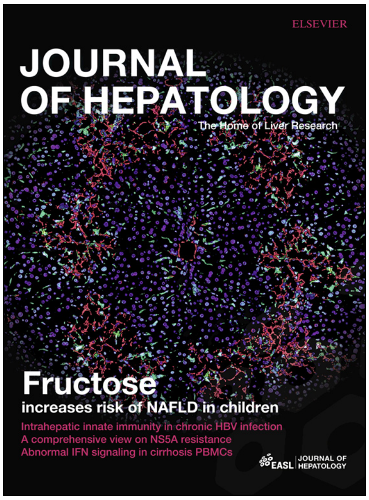

Supportive and palliative care in people with cirrhosis: international systematic review of the perspective of patients, family members and health professionals

Joseph T.S. Low, Gudrun Rohde, Katherine Pittordou, Bridget Candy, Sarah Davis, Aileen Marshall, Paddy Stone

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Supportive and palliative care in people with cirrhosis: international systematic review of the perspective of patients, family members and health professionals

Joseph T S Low[1], Principal Research Associate

Gudrun Rohde[2], Professor in Nursing

Katherine Pittordou[3], Clinical Fellow

Bridget Candy[1], Principal Research Fellow

Sarah Davis[1], Senior Research Nurse

Aileen Marshall[4], Consultant in Hepatology

Paddy Stone[1], Head of Marie Curie Palliative Care Research Department

Correspondence: Dr Joseph Low, Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, 6th Floor, Maple House, 149 Tottenham Court Road, London W1T 7NF. Telephone: 0207 679 9718 Fax: 020 7679 9426. Email: joseph.low@ucl.ac.uk

Names and full addresses of author/co-authors' institution

1. Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, 6th Floor, Maple House, 149 Tottenham Court Road, London W1T 7NF.
2. Faculty of Health and Sport Sciences, University of Agder and Department of Clinical Research, Sorlandet Hospital, Postboks 422, 4604 Kristiansand, Norway.
3. Whittington Health NHS Trust, Magdala Avenue London N19 5NF.

4. Sheila Sherlock Liver Unit, Royal Free Hospital & University College London Institute of Liver and Digestive Health, UCL Royal Free Campus, Pond Street, London, NW3 2QG.

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One figure and five tables

Table 1: Mixed Methods Assessment Tool scoring ratings

Table 2: Patients' understanding of their disease, their perceived needs and their communication with health professionals.

Table 3: Close family members' understanding of the patients' disease, their own perceived needs and their communication with health professionals.

Table 4: Health professionals' perspectives in how they communicate with patients and their family members about their disease and their treatment.

Table 5: Health professionals' perspectives on their delivery of care to patients with liver cirrhosis and how supportive care can be improved across different specialities.

Supplementary Table 1: Definition of methodical quality criteria for Mixed Methods Assessment Tool (section 1 and 4)

Figure 1: The review process

Conflict of interest statement: The authors of this paper have nothing to disclose.

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Authors contributions: JL, GR, KP, BC and PS were responsible for the study concept and design; JL, GR, KP and BC were responsible to the acquisition of the data; JL, GR, KP, SD, AM and PS were responsible for analysis or interpretation of the data; JL, GR and KP drafted the initial manuscript; BC, AM, SD and PS revised the manuscript critically for important intellectual content; all authors gave the final approval of the version to be published.

ABSTRACT

Background: People with cirrhosis have unmet needs, which could benefit from a palliative care approach. Developing effective services needs to be evidence based from those with personal experience. This review aims to explore; patient and family perspectives of perceived needs including communication; health professionals' perspectives on delivery of care and improving palliative care between specialities.

Methods: A literature search conducted in Medline, Embase and CINAHL using key words reporting on the perspectives of patients with liver cirrhosis (18 years and over), family members or health professionals on the provision of care in liver cirrhosis. Study quality was assessed using the Mixed Methods Appraisal Tool. Qualitative and quantitative findings were grouped together according to the main relevant themes identified.

Results: Nineteen research studies predominately from high income Western countries were identified, with a total sample consisting of 1413 patients, 31 family carers and 733 health professionals. Patient and family members had limited understanding about cirrhosis or its impact. They wanted better information about their disease, its treatment and help with psychological and practical needs. Health professionals had difficulty communicating about these issues to patients and their families. General Practitioners left care predominantly to the liver clinicians, who lacked confidence to have discussions about prognosis or future care preferences. The role of palliative care was recognised as important in caring for this group through earlier integration with liver and community services.

Conclusions: Health professionals need support to improve their communication with patients to address their broader needs beyond medical treatment and to develop new models to improve palliative care coordination between different medical specialities. Future research should focus on developing communication aides, testing existing tools to identify suitable patients for supportive care and explore robust ways of evaluating supportive care interventions, with more studies needed from middle and low income countries.

Lay summary: Patients and their families had poor understanding about advanced liver disease and about its impact on them. They need more information about the treatments they receive and how to get practical and psychological support.
Liver doctors and GPs found it difficult to talk to patients and their families about the seriousness of advanced liver disease and the lack of healthcare options available to them if their condition gets worse.
All doctors and nurses involved in the care of patients with advanced liver disease recognise that palliative and supportive care have an important role to help improve patient care.

Registration number: PROSPERO CRD42017064770

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Highlights

- Patients have limited understanding about liver cirrhosis, its prognosis or treatment.
- There is patient and family dissatisfaction with the quality of information, which was perceived as being too medicalised.
- Addressing unmet information needs could support patients to plan their care and reduce anxiety.
- Earlier integration of palliative care with liver and community services could improve the quality of care for patients.
- Better tools assessing current and future care needs may help to identify which patients would benefit from earlier supportive and palliative care referral.

INTRODUCTION

Advanced liver cirrhosis is characterised by the development of clinical complications of portal hypertension or liver insufficiency (1). It is a growing international public health problem due to increases in alcohol consumption, rates of obesity and viral hepatitis (2-5). It often affects people of working age (2, 6) and is the third most common cause of premature death in the United Kingdom (UK) (7).

Most people dying from liver cirrhosis are not suitable for liver transplantation and of those in the United Kingdom who are suitable, 17% will die before a donor becomes available (10). Living with cirrhosis may involve considerable symptom burden, and when liver failure ensues the prognosis is poor, often requiring repeated hospital admissions and multiple clinical interventions to deal with complex physical symptoms (11). People experience both physical and psychosocial challenges (12, 13) and often have unmet needs in five key areas: informational/educational, practical, physical, patient care and support and psychological (13). Moreover, there are difficulties with regards to accessing general health care in low and middle-incoming countries (defined using the World Bank definition)(8), where high treatment costs are an additional stressor in people with cirrhosis (9).

A supportive and palliative care approach could benefit people living with cirrhosis (14). ‘Supportive and palliative care’ are two broad encompassing terms which overlap with each other. Supportive care may be defined as care which meets the physical, informational, social, spiritual and practical needs of a person with chronic disease at all stages of the patients illness from pre-diagnosis, diagnosis, treatment and follow-up (13, 15). The WHO definition of palliative care is, interdisciplinary care to improve the quality of life of patients facing life threatening illness by addressing their physical, emotional and spiritual needs and by supporting their families (16). For the purposes of this review and to ensure consistency, the terms 'supportive and palliative care' will be used to incorporate these two related concepts together.

