are broad examples, and additional unmet health needs may surface as data collection progresses)**
- The discussion must focus on unmet health needs, which may include, but are not limited to:
- Unresolved symptoms or side effects.
- Gaps in treatment options or access to care.
- Delayed or late diagnosis, leading to worse health outcomes
- Challenges in obtaining emotional, psychological, or social support.
- Lack of information or guidance on managing the disease.
- Financial and logistical barriers to treatment/ Financial difficulties caused by being seriously ill and not able to work
- Posts that do not discuss unmet needs, such as those focused on successful treatment outcomes or general discussions of the disease, should be excluded.

- **Time Frame:**
- Data should be collected from posts and discussions within the last 6 months onwards for high engagement forums (e.g., forums with daily posts and threads). No older than three years for lower engagement forums (e.g., less than 10 posts/threads per month)
- Older posts, outside the defined time frame, should be excluded to ensure relevance to current patient needs and healthcare landscapes.
- **Type of Contributor:**
- Posts made by patients diagnosed with any type of advanced liver disease, their caregivers, or close family members should be included.
- Posts made by healthcare professionals or researchers can be included if they directly reflect on the unmet needs of patients.
- Posts from general forum users without any indication of direct experience with head and neck cancer (as a patient or caregiver) should be excluded (unless they contain relevant information to the study).
- **Format of Data:**
- Only posts or comments in text form should be included for analysis. Video, audio, and image-based content should be excluded unless accompanied by substantial textual content that meets the inclusion criteria.
- Threads/posts with a maximum number of comments or interactions may be prioritised to ensure rich data, but this can be adjusted/decided based on the available data and the relevance of the content to the research objectives.
- **Language:**

- Only posts in English should be included.
- **Accessibility:**
- Posts must be publicly accessible or accessible through appropriate permissions within closed groups. Posts behind paywalls or in inaccessible private groups should be excluded.

Appendix 2: Copy of emails to online forums

Dear [recipient name]

I am writing to you on behalf of our research team at Newcastle University. We are currently in the development phase of a research project in which we are seeking to understand unmet healthcare needs in Head and Neck Cancer/Advanced Liver Disease (DELETE AS NECESSARY FOR RECIPIENT).

Our study would seek to understand unmet healthcare needs by examining discussions and interactions within online community forums and we believe that these forums provide invaluable insights into the experiences, challenges, and needs of patients and their caregivers.

Any work we undertake would be under ethical approval granted by the university, but we are aware that individual organisations have policies concerning the use of data – are you able to advise on your policy regarding the use of data from online forums? Additionally, we would appreciate any guidelines or best practices you recommend ensuring that our research is conducted in a manner that aligns with your community standards and ethical considerations.

We believe that our research has the potential to significantly contribute to the understanding and improvement of healthcare services for patients with head and neck cancer/advanced liver disease.

Thank you for considering our request. We look forward to your response and are happy to provide any further information or clarification you may require.

Yours sincerely

Name

Appendix 3: Coding Framework

1. Medical and Clinical Needs

- **Possible codes:**

  Effective Symptom Management: Analyse patient discussions for mentions of persistent symptoms like fatigue, ascites, jaundice, and hepatic encephalopathy. Look for expressions of dissatisfaction with current symptom management and gaps in improving quality of life.

Key Indicators:

  - Frequency of symptom-related discussions.
  - Language indicating frustration, discomfort, or deterioration in life quality.
  - Mentions of insufficient relief from prescribed treatments or medications.

- **Access to Comprehensive Treatment Options:** Identify patient experiences regarding limited access to treatments like liver transplantation or other advanced procedures, particularly issues like long waiting lists, eligibility restrictions, or regional disparities.

Key Indicators:

  - Discussions on liver transplant availability and delays in starting treatment or surgery.
  - Patient concerns about eligibility or regional access disparities.
  - Recommendations or demands for alternative treatment pathways.

- **Clarity on Diagnostic and Monitoring Protocols:** Look for discussions where patients express confusion or frustration with medical terms, unclear test results, or misunderstandings regarding their condition (Possibly in interactions with healthcare professionals)

Key Indicators:

  - Complaints about unclear medical communication.
  - Requests for simpler explanations of diagnoses and test results.
  - Mentions of missing or inconsistent follow-up on diagnostic procedures.

- **Addressing Comorbidities:** Explore conversations about related complications like portal hypertension, infections, or other comorbidities that are not being adequately addressed in the patient's treatment plan.

Key Indicators:

- Discussions about other illnesses complicating their liver disease.
- Complaints about a lack of comprehensive care approaches.

2. Emotional and Psychological Needs

Possible codes:

- **Psychological Support:** Track mentions of emotional distress, anxiety, depression, and fear, with a focus on the availability and adequacy of mental health services specifically tailored for advanced liver disease patients.

Key Indicators:

- Descriptions of emotional suffering, stress, or mental health struggles.
- Complaints about the lack of access to mental health services or support groups.
- Calls for more tailored psychological interventions.

- **End-of-Life Planning and Counselling:** Look for discussions where patients express concerns about the future, including end-of-life care, palliative options, and advanced care planning.

Key Indicators:

- Mentions of confusion or discomfort around discussions of prognosis or end-of-life options.
- Desire for more open, proactive guidance on advance care planning.

- **Building Hope and Resilience:** Investigate whether patients are voicing needs for services that support their emotional resilience, such as counselling, support groups, or spiritual care.

Key Indicators:

- Expressed feelings of isolation or hopelessness.
- Mentions of lacking access to supportive care that addresses emotional well-being.

3. Social and Practical Needs

Possible codes:

- **Caregiver Support:** Identify posts highlighting the needs of caregivers, such as feelings of burnout, emotional strain, and the lack of support services for those who provide care to patients.

Key Indicators:

- Caregivers expressing stress or fatigue.
- Discussions about limited access to respite care or counselling for caregivers.
- Requests for caregiver-specific training or resources.

- **Financial Assistance:** Analyse posts discussing financial strains, such as the cost of medications, hospital stays, or transplants, as well as challenges in accessing financial support or navigating insurance systems.

Key Indicators:

- Concerns about out-of-pocket expenses for medications and treatments.
- Complaints about navigating insurance and disability benefits.
- Discussions of inadequate financial aid or support schemes.

- **Navigating Employment and Daily Life Adjustments:** Explore themes where patients discuss difficulties with employment, returning to work, or adjusting daily routines around their illness.

Key Indicators:

- Complaints about lack of workplace accommodations.
- Conversations around the difficulty of balancing work and medical treatment.
- Requests for rehabilitation services or employment accommodations.

- **Peer Support and Community Connection:** Look for unmet needs around feeling isolated or unsupported, despite the existence of platforms like HealthUnlocked. Identify calls for more structured support groups—both online and in person.

Key Indicators:

- Expressed desire for more meaningful peer engagement.
- Discussions of feeling isolated even with online forums.
- Requests for structured group meetings, either locally or virtually.

- **Coordinated Healthcare Navigation:** Examine posts about difficulties navigating the healthcare system, including problems accessing specialist care, coordinating between healthcare providers, and maintaining continuity of care.

Key Indicators:

    - Mentions of difficulty finding or accessing specialised healthcare.
    - Frustrations about lack of follow-up or communication between different healthcare providers.

