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Systematic review: unmet supportive care needs in people diagnosed with chronic liver disease

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Abstract

Objective People with chronic liver disease, particularly those with decompensated cirrhosis, experience several potentially debilitating complications that can have a significant impact on activities of daily living and quality of life. These impairments combined with the associated complex treatment means that they are faced with specific and high levels of supportive care needs. We aimed to review reported perspectives, experiences, and concerns of people with chronic liver disease worldwide. This information is necessary to guide development of policies around supportive needs screening tools and to enable prioritisation of support services for these patients.

Design Systematic searches of PubMed, MEDLINE, CINAHL, and PsycINFO. Data were extracted using standardized forms. A qualitative, descriptive approach was utilised to analyse and synthesize data.

Results The initial search yielded 2598 reports: 26 studies reporting supportive care needs among patients with chronic liver disease were included, but few of them were *patient-reported* needs, none used a validated liver disease-specific supportive care need assessment instrument, and only three included patients with cirrhosis. Five key domains of supportive care needs were identified: informational or educational, practical, physical, patient care and support, and psychological.

Conclusions Whilst several key domains of supportive care needs were identified, most studies included hepatitis patients. There is a paucity of literature describing the supportive care needs of the chronic liver disease population likely to have the most needs – namely those with cirrhosis. Assessing the supportive care needs of people with chronic liver disease have potential utility in clinical practice for facilitating timely referrals to support services.

Strengths and limitations of this study

- This systematic review comprehensively summarises reported perspectives, experiences, and concerns of people who have been diagnosed with CLD worldwide.
- The data presented highlight the shortage of information regarding unmet needs of chronic liver disease patients.
- Whilst several key domains of supportive care needs were identified, most studies included hepatitis patients, few of them reported *patient* needs, and none used a validated, liver disease-specific supportive care needs assessment instrument. There is a paucity of literature describing the supportive care needs of the chronic liver disease population likely to have the most needs – namely those with cirrhosis.
- Assessing the supportive care needs of people with chronic liver disease have potential utility in clinical practice for facilitating timely referrals to support services.

Introduction

Chronic liver disease (CLD) is a major global cause of morbidity and mortality. The prevalence of CLD differs between countries, affecting approximately 300 million people in China,[1] 29 million in the European Union[2] and more than 8 million cases in Australia.[3] The leading causes of CLD are viral hepatitis B (HBV) and C (HCV), harmful alcohol consumption and metabolic fatty liver disease associated with obesity and type 2 diabetes.[1-7] Regardless of aetiology, most of the morbidity and mortality from CLD occurs among individuals with cirrhosis, who are at risk of developing complications including ascites, hepatic encephalopathy, variceal haemorrhage and liver cancer. Liver disease is the fifth greatest cause of death in the UK, where the average age of death from liver disease is 59 years, with large impacts on loss of Quality Adjusted Life years (QALYs).[8] The number of individuals with advanced liver disease, liver related deaths and health care costs are predicted to increase over the next decade.[9-11] Despite these alarming predictions, there is inadequate awareness of the disease among the general public and health professionals, and many health care systems lack regional or national strategies to address or prevent the increasing burden from complicated CLD.[3,8]

People with cirrhosis must follow a complex and variable regimen of dietary restrictions, medications, laboratory testing, and clinic visits. In addition, patients with decompensated cirrhosis frequently suffer debilitating complications that impact on an individual's quality of life and activities of daily living. These impairments combined with the complex management of advanced liver disease are likely to mean that patients are faced with specific and high levels of supportive care needs.[12] In contrast to other advanced end-organ disease such as heart failure or chronic obstructive pulmonary disease, the potential of devolved models of supportive care in the community or home for CLD patients is yet to be established. Because hospital care traditionally focuses on medical management of the major complications of portal hypertension such as ascites and variceal bleeding it is likely that many patients' supportive care needs remain unmet.

The term supportive care needs encompasses the physical, informational, emotional, practical, social, and spiritual needs of an individual with chronic disease.[13] Health needs assessment instruments are increasingly being developed to evaluate specific areas and magnitude of need as a means of improving provision of patient care and outcomes, particularly in the arena of chronic diseases such as cancer and cardiac failure.[14-18] Advances in medical care have resulted in people with CLD living longer, through better management of disease complications.[19] An imperative

exists for a valid and reliable measure that can provide an accurate supportive care needs assessment for people with CLD.

This systematic review addresses the following questions: (i) What are the supportive care needs of people who have been diagnosed with CLD? (ii) What are the domains and specific items of need most frequently reported as unmet by CLD patients, and what is the extent of these needs? and (iii) What are the measures for assessment of unmet supportive care needs of people who have been diagnosed with CLD available in the literature? This information is necessary to guide development of policies around supportive needs screening tools and to enable prioritisation of support services for patients with CLD.

Methods

A systematic review was undertaken to review and synthesize studies investigating the supportive care needs of people diagnosed with CLD. One author (PV) searched online peer-reviewed journal articles indexed in PubMed, MEDLINE, CINAHL, and PsycINFO from the earliest records until 19 September 2014. Titles and abstracts were searched for possible combinations of the terms including chronic liver disease, or chronic hepatitis, hepatitis, non-alcoholic fatty liver disease, or NAFLD, or cirrhosis, alcoholic liver disease, and unmet need, or support needs, or supportive care needs, or perceived needs, or supportive care, or needs assessment. The search was complemented by manually reviewing the references of retrieved articles for other articles of potential relevance to the research aims.

Two investigators (PV and JM) independently reviewed all titles; those judged to be potentially helpful were examined. The following selection criteria were then applied: availability of an abstract; use of primary data; published in English, Spanish, or Portuguese; reporting patients' views, perspectives, experiences, concerns; patients were adults or children; and, if reporting on patients with cystic fibrosis, the article had to focus primarily on liver disease. We excluded reviews and editorials and reports for hepatitis A, liver transplant, hepatocellular carcinoma, and studies among people with cystic fibrosis that primarily examined respiratory or pancreatic disease. In particular, hepatocellular carcinoma was excluded as a diagnosis of cancer engenders specific supportive care needs around the cancer treatments and side effects. We also excluded papers where patient reported supportive care needs (as opposed to doctor or carer reported patient needs) were not investigated and those solely focusing on quality of life (QoL).

As seen in other disease settings (e.g. cancer), although QoL measures provide important insights into the problems experienced by patients, they do not reveal what patients ideally want from the health care system or the extent to which their needs are being satisfied.[20] Furthermore, they fail to link patient's experience directly with their service desires.

Abstracts with relevant content were selected for full manuscript review. PV and JM independently reviewed manuscripts; two other investigators (EP and NM) were available to adjudicate disagreements. Data were extracted using standardized data collection forms (record number, title, year of publication, and abstract). Information was collated (PV) and data discussed amongst investigators. A qualitative, descriptive approach was utilised to analyse and synthesize data.

Results

The initial search yielded 2598 reports: 17 were relevant for our overview, 9 additional studies were found after reviewing the reference lists of relevant articles (Figure 1; Tables 1 and 2), with a total of 26 articles included in the review. Most studies included patients with hepatitis C (n=19), three included patients with cirrhosis, two with hepatitis B or C, and two included patients with hepatitis or chronic liver disease. Fourteen studies used quantitative methodology (Table 1), 12 were cross-sectional, one was longitudinal and one was a quasi-experimental study. Sample size varied between studies with a range from 36 to 462 patients. Twelve studies (sample size range 5 to 70 patients) used qualitative methodology (Table 2) to describe patients' experiences, concerns, supportive care needs, perspectives of care, and information and knowledge about their disease. Four used focus groups to collect data, seven used semi-structured or unstructured/in-depth interviews, and one used both focus groups and individual in-depth interviews. Many of the qualitative studies began the interview with an open-ended general question about the patients experience with their disease, followed up by questions or prompts addressing specific areas or topics of interest (e.g. stigma, treatment).[21-25]

Of the fourteen quantitative studies, five used a supportive care needs assessment tool to collect the data.[26-29] Balfour et al used the Hepatitis C Needs Assessment Scale (HCNAS), an 11-item self-reported tool developed for their study.[26] For the HCNAS, patients were asked to rank the importance of their health care needs on a 5-point scale. Zandi et al used a needs assessment tool that consisted of a list of 20 questions related to common symptoms and

management (e.g. fatigue, itching, dry mouth, muscular cramps, dietary regimen).[29] Chang et al used the Inventory of Socially Supportive Behaviours (ISSB),[30] a 15-item questionnaire that asks patients to rate on a 4-point scale four types of support: emotional, appraisal, informational and tangible.[27] Jennings et al used a survey consisting of 13 questions including items on the educational needs of HCV patients (educational delivery methods, interest in support groups, topics of interest related to HCV and preferred services relating to HCV).[28] Of the abovementioned needs assessment tools, only the ISSB has been validated and shown to have adequate test-retest and internal consistency, although it is not a disease specific (liver disease) needs assessment tool.[30,31] There was no evidence on literature review of further validation of any of the other needs assessment instruments. Grogan *et al* used a validated survey tool (a 59-item questionnaire designed for the study) to collect data on informational and psychological support, however the questionnaire was designed to explore patients' level of satisfaction with support from the nurse specialist.[32] Minuk et al and Alizadeh et al's approach for data collection was the use of an open-ended question to elicit the patient's principal concern about their disease ('volunteered concern'), then patients were asked to rank a list of seven[33] or eight[34] other potential concerns. The other six studies included a mix of questions in their data collection tool, including some specific items on support needs, information needs or ability of patients to perform daily living tasks. Four studies also included questions about QoL.[27,29,35,36]

Overall, information or education needs were reported by eleven[22-24,26,28,37-42] out of 26 studies. Of the five reports using a supportive care needs assessment tool to collect the data (Table 3),[26-29] information needs (e.g. about their disease, treatment and tests, controlling symptoms, disease transmission) was a common concern. Only two studies (Chang et al and Grogan et al), reported that patients perceived themselves as having good support with regards to informational needs. Other unmet needs or concerns reported by patients included: access to supportive services[26,32,41,43,44] such as a pharmacist, a nutritionist, and psychological counselling (patients reported fear, anxiety, sadness or reported desire for access to counselling), financial stress (cost of care, assistance for obtaining drug coverage plans for medication, worried about being able to provide for their family),[21,25-27,36,45] impact on activities of daily living (e.g. dressing, bathing),[12] concerns about disease transmission (routes of infection, infecting others),[24,29,33,43] symptoms,[21,29] treatment and prognosis.[25,33-35,40]

In reviewing the literature, five common key domains of supportive care needs were identified: informational or educational, practical (including daily living, financial support), physical (including symptoms), patient care and support, and psychological (emotional) (Table 3).

