



## RESEARCH

# Palliative care for cirrhosis: a UK survey of health professionals' perceptions, current practice and future needs

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## ABSTRACT

**Objective** To determine the knowledge and practice patterns of a UK cohort of relevant healthcare professionals (HCPs) about delivering palliative care in cirrhosis, and to inform priorities for future research.

**Design** An on-line questionnaire survey with closed and open responses.

**Setting** HCPs identified from the mailing list of special interest groups in hepatology and gastroenterology (liver), general practice and specialist palliative care (SPC) across the UK.

**Results** Of the 6181 potential contacts identified, 517 HCPs responded. Most believed a role exists for SPC in caring for people with cirrhosis, but many SPC HCPs felt ill prepared to provide good care to those facing death. Further training was needed in managing liver-related symptoms, symptom control and end of life issues. All HCP groups wished to increase community provision of palliative care support, but many general practitioners felt unable to manage advanced cirrhosis in the community. There were differences in the optimal trigger for SPC referral with liver HCPs less likely to refer at symptom deterioration. Prognostication, symptom management and service configuration were key areas identified for future research.

**Conclusions** All who responded acknowledged the role of SPC in caring for those dying with cirrhosis and need for further training to improve confidence and enable joint working between SPC, general practice and liver teams. Low response rates make it difficult to generalise these findings, which require further validation.

## INTRODUCTION

Liver disease is the third largest cause of premature death in the UK<sup>1</sup> and accounts

for 2% of deaths in England.<sup>2</sup> The increases in alcohol consumption, viral hepatitis and obesity in the UK suggest that liver disease is a growing public health problem.<sup>3</sup> People with end stage liver disease (cirrhosis) have supportive and palliative care needs.<sup>4–7</sup> The recent Lancet Commission report on improving liver care acknowledges the importance of primary care and hospital services in providing high quality care for people with cirrhosis.<sup>1</sup> Nevertheless it skims over the care issues arising for those who are dying of liver disease. At present, this care is poor,<sup>8</sup> most deaths from cirrhosis occur in hospital<sup>2</sup> and more work is needed to understand how end of life (EoL) care for people with cirrhosis can be managed well.

The Royal Free Hospital London (tertiary centre) liver team and the Marie Curie Palliative Care Research Department, University College London held a national meeting of health professionals interested in these aspects of liver care in November 2013. The group recommended a national survey of primary, secondary and tertiary care providers to explore current attitudes and practices, and to identify training needs, ideas for service improvement and research priorities. Here we report the findings of this survey.

## METHODS

We developed an online survey (see online supplementary appendix ii) to explore (A) referrals to specialist palliative care (SPC)—numbers, reasons, timing; (B) health professionals' training needs;

(C) ideas for improved EoL care in cirrhosis; (d) areas for future research.

The link to the survey and an invitational email were sent to (1) those working in liver teams; (2) those working in SPC; (3) general practitioners (GPs) with an interest in gastroenterology. To identify potential participants, we gained the cooperation of key professional organisations who contacted their members with two reminders at 3-week intervals (see online supplementary appendix ii):

1. Liver teams: (A) the British Society for Gastroenterology (BSG) (liver section); (B) the British Association for the Study of the Liver (BASL) (doctors and nurses); (C) the British Liver Trust Nurses Forum; (D) Royal College of Nurses (gastroenterology forum) and (E) the London Liver group.
2. SPC teams: (A) Association of Palliative Medicine of Great Britain and Ireland; (B) the National Nurse Consultant Group (palliative care); (C) Clinical and nursing leads in SPC units ('Help the Hospice' database).
3. General Practitioners: the Primary Care Society for Gastroenterology.

We used descriptive statistics to explore data on responders' demographics, referrals to SPC, training needs in caring for people with cirrhosis and key areas for research. Open-ended questions were analysed using frequency content analysis after which we triangulated quantitative data and open responses. Statistical analyses were conducted using Stata V.13.0<sup>9</sup>

## RESULTS

A maximum of 6181 contacts received the online survey and we received data from 514 respondents: 195 liver professionals, 273 SPC and 46 general practice professionals (response rates 4%, 23% and 10%, respectively; overall response rate 8%). A breakdown of responders by specialty and discipline (see online supplementary appendix iii) showed that most were from a medical background (306/514) and worked in SPC (273/514). Analysis by National Health Service (NHS) Region (see online supplementary appendix iv) showed responses across the UK, with most from the north of England.