5. Information and Educational Needs

Possible codes:

- **Accessible and Personalised Education:** Focus on patient complaints regarding the lack of clear, accessible educational resources that explain the disease, treatment options, and future expectations.

Key Indicators:

    - Complaints about difficulty understanding complex medical information.
    - Requests for simplified or personalised health education materials.
    - Discussions about unclear treatment outcomes or disease progression.

- **Awareness of Latest Treatments and Clinical Trials:** Track mentions where patients express frustration at not being aware of newer treatments, clinical trials, or experimental therapies.

Key Indicators:

    - Complaints about not receiving information on cutting-edge treatments.
    - Discussions on the need for better communication about clinical trials.
    - Requests for updated resources on emerging therapies.

6. Alternative and Complementary Therapy Needs

Possible codes:

- **Integrative Health Approaches:** Investigate posts where patients express interest in alternative therapies such as supplements, dietary changes, or holistic care, and whether they feel they have adequate guidance from their healthcare providers.

Key Indicators:

    - Conversations about experimenting with or seeking advice on alternative treatments.
    - Complaints about the lack of guidance from clinicians on integrative approaches.

- Requests for reliable, scientifically backed information on complementary therapies

Appendix 4: Netnography Code Book

Name	Description	Files	References
Main Code: Emotional and Psychological needs (including 6 Child codes)	Emotional distress (e.g., anxiety, depression, fear), discussions related to concerns about the future, prognosis, and end-of-life care, including confusion around palliative care, unmet needs for meaningful social engagement, where patients express feeling isolated or unsupported despite existing resources, needs and challenges faced by caregivers, such as emotional strain, burnout, and the lack of support services	4	82
Child code 1: Building self-acceptance in patients	Include codes which reflect patients' feelings of shame or self-blame related to their condition. These emotions may arise from perceptions of stigma, personal responsibility, or challenges in daily life, affecting their sense of self-worth and mental well-being.	2	7
Child code 2: Caregivers' support	Include managing complex care needs, emotional stress and fatigue from balancing caregiving responsibilities with personal and professional obligations. Feelings of helplessness or frustration when witnessing a loved one's suffering.	4	21
Child code 3: Emotional support	Reflects the need for emotional reassurance, understanding, and guidance for individuals dealing with advanced liver disease. This includes support to cope with anxiety, fear of the future, depression, and feelings of powerlessness related to physical symptoms and health uncertainties. the psychological toll of physical deterioration, prolonged recovery, and lifestyle limitations.	4	28
Child code 4: End-of-Life Planning and Counselling	This code includes discussions related to concerns about the future, prognosis, and end-of-life care, including confusion around palliative care and advance planning.	2	5

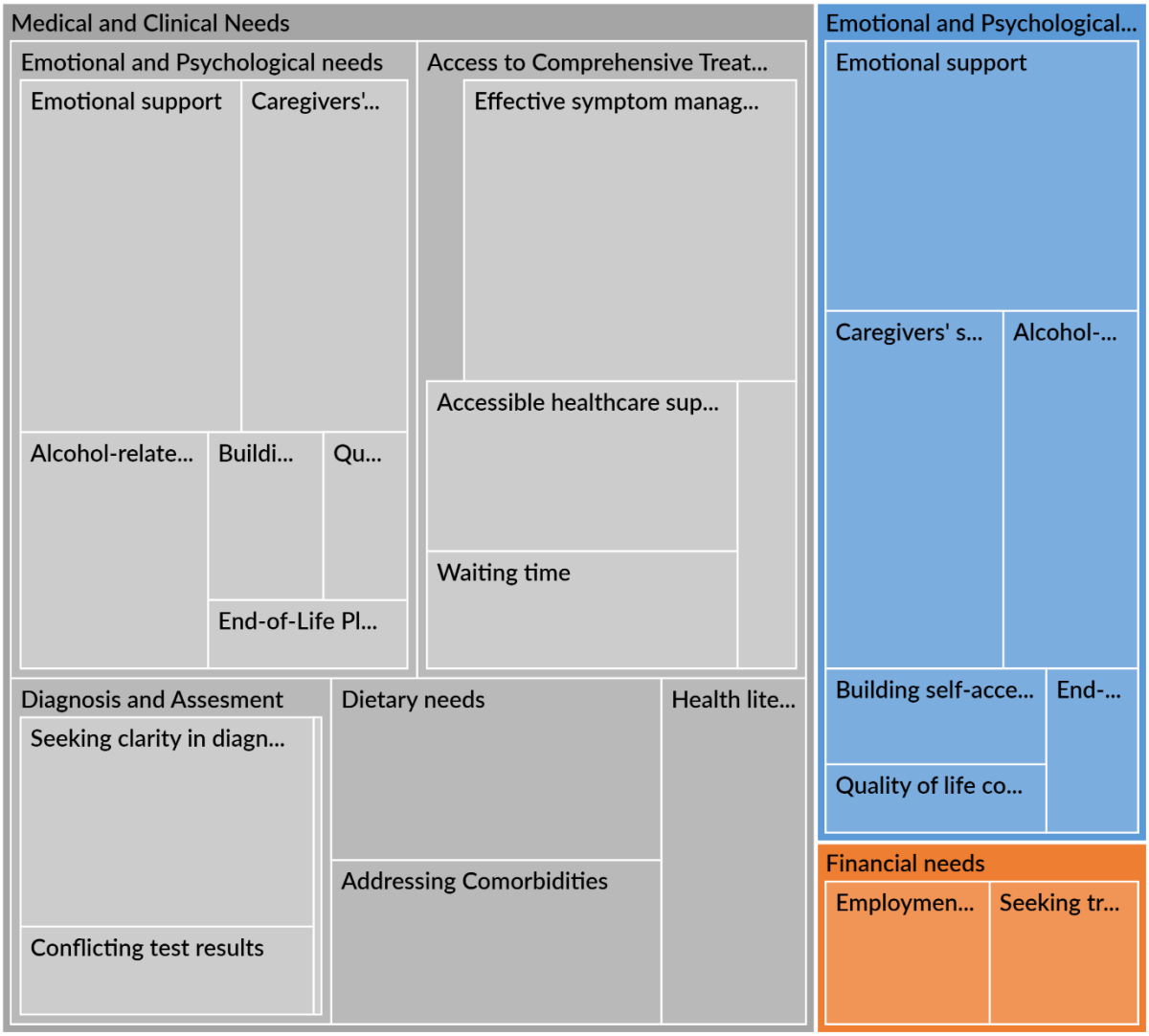
Child code 5: Quality of life considerations	Include discussions around deteriorating quality of life, and the strain on both the individual and their caregivers	3	5
Child code 6: Alcohol-related challenges	This code captures the ongoing challenges and experiences of individuals with ALD related to alcohol use and addiction. It reflects the difficulty in quitting drinking, relapses, denial, and the emotional and physical toll it takes on patients and their families	3	16
Main Code: Financial needs (including 2 child codes)	Explore patient discussions on financial difficulties, including out-of-pocket expenses, challenges navigating insurance, and the need for financial aid or government support.	3	19
Child code 1: Employment and Financial Adjustments	Capture patient challenges with employment, returning to work, or managing financial issues alongside advanced liver disease.	3	10
Child code 2: Seeking treatment beyond the NHS	Individuals express the need for quicker access to confirm diagnoses and guide necessary actions via NHS. Frustration over high costs, uncertainty about health insurance coverage, and the potential need to seek private healthcare options. This code also reflects the financial strain and worries about managing treatment costs within personal income limits.	2	9
Main code: Medical and Clinical Needs (including 5 child codes, 7grandchild codes, 2 grand grandchild codes)	Explore patient discussions on unresolved symptoms (e.g., fatigue, ascites, jaundice, hepatic encephalopathy) and dissatisfaction with symptom management strategies/Identify experiences around limited access to treatments like liver transplantation, delays, and eligibility issues/ Patient confusion or frustration with diagnostic processes, medical terminology, unclear test results, or inconsistent follow-up, particularly in interactions with healthcare professionals./Explore patient unaddressed comorbidities	4	165
Child code 1: Access to Comprehensive Treatment Options	Identify experiences around limited access to treatments like liver transplantation, delays, and eligibility issues. Identify difficulties in navigating the healthcare system, including problems accessing specialists, coordinating care, or maintaining continuity of care across different healthcare providers.	4	42