Discussion

This systematic review comprehensively summarises the available literature on reported perspectives, experiences, and concerns of people who have been diagnosed with CLD. The number of studies collecting patient-reported data is small, compared to either the number of reports of doctors and carer reported supportive care needs, or those reporting QoL. In particular, there is a paucity of data on the supportive care needs of patients with advanced liver disease and cirrhosis.

Even though the number of studies was small, this review highlights some of the unmet needs of CLD patients. Most studies were descriptive and used qualitative methodology. However, only five studies used a supportive care needs assessment tool to describe unmet needs of CLD patients with just two having been validated (one was not liver disease-specific, and the other was designed to specifically assess patients' satisfaction with information and psychological support received from the nurse specialist).

Prior to using a health status questionnaire it is important that the instrument is validated and is suitable for the population under study (e.g. translation or re-wording may be necessary).[46] The Scientific Advisory Committee of the Medical Outcomes Trust[47] developed comprehensive criteria to evaluate the measurement properties of a questionnaire. Eight attributes of an instrument properties to be considered when evaluating a questionnaire assessment tool include: (1) its conceptual and measurement model, (2) validity, (3) reliability, (4) responsiveness, (5) interpretability, (6) respondent and administrative burden, (7) alternative forms, and (8) cultural and language adaptations (translations). Although the ISSB[30] is not a liver disease specific tool, it has adequate test-retest and internal consistency (reliability coefficient of internal consistency for the total scale was 0.89).[30,31] The questionnaire used in the Grogan study had its content validity confirmed by a panel of experts, and had an adequate reliability score (Cronbach's alpha =0.85).[32]

Patient informational or educational needs (e.g. about their disease, treatment and tests, controlling symptoms, disease transmission) was the most commonly reported unmet need or concern. Education is a critical component of any healthcare intervention; it has been found to improve treatment adherence, facilitate effective decision-making, reduce healthcare costs, and improve health outcomes. Research shows that people diagnosed with CLD (e.g. cirrhosis,[48] hepatitis C[49]) have a poor understanding of their disease and lack adequate knowledge about important information needed to self-manage their disease. Furthermore, participation in an HCV education class has been shown to increase patients' understanding of disease symptoms, transmission, and treatment.[50] A recent study has shown that a simple educational intervention (providing a concise booklet about cirrhosis and emphasizing its importance) for patients with cirrhosis was associated with a 26% improvement in patient knowledge about their disease.[48] Practical, physical, patient care and support, and psychological needs were also reported as important.

The role of patient education/knowledge has even more importance with the recognition that modifiable host factors can have a substantial impact on liver disease progression and treatment outcomes. In most patients with chronic hepatitis C, fibrosis progression to cirrhosis typically requires decades. However, host risk factors such as heavy alcohol consumption (>50g/day) or increased body mass index can lead to more rapid liver disease progression.[51,52] Similarly, in alcoholic liver disease, individuals with fibrosis who continue to drink alcohol have a high risk of disease progression.[53,54] Improved education about risks of alcohol, obesity and physical inactivity may reduce the impact of co-morbidities on disease progression. Patient education is also essential to ensure compliance with prescribed medications and continued follow-up.[55] Thus an increase in knowledge around CLD has the potential to affect behavioural change, enhance patient self-efficacy, and, in turn, improve both quality of life and disease progression.[56]

While a systematic review was undertaken, using pre-specified criteria, it is possible that some relevant publications were missed. Unpublished articles or non-indexed articles may have been missed. The studies included in this review varied substantially with regards to methodology. About half the articles used qualitative methodology based on smaller numbers of patients, while half used quantitative methodology. Some studies focused specifically on needs assessment[24,26-29] or patients concerns,[33,34,44] and the reported findings were clearly the patients' views and perspectives of their supportive care needs. Some articles focused mostly on the patients' health status, quality of life, or changes in lifestyle. These were included in this review because they reported some information about patient's unmet supportive care needs or concerns, for instance Fabris et al reported that most patients wanted more detailed information about

hepatitis C virus and its transmission. Despite the fact that much of the burden of clinical care occurs in patients with cirrhosis, only three of the papers focused specifically on that population's supportive care needs.

Although this review aimed at describing the unmet supportive are needs of people diagnosed with CLD, five reports included a mixed group of study participants. Jessop et al included members of an online hepatitis support group and four in-person hepatitis and/or liver support groups. The support groups included not just hepatitis patients, but families, friends, and in some cases, patients with other liver diseases. Rakoski et al included elderly people diagnosed with cirrhosis and an age-matched comparison group. Sgorbini et al and Bajaj et al included patients (hepatitis C and cirrhosis, respectively), and their partners or carers. Jennings et al included people who had abnormal laboratory tests and who were referred for further testing for diagnosis of hepatitis C. Rakoski et al was the only group reporting information separately for cases and controls. According to Jennings et al, the relevance of studying 'potential patients' is that people were asked to describe their educational needs before confirmation of infection with hepatitis C and before being overwhelmed with the many complexities that exist with diagnosis of this disease. The proportion of 'potential patients' with subsequent diagnosis of hepatitis C was not reported in the manuscript. Nevertheless, this and the abovementioned reports were included because they provide an insight about the complex array of concerns people living with CLD may have.

Unmet supportive care needs are those needs which lack the level of service or support an individual perceives is necessary to achieve optimal well-being. One criterion for inclusion of articles was that it had to report the *patients'* views, perspectives, experiences, or concerns. In most articles included in this review, the reported unmet supportive care needs of patients are the *investigators'* interpretations of patients' needs, as patients were not specifically asked to report their perceived unmet supportive care needs or concerns. This is the case in Bornschlegel et al's study: patients were asked whether they had been counselled about not drinking alcohol and how to avoid transmitting the virus to other people. Those patients who had not been counselled may not necessarily perceive this as an unmet need or concern. Another example is the study of Gifford et al's where authors reported women's experiences of living with hepatitis C. Even though a large number of those women reported ever having symptoms and rated their health as 'fair-poor', some women may receive help or support to deal with these issues. Similarly, Rakoski et al reported over one-third of people diagnosed with cirrhosis had at least one impaired activity of daily living such as dressing or

bathing. Again, some of these people may need help with activities of daily living but they may also receive help and support (formal or informal care) with these activities, and therefore their supportive care needs are not unmet.

Some clinicians may perceive the social and financial domains of supportive care needs to be outside their realm of practice, but such factors can significantly complicate treatment, reduce adherence to treatment or lifestyle modification, and create management challenges. Poor understanding of medications is one key area known to increase hospitalisation. Clinicians inconsistently ask patients about their unmet supportive care needs and concerns, typically operating in a 'reactive mode' (e.g. acting in response to patients' pressing or self-reported problems).[57] In the USA, for example, each State has a Department of Health and Human Services, where patients can access county resources (e.g. case managers who can assist patients with navigating the health system). Eligible Medicare/Medicaid patients can seek public assistance or transportation to medical visits by county transportation.[58] In Australia, similar arrangements are in place to defray cost for patients in rural or remote areas who are required to travel for their health care. It may be that having a structured, validated supportive care needs instrument specific for the assessment of supportive care needs of patients with CLD, may allow clinicians and other health care workers (e.g. nurses, dieticians) to better address deficiencies in patients' support needs. Disease-specific supportive care needs assessments have been used widely in the heart failure setting.[59] Future research could investigate the potential for a validated liver disease-specific supportive care needs assessment instrument that can potentially be administered quickly by clinical staff (e.g. nursing) or self-administered by patients in the waiting room. Use of such an instrument could then prompt clinicians to be proactive in addressing patients' unmet supportive care needs and, where appropriate, refer to support services to enhance their quality of life.

In conclusion, this systematic review found 26 articles reporting supportive care needs among patients with liver disease, but few of them are *patient-reported* needs and none used a validated, liver disease-specific supportive care needs assessment instrument. Furthermore, most studies did not focus on the CLD population likely to have the most needs – namely those with cirrhosis. Development of a validated supportive care needs assessment instrument for people with CLD would not only advance understanding of patients' unmet needs, but have potential utility in clinical practice for facilitating timely referrals to support services. Support for areas raised in this review around knowledge and information are important for both chronic disease management, and for end of life planning for patients with liver failure from CLD.

Contributions

PCV and JM independently reviewed all manuscripts, and EP and NM adjudicated disagreements. PCV was responsible for data acquisition, and takes responsibility for the integrity and the accuracy of the data. PCV drafted the report, all authors have read and contributed to this manuscript's editing, have agreed to the submission to BMJ Open, and have agreed with the content and presentation of the paper. D Radford-Smith provided administrative assistance.

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Competing interests

None.

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Figure 1. Summary of the eligibility criteria for inclusion into the review