### Referrals to SPC

Nearly all SPC professionals (97%; 262/269) had accepted referrals from liver teams for patients with cirrhosis near the EoL; most (86%; 232/269) had been referred at least one patient during the last year. However, patients with cirrhosis made up a median 1% of SPC workload (IQR: 1–2, range: 0–20).

Numbers of referrals reported by liver professionals (table 1) to SPC were low; most referred fewer than 11 patients a year (table 1) and these were more likely to be inpatients than outpatients (table 1). Referrals from GPs were equally low, with only 19% (44/228) of SPC professionals receiving referrals for patients with cirrhosis, and no more than five patients per year.

Reasons for referrals to SPC, from liver professionals and GPs were symptom control, terminal care and the need for hospice admission (table 2). Most liver and SPC professionals identified recognition of the EoL as the key trigger for SPC referral in cirrhosis. SPC professionals also considered onset of deterioration in symptoms and recurrent hospital admissions as appropriate triggers for referral to their service (table 2).

### EoL care for cirrhosis in primary care

Over half of GPs (55%; 22/40) felt their patients could be managed in the community, but only 24% (10/41) had actually received a referral from liver centres. Confidence in managing patients in the community was attributed to good support from community nursing or local SPC teams. Barriers were the perceived unpredictable nature of cirrhosis and patients' social circumstances (especially those actively drinking).

### Skills levels and training needs

Although most SPC professionals (60%; 147/246) and GPs (54%; 22/41) were confident in their skills and knowledge to manage people with cirrhosis, all recognised the need for further training on issues specific to liver disease; liver professionals and GPs identified symptom control and training in EoL issues as the two key topics to address (table 3).

Open response data showed that liver professionals need improved awareness of supportive care including symptom control at EoL, advanced communication skills in discussing prognosis with patients and families, and help to shift the emphasis of care from an interventionist to a more supportive role; liver personnel and GPs need improved knowledge on how SPC could support them to care for people with advanced cirrhosis and the processes of accessing community SPC.

Liver professionals felt that primary care and SPC needed specific training in understanding the

**Table 1** The number of patients referred to specialist palliative care (SPC) from liver professionals by type of care and diagnosis

	Number referred by liver professionals to SPC				Number of referrals received by SPC	
	Inpatient care		Outpatient care		Cirrhosis	
	N	Per cent	N	Per cent	N	Per cent
None	7	4	71	44	37	14
1–5	45	28	51	32	158	59
6–10	49	30	14	9	45	17
11–20	38	24	16	10	25	9
21+	22	14	9	6	4	1
Total	161		161		269	

**Table 2** Referrals to SPC for cirrhosis: reasons and timings

	Liver professionals		General practice		Specialist palliative care	
	N	Per cent	N	Per cent	N	Per cent
Reasons for referral to SPC by specialty						
Symptom Control	137	88	12	75		
End of life issues	138	89	12	75		
Hospice/palliative care	123	79	9	56		
Social/family	73	47	8	50		
Bereavement support	39	25	3	19		
Ethical decision making	11	7	2	13		
Communicating difficult news	7	5	1	6		
Other	3	2	2	13		
Total	155		16			
Most appropriate times for referral to SPC by specialty						
End-stage/end of life	158	89			223	91
Deterioration in symptoms	105	59			198	81
Recurrent hospital admissions	111	63			180	74
Consideration of referral to tertiary liver centre, for example, for liver transplant assessment	32	18			59	24
Initial diagnosis	12	7			21	9
Other	13	7			0	0
Total responses	177				245	

SPC, specialist palliative care.

unpredictable trajectory of cirrhosis and the impact of impaired liver function on medication metabolism. SPC professionals recognised their training needs on liver specific issues such as the assessment and management of decompensated liver disease (86%; 198/231), pharmacology in cirrhosis (79%; 182/231), likely illness trajectory in cirrhosis (68%; 159/231), advances in the management of recurrent ascites

(68%; 158/231) and information on prognostication (68%; 158/231).