Initiating early supportive and palliative care can improve symptom control in people with cirrhosis (17, 18). Supportive and palliative interventions should seek to improve communication and care coordination whilst encouraging discussions on unmet information needs and end of life preferences (19). To achieve this, it is important to know what people with cirrhosis understand about the nature and prognosis of their disease, and to understand what unmet needs they may have as a result. As delivery of supportive and palliative care requires a multidisciplinary approach, it is key to explore how health professionals from different specialities feel they can work together to provide this care. Notably, whilst liver professionals acknowledge they have a role to play in this aspect of care (20, 21), it is important to understand how liver health professionals communicate with their patients and family members about the disease and its treatment.

Our review aims to systematically and critically reviewed the literature on supportive and palliative care in cirrhosis by exploring the evidence about: (1) patients' and family members' understanding of their disease; their perceived needs including their informational ones; and their communication with health professionals; (2) health professionals' perspectives on their communication with patients and family members about their disease and treatment; (3) health professionals' perspectives about the delivery of care to people with cirrhosis and how health professionals from different specialities can work together to improve supportive care.

METHOD

Search strategies

A literature search was conducted in three databases: Medline (1950- June 2017), Embase (1991-June 2017) and CINAHL (1982-June 2017). These searches were last conducted on 17th June 2017.

To identify articles for questions 1 and 2, the following search terms were used:
(communicat or understanding or need* or concern*) AND (cirrhosis or (advanced adj3 liver disease*) AND (perspectives or views or survey or interview*) AND (care or treatment* or disease or service*)*

To identify articles for question 3, the following search terms were used:
(health personnel or nurse or nursing staff or physician or doctor or health professional) AND (cirrhosis or (advanced liver disease) AND (perspectives or views or survey or interviews or concerns) AND (care or treatment or disease or service*)*

The inclusion criteria were research studies:

1) Reporting on the perspectives of patients or health professionals on liver cirrhosis or the provision of palliative care in cirrhosis.
2) Including adults (aged 18 years and above) with cirrhosis.

Articles in languages other than English were considered if the English translation of the abstract met the above inclusion criteria.

Study selection and data extraction

GR and KP independently assessed the citations against the inclusion criteria. For citations where there was a disagreement in eligibility, further assessment was conducted independently by JL and SD. A final consensus of eligible articles was obtained as part of a group discussion between GR, KP and JL. GR and KP read through the full text articles of all eligible articles and independently extracted the following data from the included studies where available: title, author(s), country of study, year of publication, study design, study setting; study population and participant demographics and baseline characteristics; themes/outcomes explored; key findings. GR and KP compared data extraction to obtain consensus. Any disagreements were resolved by JL. Final consensus for data extraction was obtained as part of group discussions between GR, KP and JL. As a final check, SD went through all citations and numbers to ensure accuracy.

Critical appraisal, analysis and presentation

Both qualitative and quantitative study quality was assessed independently by three members of the team (GR, KP, JL) using methodological quality criteria outlined in the Mixed Methods Appraisal Tool (MMAT) (22). This tool was selected because it was designed to be used in projects such as this that involve different study designs. The criteria used to assess methodical quality for each study is displayed in Supplementary Table 1. Using the tool after independent assessment, the three researchers mutually agreed a final quality scoring. In cases where disagreements existed, an experienced systematic reviewer (BC) reviewed the study to give a final assessment on its quality.

For qualitative studies, the key findings were summarised to reflect the different research questions. Quantitative accounts were analysed narratively. Key findings from each eligible study specifically answering any of the three research questions were extracted and imported into the relevant table. Qualitative and quantitative findings were grouped together according to their main themes relevant to this review.

Registration: This review has been registered with PROSPERO (registration number CRD42017064770) on 3rd May 2017.

RESULTS

The search strategy generated 1448 unique citations of which 19 articles met the inclusion criteria (Figure 1). There were 11 qualitative and eight quantitative studies. One study described itself as a mixed methods study, but used only a qualitative method in collecting the relevant patients and health professional data for this review. Most studies originated either from the United States (US) (6/19) or the United Kingdom (UK) (5/19). The remaining studies originated from the following countries: Denmark (2), Sweden (1), Switzerland (1) Germany (1), Australia (1), Iran (1) and Brazil (1).

Patient perspectives were described in 13 articles, three explored family members' perspectives and 8 examined health professionals' perspectives. Three studies presented data derived from both patients and health professionals, and one study presented data from both patients and family members.

Of the 11 qualitative articles, semi-structured interviews were used to collect the data in all studies except one where semi-structured interviews and focus groups were used. Most studies (7/11) used a qualitative descriptive approach in the analysis of their data. The remaining studies used the following analytical approaches: phenomenology/interpretative phenomenological approach (3) and grounded theory (1).

Of the eight quantitative studies, most used cross-sectional survey methods (7/8) in collecting their data. Using the MMAT classification, all were identified as quantitative descriptive prevalence studies without a comparison group.

Quality assessment

The MMAT quality assessment of the studies is shown in Table 1. The quality of the qualitative studies varied. In several studies, the selection of appropriate sources to address the research question were either not stated or were unclear. Most studies described the samples well, had good thematic description and robust analysis plans, and appropriately considered how the findings related to the context. In sampling their participants, five studies stated that they used purposive sampling, whilst two used convenience sampling. Of the four which did not state their sampling method, closer inspection of their recruitment procedure suggested that they used a convenience sample. Most studies did not include any appropriate consideration about how their findings related to researchers' bias. The discussion section of some of the studies were rather limited. In the quantitative studies a variance in quality was also identified. Most studies had a good sample strategy, the samples were representative of the population under study, and appropriate measurements were used. Five of the 8 studies had a response rate below 60%.

Study participants

Qualitative studies had a total sample of 78 patients with median sample size of 11 (range 6-15) and quantitative studies had a total sample of 1335 with median sample size of 238 (range

29-541) participants. Patients were mainly male (65%), with mean ages ranging from 46 to 61 years. The underlying aetiology of cirrhosis was most commonly alcohol related liver disease or hepatitis C. Five of the studies used the Model for End stage Liver Disease (MELD) (23) and/or Child Pugh scoring systems (24) to classify the severity of cirrhosis. The mean MELD score of participants was 13.65 (range 11-16.3) for the two studies using this scoring system, indicating that participants, provided they were not diagnosed with Hepatocellular Carcinoma, had a 6% chance of dying within the next 3 months. For the four studies using the Child Pugh system, most participants were classified as Child Pugh A or B, indicating that they either had well-compensated disease or had significant liver function compromise. Few studies provided details about ethnicity or education. Relatives or informal carers were included in three studies with a total of 31 participants and a median sample size of 11 (range 8-12).

The total sample size of health professionals for the qualitative studies was 88 with a median sample size of 22 (range 6-25) and for quantitative studies, the total sample size 645 participants, with a median sample of 77 (range 54-514). Nine studies (see Tables 4 and 5) included health professionals across a range of clinical specialties: these were mainly physicians and nurses from general practice, hepatology or specialist palliative care. Four studies provided details of level of clinical experience (3/4) and/or frequency with which clinicians treated patients with cirrhosis (2/4).