Grandchild code 1: Accessible healthcare support	Include situations where patients find it difficult or impossible to access the help or information, they need from healthcare providers/doctors/ nurses	4	19
Grandchild code 2: Effective symptom management	Explore patient discussions on unresolved symptoms (e.g., fatigue, ascites, jaundice, hepatic encephalopathy) and dissatisfaction with symptom management strategies.	4	36
Grandchild code 3: Transplant	This code captures experiences, challenges, and needs related to the liver transplant process. Reflecting the complexities of navigating transplant criteria and the ongoing care required post-transplantation.	2	8
Grand grandchild code 1: Post-transplant follow up	Refers to the ongoing need for medical support, monitoring, and guidance after liver transplantation	2	2
Grand grandchild code 2: Transplant criteria	Patients express frustration, disappointment, and the emotional toll of being unable to qualify for or maintain eligibility on the transplant list despite their effort	2	6
Grandchild code 4: Waiting time	Reflects the prolonged waiting periods patients face for treatments and medical procedures	3	13
Child code 2: Addressing Comorbidities	Explore patient narratives on complications or comorbidities that may or may not addressed in their treatment plans.	4	17
Child code 3: Diagnosis and Assessment	This code captures patients' experiences with the diagnostic process, including challenges such as conflicting test results, delays in receiving results and efforts to seek clarity in understanding their diagnosis and care plan.	3	36
Grandchild code 1: Conflicting test results	This code captures instances where patients receive contradictory or inconsistent information from test results or medical professionals, leading to confusion and uncertainty about their health status and treatment plan	3	10
Grandchild code 3: Seeking clarity in diagnosis and treatment	Includes codes that reflect the need for comprehensive information and guidance from healthcare providers to alleviate stress and confusion, enabling patients and their families to feel more confident and supported in managing their condition.	3	24

Grandchild code 4: Test results delay	This code captures patients' experiences of delays in receiving diagnostic test results.	2	2
Child code 4: Dietary needs	Captures the need for tailored dietary guidance for patients with ALD. Patients often seek clear advice to maintain energy, gain weight, prevent malnutrition, ease symptoms etc.	4	19
Child code 5: Disease-related Knowledge	Refers to the ability of patients with advanced liver disease to access, comprehend, and utilise relevant health information for managing their condition. This includes difficulties in understanding medical terminology, treatment plans, and care instructions, More related to diagnosis	2	16

Appendix 5: Netnography Word Cloud

Appendix 6: Netnography Hierarchy of Codes



Appendix 7: Differences between protocol and scoping review

The protocol initially specified the inclusion of systematic reviews and meta-analyses. However, we refined our inclusion criteria to focus exclusively on original studies, as no review studies were identified that specifically examined UK-based publications. Additionally, while the initial plan involved three researchers, four researchers ultimately conducted the data extraction and analysis. The extracted data were then reviewed by two researchers (SG and EJ). The data charting process was also revised to categorise unmet needs according to their relevant domains.

Appendix 8: Finalised data charting form

Domain	**Data items**
Bibliographic details	Title, Authors, URL, Year published or updated Type of source: journal article; report; book chapter; other
Context	Type of research (e.g. quantitative, qualitative, mixed method) Quantitative study designs: • Randomised Controlled Trial (RCT) • Cohort Study • Cross-Sectional Study • Case-Control Study • Survey/Questionnaire • Other (specify) Qualitative study designs: • Interviews (structured, semi-structured, unstructured) • Focus Groups • Ethnography/ Netnography • Content Analysis • Narrative Analysis

Domain	Data items
	• Other (specify) Mixed Methods Approaches: • Sequential Explanatory • Sequential Exploratory • Concurrent Triangulation • Other (specify) Country (England, Wales, Scotland, and Northern Ireland) or all (UK)
General population or specific subgroup description	Gender, age, type of ALD (e.g,. male Asian participants, over 50, with NAFLD)
Sample size	Total number of participants included in the study
	Categories of unmet health needs (e.g., physical, psychological, social, healthcare access)
Specific unmet health needs	Specific unmet health needs described in the study
Main findings	Summary of key findings related to unmet health needs and implications
Analysis Methodology	Outline of the analysis approach (e.g., thematic analysis for qualitative data, statistical methods for quantitative data)
Limitations	Noted limitations of the study (e.g., sample size, methodology, generalisability)

Appendix 9: PRISMA-ScR checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Title	1	Identify the report as a scoping review.	Click here to enter text.
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Click here to enter text.
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Click here to enter text.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Click here to enter text.
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Click here to enter text.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Click here to enter text.
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Click here to enter text.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Click here to enter text.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Click here to enter text.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Click here to enter text.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Click here to enter text.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Click here to enter text.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Click here to enter text.
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review,	Click here to enter text.

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		with reasons for exclusions at each stage, ideally using a flow diagram.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Click here to enter text.
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Click here to enter text.
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Click here to enter text.
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Click here to enter text.
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Click here to enter text.
Limitations	20	Discuss the limitations of the scoping review process.	Click here to enter text.
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Click here to enter text.
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Click here to enter text.

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;1

Appendix 10: List of studies excluded from the scoping review

Study ID	Reason for exclusion
Abbott 2022	Population
Abbott 2023	Concept
Abbott 2024	Study Design
Abdelbasset 2021	Concept
Abdelbasset 2019	Population
Abd-Elsalam 2019	Population
Abd-Elsalam 2020	Population
Abdoly 2024	Population
Abenavoli 2020	Language
Abraldes 2023	Population
Abraldes 2019b	Study Design
Acharya 2021	Population
Adda 2023	Concept
Adebayo 2024	Study Design
Afifi 2021	Population
Aggio 2024	Population
Aguiar 2023	Population
Aiyegbusi 2020	Concept
Akhter 2022	Study Design
Alavinejad 2019a	Population
Alavinejad 2019b	Population
AlDury 2024	Population
AlEid 2022	Population
Alem 2021a	Study Design
Alem 2021b	Population
Alem 2024	Population
Alkadi 2017	Population
Allampati 2019	Population
Allen 2023	Study Design
Allen 2021	Population
Aloreidi 2019	Population
Alqahtani 2021	Population
Alrabadi 2022	Population
Alrasheed 2021	Concept
Alrubaiy 2019	Population
Alswat 2022	Population
Alukal 2020	Population
Amorim 2024	Population
Amruthavarshini 2024	Population
An 2021	Population
Ananthakrishnan 2021	Study Design
Andersson 2020	Population
Ando 2019	Population