#### Initiatives for improving EoL care in cirrhosis

Liver professionals suggested enhanced provision of palliative care whereas most SPC professionals prioritised improved liaison between secondary and primary care. GPs also favoured improved liaison (33/

**Table 3** Comparison of training needs and initiatives to improve end of life care for patients with cirrhosis by specialty

	Liver professionals		General practice		Specialist palliative care	
	N	Per cent	N	Per cent	N	Per cent
Comparison of training needs of liver and general practice professionals						
Symptom control	101	66	31	91		
End of life issues	101	66	18	53		
Ethical decision making	55	36	9	27		
Bereavement counselling	52	34	7	21		
Social/family	45	29	8	24		
Communicating difficult news	40	26	8	24		
Other	4	3	2	6		
Total	154		34			
Initiatives that would improve end of life care for patients with cirrhosis by specialty						
Improved liaison between secondary and primary care	69	39			90	37
Improved provision of specialist palliative care	86	48			64	26
More education opportunities in specialist liver units	21	12			71	29
Other	3	2			20	8
Total	179				245	

39; 85%), more educational opportunities in specialist liver units (26/39; 67%) and improved provision of SPC (18/39; 46%).

Analysis of open responses from 137/195 liver professionals (88 doctors and 49 nurses), identified specific and more detailed improvements which could be made to the delivery of EoL care, in reconfiguring services and improving clinicians' skill base:

- i. *Earlier SPC involvement*: Significant time points in the patient journey, such as assessment for liver transplantation, repeated hospital admissions or onset of need for regular paracentesis could prompt SPC referral. Understanding of appropriate triggers and markers of deterioration may support health professionals to recognise when symptomatic patients would benefit from SPC which can be delivered in parallel with more aggressive treatments.
- ii. *Better community provision of liver services*: Better liaison between liver teams, primary care and SPC could enable patients to receive community nursing and paracentesis, enhanced by hospice outpatient services to provide support and symptom control as required, which may reduce emergency admissions to hospital.
- iii. *Development of clearer care pathways*: Understanding of care pathways would guide liver professionals to identify which patients with cirrhosis had reached the EoL phase and what to do next. An EoL pathway would provide a framework to consider withdrawal of medication and opportunities for patients and those close to them to access counselling and support.
- iv. *Ways of improving communication skills*: Liver professionals recognised that patients and family members had little understanding about their disease or its severity. At the same time, they themselves lacked confidence in having honest discussions about these topics. Sharing of information about the disease, its likely trajectory and symptoms might allow more open discussions about future care, and choices about place of care, interventions and services available.

### Key priorities for future research

Open responses on research priorities were received from 221 participants. Table 4 highlights the key findings. (1) Disease specific information—all groups highlighted the need to understand: symptom control (in particular how best to manage recurrent ascites, pruritus and encephalopathy, and opioid pharmacology when liver function is compromised), and prognostication (in particular identifying the earliest point when deterioration is irreversible); (2) Service models—SPC and liver professionals prioritised exploring whether palliative care adds value (economical or quality of life), the best way of managing patients in the community to avoid hospital admissions, and the evaluation of an early palliative care intervention versus usual care; understanding would be enhanced by exploring the experience of patient and their family members in (A) their understanding of prognosis and their own wishes about future preference of care (B) what specific needs they have as a result of the illness.

### DISCUSSION

This is the first UK-based national survey on the perspectives of health professionals responsible for delivering care to people with cirrhosis who are facing death.

Referrals from liver teams to SPC are relatively uncommon and usually made late in the illness when death is very close. Understanding of the role of SPC was poor. All health professionals, irrespective of specialty, recognised that they required further training to improve their skills in caring for people with advanced cirrhosis. For SPC, this training centred on increasing awareness of specific issues involved in managing patients with liver disease, such as the implications of impaired liver function on symptom control and medication use. For liver professionals, future training should support them to identify

**Table 4** Research themes identified by discipline

	SPC (n=114)	Liver professionals (n=93)	General practice (n=14)	Total (n=221)
Disease-specific information				
Symptom management	59	35	6	100
Prognosis	23	18	1	42
Needs assessment	11	15		26
Epidemiology	6			6
Psychosocial impact	4			4
Stakeholder understanding of liver disease	2	1		3
New treatments		3		3
Service model approaches				
Optimal service structure	14	5	2	21
Evaluating added value of palliative care	8	5		13
Barriers/improving access to SPC	8			8
Education				
How to improve management of liver patients	3	3		6

SPC, specialist palliative care.

patients for whom cure is no longer likely and to shift the emphasis of care from burdensome interventions to a more supportive care role. All groups recognise the need for collaborative working earlier in the illness so that discussions about the future can be raised at key points such as transplant assessments or exacerbations of symptoms. We identify symptom management, prognostication, and overall service structure as key areas for future research.