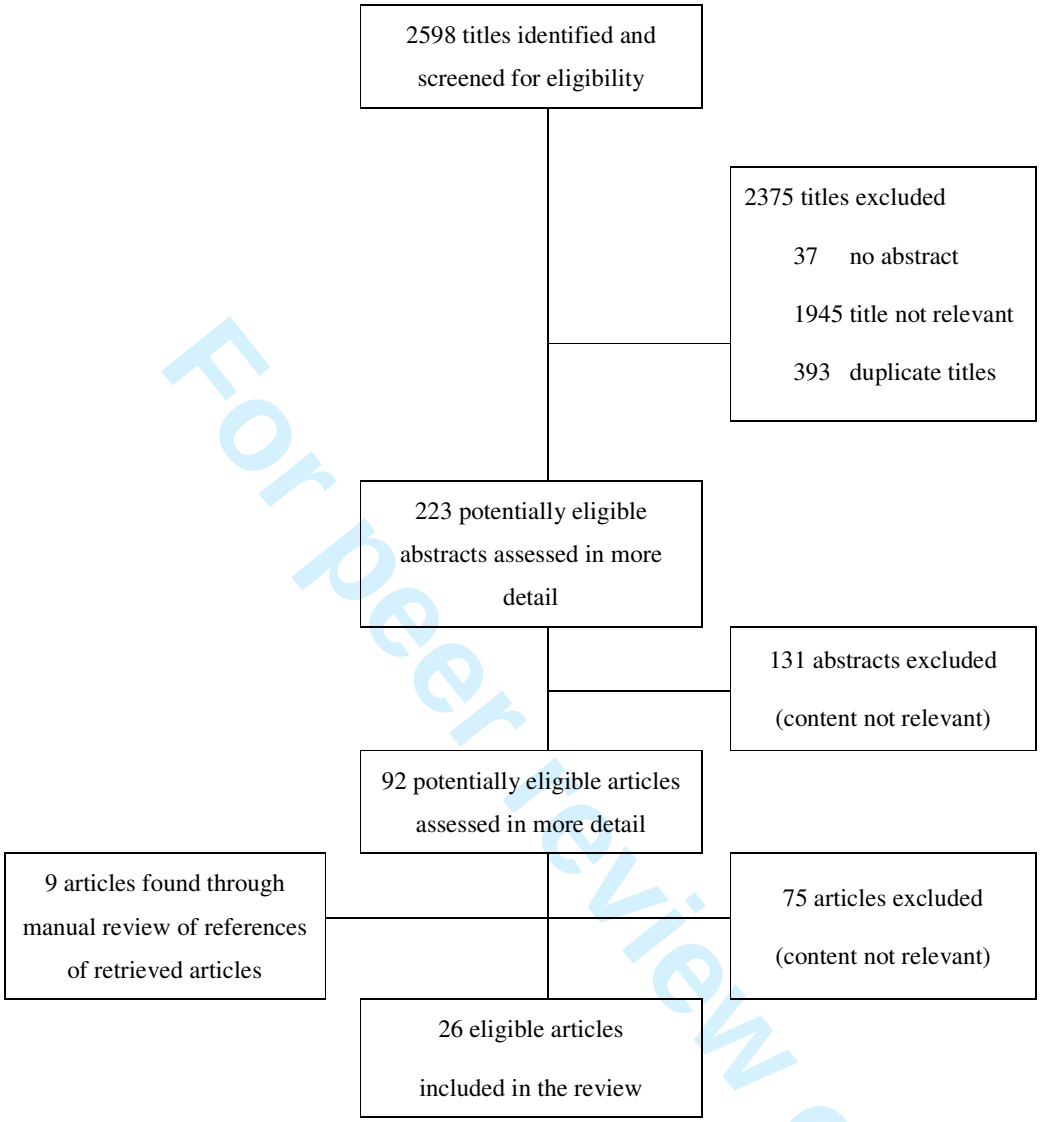

Table 1. Quantitative studies (n=14) included in the literature review

Author (year published) and country	*Study design and study participants*	*Disease group*	*Data collection methods and survey used*	*Focus of the paper and summary of findings*
Gifford et al (2003)[35] Australia	Cross-sectional study (462 female patients)	Hepatitis C	*Self-completed structured questionnaire* on diagnosis, use of health/social services, social support, medical care/treatment, disclosure and discrimination, sexual health and reproductive, caring for children, SF-12 health-related quality of life (QoL), 3 items from the Hepatitis QoL instrument and general health. Overall response rate was 75%.	*Patients experiences* - 48% of the women reported having received less favourable treatment by health professionals because of their HCV status, 58% reported ever having experienced symptoms, 48% rated their health as 'fair-poor'. At diagnosis, 39% of the women were referred to a specialist and 28% were offered information about support groups. At the time of the survey, 56% of the women were currently seeing a doctor specifically for their HCV, but only half were satisfied with their current level of medical care
Jessop et al (2004)[40] USA	Cross-sectional study (88 support group members - patients, family and friends)	Hepatitis or chronic liver disease	*Self-completed structured questionnaire* motivation for joining the support group, duration of participation, supportive and informational needs, supportive and informational aspects of the group, and lifestyle or treatment changes made as result of membership. The response rates were: 73% for the in-person support group, and unknown for the online group.	*Supportive and information needs* - The main motivation for joining the group was to get information or support (all respondents received support from the group, most received support "routinely" or "often"). Most respondents were somewhat satisfied with the information received from their doctor, but reported receiving more '*useful*' information from the support group. Information needs included available treatments, diet, and doctor-patient communication.
Balfour et al (2004)[26] Canada	Cross-sectional study (111 patients)	Hepatitis C	*Self-completed structured questionnaire*. Questions included the Hepatitis C Needs Assessment Scale (developed for this study) and Patient Satisfaction Questionnaires. Patients completed interviews at enrolment and 10 months later. 111 out of 148 eligible patients responded the questionnaire.	*Needs assessment* - Over half the patients reported that their knowledge of HCV was inadequate. Receiving information about HCV was regarded as 'important-very important' for most patients. Having access to a pharmacist, a nutritionist, psychological counselling, and assistance for obtaining drug coverage plans for antiviral therapy were also regarded as 'important'/'very important' for over two-third of the patients.
Gifford et al (2005)[36] Australia	Cross-sectional study (312 male patients)	Hepatits C	Self-completed structured questionnaire on diagnosis, use of health and social services, social support, medical care/treatment, disclosure and discrimination, sexual relationships, SF-12 health-related QoL, 3 items from the Hepatitis QoL instrument, and general health. Response rate was 54%.	*Patients experiences* - Half the men reported experiencing HCV-related symptoms, 35% rated their health as 'fair/poor', 40% believed they received less favorable treatment from health care professionals than those without HCV, 34% were satisfied with the way they were told about their diagnosis, 26% were offered information about HCV support groups, 36% were worried often/very often about being able to provide for their family, and 44% reported being concerned about feeling physically unable to work.
Zandi et al (2005)[29] Iran	Quasi-experimental study (44 patients)	Cirrhosis	*Self-completed structured questionnaire* on educational needs, QoL, and 20 items need assessment items (e.g. fatigue, itching, dry mouth). 44 patients were eligible and included in the study, 4 died during the study.	*Needs assessment* - The most commonly reported needs were: controlling/ reducing abdominal distention, curative ways in cirrhosis (being treatable/not treatable), ways of controlling symptoms (e.g. fatigue, pruritus), principles of care and proper medications, worry, patterns of activity, rest, and sleep; routes of transmission as well as diagnostic tests and procedures.
Minuk et al (2005)[33] Canada	Cross-sectional study (185 patients)	Hepatitis C	*Face-to-face semi-structured interviews*. Initial open-ended question about their principal concern regarding their HCV infection (volunteered concern). Patients were then asked to prioritize from a list of 7 potential concerns. No patient refused to be interviewed.	*Patient concerns* - The most common volunteered concerns were disease progression (27%) followed by premature death (19%), infecting family members (13%) and side-effects of treatment (11%). From the list of potential concerns, the highest priority was given to infecting family members followed by developing liver cancer, infecting others, and developing cirrhosis.

Fabris et al (2006)[38] Italy	Cross-sectional study (364 patients)	Hepatitis C	Multiple-choice *self-completed structured questionnaire* on source of infection, impact on family, sex life, diet and alcohol consumption, and psychological status, and the need for treatment and information about HCV. Response rate not reported.	*Need for treatment and information* - The need for specific treatment was reported by 60% of patients. A demand for more detailed information about hepatitis C virus was expressed by 90% of the patients. The amount of knowledge they possessed was directly proportional to their schooling.
Alizadeh et al (2008)[34] Iran	Cross-sectional study (36 patients)	Hepatitis B and C	*Face-to-face semi-structured interviews*. Initial open-ended question about patients' main concerns regarding their disease. Patients were then asked to rank 8 potential concerns (e.g. liver cancer/cirrhosis). No patient refused to be interviewed.	*Patient concerns* - Concerns about viral transmission, side-effects of treatment, and disease progression to cirrhosis were the most commonly reported.
Chang et al (2008)[27] Taiwan	Cross-sectional study (115 patients)	Hepatitis C	*Self-completed structured questionnaire*. Questions included the Hepatitis Quality of Life Questionnaire (HQLQ) and Inventory of Socially Supportive Behaviours (ISSB) questionnaire. The response rate was 86%.	*QoL and social support* - In general, patients included perceived themselves as having relatively good support (appraisal, emotional, informational, and tangible). Almost half the patients reported moderate to severe financial stress, and they were found to have significantly poorer QOL during treatment compared to those without financial stress.
Grogan et al (2010)[32] Ireland	Cross-sectional study	Hepatitis C	*Self-completed structured questionnaire* on means of contracting HCV, symptoms, and treatment success. Using a six-point Likert scale patients rated their level of satisfaction with information and psychological support received from the nurse specialist. The response rate was 53%.	*Supportive and information needs* - Overall, patients were very satisfied with support received from the nurse specialist; 57% reported that their needs were met and 76% that support received helped them cope with their treatment better. Most patients agreed that the nurse provided informational support. Items fewer patients felt supported with included counselling related to mood disorders and depression, sleep management, information about support groups, and ongoing support post completion of treatment.
Bajaj et al (2011)[45] USA	Cross-sectional study (104 patients and 104 caregivers)	Cirrhosis	*Structured interviews* socio-demographic, and financial questions as well as a cognitive battery of tests. 142 patients were approached: 13 refused participation, 25 were not eligible, and 104 were included.	*Emotional and financial burden on patients and caregivers* - The effect of the financial burden was seen on medical adherence (missed appointments or procedures, did not take or took less prescribed medications) and was associated with the severity of liver disease.
Bornschlegel, et al (2011)[60] USA	Cross-sectional study (180 patient interviews - 145 charts reviews)	Hepatitis C	*Structured interviews* and *medical chart review*. Close-ended questions about the patients understanding of their clinicians' explanation of their diagnosis, counselling about alcohol, information about support group attendance, vaccination against hepatitis, health status, and treatment. The response rate was 47%.	*Patients understanding and needs* - 7% of the patients had not understood their clinicians' explanation of their diagnosis, 26% had not been counselled about avoiding alcohol, 28% had not been counselled about preventing spreading hepatitis C to others, and most (90%) had not attended a hepatitis support group (31% were interested in attending)
Jennings et al (2011)[28] USA	Cross-sectional study (152 patients)	Hepatitis C	*Structured interviews* on the educational needs (delivery methods, interest in support groups, topics of interest and preferred services relating to hepatitis C). The response rate was 100%.	*Educational needs* - Most respondents did not agree that there was an adequate amount of educational material about hepatitis C in the clinic, most thought that their support person was interested in receiving educational materials about hepatitis C and in participating in educational sessions.
Rakoski et al (2012)[12] USA	Longitudinal study (317 patients and 951 comparison group)	Elderly subjects with Cirrhosis	*Structured interviews* on subjects' ability to perform tasks of daily living. Two domains were assessed: activities of daily living (ADL) (e.g. dress oneself), and instrumental activities of daily living (IADL) (e.g. manage shopping or housework). Response rate not reported.	*Patient abilities to perform tasks* - 38% of patients indicated that they had at least one impaired ADL. Commonly reported ADL included "dressing", "bathing", and "walking across room". The most IADL impairments among those with cirrhosis were ''grocery shopping'', "cooking" and "managing money". 10% of individuals with cirrhosis reported 4-5 impaired IADLs.