Principal Findings

Perspectives of people with cirrhosis (Table 2) and their family members (Table 3)

Understanding of disease and its associated treatments

Five qualitative (25-29) and two quantitative studies (30, 31) contributed to the theme of understanding of disease and its associated treatments. Some people with cirrhosis had accepted that their disease would lead to a shorter life expectancy (27), although evidence about what they understood about their illness was mixed. One study showed that patients could correctly answer questions concerning knowledge about, and treatments of, their disease. Most indicated that people lacked understanding of their disease or its prognosis; were unaware that their symptoms were related to their cirrhosis (25-27, 31); how their liver disease would progress (25); or why certain patients needed to be screened for hepatocellular carcinoma (31). Many patients did not consider their disease to be palliative in nature (28). Although patients understood that they may need to undergo complex procedures such as paracentesis (28), they were still unclear about the implications of many aspects of their care (28, 29).

Communication with health professionals

Six qualitative (25, 27-29, 32, 33) and two quantitative studies (34, 35) contributed to the theme of communication with health professionals. Although patients with cirrhosis were twice as likely to talk to their doctors about liver disease than those not diagnosed with cirrhosis (34), they were not satisfied with the quality of information provided by their health professionals. Patients felt that the explanations were too medicalised, and that more time was needed during their medical consultation for more effective information exchange (25). Patients with alcohol related cirrhosis wanted to communicate with their professionals about strategies to combat craving for alcohol as part of an attempt to maintain control of their lives (29). Family members reported that hepatologists found it easier to understand their situation and preferred to take their relatives to see these professionals, but reported difficulties in discussing issues related to overt hepatic encephalopathy (33).

Patients and their family members often felt stigmatized in their communications and interactions with health professionals (33), due to a perception that liver disease is associated with substance misuse (27, 28, 32, 35), particularly among those professionals who had limited experience of working with patients with cirrhosis (27, 35). Younger patients and those with Hepatitis C felt socially isolated (32), with increased anxiety and depression (35).

Patients' perceived needs:

Four qualitative (9, 27, 28, 32) and three quantitative studies (30, 35, 36) contributed to the theme of patients' perceived needs. Patients wanted to have better information about their cirrhosis and different aspects of care such as the admission process, the option of home-based care (9, 27) and about how to manage their symptoms (36). They also wanted information on a range of psychological and practical needs, such as stopping alcohol and substance misuse, developing cancer, losing the ability to do daily tasks, and fears about dying, the unknown and what the future holds (36). Some patients raised issues about the practical difficulties of living with semi-permanent abdominal drains (28). Many patients felt that their pain was undertreated (35).

Having clearer information about their next appointments and a better understanding of their disease may enable patients to plan their life better (27), encourage them to continue with their treatment (9) or reduce their level of anxiety (9). Relatives felt that better information would increase their ability to detect hepatic encephalopathy, which in turn would both reduce their own anxiety and give them greater control (32). These findings suggest that improving health professional - patient communication with the aim of increasing patient understanding of their disease, its treatments and its consequences, may improve patient and family carer outcomes. However, having improved knowledge about their disease or their medication may not improve a person's adherence to their medication regimen (30).

Health professionals' perspectives

Communication with patients with cirrhosis and family members about their disease and their treatment (Table 4)

Three qualitative (11, 25, 37) and three quantitative studies (20, 36, 38) contributed to the theme of health professionals' perspectives of their communication with patients and families about liver disease and its treatments. Health professionals were aware that both patients and family members had little understanding about their liver disease or its severity (11, 20) which if addressed, would greatly benefit patients (36). General Practitioners believed that patients with cirrhosis wanted to discuss hepatocellular carcinoma (HCC) screening, but many had difficulty in discussing this topic with them (38). There was recognition amongst health professionals, particularly General Practitioners (GP) that hepatologists, as the 'liver experts', were responsible for conversations about prognosis, disease progression and treatments (25, 37). However, liver clinicians lacked both confidence and skills to have these conversations, only addressing these issues near the ends of patients' lives (11, 25). The two main reasons identified were the unpredictable nature of liver disease, (which made it difficult to identify the point of deterioration and so allowed health care professionals to avoid discussing the topic) (11) and the negative perceptions that patients and family members had about palliative care (11).

Delivery of care and treatment to people with cirrhosis (Table 5)

Three qualitative (11, 37, 39) and three quantitative studies (20, 36, 40) contributed to the theme of health professionals' perspectives on delivery of care and treatment to people with cirrhosis. They identified that health professionals irrespective of speciality recognised that they provided suboptimal care for people with cirrhosis (20). Although gastroenterologists recognised both the importance and relevance of following guidelines for everyday practice, including the provision of dietary counselling by professional dieticians (40), liver clinicians generally did not address quality of life issues or palliative care options with patients or their family members, unless specifically raised by these groups (11). At the same time, liver clinicians recognised that poor disease and symptom management, and a lack of adequate information were considered major issues for patients (36), together with fears about losing functional ability, thoughts about dying, and uncertainty about their future (36).

Studies identified the delineation in the roles performed by primary care and liver specialists in caring for people with cirrhosis. Primary care providers, such as GPs, perceived that they lacked both the expertise and experience of caring for people with cirrhosis (37) and felt it more appropriate for these patients to be managed by liver specialists (20, 37). They saw liver clinicians as the experts in making major decisions about cirrhosis management (39), especially in managing end of life complications such as hepatic encephalopathy (37). GPs saw their role as care co-ordinators, providing their patients with advocacy, education and preventative advice, as well as setting expectations about the disease course and acting as gatekeepers to specialty liver services (39). They also found it difficult to care for this group of people, citing issues such as comorbid mental illness and/or substance misuse, perceived low motivation and poor adherence to treatment which acted as barriers to providing good quality care (37, 39).

How health professionals from different specialities can work together to improve supportive and palliative care (Table 5).

Two qualitative (11, 37) and one quantitative studies (20) contributed to this theme. Most GPs, liver and palliative care health professionals believed palliative care had a role in caring for people with cirrhosis, but recognised that the provision of palliative care to this group needed to be improved. All these professionals recognised that there was a lack of coordinated care for people with cirrhosis which was attributed to the different care approaches taken by the different specialities. For liver clinicians, factors such as the unpredictable trajectory of liver disease, management of patient treatment expectations, clinician/patient perceptions of the palliative care role, poor continuity of care and perceived lack of skill and confidence were identified as reasons for not referring to palliative care (11). Conversely, GPs felt that liver specialists were more focused on pursuing active treatment, which made it more difficult for them to discuss prognosis with their patients (37).

Each medical speciality differed in their opinions about how supportive and palliative care for people with cirrhosis could be improved. Both liver and palliative care clinicians felt that the integration of palliative care with liver services and multidisciplinary team working would enhance patient care (11). Palliative care clinicians also felt that it was important to prioritise improved liaison between secondary and primary care (20). All these professionals wanted to increase community provision of supportive and palliative care and to have a collaborative approach earlier in the illness trajectory (20). In adopting this approach, many GPs felt that they could manage their patients in the community (20).

Liver and palliative care clinicians, and GPs each had their own specific training needs in caring for people with cirrhosis at the end of life (20). For palliative care and GPs, more understanding was needed about the unpredictable trajectory of cirrhosis and the impact of impaired liver function on medication metabolism. Liver health professionals needed improved awareness of supportive care available to them and when to refer to palliative care whilst GPs need improved knowledge about how palliative care can provide support in the community (20, 37).

Discussion

This review explored: what patients and family members understood about cirrhosis and its treatment, their perceptions of unmet needs and the quality of communication between health professionals and patients/close family members. It also explored health professionals' perspectives about delivering care to people with cirrhosis. The following key themes were identified by patients, family members and health professionals: limited understanding of liver disease, unmet information needs, poor communication and a limited understanding of the palliative care role.