Study ID	Reason for exclusion
Angelico 2021	Population
Angelidi 2024	Population
Anghelici 2022	Context
Anghelici 2019	Context
Annicchiarico 2019	Population
Anonymous 2019	Study Design
Anonymous 2020	Study Design
Anstee 2020	Study Design
Armstrong 2020	Study Design
Arrese 2020	Population
Allopurinol 2024	Population
Arshad 2019	Population
Artyomenko 2023	Population
Asadzadeh 2024	Population
Atamla 2021	Population
Athanasopoulou 2023	Study Design
Azoulay 2022z	Population
Bachrach 2022	Population
Bager 2021a	Population
Bager 2021b	Context
Bager 2020	Population
Bailey 2021	Population
Bajaj 2020a	Population
Bajaj 2020b	Study Design
Bajaj 2020c	Study Design
Bajaj 2019	Population
Bajre 2022	Concept
Baka 2019	Population
Bakulin 2023	Population
Balak 2021	Population
Balakrishnan 2019a	Study Design
Balbinot 2023	Population
Banales 2019	Context
Barber 2021	Population
Barbera 2024	Population
Barfod O'Connell 2024	Population
Batisti 2024a	Population
Baysal 2020	Population
Beal 2022	Population
Beal 2022e	Population
Bellavance 2019e	Study Design
Beresford 2024	Study Design
Beresford 2024	Concept

Study ID	Reason for exclusion
Bergaoui 2021	Population
Bernal 2022	Population
Berry 2022e	Study Design
Best 2019	Study Design
Beuers 2023	Study Design
Bhalla 2024	Population
Bhandari 2022h	Population
Bhandari 2022h	Population
Biliotti 2021	Population
Bjelakovic 2021	Population
Bjornsdottir 2024	Population
Block 2024	Population
Bloom 2021	Population
Bloom 2024	Population
Bloom 2020	Population
Bonacchi 2023	Population
Borges 2024	Population
Bose 2019	Population
Bossi 2020o	Population
Boudreault 2020	Population
Bowers 2023	Population
Brahmania 2024	Population
Brandman 2019	Population
Bravo 2022	Population
Breckons 2020	Study Design
Brennan 2021	Study Design
Brennan 2023	Study Design
Brierley 2024	Study Design
Bril 2023	Study Design
Brown 2020	Study Design
Stve iersorg/10.1177/08850666241280892 2024	Population
Brown 2023	Population
Brown 2024	Population
Brown 2020	Context
Brumand 2020	Population
Brzdek 2023	Population
Buchanan 2019	Population
Budis 2020u	Population
Buganza-Torio 2019	Population
Bugazia 2023u	Population
Buti 2021	Population
Buti 2019	Population

Study ID	Reason for exclusion
Butterworth 2019	Population
Byambasukh 2019	Population
Caddick 2021	Population
Cai 2019	Population
Cai 2021	Population
Caines 2024a	Population
Caines 2024b	Study Design
Camarata 2020a	Study Design
Camarata 2020b	Study Design
Campbell 2021	Population
Capuano 2023	Population
Cardaba-Garcia 2021	Population
Cargill 2021	Study Design
Carlson 2024	Study Design
Carol 2022	Study Design
Carrieri 2022	Population
Carroll 2024	Population
Casciola 2023	Population
Casler 2020	Population
Castera 2023	Study Design
NCT04677101	Population
Cayir 2024	Study Design
Cazac 2023	Population
Cazzagon 2019	Population
Celik 2023	Study Design
Celik 2022	Population
Cevik 2020	Population
Chalouni 2019	Population
Chan 2020	Study Design
Chandok 2024h	Population
Chang 2019	Study Design
Chang 2022a	Population
Chapman 2022	Study Design
Chapman 2019	Study Design
Chauhan 2023	Population
Chavez-Tapia 2019h	Population
Chazouilleres 2022h	Context
Cheema 2019	Population
Chen 2022a	Population
Chen 2020a	Population
Chen 2020b	Population
Chen 2020c	Population
Chen 2022b	Population

Study ID	Reason for exclusion
Chen 2022c	Population
Cheng 2024	Population
Cheung 2019	Population
Chhatwal 2022	Population
Chirchiglia 2019	Population
Chiu 2020	Population
Choo 2022	Population
Chopra 2020	Study Design
Choudhary 2019	Population
Choudhury 2024	Population
Christensen 2023	Study Design
Cimolai 2019	Study Design
Clark 2023	Study Design
Clayton 2021	Population
Clayton 2020	Study Design
Cleveland 2019	Population
Coates 2019	Study Design
Cohn 2020	Study Design
Coilly 2024	Population
Colli 2023a	Population
Colli 2023b	Population
Colombo 2023	Population
Colombo 2024	Study Design
Colosimo 2023	Population
Colwell 2019	Population
Conthe 2023o	Language
Cook 2019	Population
Cooper 2023	Population
Cooper 2024	Population
Cornberg 2022	Population
Cornberg 2023	Population
Correa 2021	Language
Correa 2024	Population
Correia 2024	Population
Costa 2019	Population
Costache 2019	Study Design
Cotter 2022	Study Design
Craig 2022	Population
Cristoferi 2021	Population
Crocombe 2022	Study Design
Crowley 2019	Population
Cui 2020	Population
Cui 2021	Population

Study ID	Reason for exclusion
Dai 2023	Study Design
Dang 2022	Population
Daniela 2019	Population
Das 2023	Study Design
Das 2019	Population
Das 2021	Study Design
Das 2024	Population
Davis 2019	Population
Dawkins 2023	Population
Day 2019	Population
de Goede 2021	Population
de Lange 2023	Population
de Siqueira 2021	Population
Deng 2020	Study Design
Deng 2021	Population
Deng 2023	Population
Dennis 2020	Population
Desai 2023a	Population
Desai 2023b	Population
Devan 2023	Population
Dhaliwal 2021	Population
Dhiman 2022a	Population
Dhiman 2022b	Population
Di Stefano 2021	Population
DiMartini 2022	Population
Ding 2022	Population
Dixon 2022	Study Design
Dixon 2021	Study Design
Dizdar 2021	Population
Dogra 2020	Population
Dokmak 2021	Population
Dong 2022	Population
Donlan 2021	Population
Donlan 2019	Population
Dos Santos 2021	Population
Douros 2024	Population
Doward 2021a	Study Design
Doward 2021b	Population
Doycheva 2019	Population
Doyle 2023	Population
Drysdale 2022	Population
Du 2019	Study Design
Du 2022	Population