Our findings support key recommendations from a recent review of palliative care in end stage liver disease including better collaboration between liver health professionals and SPC and the identification of potential triggers for palliative care consultations.<sup>4</sup> Our work also supports recommendations from the Lancet Commission report on the role of primary care in liver disease and the need for community hepatology posts for GPs to work more closely with liver professionals.<sup>1</sup>

Lessons can be learned from research on the management of people with other advanced non-malignant diseases. In the UK, in advanced heart failure<sup>10</sup> and advanced kidney disease<sup>11</sup> shared care approaches have been developed involving multiprofessional collaboration between primary care and specialist services, and SPC input when required. The key elements are sensitive communication with patients and their families especially earlier in the illness, holistic assessment and care involving multiprofessional working across boundaries. While planning at a national level is not easy, on a local level, it would be important to improve education and coordination of service provision between liver specialists, GPs and SPC professionals.

We note the very low response rate to our survey, which currently limits the generalisability of our findings which require further validation. This low response rate may be due to limitations in our methods. Data protection issues prevented us from accessing mailing lists directly, which was the responsibility of the special interest groups, so the delivery of the mail-out was inconsistent. Email circulations may have been incomplete, and overlap in the membership of our targets groups (eg, BASL and the BSG liver section) may underestimate the response rate. However, our highest response rate of 24% achieved from SPC is still lower than the 33%<sup>12</sup> considered standard for on-line surveys. It is possible, but we cannot be certain that there is currently a reluctance to consider issues of EoL care among those working with people with cirrhosis. However, it is likely that the potential benefits of a palliative approach to care, either early and in parallel to more aggressive treatments, or in managing the terminal phase are not yet recognised.

Our response rates might have been higher had the research team been able to access directly the mailing list from each of the different organisations. This

would have enabled the research team to check for duplicate participants and personalise the invitation letter before sending out to each health professional. We might also have been able to ensure that each non-responding professional received up to two follow-up emails to encourage their participation in the survey. Furthermore, if finances were available, we would have given participants on receipt of their response a non-monetary incentive such as Amazon gift cards to be used for educational purposes. Some of these initiatives have been identified in a Cochrane review as increasing response rates in electronic surveys.<sup>13</sup>

## CONCLUSION

While there are plans to address the high mortality from liver disease, these initiatives will be slow to demonstrate any impact on mortality figures and many will continue to die with high symptom burden and little care planning at the EoL. The financial challenges faced by the NHS over the next years as outlined by the NHS England Chief Executive<sup>14</sup> confirm that we cannot expect significant financial support to address the problem. We recommend research that takes account of economic costs and benefits, and improves our understanding of the needs of patients with cirrhosis and their families, enhances communication with those at risk of death, enables smoother links across care boundaries, and informs training for all professionals involved in treatments and care.

## Key messages

### What is already known about this subject?

- ▶ There is increasing number of deaths from liver disease in the UK.
- ▶ Most deaths from liver disease occur at a relatively young age and in patients with a higher degree of social deprivation.
- ▶ Access to palliative care for people with end stage liver disease (cirrhosis) has been limited and most deaths from cirrhosis occur in hospital.

### What this paper adds?

- ▶ This study is the first UK national survey to specifically explore current attitudes and practices of different health professionals caring for patients with cirrhosis near the end of life, using on-line survey methodology.
- ▶ We identify symptom management, prognostication, and overall service structure as key areas for future research.

### How might it impact on future clinical practice?

- ▶ Increase collaborative working between liver professionals and specialist palliative care to meet the needs of patients with end stage liver disease.