Strengths and Limitations of the review

This review is the first to critically examine studies exploring the experiences of people with cirrhosis and their family members, and the health professionals who provide care for them. In this review, nearly all the included studies were published after 2013, indicating that this is a relatively recent area of interest. Using the MMAT scoring rating, most studies were of fair to good quality (scoring between 50-75%).

Studies, whether qualitative or quantitative, were methodologically variable in quality. There was poor reporting on the key demographics of the different populations recruited in the studies. Few patient studies used any measure to classify the severity of cirrhosis, or to document the ethnicity or educational status of their patients. Health professional studies were limited in recording the professionals' experience in caring for liver patients. Therefore confidence in these findings should be limited because this variability cannot be accounted for.

The review was successful in identifying studies from nine countries across four continents, and incorporating a mix of different health care systems, but a limitation to the review is that the findings are based mainly on studies from the USA,the UK or other high-income Western countries. Although our findings are consistent across different health care systems found in Northern Europe and the USA, both which have different systems of charging for health care, only one study was identified from middle and low income countries in Central Asia, Central and Eastern Europe and Latin America, areas where cirrhosis is an endemic health problem (4). This limits the applicability of these findings to other settings as the perception, communication and access to health care may be very different between continents and countries.

Implications of the review

Our findings suggest several recommendations to improve practice in this area. Specifically, services for people with cirrhosis need to incorporate: 1) better patient-professional communication could be developed through the use of communication aides such as Question Prompt Lists (QPL); 2) the provision of written information by health professionals to meet the needs of both patients and their families; 3) awareness by health professionals of the broader needs of patients and their families beyond their medical treatment; 4) improving palliative care coordination between the different medical specialities in caring for people with cirrhosis and developing new models of palliative care provision. The following sections highlight possible ways in which these areas can be improved.

Patient-Professional communication and awareness of patient unmet informational needs disease

This review has identified communication difficulties between liver health professionals, patients and family members about liver disease and its prognosis, which were highlighted in many studies as a major area for improvement. One practical implication is the provision of written information by liver clinicians to patients and their family members to address their information needs concerning liver disease, its treatments and its impact. Providing liver clinicians with advanced communication skills training may tackle some of these issues, but simple alternative pragmatic methods requiring minimal training, such as the development of communication aides should also be considered. One such aide is the QPL, an evidence-based list of "recommended questions" given both to patients and family members prior to their consultation with health professionals (41). Although no QPLs have been developed specifically for people with cirrhosis, studies in other advanced diseases have shown that QPLs are effective at improving patient participation during the consultation and in stimulating discussions about prognosis in advanced cancer, and in helping patients to discuss difficult issues without interfering with the flow of the medical consultation. Finally, strategies need to be developed to reduce the perception of stigma felt by patients when talking to health professionals.

Improving supportive and palliative care in cirrhosis

This review identified two key areas where supportive and palliative care for patients with cirrhosis could be improved: 1) identifying appropriate patients for early supportive and palliative care; 2) reconfiguring service delivery and improving care coordination between the different specialities responsible for providing care to patients with cirrhosis. More specific initiatives include the need to design clearer pathways for interdisciplinary care for people with cirrhosis who are not for transplant and joint work by specialist hepatology and palliative care in drawing up guidelines and care frameworks for people with cirrhosis. In identifying which patients would be suitable for early palliative care referral, screening tools such as the Bristol Screening Tool (42) or the Specialist Palliative Care Indicator Tools(43) have now been developed for use in a clinical environment, and may help support health professionals to identify suitable patients. Improving care coordination was identified as an important element in improving early delivery of palliative care. Shared care models or joint multidisciplinary teams were suggested as ways to improve care coordination between liver, palliative care teams and GPs such as setting up combined hepatology/palliative care multidisciplinary teams, similar to those set up in heart failure (44).

Implications for Research

QPLs may be useful in improving communication between liver clinicians and patients and their family members. Future research should focus on developing and validating such a communication tool specifically for people with cirrhosis.

This review indicates potential mechanisms for developing shared care models and joint working between hepatology and palliative care. In addition, there are currently several examples in the UK of early palliative care interventions in people with cirrhosis in Basildon

(Essex) (45) and Edinburgh (18) which have illustrated potential improvement in patient outcomes, though findings are limited by a lack of baseline data. Future studies need to be more robust with the use of control groups, collection of baseline data and the identification of appropriate outcomes. Finally, further testing is required to see whether prognostic tools can reliably identify people with cirrhosis in the last year of their life.

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Figure 1: The review process