Study ID	Reason for exclusion
Duijzer 2022	Population
Dunn 2019	Population
Durcan 2020	Population
Dyson 2019a	Study Design
Dyson 2019b	Study Design
Eder 2021	Population
Edwards 2023	Population
Eisa 2020	Study Design
Ekpanyapong 2019	Study Design
El Dika 2022	Population
El Hadi 2019	Population
El-Arabey 2022	Population
Elhelbawy 2019	Population
El-Kady 2022	Population
Elkholy 2021	Population
Elsabaawy 2024	Population
Elsaid 2022	Population
Elsayed 2020	Population
Emamaullee 2020	Population
Emmanuel 2023	Study Design
Erard 2024	Population
Erdogan 2019	Study Design
Erdogan 2022	Population
Eso 2022	Study Design
Espina 2022	Population
Essa 2019	Population
Estevez 2020	Study Design
Evon 2022	Population
Ezaz 2019	Study Design
Fabrazzo 2020	Population
Fabrellas 2020a	Population
Fabrellas 2023a	Population
Fabrellas 2020b	Population
Faccia 2019	Population
Faccioli 2022	Population
Fagan 2023	Population
Fagan 2022	Study Design
Fagundes 2020	Population
Fahnoe 2021	Population
Fakhry 2024	Population
Fan 2020	Concept
Farag 2021	Concept
Farhat 2019	Population

Study ID	Reason for exclusion
Farooq 2023	Population
Farooq 2022	Population
Farrugia 2023	Concept
Fasano 2022	Study Design
Fatima 2024	Population
Faust 2022	Population
Fawsitt 2020	Concept
Fedorchenko 2021	Population
Fedorchenko 2020	Population
Feld 2022	Population
Ferguson 2021	Concept
Fernandez 2023	Population
Fernandez 2024	Concept
Fernandez 2019	Context
Fernandez 2022	Population
Ferrigno 2021	Concept
Flamm 2023	Population
Flavin 2024	Population
Florescu 2021	Population
Foghis 2023	Population
Foghis 2024	Population
Forbes 2023	Concept
Foster 2019a	Concept
Foster 2020	Population
Foster 2019b	Concept
Francque 2019	Study Design
Francque 2023	Study Design
Francque 2021a	Concept
Franque 2021b 2021	Concept
Frenette 2022	Population
Fricker 2019	Study Design
Friedman 2022	Study Design
Fry 2019	Study Design
Fu 2020	Context
Funuyet-Salas 2021	Population
Funuyet-Salas 2023	Study Design
Funuyet 2024	Population
Funuyet-Salas 2022	Population
Gadour 2021	Study Design
Gairing 2023	Study Design
Gambino 2021	Concept
Gane 2019	Concept
Garcia 2023	Population

Study ID	Reason for exclusion
Gedallovich 2024	Study Design
Gelape 2023	Study Design
Gellad 2019e	Concept
George 2024	Population
Gerber 2020	Context
Gerussi 2023	Concept
Ghoshal 2024	Study Design
Gines 2021	Study Design
Giri 2022	Study Design
Glaspy 2021	Population
Glass 2022a	Population
Glass 2022b	Population
Golubeva 2022	Concept
Gong 2023	Concept
Goni-Esarte 2019	Population
Gonzalez 2020	Population
Gonzalez 2024	Concept
Goyes 2020	Context
Gronkjaer 2021a	Population
Gray 2022	Population
Greenslade 2020	Context
Grewal 2024	Population
Grodin 2024	Concept
Gronkjaer 2023	Concept
Gronkjaer 2021b	Study Design
Gronkjaer 2022	Concept
Grover 2021	Population
Gruneau 2023	Concept
Gruneau 2023	Population
Guarino 2022	Concept
Guernsey 2024	Concept
Guggisberg 2022	Concept
Gungabissoon 2024	Concept
Guo 2024	Concept
Gupta 2023	Concept
Gupta 2021	Population
Ha 2022a	Population
Ha 2022b	Study Design
Hadefi 2023	Population
Haghighi 2020	Population
Haire 2024	Population
Hajifathali 2021	Concept
Halliday 2023	Concept

Study ID	Reason for exclusion
Hammerich 2023	Concept
Hammoudeh 2021	Concept
Hanai 2019	Population
Hanna 2021	Concept
Hanscom 2024	Concept
Hardesty 2024	Population
Haridy 2021	Concept
Hartl 2022	Population
Hashida 2022	Population
Hashida 2024	Population
Hassan 2024	Population
Hatipoglu 2023	Population
Hatton 2019	Concept
Hayes 2022	Study Design
Hayward 2020	Concept
Heintz 2019a	Population
Heintz 2019b	Population
Heintz 2019c	Population
Hemrage 2024	Study Design
Henkel 2020	Concept
Henry 2022	Population
Henson 2023	Population
Henson 2022	Population
Henson 2020	Population
Heo 2019	Population
Heo 2023e	Population
Heredia 2022	Population
Herta 2019	Population
Hey 2024	Population
Hill 2024	Population
Hiraoka 2020	Population
Hiraoka 2021	Population
Hiraoka 2019	Population
Hirschfield 2024	Study Design
Hjorth 2020	Population
Hjorth 2023	Population
Hjorth 2024	Population
Holeksa 2019	Context
Holmes 2022	Population
Holyoak 2023	Study Design
Hong 2019	Context
Hong 2023	Population
Hoozemans 2021	Concept

Study ID	Reason for exclusion
Hoppmann 2020	Population
Hsieh 2024	Population
Hu 2020	Context
Hu 2023	Population
Huang 2020a	Concept
Huang 2023a	Concept
Huang 2023b	Study Design
Huang 2024	Population
Huang 2023c	Population
Huang 2020b	Population
Huang 2021	Concept
Huber 2019	Population
Hughes 2024	Population
Hui 2024	Population
Hui 2023	Population
Hulden 2020	Population
Hulme 2022	Concept
Hyde 2022	Concept
Ibanez-Samaniego 2022	Concept
Idilman 2020	Concept
Im 2022	Study Design
Incerti 2019	Concept
Inciardi 2023	Population
Insausti-Urkia 2020	Concept
Iogna 2019	Study Design
Iqbal 2021	Population
Iruzubieta 2023	Study Design
Ismail 2023	Population
Ismond 2020	Population
Ismond 2019	Population
Ismond 2024	Population
Itakura 2021	Concept
Jackson 2022	Study Design
Jafree 2024	Population
Jagdish 2020a	Population
Jagdish 2022	Concept
Jagdish 2023	Concept
Jagdish 2020b	Concept
Jagdish 2020c	Concept
Jamali 2022	Concept
Jamali 2021	Concept
Jang 2021	Concept
Janicko 2023	Concept

Study ID	Reason for exclusion
Janik 2023a	Population
Janik 2023b	Population
Janik 2019a	Study Design
Janik 2019b	Concept
Janko 2024	Population
Janota 2023	Population
Jarmakiewicz-Czaja 2023	Concept
Jaroenlapnopparat 2023	Concept
Jarvis 2021	Study Design
Javaid 2021	Population
Jeji 2023	Population
Jeong 2022	Study Design
Jepsen 2020	Concept
Jepsen 2021e	Population
Jiang 2022	Population
Jiang 2023	Population
Jindal 2023	Study Design
Jirapinyo 2024	Concept
Jirapinyo 2023	Concept
Jogiraju 2024	Concept
Johnson 2023a	Population
Johnson 2023b	Population
Jones 2023	Population
Jordan 2020	Population
Ju 2019	Study Design
Juanbeltz 2019	Concept
Jung 2024	Concept
Jung 2020	Population
Juo 2019	Concept
Jyoti 2021	Population
Kahi 2023	Concept
Kahn-Boesel 2024	Population
Kallwitz 2020	Concept
Kalo 2024	Study Design
Kang 2021	Concept
Kanwal 2019	Concept
Kanwal 2021a	Concept
Kanwal 2021b	Concept
Kao 2024	Concept
Kaplan 2023a	Population
Kaplan 2023b	Population
Kapoor 2023	Concept
Kapur 2019	Population