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**REFERENCES**

- Williams R, Aspinall R, Bellis M, *et al.* Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis. *Lancet* 2014;384:1953–97.
- Effong K, Osinowo A, Pring A, Verne J. Deaths From Liver Disease: Implications for End of Life Care in England. National End of life Care Intelligence Network, Leicester. 2012 <http://tinyurl.com/bogzgsu> (accessed 13 Feb 2015).
- National Health Service Right Care. *Liver disease: the NHS atlas of variation in healthcare for people with liver disease*. 2013. <http://www.rightcare.nhs.uk/index.php/atlas/liver-disease-nhs-atlas-of-variationin-healthcare-for-people-with-liver-disease> (accessed 22 Jan 2015).
- Potosek J, Curry M, Buss M, *et al.* Integration of palliative care in end-stage liver disease and liver transplantation. *J Palliat Med* 2014;17:1271–7.
- Roth K, Lynn J, Zhong Z, *et al.* (2000). Dying with end stage liver disease with cirrhosis: insights from SUPPORT. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc* 2000;48(5 Suppl): S122–30.
- Sanchez W, Talwalker JA. Palliative care for patients with end-stage liver disease ineligible for liver transplantation. *Gastroenterol Clin North Am* 2006;35:201–19.
- Hansen L, Sasaki A, Zucker B. End-stage liver disease: challenges and practice implications. *Nurs Clin North Am* 2010;45:411–26.
- National Confidential Enquiry into Patient Outcome and Death (NCEPOD). *Alcohol-related liver disease: measuring the units*. 2013. <http://www.ncepod.org.uk/2013arld.htm> (accessed 13 Feb 2015).
- StataCorp. 2013. Stata Statistical Software: Release 13. College Station, TX: StataCorp LP.
- Scottish Partnership for Palliative Care. Living and dying with advanced heart failure: a palliative care approach. Edinburgh. 2008. <http://www.palliativecarescotland.org.uk/content/publications/HF-final-document.pdf> (accessed 20 Feb 2015).
- NHS Kidney Care. (2009b). End of life care in advanced kidney disease: a framework for implementation. <http://www.npc.org.uk/sites/default/files/EndOfLifeCareInAdvancedKidneyDisease.pdf> (accessed 13 Feb 2015).
- Nulty DD. The adequacy of response rates to online and paper surveys: what can be done? *Assess Eval Higher Educ* 2008;33:301–14.
- Edwards PJ, Roberts I, Clarke MJ, *et al.* Methods to increase response to postal and electronic questionnaires. *Cochrane Database Syst Rev* 2009, (3):MR000008. DOI:10.1002/14651858.MR000008.pub4.
- NHS England. *Five year forward view* 2014. <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> (accessed 6 Feb 2015).

## Appendix i: Paper version of the on-line survey titled “National e-survey – Provision of end of life care in patients with cirrhosis

Thank you for taking the time to answer our survey. Please answer the questions as accurately and thoroughly as you can.

### Demographics

#### 1. What is your professional background?

- Doctor
- Nurse
- Allied Health Professional
- Other  Please specify: \_\_\_\_\_

#### 2. In which geographical (NHS) Regions do you work?

- England
- North of England
- Midlands and East of Anglia
- South of England
- London
- Wales
- Scotland
- Northern Ireland

What Trust do you work for? Name of Trust: \_\_\_\_\_

### **What is the name of the Trust that you work in**

#### 3. Do you work in

- Primary Care  [if clicked, will take user directly to GP section]
- Hepatology  [if clicked, will take user directly to liver specific section]
- Gastroenterology  [if clicked, will take user directly to liver specific questions]
- Specialist palliative care  [if clicked, will take user to 3(a)].

#### 3a. Do you work in:

- Hospital
- Hospice
- Community

[After options in 3a answered, then take user to SPC section]

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SPC – Specific Questionnaire

4a. In principal, do you accept referrals for patients with cirrhosis near the end of life from liver teams?

Yes / No

---

b) How many patients did you see with a diagnosis of end stage liver disease in the last year?

(Please just give a rough estimate)

- |       |                          |                             |
|-------|--------------------------|-----------------------------|
| None  | <input type="checkbox"/> | If this box ticked, go to 5 |
| 1-5   | <input type="checkbox"/> |                             |
| 6-10  | <input type="checkbox"/> |                             |
| 11-20 | <input type="checkbox"/> |                             |
| 21 +  | <input type="checkbox"/> |                             |

c) What percentage of your patient load has a principal diagnosis of cirrhosis/liver disease?

(Please just give a rough estimate) \_\_\_\_\_ %

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d).Did any of these referral originate from GPs?