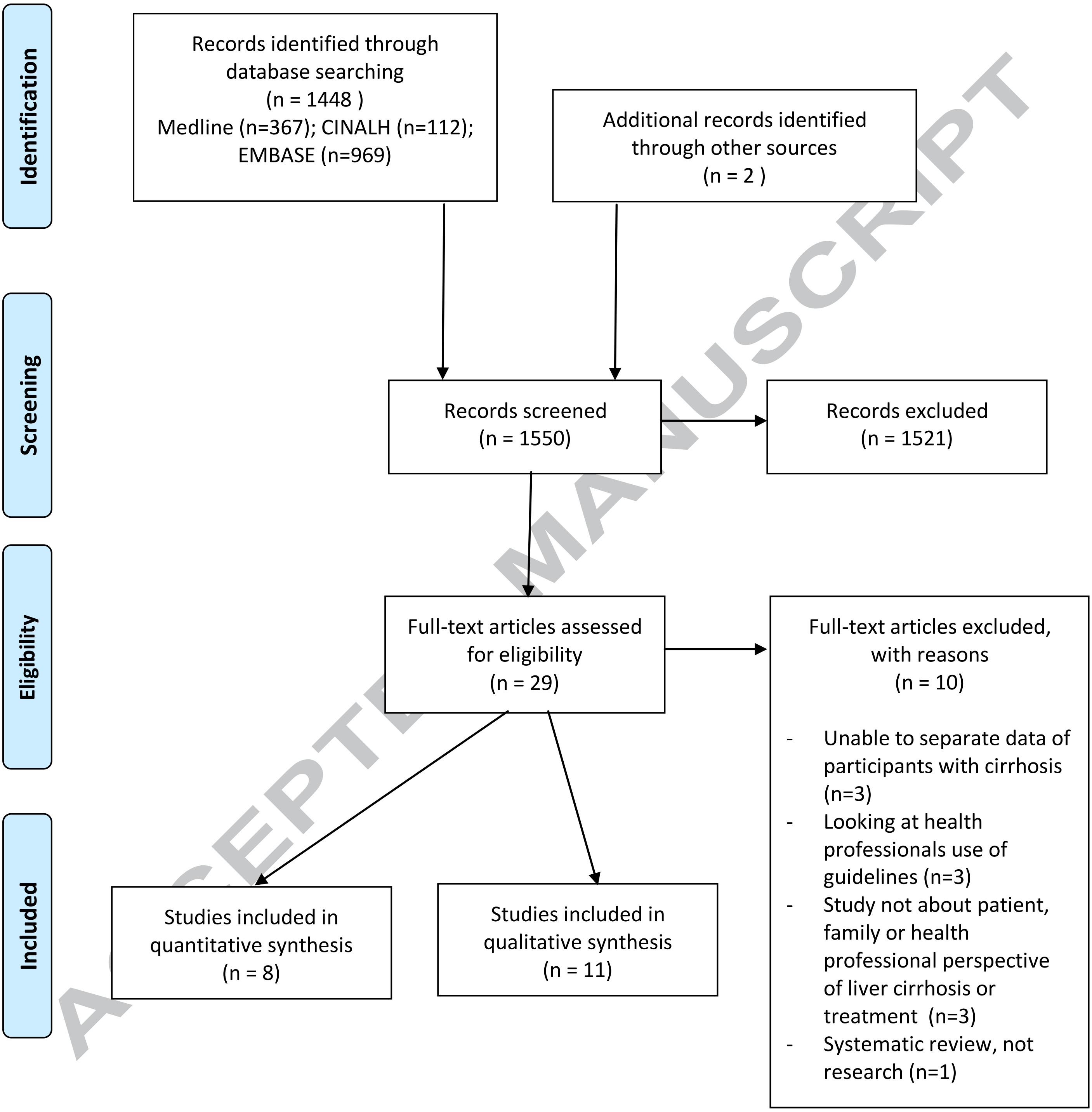


Table 1: Mixed Methods Appraisal Tools (MMAT) scoring ratings

Authors (Year), Country	1.1	1.2	1.3	1.4	4.1	4.2	4.3	4.4	Score (%)
QUESTION 1									
Qualitative – Patients									
Abdi et al (2015) Iran	N	Y	Y	N					50
Fagerstrom et al (2017) Sweden	Y	Y	Y	N					75
Kimbell et al (2015), UK, Edinburgh	Y	Y	Y	N					75
Grønkjær et al 2017 Denmark	Y	Y	Y	N					75
Day et al 2015, UK	N	Y	Y	N					50
Mikkelsen et al 2015, Denmark	N	Y	Y	Y					75
Rocha et al (2007) Brazil	N	N	N	N					0
Quantitative – Patients									
Valery et al (2017) Australia					Y	N	Y	Y	75
Li et al (2017) USA					Y	Y	Y	Y	100
Polis et al (2015) Australia					Y	Y	Y	N	75
Vaughn-Sandler et al 2014, USA					N	Y	Y	N	50
Farvardin et al (2017), USA					Y	Y	N	Y	75
Qualitative - Family members									
Kunzler-Heule et al (2016) Switzerland	N	Y	Y	N					50
Grønkjær et al 2017 Denmark	Y	Y	Y	N					75
QUESTION 2									
Qualitative									
Kimbell et al (2015)	U	Y	Y	N					50
Low et al (2017)	U	Y	Y	N					50
Quantitative									
Dalton-Fitzerald et al (2015)					Y	U	U	N	25
Low et al (2016)					Y	Y	Y	N	75
Valery et al (2017)					Y	U	U	Y	50
QUESTION 3									
Qualitative									
Beste et al (2015) USA	U	Y	Y	N					50
Low et al (2017) UK	U	Y	Y	N					50
Grønkjær et al (2017)	Y	Y	N	N					50
Standing et al (2017)	U	Y	Y	N					50
Quantitative									
Valery et al (2017) Australia					Y	U	U	Y	50

Gundling et al (2017) Germany	Y	N	Y	N	50
Low et al (2016) UK	Y	Y	Y	N	75

Table 5: Health professionals' perspectives about how they deliver care and treatment to people with liver cirrhosis and how health professionals from different specialities can work together in improving supportive care

Authors (Year), Country	**Number healthcare professionals in study / Total sample in study**	**Site of Participants recruitment**	**Demographic details 1) Mean Age (y); 2) Male (%); 3) professional designation (%); 4) Experience in liver care; 5) Number of patients with cirrhosis seen**	**Study design** **Data collection method** **Sampling**	**Aims**	**Main Findings**
Qualitative						
Beste et al (2015)[39], USA	24/24	7 Veterans Affairs facilities; 3 medical centres and 4 community-based outpatient clinics in 4 US states.	1) 51.7; 2) 35; 3) 6 doctors (25), nurse practitioners (54), physician assistant (4), unspecified (17); 4) mean years in practice 19.1.; 5) 79% see ≥ 1 patient with cirrhosis / month.	Qualitative descriptive Structured interview Purposive	To explore primary care practitioners' attitudes and self-reported roles in caring for patients with cirrhosis.	• PCP providers preferred liver specialists to make major decisions about cirrhosis management. • PCP saw their main roles as supporting patients in self-management, acting as care co-ordinators, advocates, setting expectations about disease trajectory, giving preventative advice and acting as gatekeepers to specialty liver services. • Low motivation and adherence, comorbid mental illness, substance misuse and a negative stereotype were identified as barriers to providing care.
Grønkjær et al (2017)[32], Denmark	6/22 (8 patients, 8 relatives)	One hepatology and gastroenterology department at a large university hospital.	1) 32; 2) 0; 3) nurses (100); 4) mean 6 years; 5) not reported.	Qualitative description Semi-structured interview Convenience	To describe nurses' perspectives of the challenges related to caring for patients with HE	• Nurses reported caring for patients with HE was difficult and challenging. They felt unable to provide the best care and sometimes compromised care delivery to protect themselves.
Low et al (2017)[11] UK	22/52 (22 healthcare professionals,	A tertiary referral liver transplant centre in	1-2) not reported; 3) doctors (35), nurses - ward,	Mixed methods health professional	To explore how healthcare in liver services is provided	• Liver clinicians did not address quality of life issues and palliative care options unless raised by the patient.

Table 5: Health professionals' perspectives about how they deliver care and treatment to people with liver cirrhosis and how health professionals from different specialities can work together in improving supportive care

	30 patients)	southern England.	transplant, senior hepatology, alcohol liaison (45), dietician (5), pharmacist (5), healthcare assistant (5), SPC nurse (5); 4-5) not reported	arm – Qualitative description. Focus groups (n=13) and semi-structured interviews (n=9) Convenience	in the last year of life to people with advanced liver disease, to identify limitations, challenges and improvements in provision of palliative care for liver patients.	• Patient treatment expectations, clinician/patient perceptions of palliative care, poor continuity of care and perceived lack of skill and confidence identified as reasons for not referring to palliative care. Integration of specialty services and multidisciplinary team working would enhance patient care.
Standing et al (2017)[37] UK	25/25	GP surgeries in London, Thames Valley, Wessex, Yorkshire and North East of England.	1) not reported 2) 48%; 3) GPs, 4/25 specialist gastroenterology or hepatology experience; 4-5) not reported	Qualitative description Semi structured interview Purposive	To explore GPs experiences and perceptions of how primary care can enhance end of life care for patients with liver disease.	• GPs wanted more involvement in end of life care for this patient group, but had limited experience in caring for this group. • GPs experienced tension between wanting to provide palliative care for patients, and the active treatment approach adopted by liver hospital-led care. • Need for collaborative care pathways to support GPs and patients in the community. • GP recognised challenges of providing complex social support for patient and family in addition to managing complex symptoms.
Quantitative						
Gundling et al (2009)[40], Germany	239/239	Members of the Bavarian Society of Gastroenterology.	1-5) not reported	Quantitative description Cross sectional survey Convenience	To investigate dietary recommendations of patients with liver cirrhosis.	• 92% believed evidence based guidelines are important and 84% felt this was realisable in everyday practice. • 85% responded that careful dietary counselling by professional dieticians is important.