Study ID	Reason for exclusion
Kardashian 2023	Population
Kardashian 2022	Population
Karimi-Sari 2020	Population
Kassa 2024	Population
Kaushik 2024	Concept
Kayed 2023	Concept
Kefalakes 2022	Study Design
Kennedy 2024	Study Design
Kesen 2019	Population
Khanna 2019	Concept
Kim 2021a	Study Design
Kim 2022	Study Design
Kim 2021b	Concept
Kim 2019	Population
NCT06111859	Concept
Kinney 2022	Population
Kiratli 2023	Population
Kirupakaran 2023	Concept
Kleinert 2022	Study Design
Kogiso 2023	Study Design
Kokkorakis 2023	Study Design
Konerman 2019	Concept
Koval 2021	Population
Kremer 2024	Concept
Kulkarni 2023	Concept
Kumar 2019	Concept
Kumar 2022	Concept
Kumar 2023	Concept
Kushner 2024	Study Design
Kwong 2024	Population
Labenz 2019	Population
Labidi 2019	Population
Laupeze 2023	Concept
Lazarus 2023	Concept
Lee 2023	Population
Lee 2021	Concept
Leighton 2021	Study Design
Lewis 2020	Concept
Li 2023	Population
Li 2022a	Concept
Li 2022b	Population
Li 2024	Concept
Liang 2019	Population

Study ID	Reason for exclusion
Lichtenstein 2023	Population
Lin 2019	Population
Lin 2024	Population
Lindqvist 2020i	Population
Liu 2022a	Concept
Liu 2022b	Concept
Llerena 2022	Concept
Loesken 2023	Population
Ludlow 2024	Population
Luis 2021	Population
Madathanapalli 2022	Population
Madathanapalli 2020	Population
Maggio 2024	Population
Majid 2023	Study Design
Makin 2019	Study Design
Mallolas 2019	Language
Malnick 2019	Concept
Mancinelli 2024	Concept
Manning 2024	Population
Marcus 2021	Study Design
Marenco-Flores 2024	Population
Marshall 2021	Concept
Martin 2020	Concept
Martinez 2024	Population
Mattingly 2019	Concept
Maxwell 2024	Study Design
Mayer 2024	Study Design
Mazeaud 2023	Concept
McAlees 2019	Concept
McNaughton 2021	Study Design
McSweeney 2020	Study Design
Mehraban 2021	Concept
Mellinger 2024	Context
Mera 2019	Study Design
Michel 2021	Context
Miftahussurur 2020	Context
Mitra 2022	Population
Mitrani 2021	Population
Miwa 2022	Context
Mohan 2024	Concept
Montagnese 2019	Population
Montague 2019	Study Design
Moon 2023	Context

Study ID	Reason for exclusion
Moriya 2024	Context
Morrow 2022	Population
Moss 2019	Concept
Moyo-Hlahla 2023	Concept
Mudumbi 2019	Concept
Mukhtar 2021	Context
Nadolsky 2023	Context
Nagel 2020	Context
Nagel 2022	Context
Naggie 2020	Concept
Nascimento 2022	Context
NCT04501042	Context
Natour 2024	Context
Nayagam 2022	Population
Newman 2023	Context
Ng 2022	Population
Nguwen 2023	Concept
Niezen 2024	Population
Noeman 2020a	Context
Noeman 2020b	Concept
Noeman 2020c	Concept
Noeman 2021	Concept
Noll 2024	Study Design
Notarnico 2021	Study Design
O'Connell 2020	Concept
Oldroyd 2023	Population
Olveira 2021	Study Design
Ongaro 2021	Population
Orman 2022	Context
Ozawa 2021	Context
Palazzo 2019	Context
Papatheodoridi 2022	Concept
Papavasiliou 2024	Study Design
Pashley 2023	Study Design
Patel 2021	Study Design
Patel 2020	Population
Peng 2019	Population
Philips 2023	Population
Phoolchund 2024	Concept
Picinbono-Larose 2019	Population
Pinderup 2019	Concept
Plotogea 2021	Study Design
Polukchi 2023	Concept

Study ID	Reason for exclusion
Polyzos 2021	Study Design
Pomej 2024	Study Design
Pourmarzi 2020	Context
Povsic 2019	Population
Price 2022a	Study Design
Price 2022b	Population
Przybyszewski 2023	Concept
Pulous 2023	Context
Purssell 2022	Concept
Qin 2021	Context
Rabiee 2021	Study Design
Rajpurohit 2023	Context
Rajpurohit 2024a	Context
Rajpurohit 2024b	Study Design
Rakoski 2019	Study Design
Ramai 2021	Concept
Rammohan 2023	Concept
Ranieri 2019a	Study Design
Ranieri 2019b	Population
Rao 2022	Concept
Rashidi-Alavijeh 2021	Context
Rathi 2021	Concept
Rathod 2022	Study Design
Ratziu 2023	Context
Ratziu 2020	Study Design
Ravanbaki 2024	Concept
Rawat 2022	Context
Rebelos 2021	Concept
Reed 2022	Population
Rehman 2021	Concept
Reichardt 2022	Context
Reid 2022	Context
Reis Aruda 2023	Concept
Ren 2019	Study Design
Ren 2022	Context
Reuter 2019	Context
Revill 2019	Concept
Revoredo 2023	Concept
Riggio 2019	Study Design
Rinella 2023	Concept
Rini 2023	Concept
Riveiro 2024	Context
Robles-Medranda 2020	Context

Study ID	Reason for exclusion
Roccarina 2021	Study Design
Rockstroh 2020	Population
Rodas 2023	Concept
Rodijk 2020	Population
Rogal 2020a	Context
Rogal 2020b	Study Design
Rogoveanu 2022	Context
Roman 2019	Study Design
Roman 2024	Context
Romano 2022	Study Design
Romero 2022	Population
Romero-Gomez 2023	Context
Roncero 2019	Context
Rondon-Berrios 2022	Concept
Ronot 2024	Study Design
Rosenberg 2023	Study Design
Rossi 2022	Context
Rosso 2022	Context
Rubin 2021	Context
Rubio 2022	Context
Ruiz 2019	Context
Rustgi 2022	Concept
Rustgi 2021	Context
Ruther 2021	Context
Rybina 2022	Context
Sabourin 2021	Context
Sabry 2023	Study Design
Sack 2021	Context
Saeed 2020	Population
Saeki 2024	Concept
Saeki 2020	Context
Saeki 2019	Context
Safarian 2019	Context
Sagara 2023	Context
Sahu 2022	Context
Saif 2019	Context
Sakamaki 2022	Context
Sakamoto 2019	Study Design
Salah 2021	Context
Salazar 2023	Context
Saleh 2021	Study Design
Saleh 2022	Study Design
Saleh 2023	Concept