Table 2. Qualitative studies (n=12) included in the literature review

Author (year published) and country	*Disease group and study participants*	*Methodology*	*Focus of the paper and summary of findings*
Temple-Smith et al (2004)[61] Australia	Hepatitis C (32 patients)	*In-depth interviews* - Theme list included circumstances surrounding diagnosis, disclosure of HCV status to others, feelings toward self/others after diagnosis, seeking information & knowledge about HCV, barriers to maintaining health living, access/need for support networks, impact of HCV on view of health/lifestyle, thoughts of the future, and knowledge/concerns about transmission	*Patients experiences* - There were gender related differences in relation to symptom recognition, health seeking attitudes and notions of social support. Men tended to dismiss the impact of their illness, deny needing social support to help them cope with HCV, and did not see the need for information about self-care. In contract, women talked about the benefits and the desire for social support, and were more willing to seek health information to better manage their HCV.
Harris et al (2005)[22] New Zealand	Hepatitis C (20 patients)	Questions and data collection methods not described.	*Patients experiences* - Participants consistently expressed a desire for information regarding the maintenance of their health, and a frustration with the inability of the medical profession to provide this information.
Sutton et al (2007)[41] Australia	Hepatitis C (32 patients)	*Semi-structured interviews* - Participants were asked to discuss the impact of the hepatitis C diagnosis and their experience of clinical markers and understandings and perceptions of test results.	*Information and knowledge* - The social consequences of living with HCV (e.g. social limitations/isolation) were more significant and had greater impact than clinical markers of disease progress. Participants experienced many negative feelings following diagnosis (e.g. shock, fear and denial). Misinformation and lack of information was a major problem experienced by this group, some people were exposed to contradictory information. The belief that HCV is always a terminal illness, in particular, was an impression still held by some participants.
Groessl et al (2008)[39] USA	Hepatitis C (22 patients)	*Semi-structured interviews* - Questions focused on three areas: medical history, experiences of contracting and being diagnosed with HCV, and the ways in which HCV affected their lives.	*Patients experiences* - Most patients received HCV education from trained professionals but some reported misconceptions and would appear to benefit from additional education. Participants had difficulty with social and occupational functioning, while some received valued support from others for their condition. Living with chronic HCV often had a psychological impact.
Sgorbini et al (2009)[25] Australia	Hepatitis C (5 patients and their partners)	*Semi-structured interviews* - Interviews began with an open-ended question: 'Living with hepatitis C and undergoing combination therapy, what is it like for you?'	*Patients experiences* - Chronic hepatitis C and combination therapy had an enormous impact on the lives of the patients, their partners and families. The illness and treatment had significant physiological effects that had an impact on QoL; however, the social and psychological consequences of living with a highly stigmatised disease with an unknown course and outcome cannot be underestimated. Patients reported enduring struggles with their finances, lack of a holistic care approach from services, and fears of a threatened future (risk of complications of hepatitis C and lingering effects of treatment).
Janke et al (2008)[44] USA	Hepatitis C (40 patients)	*Focus groups* - A structured discussion guide covered questions about treatment, and the decision-making process. Demographic and self-reported health status were collected via self- reported questionnaire.	*Patients concerns* - Patients reported a remarkable level of emotional volatility that was associated with reduced impulse control, anger, and feelings of sadness and depression. Participants also reported stigmatization, communication difficulties related to their HCV diagnosis from providers/social peers, and feelings of isolation.
Ng et al (2013)[24] Malaysia	Hepatitis B (44 patients)	*Focus groups* - Open ended questions about health care experiences (at diagnosis/follow-up), physical, psychological, and social impact of hepatitis B; and health care needs	*Patients experiences and needs* - Patients' needs at diagnosis include desire for emotional support and information. Patients wanted to know more about the disease (transmission, complications, treatment, and prognosis), however, information was not easily accessible. They also reported a wide variation in how patients were counselled and managed.

Trelor et al (2010)[42] Australia	Hepatitis C (24 patients)	*Semi-structured interviews* - Themes included HCV and tests, timing/reason for HCV testing, explanation at diagnosis/referrals, attitudes, awareness, readiness/willingness to undertake treatment, and changes in risk practices.	*Patients experiences* - Overall, the HCV diagnosis experience of participants was poor. Participants reported confusion in relation to HCV tests performed and the implications of test results. Post-test discussions were inadequate – there was a reported lack of information, support and referral provided to participants.
Brunings et al (2013)[37] Canada	Hepatitis C (21 patients)	*Focus groups* - Questions not described.	*Patients perspectives of care* - Four main themes accounted for most of the statements by participants: communication, professional competence, education/information, and continuity of care. Participants emphasized the importance of being treated holistically, receiving HCV education and information was critical to their ability to manage disease
Hill et al (2014)[23] England	Hepatitis C (23 patients)	*Unstructured interviews* – Interviews began with an open-ended question 'Can you tell me how it has been for you, living with hepatitis C?'	*Patients experiences* - Experiences of diagnosis were frequently disappointing. Many were told insensitively and felt poorly prepared; this lack of support, advice and information negatively impacted on how they felt about themselves. A lack of practical advice, information and support dominated people's experiences. This created difficultly when trying to achieve recommended lifestyle changes or gain any sense of control, knowledge or understanding of the condition. Most felt uncertain about how to manage the disease and feared disease progression/health decline.
Burnham et al (2014)[21] USA	Chronic liver disease (13 patients)	*Focus groups* - Open-ended questions regarding patients' beliefs of causes of chronic liver disease, risk beliefs, attitude towards themselves, towards patients with chronic liver disease and towards prevention, perceived benefits of healthy behaviours and risk of liver disease, and barriers to care.	*Knowledge and beliefs* - General lack of knowledge about CLD (causes and risks, screening, disease symptoms, and available treatments) was the most common response. When asked to share how they felt about having CLD, patients reported realistic attitudes and emotions, discriminate sharing of their diagnosis, negative medical side effects, fatalism, and general negativity. The most commonly reported barriers to treatment included: lack of or inadequate health insurance, cost of care, general lack of knowledge (about symptoms and outcomes), negative attitudes and emotions, and low economic status.
Conrad et al (2006)[43] Australia	Hepatitis C (70 patients)	*Focus groups* and individual in-depth interview - 13 guiding questions were use in semi-structured interviews to elicit open-ended discussion	*Psychosocial factors and QoL* - Uncertainty related to disease progression and transmission of the HCV, as well as fear and anxiety about stigma and discrimination were common experiences among HCV patients.

Table 3. Domains and commonly reported specific need items reported by the four studies which used a needs assessment tool to collect data

Author	*Diseased group*	*Domains*	*Need items commonly reported by study participants*
Balfour et al [26]	Hepatitis C	Information/education needs	• 52% rated their current knowledge of liver disease as being inadequate • 91% regarded receiving information about HCV as 'important/very important'
		Patient care and support	• 31% were very dissatisfied/dissatisfied with access to specialists services (e.g. pharmacist, psychologists) • Percentages regarding access to services as 'important-very/important': 76% HCV drug plans, 68% psychological counselling, 66% nutritionist, 63% pharmacist, 63% support for family/partners, 48% support groups
Zandi et al [29]	Cirrhosis		The study assessed patients' educational needs. Below is the percentage of patients reporting need for:
		Information/education needs	• 65% curative ways in cirrhosis (being treatable/not treatable); • 45% routes of transmission as well as diagnostic tests
		Physical needs	• 70% controlling or reducing abdominal distention • 65% ways of controlling fatigue • 60% principles of care and proper medications • 50% controlling pruritus and fatigue
		Psychological	• 55% worry
Chang et al [27]	Hepatitis C	Practical support	• 47.8% reported moderate to severe financial stress
Jennings et al [28]	Hepatitis C	Information/education needs	• 71% disagreed that there was an adequate amount of educational material about hepatitis C in the clinic • 67% thought that their support person was interested in receiving educational materials about hepatitis C • 78% thought that their support person would be interested in participating in educational sessions
		Patient support	• 61% would be interested in joining a regular support group at the clinic • 42% thought that it would be beneficial for their support person to join a caregiver support group
Grogan et al[32]	Hepatitis C		The study assessed patients' perceptions of support received from the nurse specialist during HCV treatment. There were low levels of disagreement that 'The nurse provided …':
		Information/education needs	• 17% advice on how to maintain a healthy balanced diet • 14% advice on sleep management • 12% advices on energy conservation • 12% advice on physical exercise
		Patient support	• 14% information on support groups that were available to me • 18% ongoing support post completion of treatment

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3-4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Not applicable
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4-5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Tables 1 and 2 (pages 18-21)
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Not applicable

PRISMA 2009 Checklist

Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	5

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	9 (Discussion)
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Not applicable
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Figure 1, page 16
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Tables 1 and 2 (pages 17-20)
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Tables 1 and 2 (pages 17-20)
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Not applicable
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Not applicable
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Tables 1 and 2 (pages 17-20)
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Not applicable
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	7-8
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	9
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	11
FUNDING			

PRISMA 2009 Checklist

Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	11

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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Systematic review: unmet supportive care needs in people diagnosed with chronic liver disease

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Systematic review: unmet supportive care needs in people diagnosed with chronic liver disease

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Abstract

Objective People with chronic liver disease, particularly those with decompensated cirrhosis, experience several potentially debilitating complications that can have a significant impact on activities of daily living and quality of life. These impairments combined with the associated complex treatment means that they are faced with specific and high levels of supportive care needs. We aimed to review reported perspectives, experiences, and concerns of people with chronic liver disease worldwide. This information is necessary to guide development of policies around supportive needs screening tools and to enable prioritisation of support services for these patients.

Design Systematic searches of PubMed, MEDLINE, CINAHL, and PsycINFO from the earliest records until 19 September 2014. Data were extracted using standardized forms. A qualitative, descriptive approach was utilised to analyse and synthesize data.

Results The initial search yielded 2598 reports: 26 studies reporting supportive care needs among patients with chronic liver disease were included, but few of them were *patient-reported* needs, none used a validated liver disease-specific supportive care need assessment instrument, and only three included patients with cirrhosis. Five key domains of supportive care needs were identified: informational or educational (e.g. educational material, educational sessions), practical (e.g. daily living), physical (e.g. controlling pruritus and fatigue), patient care and support (e.g. support groups), and psychological (e.g. anxiety, sadness).