Table 5: Health professionals' perspectives about how they deliver care and treatment to people with liver cirrhosis and how health professionals from different specialities can work together in improving supportive care

Low et al (2015)[20] UK	514/514	Members of UK specialist groups in liver, specialist palliative care and general practice	1, 2, 4, 5) not reported, 3) liver professionals (38), SPC professionals (53) and GPs (9)	Quantitative description cross sectional survey Convenience	To determine the knowledge and practice of a UK cohort of relevant healthcare professionals in cirrhosis	• Patients with cirrhosis and end of life care needs could be managed in the community with good support from community or local SPC teams. • More understanding about the unpredictable trajectory of cirrhosis and the impact of impaired liver function on medication metabolism is needed. • All HP groups wanted to increase community provision of palliative care and a collaborative approach earlier in the illness trajectory.
Valery et al (2017)[36] Australia	50/104. (54 health professionals, 50 patients with cirrhosis)	A tertiary hospital hepatology health care facility in Queensland, Australia.	1) 54% 25-44, 9% <25, 37% >44; 2) 26; 3) doctors (28), nurses (56), administrative support (4), dieticians (4), social worker (2), pharmacists (7); 4) <1 year (15), 1-5 years (41), >5 years (44); 5) 63% daily contact, 23% weekly contact	Quantitative description Cross-sectional survey Convenience	To describe health professionals' perspectives of patients' concerns.	• Most HP felt that patients would benefit from alcohol/drug abstinence support (94%), a dedicated care co-ordinator to address frequent hospital visits and admissions (93%), and from palliative care and end-of-life planning (91%). • Most felt support services should be free and easily accessible by patients and their families.

Hepatic encephalopathy (HE), General Practitioner (GP), Primary care providers (PCP), specialist palliative care (SPC), Health professionals (HP)

Table 4: Health professionals' perspectives in how they communicate with patients and family members about their disease and their treatment.

Authors (Year), Country	**No healthcare professionals in study / Total sample in study**	**Site of Participants recruitment**	**Health Professionals Group Demographic details 1) Mean Age (years); 2) Male (%); 3) professional designation (%); 4) Experience in liver care (years); 5) Number of patients with cirrhosis seen**	**Study design** **Data collection methods** **Sampling**	**Key aims of study**	**Main Findings**
Qualitative						
Kimbell et al (2015)[25], UK	11/37 (15 patients, 11 informal carers)	Health professionals nominated by patients came from primary and secondary care, South East Scotland.	1-2) not reported; 3) GPs (73), consultant hepatologist (9), nurse - hospital-based liaison (9), community palliative care (9); 4-5) not reported	Qualitative Description Semi-structured interviews (longitudinal serial interviews) Purposive.	To understand how health professionals experience the needs and priorities of patients with cirrhosis	• GPs lacked expertise and confidence to discuss prognosis and disease progression, and felt it should be done by liver specialists. • Liver specialists addressed end of life issues with patients at the terminal phase, when these conversations could be difficult to conduct.
Low et al (2017)[11], UK	22/52 (30 patient case notes) Focus groups (n=13) and semi-structured interviews (n=9)	A tertiary referral liver transplant centre in southern England.	1-2) not reported; 3) doctors (35), nurses (ward transplant, senior hepatology, alcohol liaison) (45), dietician (5), pharmacist (5), HCA (5), SPC nurse (5); 4-5) not reported	Health professional arm Qualitative description Semi structured interviews Convenience	To understand the challenges in palliative care provision in liver care and identify how this can be improved.	• Unpredictable trajectory made it difficult to identify when to discuss palliative care. • Palliative care was perceived negatively by patients and families. • Patients had unrealistic expectations and limited understanding of their disease, but professionals lacked the skills and confidence to initiate discussions about future care.
Quantitative						
Dalton-Fitzgerald et al (2014)[38],	77/77	Network of 12 primary care clinics, Texas, USA	1) 10% <35 y, 60% 35-50 y, 30% > 50 y; 2) 44; 3) Doctors	Quantitative Description	To explore factors associated with adherence to	• 56% of participants experienced difficulty with communicating effectively with patients about HCC

Table 4: Health professionals' perspectives in how they communicate with patients and family members about their disease and their treatment.

USA			(100); 4) Clinical Work Experience: 10% <10 y, 61% 11-25 years, 29% > 25 y; 5) not reported	Cross-sectional survey. Purposive	guidelines for HCC surveillance by primary care providers.	surveillance. • Two-thirds (66%) believed patients with cirrhosis wanted to discuss HCC.
Low et al (2015)[20], UK	514/514	Mailing list of relevant UK special interest groups in liver, specialist palliative care and general practice.	1-2) not reported; 3) liver professionals (38), SPC professionals (53) and GPs (9); 4-5) not reported	Quantitative Description Cross-sectional survey. Convenience	To determine the knowledge and practice of a UK cohort of relevant healthcare professionals about delivering palliative care in cirrhosis.	• Liver professionals recognised that patients and relatives had little understanding about the disease or its severity, but lacked the confidence and communication skills to have honest discussions about these issues. • Information sharing about the disease, its trajectory and symptoms could open discussion about future care, preferred place of care and treatment choices.
Valery et al (2017)[36], Australia	54/107 (53 patients)	A hepatology and transplant service in a tertiary healthcare facility, Queensland.	1) range 25-44 years; 2) 26; 3) doctors (28), nurses (56), administrative support personnel (4), dieticians (4), social worker (2), pharmacists (7); 4) 7% < 1 y, 30% 1-5 y, 63% >5 y; 5) 63% daily contact, 23% weekly contact	Quantitative description Cross-sectional survey Convenience	To describe health professionals' perspectives of patients with cirrhosis concerns about their unmet supportive needs.	• 41% professionals reported information/knowledge as an unmet need for patients. • Professionals felt patients would benefit from information services providing information pamphlets, educational services and low salt recipes.

Hepatocellular carcinoma (HCC), Specialist Palliative Care (SPC), General Practitioner (GP), Healthcare Assistant (HCA),

Table 3: Close family members' understanding of the patients' disease, their own perceived needs and their communication with health professionals

Authors (Year), Country	**No in study with cirrhosis / Total sample in study**	**Source of Participant recruitment**	**close family members Demographic details 1) Mean Age (y); 2) Female (%); 3) White (%); 4) Relationship status with patient (%); 5) University education (%); 6) Years of caring (y)**	**Study design Data collection Sampling**	**Study aims**	**Key findings**
Qualitative						
Kimbell et al (2015)[25] UK	11/47 (25 patients, 11 lay carers, 11 health professionals)	Lay carers identified by participating patients	1– 7) not reported	Qualitative description Semi structured interviews	To explore lay carers' experience of liver disease, and their unmet needs.	• Lay carers were unaware of the types of support available to them.
Kunzler-Heule et al (2016)[33] Switzerland	12/12 - 12 informal carers	Informal caregivers of relatives with liver cirrhosis and overt encephalopathy	1) 50; 2) 67; 3) not reported; 4) spouse/partner (50), daughter/son (33), brother (8.5), sister-in-law (8.5); 5) not reported; 6) mean patient years of illness = 11	Qualitative phenomenology (Interpretative Phenomenological Analysis) Semi-structured interviews Convenience	To explore the experiences of an informal caregiver for a relative with liver cirrhosis and overt HE	• Overt HE increased responsibility in all aspects of carers' daily life, leading to a feeling of being tied down. • Carers experienced difficulties communicating with professionals about overt HE due to difficulty in describing their observations and feeling stigmatised. • Carers preferred bringing relatives to empathetic professionals. They felt hepatologists found it easier to understand their situation.
Grønkjær et al (2017)[32] Denmark	8/22 (8 patients, 8 relatives and 6 nurses)	Relatives of patients recruited to the study	1) 46; 2) 62; 3) not reported; 4) son/daughter (50), spouse/ex-spouse (37.5), sister (12.5); 5&6) not reported	Qualitative description Semi structured interviews	To explore how close relatives experience having a relative with overt HE.	• Relatives wanted more information about HE and its symptoms to increase their ability to detect HE, reduce their anxiety and give them greater control. • Relatives felt stressed being responsible for practical activities for the patients and monitoring the patients' treatment. • Nurses provided practical and psychological support, and a network to

Table 3: Close family members’ understanding of the patients’ disease, their own perceived needs and their communication with health professionals

						discuss issues which was important for relatives.