Study ID	Reason for exclusion
Salmon 2021	Concept
Salomone 2021	Context
Salpini 2019	Context
Samala 2020	Context
Samarasekera 2021	Study Design
Samuel 2023	Concept
Sanchez-Torrijos 2019	Context
Sangouni 2022	Population
Sanyal 2019	Context
Sanyal 2024	Study Design
Saracco 2023	Context
Saraswat 2022	Study Design
Sarin 2020	Concept
Saroso Olivia 2020	Context
Sato 2020	Context
Savanti 2023	Population
Sawada 2020	Context
Sbarigia 2020	Concept
Scalera 2022	Context
Schattenberg 2023	Population
Schattenberg 2019	Study Design
Schattenberg 2022	Study Design
Schlogl 2021	Concept
Schnefeld 2023	Context
Schneider 2024	Concept
Schnurr 2022	Concept
Schomerus 2022	Population
Schramm 2019	Population
Schregel 2023	Context
Schregel 2024	Context
Schreiner 2022	Context
Schreiner 2023	Context
Schulte 2020	Context
Sciarrone 2021	Concept
Seen 2021	Concept
Sehgal 2023	Context
Selim 2023e	Study Design
Seliverstov 2019	Context
Semmler 2021	Context
Sena 2023	Study Design
Seppelt 2020	Context
Serper 2022	Study Design
Serper 2023	Context

Study ID	Reason for exclusion
Serper 2020	Context
Serper 2024	Study Design
Serper 2019	Context
Seto 2021	Study Design
Shaat 2020	Context
Shah 2024	Concept
Shah 2020	Study Design
Shah 2019	Study Design
Shah 2021	Study Design
Shaikh 2024	Concept
Shalaby 2023h	Study Design
Shamseddeen 2021	Context
Sharma 2023a	Context
Sharma 2023b	Context
Sharma 2019a	Context
Sharma 2019b	Context
Sharma 2023c	Context
Sharma 2024a	Context
Sharma 2024b	Study Design
Sharshar 2020	Context
Shavali 2024	Context
Shaw 2023	Context
Shaw 2021	Context
Sheils 2020	Study Design
Shen 2024	Context
Shengir 2021	Concept
Shenoy 2024	Study Design
Sheptulina 2023	Context
Shetty 2019	Context
Shi 2022	Context
Shi 2024	Study Design
Shiha 2021	Context
Shinall 2019	Context
Siler 2022	Context
Silva Filho 2019	Context
Simonetti 2021	Concept
Simonetti 2019	Concept
Singal 2020	Concept
Singal 2021i	Context
Singal 2022	Study Design
Singal 2024	Study Design
Singh 2023a	Context
Singh 2022a	Study Design

Study ID	Reason for exclusion
Singh 2022b	Context
Singh 2023	Context
Singh 2022c	Context
Singhal 2019a	Context
Singhal 2019b	Context
Singla 2024	Context
Singleton 2024	Context
Siqueira 2022	Context
Siramolpiwat 2021	Context
Siramolpiwat 2023	Context
Siraw 2024	Context
Sirisunhirun 2020a	Context
Sirisunhirun 2020b	Context
Sirisunhirun 2022	Context
Sivakumar 2021	Study Design
Skladany 2020	Context
Slonka 2022	Context
Smith 2023	Study Design
Smith 2019	Context
Snijders 2023	Population
Socias 2019	Study Design
Sofia 2021	Concept
Sola 2019	Study Design
Sola 2021	Context
Soldera 2020	Context
Song 2021	Study Design
Soontararatpong 2020	Context
Soosapilla 2019	Context
Sophasath 2023	Study Design
Soto-Angona 2020	Study Design
Souza-Silva 2022	Study Design
Spagnuolo 2019	Context
Spann 2024	Study Design
Sporea 2020	Study Design
Stafford 2021	Concept
Stavar 2019	Concept
Stefan 2024	Concept
Stefanaki 2023	Concept
Stelmach2021	Concept
Stemmer 2019	Concept
Stengaard 2022	Concept
Stepanova 2023t	Population
Stepanova 2019	Context

Study ID	Reason for exclusion
Stine 2020	Population
Stoelinga 2024	Context
Stotts 2019	Study Design
Strnad 2023a	Context
Strnad 2023b	Concept
Su 2023a	Concept
Su 2023b	Population
Su 2019	Study Design
Su 2024	Population
Suda 2023	Context
Suda 2019	Concept
Sugiyama 2021	Population
Sugiyama 2022	Population
Sulehria 2023	Population
Sulkowski 2022	Context
Sun 2022	Context
Sun 2020	Population
Sun 2024	Population
Suzuki 2024	Population
Swain 2019a	Study Design
Swain 2023	Population
Sweeney 2019	Concept
Syed 2023	Population
Szabo 2019	Population
Tabish 2024	Population
Tabish 2023	Population
Tagliamento 2019	Population
Tagliapietra 2020	Population
Tajiri 2022	Population
Takada 2024	Population
Talal 2019	Population
Tamaki 2020	Population
Tan 2023	Population
Tanaka 2020	Population
Tanaka 2024a	Population
Tanaka 2019	Population
Tanaka 2020b	Population
Tandon 2020	Study Design
Taneja 2021	Population
Tantry 2021	Population
Tao 2020	Population
Tapper 2019	Population
Tapper 2023a	Study Design

Study ID	Reason for exclusion
Tapper 2023b	Population
Tapper 2023c	Population
Tapper 2021a	Population
Tapper 2022	Population
Tapper 2020	Population
Tapper 2021b	Population
Tarantino 2020	Study Design
Tarcoveanu 2020	Population
Tavoschi 2019	Population
Taylor 2020	Study Design
Tellez 2023	Population
Temime 2024	Population
Terrault 2023	Population
Thiagarajan 2020	Population
Thibonnier 2023	Population
Thomas 2019	Population
Thompson 2022	Population
Thomson 2021	Population
Thuluvath 2020	Population
Thursz 2019	Study Design
Tincopa 2023	Population
Tincopa 2022	Population
Tincopa 2024	Population
Tincopa 2021	Population
Tiotiu 2022	Population
Tiwari 2024	Population
Tong 2023	Population
Tonon 2020	Population
Tornai 2021	Population
Torres-Hernandez 2024	Population
Toumi 2024	Population
Toussaint 2022	Population
Toussaint 2023	Population
Towey 2022	Study Design
Toyoda 2020	Population
Toyoda 2022	Population
Tran 2021	Population
Trauner 2023	Population
Traunero 2024	Population
Trebicka 2022	Population
Trigui 2023	Population
Tripathi 2019	Study Design
Trivedi 2022	Population

Study ID	Reason for exclusion
Trivedi 2021	Study Design
Trivedi 2024	Population
Trotter 2022	Study Design
Trovato 2020	Population
Tsai 2024	Study Design
Tsauo 2019	Population
Tu 2020	Population
Tudor 2024	Population
Twiss 2023	Population
Ufere 2024	Population
Ufere 2019	Population
Ufere 2023	Population
Ufere 2022a	Population
Ufere 2022b	Population
Ufere 2021	Population
Uhlenbusch 2023	Population
Umashankar 2022	Population
NCT06318949	Population
Urda-Romacho 2021	Population
Vacca 2020	Population
Vachliotis 2022	Population
Valenzuela-Vallejo 2022a	Study Design
Valenzuela 2023	Concept
Valeriani 2023	Population
Valery 2022a	Population
Valery 2022b	Concept
Valery 2022c	Population
van Akkooi 2022	Population
van Munster 2020	Population
Van Thiel 2023	Concept
VanHuis 2019	Study Design
VanWagner 2020	Study Design
Varganova 2019	Concept
Varshney 2020	Population
Vedadi 2023	Concept
Venkitaraman 2022	Concept
Veracruz 2022a	Population
Veracruz 2022a	Population
Verbinnen 2023	Population
Verma 2020a	Concept
Verma 2023a	Population
Verma 2021	Population
Verma 2020b	Population