Yes [if ticked, go to 5e]/ No [if ticked, go to 5f]

e) How many? (Please just give a rough estimate) \_\_\_\_\_

---

Of all referrals in the last year:

f) How many were for hospital Specialist Palliative Care? (Please just give a rough estimate)

- |       |                          |
|-------|--------------------------|
| None  | <input type="checkbox"/> |
| 1-5   | <input type="checkbox"/> |
| 6-10  | <input type="checkbox"/> |
| 11-20 | <input type="checkbox"/> |
| 21 +  | <input type="checkbox"/> |

g) How many were for specialist palliative care at home? (Please just give a rough estimate)

- |       |                          |
|-------|--------------------------|
| None  | <input type="checkbox"/> |
| 1-5   | <input type="checkbox"/> |
| 6-10  | <input type="checkbox"/> |
| 11-20 | <input type="checkbox"/> |
| 21 +  | <input type="checkbox"/> |

h) How many were for hospice admission? (Please just give a rough estimate)

- |      |                          |
|------|--------------------------|
| None | <input type="checkbox"/> |
|------|--------------------------|

- 1-5
- 6-10
- 11-20
- 21 +

5. What were the reasons for patients with cirrhosis (near the end of life) being referred to Specialist palliative care by liver teams/General Practitioners?

Tick all reasons that apply:

- Symptom Control
- End of life issues
- Hospice/Palliative Care
- Communicating difficult news
- Ethical decision making
- Social/family
- Bereavement support
- Other  If other ticked, List main reason [Open text]: \_\_\_\_\_

6. Do you believe Specialist Palliative Care services have a role in patients with cirrhosis?  
Yes/No/Don't know

7. If you answered yes to question 6: In your view, when is the most appropriate time for referral? (tick all that apply)

Tick all reasons that apply:

- Initial diagnosis
- Deterioration in symptoms
- Consideration of advanced liver management
- Recurrent hospital admissions
- End-stage/end-of-life

8. If you answered no to question 6: Why not? (tick all that apply)

- lack of resources
- lack of beds (including respite bed facilities)
- implications for staff training
- organisational decision
- lack of expertise
- none/few referred (by liver team or GP)
- Cardiac professionals can do this
- Unable to provide specialised liver therapy

Other  If other ticked, List main reason [Open text]: \_\_\_\_\_

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9. Do you feel you have the appropriate skills and knowledge to look after this group of patients?  
Yes/No

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10. Please list what training (if any) you would need to improve your skills and knowledge in caring for this group of patients with cirrhosis.

Tick all reasons that apply:

Education on assessment and management of decompensated liver disease

Up to date information about advances in managing recurrent ascites

Education on pharmacology in cirrhosis

Information on prognostication

Likely illness trajectory in cirrhosis

Other  If other ticked, List main reason [Open text]: \_\_\_\_\_

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11. What do you think are the barriers to providing care to this patient group?

Tick all reasons that apply:

High frequency of complex and difficult social circumstances

Lack of education of SPC providers on managing cirrhosis patients

Lack of education of liver teams in end of life care

Lack of possibilities for joint working between SPC/GP/liver teams

Other

If other ticked, List main reason [Open text]: \_\_\_\_\_

---

12. Which of the following do you think would improve end of life care for patients with cirrhosis?

Tick your main answer:

Improved liaison between secondary and primary care

Improved provision of specialist palliative care

More education opportunities in specialist liver units

Other  Please specify what: \_\_\_\_\_

---

10a. Have you received any referrals for patients with hepatocellular carcinoma? Yes//No

Yes [if ticked, go to 10b]/ No [if ticked, go to 11]

---

b) How many referrals for patients with hepatocellular carcinoma did you receive in the last year?  
(Please just give a rough estimate)

- |       |                          |
|-------|--------------------------|
| None  | <input type="checkbox"/> |
| 1-5   | <input type="checkbox"/> |
| 6-10  | <input type="checkbox"/> |
| 11-20 | <input type="checkbox"/> |
| 21 +  | <input type="checkbox"/> |
- 

11. What are your key priorities for research in end stage liver disease?

OPEN TEXT

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**Thank you for completing this questionnaire**

**Liver Teams**

4a) Do you refer any of your patients to Specialist Palliative care? Yes /No

Yes [if ticked, go to 4b]/ No [if ticked, go to 4d]

b) How many patients from in-patient care did you refer to specialist palliative care in the last year?

(Please just give a rough estimate)

- None
- 1-5
- 6-10
- 11-20
- 21+

c) How many from out-patient care in the last year?

(Please just give a rough estimate)

- None
- 1-5
- 6-10
- 11-20
- 21 +

If responses to 4[b] and 4[c] were BOTH ticked as None, go to 5 [ii]

Otherwise, go to 5 [i]

---

5 i. What are the reasons for referral to SPC?