Key: Hepatic encephalopathy (HE)

Table 2: Patients' understanding of their disease, their perceived needs and their communication with health professionals.

Authors (Year), Country	**No in study with cirrhosis / Total sample in study**	**Site of Participant recruitment**	**Patient group Demographic details 1) Mean Age (y); 2) Male (%); 3) type of cirrhosis (%); 4) severity of cirrhosis; 5) White (%); 6) Living Alone (%); 7) University education (%)**	**Study design** **Data collection methods** **Sampling**	**Study aims**	**Key Findings**
Qualitative						
Abdi et al (2015)[9] Iran	10/10	Not stated	1) 39-54 (range); 2) 70; 3-7) not reported	Qualitative phenomenology Semi-structured interviews Convenience	To explore individuals' experiences of liver cirrhosis	• Patients wanted better information about cirrhosis, the admission process and home-based care, to cope better with their illness and reduce anxiety. • Effective interaction and trust with their treatment team, encouraged patients to continue treatment and reduced their stress.
Day et al (2015)[28], UK	6/6	Patients with ascites attending hospital for large volume paracentesis	1-7) not reported	Qualitative phenomenology semi structured interviews Convenience	To explore the experience of patients with non-malignant ascites, its management and services available.	• Patients understood the need to undergo paracentesis, but questioned the benefit of diuretic medication due to its impact on renal function. • Patients did not consider their disease to be palliative. • Patients highlighted the practical difficulties of living with semi-permanent drains. • Some patients felt stigmatised as being an 'alcoholic'.
Fagerstrom et al[27] (2017) Sweden	13/13	A gastroenterology clinic in a	1) 46-75 (range); 2) 45; 3) ARLD (38), AIH (23), NASH (8),	Qualitative description	To explore the life situation and self-care of patients	• Patients did not understand their diagnosis of liver cirrhosis and its consequences, as different terms were used for these.

Table 2: Patients' understanding of their disease, their perceived needs and their communication with health professionals.

		university hospital	Haemochromitosis (8), HCV (8), unknown (16); 4 &5) not reported 6) 45; 7) not reported	Semi-structured interviews Convenience	with liver cirrhosis and complications	• Patients accepted the consequences of their disease was a shortened life and lifelong medical treatment. • Patients wanted to know more about liver cirrhosis, its complications, treatment and prognosis. They had little information about this, limiting their ability to plan for the future. • Patients needed a professional contact when experiencing decreased well-being. • Patients felt stigmatised by professionals with limited experience of caring for people with cirrhosis.
Grønkjær et al 2017[32] Denmark	8/22 (8 patients, 8 relatives and 6 nurses)	Department of hepatology and gastroenterology of a university hospital	1) 61; 2) 38; 3) ARLD (50), cryptogenic (25), AIH (25); 4) mean Childs-Pugh score 7; 5-7) not reported	Qualitative description Semi structured interviews Convenience	To explore how patients with cirrhosis experience overt hepatic encephalopathy (HE)	• During HE episodes, patients experienced: a) loss of communication, cognitive and physical skills, and decreased ability to perform basic activities, increasing their dependency on relatives and nurses; b) increased social isolation and unwillingness to discuss their illness for fear of stigmatisation .
Kimbell et al (2015)[25], UK	15/37 11 lay carers 11 professionals	In-patient liver clinic in a tertiary unit, Scotland	1) 58.8; 2) 47; 3) ARLD (40), ARLD/HCV (13), NAFLD (20), HCC/NAFLH (7), ARLD/NAFLD (7), HCC (7), AIH (7), cryptogenic liver disease (7); 4) mean MELD 16.3; 5-7) not reported	Qualitative description Semi-structured longitudinal serial interviews Purposive	- To understand the experiences and support needs of people with advanced liver disease. - To explore the adequacy of services and support provided.	• Patients felt appointment times were too short for effective information exchange. • Patients had poor understanding of their disease and felt explanations were too medicalised. • Patients were poorly informed about how their illness would progress or which physical symptoms were attributed to their liver disease. • Patients were unsure of the support available to them.
Mikkelsen et al 2015[29], Denmark	11/11	An urban and a provisional cirrhosis clinic attached to university	1) 58; 2) 82; 3) ARLD (100), 4-5) not reported; 6) 73; 7) not reported	Qualitative grounded theory Semi-	To describe conditions limiting or supporting patient after HE, ability to cope with	• Patients needed supportive acknowledgement from professionals and relatives to help them maintain control and feel secure. • Patients felt some responsibility to their professionals, because of the time they spent in caring for them.

Table 2: Patients' understanding of their disease, their perceived needs and their communication with health professionals.

		hospital gastroenterology department		structured interviews Purposive	current physical and psychosocial problems. To provide knowledge about the framework for potential interventions.	- Patients consulted professionals for support with physical health problems. - Patients communicate with professionals on ways of combatting craving for alcohol as an attempt to maintain control of their lives.
Rocha et al (2007)[26] Brazil	15/15	A single tertiary liver unit	1) not reported; 2) 100; 3) ARLD (100); 4-6) not reported; 7) 13.	Qualitative description Semi structured interviews Convenience	To understand the social representation of those with alcohol-related liver cirrhosis	- Patients had limited understanding of their liver disease and confused cirrhosis-related symptoms with other illnesses.
Quantitative						
Farvardin et al (2017)[31], USA	541/541	Patients attending clinic based in a teaching hospital	1) 56; 2) 56.4; 3) HCV (50.7), ALD (26), NASH /cryptogenic (10.2) other (13.1); 4) Child Pugh A - 48.7%, Child-Pugh B - 36.5%, Child-Pugh C -14.8%; 5) 27.4; 6) 23; 7) 5.5.	Quantitative description Cross-sectional survey	To characterise patient knowledge, attitudes, barriers and demographic factors associated with HCC surveillance	- Patients worried about developing HCC in their lifetime and dying from it. - Most patients were aware that patients with cirrhosis are at greater risk for HCC. - Patients lacked knowledge about HCC surveillance, with many believing that surveillance was not required if they ate a healthy diet, had no abdominal pain or if their physical exam was normal.
Li et al (2017)[34] USA	327/467	A single tertiary liver unit	1-2) not specifically reported; 3) ARLD n=88; other aetiologies not specified; 4-7) not reported.	Quantitative description Cross-sectional survey	To determine patients' awareness of HCC screening and explore doctor-patient communication	- Patients with cirrhosis were more likely to receive consistent liver imaging when they were aware of HCC screening, and when their doctor talked to them about liver cancer. - Patients with cirrhosis were twice as likely to talk to their doctors about liver disease.