Conclusions Whilst several key domains of supportive care needs were identified, most studies included hepatitis patients. There is a paucity of literature describing the supportive care needs of the chronic liver disease population likely to have the most needs – namely those with cirrhosis. Assessing the supportive care needs of people with chronic liver disease have potential utility in clinical practice for facilitating timely referrals to support services.

Strengths and limitations of this study

- This systematic review comprehensively summarises reported perspectives, experiences, and concerns of people who have been diagnosed with CLD worldwide.
- The data presented highlight the shortage of information regarding unmet needs of chronic liver disease patients.
- Whilst several key domains of supportive care needs were identified, most studies included hepatitis patients, few of them reported *patient* needs, and none used a validated, liver disease-specific supportive care needs assessment instrument. There is a paucity of literature describing the supportive care needs of the chronic liver disease population likely to have the most needs – namely those with cirrhosis.
- Assessing the supportive care needs of people with chronic liver disease have potential utility in clinical practice for facilitating timely referrals to support services.

Introduction

Chronic liver disease (CLD) is a major global cause of morbidity and mortality. The prevalence of CLD differs between countries, affecting approximately 300 million people in China,[1] 29 million in the European Union[2] and more than 8 million cases in Australia.[3] The leading causes of CLD are viral hepatitis B (HBV) and C (HCV), harmful alcohol consumption and metabolic fatty liver disease associated with obesity and type 2 diabetes.[1-7] Regardless of aetiology, most of the morbidity and mortality from CLD occurs among individuals with cirrhosis, who are at risk of developing complications including ascites, hepatic encephalopathy, variceal haemorrhage and liver cancer. Liver disease is the fifth greatest cause of death in the UK, where the average age of death from liver disease is 59 years, with large impacts on loss of Quality Adjusted Life years (QALYs).[8] The number of individuals with advanced liver disease, liver related deaths and health care costs are predicted to increase over the next decade.[9-11] Despite these alarming predictions, there is inadequate awareness of the disease among the general public and health professionals, and many health care systems lack regional or national strategies to address or prevent the increasing burden from complicated CLD.[3,8]

People with cirrhosis must follow a complex and variable regimen of dietary restrictions, medications, laboratory testing, and clinic visits. In addition, patients with decompensated cirrhosis frequently suffer debilitating complications that impact on an individual's quality of life and activities of daily living. These impairments combined with the complex management of advanced liver disease are likely to mean that patients are faced with specific and high levels of supportive care needs.[12] In contrast to other advanced end-organ disease such as heart failure or chronic obstructive pulmonary disease, the potential of devolved models of supportive care in the community or home for CLD patients is yet to be established. Because hospital care traditionally focuses on medical management of the major complications of portal hypertension such as ascites and variceal bleeding it is likely that many patients' supportive care needs remain unmet.

The term supportive care needs encompasses the physical, informational, emotional, practical, social, and spiritual needs of an individual with chronic disease.[13] Health needs assessment instruments are increasingly being developed to evaluate specific areas and magnitude of need as a means of improving provision of patient care and outcomes, particularly in the arena of chronic diseases such as cancer and cardiac failure.[14-18] Advances in medical care have resulted in people with CLD living longer, through better management of disease complications.[19] An imperative

exists for a valid and reliable measure that can provide an accurate supportive care needs assessment for people with CLD.

This systematic review addresses the following questions: (i) What are the supportive care needs of people who have been diagnosed with CLD? (ii) What are the domains and specific items of need most frequently reported as unmet by CLD patients, and what is the extent of these needs? and (iii) What are the measures for assessment of unmet supportive care needs of people who have been diagnosed with CLD available in the literature? This information is necessary to guide development of policies around supportive needs screening tools and to enable prioritisation of support services for patients with CLD.

Methods

A systematic review was undertaken to review and synthesize studies investigating the supportive care needs of people diagnosed with CLD. One author (PV) searched online peer-reviewed journal articles indexed in PubMed, MEDLINE, CINAHL, and PsycINFO from the earliest records until 19 September 2014. Titles and abstracts were searched for possible combinations of the terms including chronic liver disease, or chronic hepatitis, hepatitis, non-alcoholic fatty liver disease, or NAFLD, or cirrhosis, alcoholic liver disease, and unmet need, or support needs, or supportive care needs, or perceived needs, or supportive care, or needs assessment. The search was complemented by manually reviewing the references of retrieved articles for other articles of potential relevance to the research aims.

Two investigators (PV and JM) independently reviewed all titles; those judged to be potentially helpful were examined. Data were extracted using standardized data collection forms on to a Microsoft Excel spreadsheet (Microsoft Corp, Redmond, WA, USA). The form included record number, title, year of publication, and abstract for each study, and outcome (inclusion/exclusion) and reason for exclusion were extracted. The following selection criteria were then applied: availability of an abstract; use of primary data; published in English, Spanish, or Portuguese; reporting patients' views, perspectives, experiences, concerns; patients were adults or children; and, if reporting on patients with cystic fibrosis, the article had to focus primarily on liver disease. We excluded reviews and editorials and reports for hepatitis A, liver transplant, hepatocellular carcinoma, and studies among people with cystic fibrosis that primarily examined respiratory or pancreatic disease. In particular,

hepatocellular carcinoma was excluded as a diagnosis of cancer engenders specific supportive care needs around the cancer treatments and side effects. We also excluded papers where patient reported supportive care needs (as opposed to doctor or carer reported patient needs) were not investigated and those solely focusing on quality of life (QoL). As seen in other disease settings (e.g. cancer), although QoL measures provide important insights into the problems experienced by patients, they do not reveal what patients ideally want from the health care system or the extent to which their needs are being satisfied.[20] Furthermore, they fail to link patient's experience directly with their service desires.

Abstracts with relevant content were selected for full manuscript review. PV and JM independently reviewed manuscripts; two other investigators (EP and NM) were available to adjudicate disagreements. Data were extracted using predesigned forms on to a Microsoft Excel spreadsheet. The following data were extracted for each study: author, year published, country, disease group, study design, data collection method, survey used for data collection (Was it validated? If yes, the details about validation were collected), number of study participants, inclusion criteria, response rate, summary of findings (key points with regards to perspectives, experiences, and concerns of people with CLD), main focus of the paper (e.g. needs assessment, patients experiences), and study limitations. Data extraction was conducted by a single reviewer (PV), and independent verified by a second reviewer (JM) (outcome [inclusion/exclusion] and reason for exclusion were recorded). Study quality was assessed against the following quality criteria: aims and/or research question stated clearly, study design, recruitment strategy stated clearly, data collection methods, analysis (sufficient presentation of data to permit assessment of analysis), and response rate and assessment of confounding for quantitative studies only. We decided to exclude from our review studies not describing at least 3 of these criteria. Failure to mention the quality measure in the articles was considered a failure to fulfil the criterion. A qualitative, descriptive approach was utilised to analyse and synthesize data with the reporting of most of the abovementioned details in Tables 1 and 2.

Results

The initial search yielded 2598 reports: 17 were relevant for our overview, 9 additional studies were found after reviewing the reference lists of relevant articles (Figure 1; Tables 1 and 2), with a total of 26 articles included in the review. Most studies included patients with hepatitis C (n=19), three included patients with cirrhosis, two with hepatitis B or C, and two included patients with hepatitis or chronic liver disease. Of studies including patients with

hepatitis, in addition to the confirmation of diagnosis, in three studies participants had to be on combination therapy (interferon and ribavirin).[21-23] Of the abovementioned studies, five included a mixed group of participants (not only patients). Jessop et al[24] included members of hepatitis and/or liver support groups; these groups included not just hepatitis patients, but families, friends, and in some cases, patients with other liver diseases. Rakoski et al[12] included elderly people diagnosed with cirrhosis and an age-matched comparison group. Sgorbini et al[23] and Bajaj et al[25] included patients (hepatitis C and cirrhosis, respectively), and their partners or carers. Jennings et al[26] included people who had abnormal laboratory tests and who were referred for further testing for diagnosis of hepatitis C. Rakoski et al[12] was the only group reporting information separately for cases and controls.

Fourteen studies used quantitative methodology (Table 1), 12 were cross-sectional, one was longitudinal and one was a quasi-experimental study. Sample size varied between studies with a range from 36 to 462 patients. Twelve studies (sample size range 5 to 70 patients) used qualitative methodology (Table 2) to describe patients' experiences, concerns, supportive care needs, perspectives of care, and information and knowledge about their disease. Four used focus groups to collect data, seven used semi-structured or unstructured/in-depth interviews, and one used both focus groups and individual in-depth interviews. Many of the qualitative studies began the interview with an open-ended general question about the patients experience with their disease, followed up by questions or prompts addressing specific areas or topics of interest (e.g. stigma, treatment).[23,27-30]

In reviewing the literature, five common key domains of supportive care needs were identified: '*informational or educational*' (e.g. educational material, educational sessions), '*practical'* (e.g. daily living, financial support), '*physical'* (e.g. reducing abdominal distention, controlling pruritus and fatigue), '*patient care and support*' (e.g. support group at the clinic, caregiver support group), and '*psychological'* (e.g. anxiety, sadness) (Table 3).