Study ID	Reason for exclusion
Verma 2019a	Population
Verma 2022	Population
Verma 2019b	Population
Verma 2023b	Population
Verma 2020c	Population
Verma 2023c	Concept
Verna 2020	Population
Vidal 2024	Population
Viera 2019	Population
Vigano 2023	Population
Vigano 2020	Concept
Vion 2019	Population
Virseda 2022	Population
Visseren 2020	Population
Viveiros 2021	Population
Vold 2019	Population
Volk 2020	Population
Volpes 2020	Population
Vu 2019	Population
Wadhavkar 2024	Context
Wadhwani 2023	Concept
Wahid 2019	Population
Wahid 2022	Context
Waljee 2020	Population
Wallington 2022	Population
Walter 2023	Population
Wang 2024	Population
Wang 2019a	Population
Wang 2019b	Population
Wang 2019c	Population
Wang 2022	Population
Wang 2019d	Population
Wang 2021a	Population
Wang 2020	Concept
Wang 2023a	Population
Wang 2023b	Population
Wang 2019e	Population
Wang 2021b	Population
Wang 2021c	Population
Wani 2022	Population
Ward 2022	Population
Ward 2020	Context
Waterman 2021	Population

Study ID	Reason for exclusion
Wedd 2023	Population
Wee 2020	Study Design
Welch 2020	Population
Wells 2023	Concept
Welyczko 2023	Concept
Wen 2022	Concept
Wernberg 2019	Population
Westermann 2019	Population
Whitsett 2022	Concept
Wilkens 2021	Concept
Williams 2024	Concept
Williams 2019	Study Design
Williams 2022	Context
Williams 2020	Concept
Williams 2021	Population
Winder 2022	Population
Winter 2024	Concept
Winterdahl 2019	Population
Wolf 2021	Study Design
Wong 2023a	Population
Wong 2023b	Study Design
Wong 2021	Concept
Wong 2020a	Concept
Wong 2020b	Population
Wong 2019	Study Design
Woodland 2020	Study Design
Worsfold 2021	Concept
Wright 2023	Population
Wronka 2021	Population
Wu 2020a	Concept
Wu 2021	Population
Wu 2019	Population
Wu 2020b	Population
Wunsch 2023	Population
Wunsch 2021	Population
Xanthakos 2023	Concept
Xia 2021	Population
Xie 2023	Concept
Xie 2019	Study Design
Xu 2019	Population
Yale 2024	Population
Yamamoto 2023	Population
Yan 2020	Population

Study ID	Reason for exclusion
Yan 2019a	Population
Yan 2019b	Population
Yanes-Lane 2020	Population
Yang 2024a	Population
Yang 2024b	Study Design
Yang 2020	Study Design
Yang 2022a	Population
Yang 2023	Population
Yang 2022b	Population
Yaqin 2024	Population
Yau 2024a	Population
Yeo 2023	Population
Yepes-Barreto 2024	Study Design
Yibirin 2023	Population
Yilmaz 2023	Population
Yim 2020	Population
Yip 2023	Study Design
Yoh 2020	Population
Yokohama 2020	Population
Yoo 2019	Population
Yoo 2020	Population
Youn 2022	Population
Younossi 2019a	Population
Younossi 2019b	Study Design
Younossi 2024a	Population
Younossi 2024b	Population
Younossi 2019c	Population
Younossi 2022a	Population
Younossi 2023a	Population
Younossi 2020a	Context
Younossi 2022b	Population
Younossi 2019d	Concept
Younossi 2019e	Study Design
Younossi 2023b	Population
Younossi 2021	Population
Younossi 2022c	Population
Younossi 2022d	Population
Younossi 2019f	Study Design
Younossi 2019g	Population
Younossi 2020b	Population
Younossi 2019h	Population
Younossi 2019i	Population
Younossi 2019j	Population

Study ID	Reason for exclusion
Younossi 2024c	Population
Yousef 2020	Population
Youssef 2022	Population
Yuen 2023	Population
Yuen 2020	Population
Yukawa 2019	Population
Zaccherini 2019	Population
Zacharias 2023	Study Design
Zamani 2022	Population
Zanone 2021	Population
Zappulo 2020	Population
Zeng 2020	Population
Zeng 2024	Concept
Zeuzem 2015	Population
Zhang 2022a	Population
Zhang 2023	Population
Zhang 2024a	Population
Zhang 2022b	Population
Zhang 2024b	Population
Zhang 2022c	Population
Zhang 2022d	Population
Zhang 2021a	Population
Zhang 2019a	Population
Zhang 2019b	Population
Zhang 2022e	Population
Zhang 2022f	Population
Zhang 2019c	Population
Zhang 2024c	Population
Zhang 2019d	Population
Zhang 2021b	Population
Zhang 2021c	Population
Zhao 2023	Population
Zhong 2019	Population
Zhong 2024	Population
Zhou 2020	Study Design
Zhou 2023a	Study Design
Zhou 2023b	Concept
Zhou 2019	Population
Zhu 2021a	Study Design
Zhu 2023	Study Design
Zhu 2021b	Population
Zhu 2024	Population
Zhu 2019	Population

Study ID	Reason for exclusion
Zingg 2024	Population
Zito 2019	Population
Zou 2024	Study Design
Zou 2020o	Study Design
Zoulim 2022	Population
Zuo 2019	Population
Anon 2023	Population

Appendix 11: Search strategy for one data base

Medline (OVID) 18 October 2024

1.	*Liver Diseases/ or *Hepatitis, Alcoholic/ or *Hepatitis, Autoimmune/ or *Hepatitis B, Chronic/ or *Hepatitis C, Chronic/ or *Hepatitis, Viral, Human/ or *Non-alcoholic Fatty Liver Disease/ or *Liver Cirrhosis/ or *Cholangitis, Sclerosing/ or *Liver Diseases, Alcoholic/ or *Liver Cirrhosis, Biliary/ or metabolic liver disease.kf,ti. or steatosis.kf,ti. or ((chronic or advanced) and liver and disease*).kf,ti. or ((liver and disease*).ti. and palliat*.mp.
2.	Patient Satisfaction/ or "Health Services Needs and Demand"/ or *Quality of Life/ or Health Knowledge, Attitudes, Practice/ or Health Behavior/ or Patient Education as Topic/ or (unmet adj2 need*).ab. /freq=2 or (unmet adj3 need*).kf,ti. or (social adj3 need*).mp. or needs.ab. /freq=4 or ldqol.mp. or hrqol.ab. /freq=2 or (patient* adj2 educat*).mp. or (patient* adj3 (perspective* or experience*)).kf,ti. or ((patient* or person? or people or individual*) adj3 (perspective? or experience*)).mp.
3.	1 and 2
4.	limit 3 to (english language and yr="2019 -Current")

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