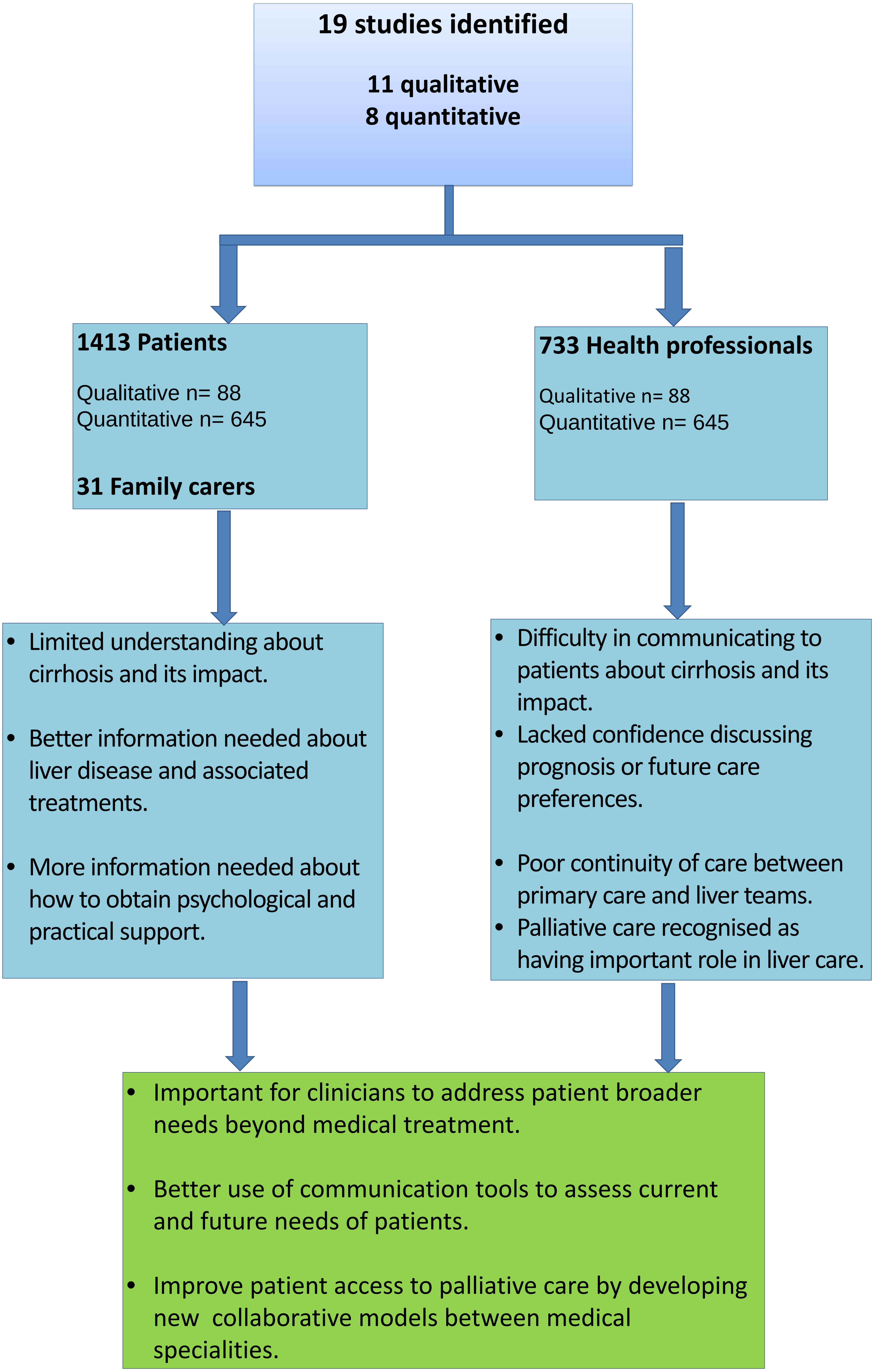
Table 2: Patients' understanding of their disease, their perceived needs and their communication with health professionals.

				Convenience	regarding HCC.	
Polis et al (2015)[30] Australia	29/29	A single tertiary liver unit	1) 57 (median); 2) 83; 3) ARLD (45), HCV (24), combined HCV and alcohol (14) and NASH (7); 4) Mean Child Pugh 7.3; mean MELD 11; 5-7) not reported	Quantitative description Prospective Cross-sectional survey Convenience	To determine adherence patterns, and to identify which factors contribute to nonadherence in patients with liver cirrhosis	• 62% answered >75% of questions on knowledge of their disease and treatments correctly. • No significant correlation between medication adherence and knowledge of disease and treatment, or beliefs about effectiveness of medication.
Valery et al (2017)[36] Australia	50/104. (50 patients, 54 health professionals)	Outpatient clinic at a single tertiary liver unit	1) 58; 2) 78; 3) HCV (52), NAFLD (22) and ARLD (18), 14% had alcohol as a co-factor. 60% compensated cirrhosis; 4) not reported; 5) 86; 6) not reported 7) 74%	Quantitative description Cross-sectional Convenience	To describe the main concerns and unmet supportive care needs of people with cirrhosis, and their use of supportive services	• Common patient concerns were symptom management (34%), emotional issues (28%), disease management (20%) and stopping alcohol/substance abuse (12%). • The most prioritised concerns were: developing cancer (79%), losing ability to do daily tasks (76%), fear of dying (64%) and fear of the unknown (64%).
Vaughn-Sandler et al (2014)[35] USA	149/149	Participants enrolled in a 'Cirrhosis Program' at a liver centre based in a teaching hospital	1) 49; 2) 49; 3) 12.1 % ALD (12.1), HCV/HBV (34.2), NAFLD (28.2), other (25.5); 4) 58% Child Pugh A, 36%, Child Pugh class B; 5) 92; 6-7) not reported	Quantitative description Cross-sectional survey Purposive	To quantify the presence of stigma among patients with cirrhosis, and its association with social support, QOL, and interaction with healthcare	• Most patients felt stigmatized with at least one aspect of their life. Younger patients and those with HCV felt more stigmatized. • Patients with high level of perceived stigma had less social support, were less likely to seek medical care, and had worse QOL and depression. • Patients felt that many doctors or nurses did not like to treat people with liver disease. Pain was undertreated.

Alcohol related liver disease (ARLD), Autoimmune hepatitis (AIH), Non-alcoholic steatohepatitis (NASH), Hepatitis C (HCV), Non-alcoholic fatty liver disease (NAFLD), Hepatocellular carcinoma (HCC), Model for End-stage Liver Disease (MELD), Hepatitis B (HBV), Quality of Life (QOL).

Supportive and palliative care in cirrhosis

Supportive and palliative care in people with liver cirrhosis: international systematic review of the perspective of patients, family members and health professionals



19 studies identified

11 qualitative
8 quantitative

Participants

1413 Patients

Qualitative n= 88
Quantitative n= 645

31 Family carers

733 Health professionals

Qualitative n= 88
Quantitative n= 645

Key findings

- Limited understanding about cirrhosis and its impact.
- Better information needed about liver disease and associated treatments.
- More information needed about how to obtain psychological and practical support.

- Difficulty in communicating to patients about cirrhosis and its impact.
- Lacked confidence discussing prognosis or future care preferences.
- Poor continuity of care between primary care and liver teams.
- Palliative care recognised as having important role in liver care.

Conclusions

- Important for clinicians to address patient broader needs beyond medical treatment.
- Better use of communication tools to assess current and future needs of patients.
- Improve patient access to palliative care by developing new collaborative models between medical specialities.