Most studies reported unmet needs or concerns in the '*informational or educational*' domain (15 out of 26 studies). Need for or lack of information about their disease, treatment and tests, controlling symptoms, and disease transmission were amongst commonly reported concerns reported by eleven.[24,26,28-35,36] Of the five reports using a supportive care needs assessment tool to collect the data (Table 3), information needs was a common concern in four studies.[21,26,31,37,38] Only two studies (Chang et al and Grogan et al),[21,38] reported that patients perceived themselves as having good support with regards to informational needs. Temple-Smith et al report mixed results for men and

women, with the former denying need for information while the latter were willing to seek health information to better manage their disease.[39]

Other domains of unmet needs or concerns were also reported. Items pertained in the '*patient care and support*' domain were reported by eight studies, including access to a pharmacist, a nutritionist, support groups, [29,31,33,36,38-41] '*Practical needs*' including financial stress (cost of care, assistance for obtaining drug coverage plans for medication, worried about being able to provide for their family impact on activities of daily living (e.g. dressing, bathing), were reported by seven studies.[12,21,23,25,27,31,34,42] Concerns about symptoms, treatment and prognosis, disease transmission (routes of infection, infecting others), were reported by seven studies (here grouped as '*physical*' domain).[23,37,40,42-44] In seven studies patients reported fear, anxiety, sadness, feelings of isolation, or reported desire for access to psychological counselling ('*psychological*' domain).[22,23,30,34,37,38,45]

Of the fourteen quantitative studies, five used a supportive care needs assessment tool to collect the data.[21,26,31,37] Balfour et al used the Hepatitis C Needs Assessment Scale (HCNAS), an 11-item self-reported tool developed for their study.[31] For the HCNAS, patients were asked to rank the importance of their health care needs on a 5-point scale. Zandi et al used a needs assessment tool that consisted of a list of 20 questions related to common symptoms and management (e.g. fatigue, itching, dry mouth, muscular cramps, dietary regimen).[37] Chang et al used the Inventory of Socially Supportive Behaviours (ISSB),[46] a 15-item questionnaire that asks patients to rate on a 4-point scale four types of support: emotional, appraisal, informational and tangible.[21] Jennings et al used a survey consisting of 13 questions including items on the educational needs of HCV patients (educational delivery methods, interest in support groups, topics of interest related to HCV and preferred services relating to HCV).[26] There was no evidence on literature review of further validation of any of the other needs assessment instruments. Grogan *et al* used a validated survey tool (a 59-item questionnaire designed for the study) to collect data on informational and psychological support, however the questionnaire was designed to explore patients' level of satisfaction with support from the nurse specialist.[38] Minuk et al and Alizadeh et al's approach for data collection was the use of an open-ended question to elicit the patient's principal concern about their disease ('volunteered concern'), then patients were asked to rank a list of seven[44] or eight[43] other potential concerns. The other six studies included a mix of questions in their data collection tool, including some specific items on support needs, information needs or ability of patients to perform daily living tasks. Four studies also included questions about QoL.[21,37,40,42]

Discussion

This systematic review comprehensively summarises the available literature on reported perspectives, experiences, and concerns of people who have been diagnosed with CLD. The number of studies collecting patient-reported data is small, compared to either the number of reports of doctors and carer reported supportive care needs, or those reporting QoL. In particular, there is a paucity of data on the supportive care needs of patients with advanced liver disease and cirrhosis.

Even though the number of studies was small, this review highlights some of the unmet needs of CLD patients. Most studies were descriptive and used qualitative methodology. However, only five studies used a supportive care needs assessment tool to describe unmet needs of CLD patients with just two having been validated. One, the Inventory of Socially Supportive Behaviours has shown to have adequate test-retest and internal consistency, although it is not a disease specific (liver disease) needs assessment tool,[46,47] and the other was designed to specifically assess patients' satisfaction with information and psychological support received from the nurse specialist~~)~~.[26]

Prior to using a health status questionnaire it is important that the instrument is validated and is suitable for the population under study (e.g. translation or re-wording may be necessary).[48] The Scientific Advisory Committee of the Medical Outcomes Trust[49] developed comprehensive criteria to evaluate the measurement properties of a questionnaire. Eight attributes of an instrument properties to be considered when evaluating a questionnaire assessment tool include: (1) its conceptual and measurement model, (2) validity, (3) reliability, (4) responsiveness, (5) interpretability, (6) respondent and administrative burden, (7) alternative forms, and (8) cultural and language adaptations (translations). Although the ISSB[46] is not a liver disease specific tool, it has adequate test-retest and internal consistency (reliability coefficient of internal consistency for the total scale was 0.89).[46,47] The questionnaire used in the Grogan study had its content validity confirmed by a panel of experts, and had an adequate reliability score (Cronbach's alpha =0.85).[38]

Education is a critical component of any healthcare intervention; it has been found to improve treatment adherence, facilitate effective decision-making, reduce healthcare costs, and improve health outcomes. Research shows that people diagnosed with CLD (e.g. cirrhosis,[50] hepatitis C[51]) have a poor understanding of their disease and lack adequate knowledge about important information needed to self-manage their disease. Furthermore, participation in an

HCV education class has been shown to increase patients' understanding of disease symptoms, transmission, and treatment.[52] A recent study has shown that a simple educational intervention (providing a concise booklet about cirrhosis and emphasizing its importance) for patients with cirrhosis was associated with a 26% improvement in patient knowledge about their disease.[50] Practical, physical, patient care and support, and psychological needs were also reported as important.

The role of patient education/knowledge has even more importance with the recognition that modifiable host factors can have a substantial impact on liver disease progression and treatment outcomes. In most patients with chronic hepatitis C, fibrosis progression to cirrhosis typically requires decades. However, host risk factors such as heavy alcohol consumption (>50g/day) or increased body mass index can lead to more rapid liver disease progression.[53,54] Similarly, in alcoholic liver disease, individuals with fibrosis who continue to drink alcohol have a high risk of disease progression.[55,56] Improved education about risks of alcohol, obesity and physical inactivity may reduce the impact of co-morbidities on disease progression. Patient education is also essential to ensure compliance with prescribed medications and continued follow-up.[57] Thus an increase in knowledge around CLD has the potential to affect behavioural change, enhance patient self-efficacy, and, in turn, improve both quality of life and disease progression.[58]

Although this review aimed at describing the unmet supportive are needs of people diagnosed with CLD, five reports included a mixed group of study participants. Nevertheless, these reports were included because they provide an insight about the complex array of concerns people living with CLD may have. Additional information could also potentially be found from patients' Blog, or Facebook page. However, as these are not standardised they were not be included in this review.

Unmet supportive care needs are those needs which lack the level of service or support an individual perceives is necessary to achieve optimal well-being. One criterion for inclusion of articles was that it had to report the *patients'* views, perspectives, experiences, or concerns. In most articles included in this review, the reported unmet supportive care needs of patients are the *investigators'* interpretations of patients' needs, as patients were not specifically asked to report their perceived unmet supportive care needs or concerns, rather asked whether they had been counselled about not drinking alcohol and how to avoid transmitting the virus to other people.[41] Those patients who had not been counselled may not necessarily perceive this as an unmet need or concern. In Gifford et al's[40] study, a large number of

women reported ever having symptoms and rated their health as 'fair-poor' yet, some women may have received outside help or support to deal with these issues. Similarly, Rakoski et al[12] reported over one-third of people diagnosed with cirrhosis had at least one impaired activity of daily living such as dressing or bathing, yet it is possible that they may also have received help and support (formal or informal care) with these activities, and therefore their supportive care needs are not unmet.

Some clinicians may perceive the social and financial domains of supportive care needs to be outside their realm of practice, but such factors can significantly complicate treatment, reduce adherence to treatment or lifestyle modification, and create management challenges. Poor understanding of medications is one key area known to increase hospitalisation. Clinicians inconsistently ask patients about their unmet supportive care needs and concerns, typically operating in a 'reactive mode' (e.g. acting in response to patients' pressing or self-reported problems).[59] In the USA, for example, each State has a Department of Health and Human Services, where patients can access county resources (e.g. case managers who can assist patients with navigating the health system). Eligible Medicare/Medicaid patients can seek public assistance or transportation to medical visits by county transportation.[60] In Australia, similar arrangements are in place to defray cost for patients in rural or remote areas who are required to travel for their health care. It may be that having a structured, validated supportive care needs instrument specific for the assessment of supportive care needs of patients with CLD, may allow clinicians and other health care workers (e.g. nurses, dieticians) to better address deficiencies in patients' support needs. Disease-specific supportive care needs assessments have been used widely in the heart failure setting.[61] Future research could investigate the potential for a validated liver disease-specific supportive care needs assessment instrument that can potentially be administered quickly by clinical staff (e.g. nursing) or self-administered by patients in the waiting room. Use of such an instrument could then prompt clinicians to be proactive in addressing patients' unmet supportive care needs and, where appropriate, refer to support services to enhance their quality of life.

While a systematic review was undertaken, using pre-specified criteria, it is possible that some relevant publications were missed. Unpublished articles or non-indexed articles may have been missed. The studies included in this review varied substantially with regards to methodology. About half the articles used qualitative methodology based on smaller numbers of patients, while half used quantitative methodology. Some studies focused specifically on needs assessment[21,26,30,31,37] or patients concerns,[22,43,44] and the reported findings were clearly the patients' views and

perspectives of their supportive care needs. Some articles focused mostly on the patients' health status, quality of life, or changes in lifestyle. These were included in this review because they reported some information about patient's unmet supportive care needs or concerns, for instance Fabris et al[33] reported that most patients wanted more detailed information about hepatitis C virus and its transmission. Despite the fact that much of the burden of clinical care occurs in patients with cirrhosis, only three of the papers focused specifically on that population's supportive care needs. Lastly, this review is limited by the varying quality and rigor of the included studies, which had significant heterogeneity in terms of the population group (disease, age, gender, and concurrent comorbidity), numbers and types of domains interrogated.

In conclusion, this systematic review found 26 articles reporting supportive care needs among patients with liver disease, but few of them are *patient-reported* needs and none used a validated, liver disease-specific supportive care needs assessment instrument. Furthermore, most studies did not focus on the CLD population likely to have the most needs – namely those with cirrhosis. Development of a validated supportive care needs assessment instrument for people with CLD would not only advance understanding of patients' unmet needs, but have potential utility in clinical practice for facilitating timely referrals to support services. Support for areas raised in this review around knowledge and information are important for both chronic disease management, and for end of life planning for patients with liver failure from CLD.

Contributions

PCV and JM independently reviewed all manuscripts, and EP and NM adjudicated disagreements. PCV was responsible for data acquisition, and takes responsibility for the integrity and the accuracy of the data. PCV drafted the report, all authors have read and contributed to this manuscript's editing, have agreed to the submission to BMJ Open, and have agreed with the content and presentation of the paper. D Radford-Smith provided administrative assistance.

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Competing interests

None.

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Figure 1. Summary of the eligibility criteria for inclusion into the review

Table 1. Basic characteristics (setting, disease group, study design, participant characteristics, and data collection methods) and main findings) including domains of commonly reported supportive care needs items of quantitative studies (n=14) included in the literature review

Author (year published) and country	*Study design and study participants*	*Disease group*	*Data collection methods and survey used*	*Focus of the paper, summary of findings, and domains of supportive care needs*
Gifford et al (2003)[40] Australia	Cross-sectional study (462 female patients)	Hepatitis C	*Self-completed structured questionnaire* on diagnosis, use of health/social services, social support, medical care/treatment, disclosure and discrimination, sexual health and reproductive, caring for children, SF-12 health-related quality of life (QoL), 3 items from the Hepatitis QoL instrument and general health. Overall response rate was 75%.	*Patients experiences* - 48% of the women reported having received less favourable treatment by health professionals because of their HCV status, 58% reported ever having experienced symptoms, 48% rated their health as 'fair-poor'. At diagnosis, 39% of the women were referred to a specialist and 28% were offered information about support groups. At the time of the survey, 56% of the women were currently seeing a doctor specifically for their HCV, but only half were satisfied with their current level of medical care *Domains*: physical, patient care and support
Jessop et al (2004)[24] USA	Cross-sectional study (88 support group members - patients, family and friends)	Hepatitis or chronic liver disease	*Self-completed structured questionnaire* motivation for joining the support group, duration of participation, supportive and informational needs, supportive and informational aspects of the group, and lifestyle or treatment changes made as result of membership. The response rates were: 73% for the in-person support group, and unknown for the online group.	*Supportive and information needs* - The main motivation for joining the group was to get information or support (all respondents received support from the group, most received support "routinely" or "often"). Most respondents were somewhat satisfied with the information received from their doctor, but reported receiving more '*useful'* information from the support group. Information needs included available treatments, diet, and doctor-patient communication. *Domains*: informational/educational
Balfour et al (2004)[31] Canada	Cross-sectional study (111 patients)	Hepatitis C	*Self-completed structured questionnaire*. Questions included the Hepatitis C Needs Assessment Scale (developed for this study) and Patient Satisfaction Questionnaires. Patients completed interviews at enrolment and 10 months later. 111 out of 148 eligible patients responded the questionnaire.	*Needs assessment* - Over half the patients reported that their knowledge of HCV was inadequate. Receiving information about HCV was regarded as 'important-very important' for most patients. Having access to a pharmacist, a nutritionist, psychological counselling, and assistance for obtaining drug coverage plans for antiviral therapy were also regarded as 'important'/'very important' for over two-third of the patients. *Domains*: informational/educational, patient care and support
Gifford et al (2005)[42] Australia	Cross-sectional study (312 male patients)	Hepatits C	Self-completed structured questionnaire on diagnosis, use of health and social services, social support, medical care/treatment, disclosure and discrimination, sexual relationships, SF-12 health-related QoL, 3 items from the Hepatitis QoL instrument, and general health. Response rate was 54%.	*Patients experiences* - Half the men reported experiencing HCV-related symptoms, 35% rated their health as 'fair/poor', 40% believed they received less favorable treatment from health care professionals than those without HCV, 34% were satisfied with the way they were told about their diagnosis, 26% were offered information about HCV support groups, 36% were worried often/very often about being able to provide for their family, and 44% reported being concerned about feeling physically unable to work. *Domains*: physical, practical
Zandi et al (2005)[37] Iran	Quasi-experimental study (44 patients)	Cirrhosis	*Self-completed structured questionnaire* on educational needs, QoL, and 20 items need assessment items (e.g. fatigue, itching, dry mouth). 44 patients were eligible and included in the study, 4 died during the study.	*Needs assessment* - The most commonly reported needs were: controlling/ reducing abdominal distention, curative ways in cirrhosis (being treatable/not treatable), ways of controlling symptoms (e.g. fatigue, pruritus), principles of care and proper medications, worry, patterns of activity, rest, and sleep; routes of transmission as well as diagnostic tests and procedures. *Domains*: physical, informational/educational, psychological

Minuk et al (2005)[44] Canada	Cross-sectional study (185 patients)	Hepatitis C	*Face-to-face semi-structured interviews*. Initial open-ended question about their principal concern regarding their HCV infection (volunteered concern). Patients were then asked to prioritize from a list of 7 potential concerns. No patient refused to be interviewed.	*Patient concerns* - The most common volunteered concerns were disease progression (27%) followed by premature death (19%), infecting family members (13%) and side-effects of treatment (11%). From the list of potential concerns, the highest priority was given to infecting family members followed by developing liver cancer, infecting others, and developing cirrhosis. *Domains*: physical
Fabris et al (2006)[33] Italy	Cross-sectional study (364 patients)	Hepatitis C	Multiple-choice *self-completed structured questionnaire* on source of infection, impact on family, sex life, diet and alcohol consumption, and psychological status, and the need for treatment and information about HCV. Response rate not reported.	*Need for treatment and information* - The need for specific treatment was reported by 60% of patients. A demand for more detailed information about hepatitis C virus was expressed by 90% of the patients. The amount of knowledge they possessed was directly proportional to their schooling. *Domains*: patient care and support, informational/educational
Alizadeh et al (2008)[43] Iran	Cross-sectional study (36 patients)	Hepatitis B and C	*Face-to-face semi-structured interviews*. Initial open-ended question about patients' main concerns regarding their disease. Patients were then asked to rank 8 potential concerns (e.g. liver cancer/cirrhosis). No patient refused to be interviewed.	*Patient concerns* - Concerns about viral transmission, side-effects of treatment, and disease progression to cirrhosis were the most commonly reported. *Domains*: physical
Chang et al (2008)[21] Taiwan	Cross-sectional study (115 patients)	Hepatitis C	*Self-completed structured questionnaire*. Questions included the Hepatitis Quality of Life Questionnaire (HQLQ) and Inventory of Socially Supportive Behaviours (ISSB) questionnaire. The response rate was 86%.	*QoL and social support* - In general, patients included perceived themselves as having relatively good support (appraisal, emotional, informational, and tangible). Almost half the patients reported moderate to severe financial stress, and they were found to have significantly poorer QOL during treatment compared to those without financial stress. *Domains*: practical
Grogan et al (2010)[38] Ireland	Cross-sectional study	Hepatitis C	*Self-completed structured questionnaire* on means of contracting HCV, symptoms, and treatment success. Using a six-point Likert scale patients rated their level of satisfaction with information and psychological support received from the nurse specialist. The response rate was 53%.	*Supportive and information needs* - Overall, patients were very satisfied with support received from the nurse specialist; 57% reported that their needs were met and 76% that support received helped them cope with their treatment better. Most patients agreed that the nurse provided informational support. Items fewer patients felt supported with included counselling related to mood disorders and depression, sleep management, information about support groups, and ongoing support post completion of treatment. *Domains*: psychological, patient care and support
Bajaj et al (2011)[25] USA	Cross-sectional study (104 patients and 104 caregivers)	Cirrhosis	*Structured interviews* socio-demographic, and financial questions as well as a cognitive battery of tests. 142 patients were approached: 13 refused participation, 25 were not eligible, and 104 were included.	*Emotional and financial burden on patients and caregivers* - The effect of the financial burden was seen on medical adherence (missed appointments or procedures, did not take or took less prescribed medications) and was associated with the severity of liver disease. *Domains*: practical
Bornschlegel, et al (2011)[41] USA	Cross-sectional study (180 patient interviews - 145 charts reviews)	Hepatitis C	*Structured interviews* and *medical chart review*. Close-ended questions about the patients understanding of their clinicians' explanation of their diagnosis, counselling about alcohol, information about support group attendance, vaccination against hepatitis, health status, and treatment. The response rate was 47%.	*Patients understanding and needs* - 7% of the patients had not understood their clinicians' explanation of their diagnosis, 26% had not been counselled about avoiding alcohol, 28% had not been counselled about preventing spreading hepatitis C to others, and most (90%) had not attended a hepatitis support group (31% were interested in attending). *Domains*: informational/educational, patient care and support`
Jennings et al	Cross-sectional	Hepatitis C	*Structured interviews* on the educational needs	*Educational needs* - Most respondents did not agree that there was an adequate

(2011)[26] USA	study (152 patients)		(delivery methods, interest in support groups, topics of interest and preferred services relating to hepatitis C). The response rate was 100%.	amount of educational material about hepatitis C in the clinic, most thought that their support person was interested in receiving educational materials about hepatitis C and in participating in educational sessions. *Domains*: informational/educational
Rakoski et al (2012)[12] USA	Longitudinal study (317 patients and 951 comparison group)	Elderly subjects with Cirrhosis	*Structured interviews* on subjects' ability to perform tasks of daily living. Two domains were assessed: activities of daily living (ADL) (e.g. dress oneself), and instrumental activities of daily living (IADL) (e.g. manage shopping or housework). Response rate not reported.	*Patient abilities to perform tasks* - 38% of patients indicated that they had at least one impaired ADL. Commonly reported ADL included "dressing", "bathing", and "walking across room". The most IADL impairments among those with cirrhosis were ''grocery shopping'', "cooking" and "managing money". 10% of individuals with cirrhosis reported 4-5 impaired IADLs. *Domains*: practical

Table 2. Basic characteristics (setting, disease group, participant characteristics, methodology, and research questions) and main findings including domains of commonly reported supportive care needs items of qualitative studies (n=12) included in the literature review

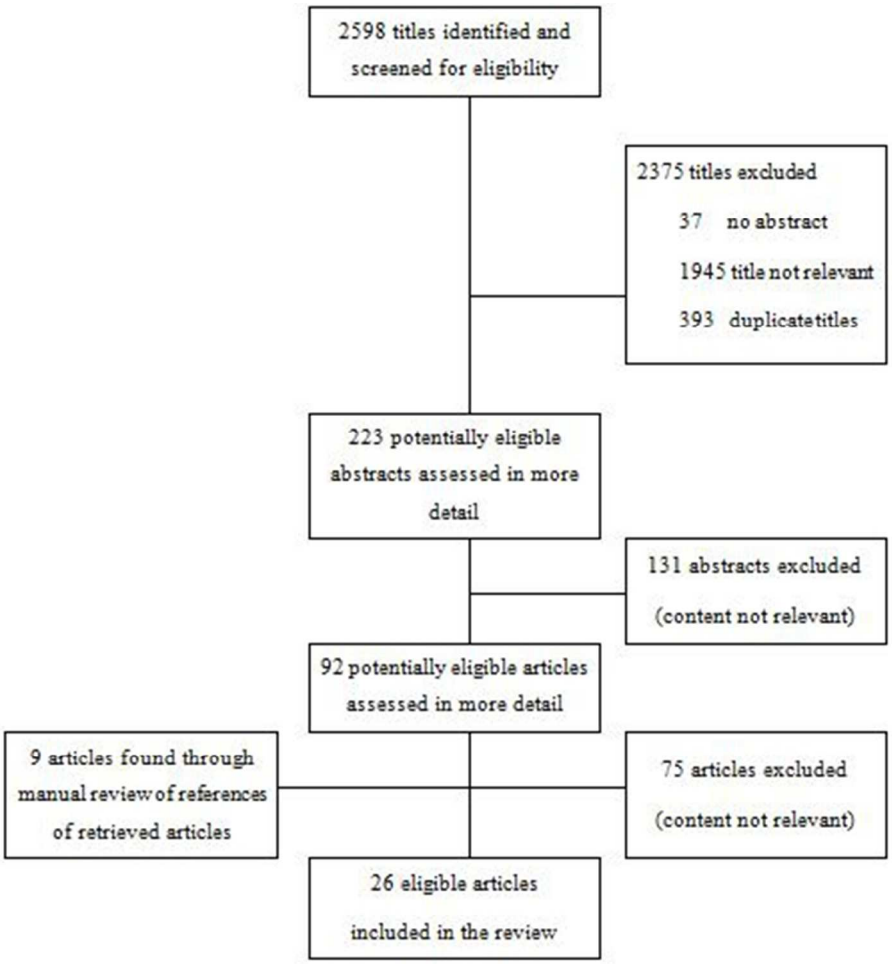
Author (year published) and country	*Disease group and study participants*	*Methodology*	*Focus of the paper, summary of findings, and domains of supportive care needs*
Temple-Smith et al (2004)[39] Australia	Hepatitis C (32 patients)	*In-depth interviews* - Theme list included circumstances surrounding diagnosis, disclosure of HCV status to others, feelings toward self/others after diagnosis, seeking information & knowledge about HCV, barriers to maintaining health living, access/need for support networks, impact of HCV on view of health/lifestyle, thoughts of the future, and knowledge/concerns about transmission	*Patients experiences* - There were gender related differences in relation to symptom recognition, health seeking attitudes and notions of social support. Men tended to dismiss the impact of their illness, deny needing social support to help them cope with HCV, and did not see the need for information about self-care. In contract, women talked about the benefits and the desire for social support, and were more willing to seek health information to better manage their HCV. *Domains*: informational/educational, patient care and support
Harris et al (2005)[28] New Zealand	Hepatitis C (20 patients)	*Semi-structured in-depth interviews* - Each interview (typically) began with the interviewer asking patients 'how they first found out about their hepatitis C', with subsequent areas of discussion addressing experiences of disclosure, stigma, the impact of hepatitis C on relationships, medical encounters, and views on and experiences of HCV treatment. *Narrative theory was used.**	*Patients experiences* - Participants consistently expressed a desire for information regarding the maintenance of their health, and a frustration with the inability of the medical profession to provide this information. *Domains*: informational/educational
Sutton et al (2007)[35] Australia	Hepatitis C (32 patients)	*Semi-structured interviews* - Participants were asked to discuss the impact of the hepatitis C diagnosis and their experience of clinical markers and understandings and perceptions of test results. *The illness trajectories and shifting perspectives of wellness and illness models* were used.	*Information and knowledge* - The social consequences of living with HCV (e.g. social limitations/isolation) were more significant and had greater impact than clinical markers of disease progress. Participants experienced many negative feelings following diagnosis (e.g. shock, fear and denial). Misinformation and lack of information was a major problem experienced by this group, some people were exposed to contradictory information. The belief that HCV is always a terminal illness, in particular, was an impression still held by some participants. *Domains*: informational/educational
Groessl et al (2008)[34] USA	Hepatitis C (22 patients)	*Semi-structured interviews* - Questions focused on three areas: medical history, experiences of contracting and being diagnosed with HCV, and the ways in which HCV affected their lives.The *theoretical construct of health-related quality of life* was used.	*Patients experiences* - Most patients received HCV education from trained professionals but some reported misconceptions and would appear to benefit from additional education. Participants had difficulty with social and occupational functioning, while some received valued support from others for their condition. Living with chronic HCV often had a psychological impact. *Domains*: informational/educational, practical, psychological
Sgorbini et al (2009)[23] Australia	Hepatitis C (5 patients and their partners)	*Semi-structured interviews* - Interviews began with an open-ended question: 'Living with hepatitis C and undergoing combination therapy, what is it like for you?'. *Heideggerian phenomenology* was used.	*Patients experiences* - Chronic hepatitis C and combination therapy had an enormous impact on the lives of the patients, their partners and families. The illness and treatment had significant physiological effects that had an impact on QoL; however, the social and psychological consequences of living with a highly stigmatised disease with an unknown course and outcome cannot be underestimated. Patients reported enduring struggles with their finances, lack of a holistic care approach from services, and fears of a threatened future (risk of complications of hepatitis C and lingering effects of treatment). *Domains*: practical, physical, psychological

Janke et al (2008)[22] USA	Hepatitis C (40 patients)	*Focus groups* - A structured discussion guide covered questions about treatment, and the decision-making process. Demographic and self-reported health status were collected via self- reported questionnaire.	*Patients concerns* - Patients reported a remarkable level of emotional volatility that was associated with reduced impulse control, anger, and feelings of sadness and depression. Participants also reported stigmatization, communication difficulties related to their HCV diagnosis from providers/social peers, and feelings of isolation. *Domains*: psychological
Ng et al (2013)[30] Malaysia	Hepatitis B (44 patients)	*Focus groups* - Open ended questions about health care experiences (at diagnosis/follow-up), physical, psychological, and social impact of hepatitis B; and health care needs	*Patients experiences and needs* - Patients' needs at diagnosis include desire for emotional support and information. Patients wanted to know more about the disease (transmission, complications, treatment, and prognosis), however, information was not easily accessible. They also reported a wide variation in how patients were counselled and managed. *Domains*: psychological, informational/educational
Trelor et al (2010)[36] Australia	Hepatitis C (24 patients)	*Semi-structured interviews* - Themes included HCV and tests, timing/reason for HCV testing, explanation at diagnosis/referrals, attitudes, awareness, readiness/willingness to undertake treatment, and changes in risk practices.	*Patients experiences* - Overall, the HCV diagnosis experience of participants was poor. Participants reported confusion in relation to HCV tests performed and the implications of test results. Post-test discussions were inadequate – there was a reported lack of information, support and referral provided to participants. *Domains*: informational/educational, patient care and support
Brunings et al (2013)[32] Canada	Hepatitis C (21 patients)	*Focus groups* - Questions not described. *Concept mapping methodology* was used.	*Patients perspectives of care* - Four main themes accounted for most of the statements by participants: communication, professional competence, education/information, and continuity of care. Participants emphasized the importance of being treated holistically, receiving HCV education and information was critical to their ability to manage disease. *Domains*: informational/educational
Hill et al (2014)[29] England	Hepatitis C (23 patients)	*Unstructured interviews* – Interviews began with an open-ended question 'Can you tell me how it has been for you, living with hepatitis C?'. *Descriptive phenomenological methodology* was used.	*Patients experiences* - Experiences of diagnosis were frequently disappointing. Many were told insensitively and felt poorly prepared; this lack of support, advice and information negatively impacted on how they felt about themselves. A lack of practical advice, information and support dominated people's experiences. This created difficultly when trying to achieve recommended lifestyle changes or gain any sense of control, knowledge or understanding of the condition. Most felt uncertain about how to manage the disease and feared disease progression/health decline. *Domains*: informational/educational, patient care and support
Burnham et al (2014)[27] USA	Chronic liver disease (13 patients)	*Focus groups* - Open-ended questions regarding patients' beliefs of causes of chronic liver disease, risk beliefs, attitude towards themselves, towards patients with chronic liver disease and towards prevention, perceived benefits of healthy behaviours and risk of liver disease, and barriers to care. The *Health Belief Model* constructs were used.	*Knowledge and beliefs* - General lack of knowledge about CLD (causes and risks, screening, disease symptoms, and available treatments) was the most common response. When asked to share how they felt about having CLD, patients reported realistic attitudes and emotions, discriminate sharing of their diagnosis, negative medical side effects, fatalism, and general negativity. The most commonly reported barriers to treatment included: lack of or inadequate health insurance, cost of care, general lack of knowledge (about symptoms and outcomes), negative attitudes and emotions, and low economic status. *Domains*: informational/educational, practical
Conrad et al (2006)[45] Australia	Hepatitis C (70 patients)	*Focus groups* and individual in-depth interview - 13 guiding questions were use in semi-structured interviews to elicit open-ended discussion. *Grounded-theory* methodology was used.	*Psychosocial factors and QoL* - Uncertainty related to disease progression and transmission of the HCV, as well as fear and anxiety about stigma and discrimination were common experiences among HCV patients. *Domains*: psychological

* Some details about study methods were obtained from M Harris thesis[62]

Table 3. Domains of supportive care needs and commonly reported specific need items reported by patients included four studies which used a needs assessment tool to collect data

Author	*Diseased group*	*Domains*	*Need items commonly reported by study participants*
Balfour et al [31]	Hepatitis C	Information/education needs	• 52% rated their current knowledge of liver disease as being inadequate • 91% regarded receiving information about HCV as 'important/very important'
		Patient care and support	• 31% were very dissatisfied/dissatisfied with access to specialists services (e.g. pharmacist, psychologists) • Percentages regarding access to services as 'important-very/important': 76% HCV drug plans, 68% psychological counselling, 66% nutritionist, 63% pharmacist, 63% support for family/partners, 48% support groups
Zandi et al [37]	Cirrhosis		The study assessed patients' educational needs. Below is the percentage of patients reporting need for:
		Information/education needs	• 65% curative ways in cirrhosis (being treatable/not treatable); • 45% routes of transmission as well as diagnostic tests
		Physical needs	• 70% controlling or reducing abdominal distention • 65% ways of controlling fatigue • 60% principles of care and proper medications • 50% controlling pruritus and fatigue
		Psychological	• 55% worry
Chang et al [21]	Hepatitis C	Practical support	• 47.8% reported moderate to severe financial stress
Jennings et al [26]	Hepatitis C	Information/education needs	• 71% disagreed that there was an adequate amount of educational material about hepatitis C in the clinic • 67% thought that their support person was interested in receiving educational materials about hepatitis C • 78% thought that their support person would be interested in participating in educational sessions
		Patient support	• 61% would be interested in joining a regular support group at the clinic • 42% thought that it would be beneficial for their support person to join a caregiver support group
Grogan et al[38]	Hepatitis C		The study assessed patients' perceptions of support received from the nurse specialist during HCV treatment. There were low levels of disagreement that 'The nurse provided …':
		Information/education needs	• 17% advice on how to maintain a healthy balanced diet • 14% advice on sleep management • 12% advices on energy conservation • 12% advice on physical exercise
		Patient support	• 14% information on support groups that were available to me • 18% ongoing support post completion of treatment



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PRISMA 2009 Checklist

NOTE – page numbers refer to the revised document without marked changes (clean copy)

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Not applicable
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	5
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5-6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Not applicable

PRISMA 2009 Checklist

Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	6

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	11-12 (Discussion)
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Not applicable
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Figure 1, page 18
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Tables 1 and 2 (pages 19-23)
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Tables 1 and 2 (pages 19-23)
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Not applicable
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Not applicable
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	11-12 (Discussion)
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Not applicable
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	9-11
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	11-12
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	12
FUNDING			

PRISMA 2009 Checklist

Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	12

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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