*Tick all reasons that apply:*

- Symptom Control
- End of life issues
- Hospice/Palliative Care
- Communicating difficult news
- Ethical decision making
- Social/family
- Bereavement support
- Other

If other ticked, list main reason [Open text]: \_\_\_\_\_

---

5 ii) Patients were not referred to specialist palliative care for the following reasons;

*Tick all reasons that apply:*

- Patients were not identified as at the EOL
  - The liver team were able to manage the patients' needs
  - Palliative care do not accept referrals for liver patients
  - No palliative care service to refer to
  - Other  Please specify: \_\_\_\_\_
- 

6. Do you believe Specialist Palliative Care services have a role in patients with cirrhosis?  
Yes/No/Don't know

7. If you answered yes to question 6: In your view, when is the most appropriate time for referral? (tick all that apply)

Tick all reasons that apply:

- Initial diagnosis
- Deterioration in symptoms
- Consideration of advanced liver management
- Recurrent hospital admissions
- End-stage/end-of-life

8. If you answered no to question 6: Why not? (tick all that apply)

- lack of resources
  - lack of beds (including respite bed facilities)
  - implications for staff training
  - organisational decision
  - lack of expertise
  - none/few referred (by liver team or GP)
  - Cardiac professionals can do this
  - Unable to provide specialised liver therapy
  - Other  If other ticked, List main reason [Open text]: \_\_\_\_\_
- 

9. How could care for patients with cirrhosis at the end of life be improved?

Open TEXT

---

10. Please list what training (if any) you would need to improve your skills in caring for this group of patients with cirrhosis near the end of life.

*Tick all reasons that apply:*

- Symptom Control
  - End of life issues
  - Communicating difficult news
  - Ethical decision making
  - Social/family
  - Bereavement counselling
  - Other  Please specify what: \_\_\_\_\_
- 

11. Which of the following do you think would improve end of life care for patients cirrhosis?

- Improved liaison between secondary and primary care
  - Improved provision of specialist palliative care
  - More education opportunities in specialist liver units
  - Other  Please specify what: \_\_\_\_\_
- 

12. What are your key priorities for research in end stage liver disease?

OPEN TEXT

---

**Thank you for completing this questionnaire**

**Primary Care**

- 4) a) Do you receive referrals from liver centres for palliative care/end of life care? Yes/No  
b) Do you routinely provide end of life care for your patients? Yes/No  
c) Do you take part in a GSF? Yes/No
- 

5) Do you feel you have the skills to manage patients with cirrhosis near the end of life in the community? Yes/No

---

6) Have you referred ANY patients with cirrhosis to specialist palliative care? Yes/No

If Yes, go to 7; If No, go to 9

---

7) For those who have referrals to Specialist PC, reasons for your referral?

*Tick all reasons that apply:*

- |                              |                          |   |
|------------------------------|--------------------------|---|
| Symptom Control              | <input type="checkbox"/> |   |
| End of life issues           | <input type="checkbox"/> |   |
| Hospice/Palliative Care      | <input type="checkbox"/> |   |
| Communicating difficult news | <input type="checkbox"/> |   |
| Ethical decision making      | <input type="checkbox"/> |   |
| Social/family                | <input type="checkbox"/> |   |
| Bereavement support          | <input type="checkbox"/> |   |
| Other                        | <input type="checkbox"/> | If other tick, List main reason(s): _____ |
- 

8) How many patients with cirrhosis have you referred in the last year? (Please just give a rough estimate)

- |       |                          |
|-------|--------------------------|
| None  | <input type="checkbox"/> |
| 1-5   | <input type="checkbox"/> |
| 6-10  | <input type="checkbox"/> |
| 11-20 | <input type="checkbox"/> |
| 21    | <input type="checkbox"/> |
- 

9) a) Do you think that patients with cirrhosis can be adequately managed in the community?  
Yes/No/Don't Know

b) Please give a reason for your responses?

Open TEXT

---

10) Please list what training (if any) you would need to improve your skills in caring for patients with cirrhosis near the end of life.

*Tick all reasons that apply:*

- Symptom Control
  - End of life issues
  - Communicating difficult news
  - Ethical decision making
  - Social/family
  - Bereavement counselling
  - Other  Please specify what: \_\_\_\_\_
- 

11. Which of the following do you think would improve end of life care for patients with cirrhosis?

- Improved liaison between secondary and primary care
- Improved provision of specialist palliative care
- More education opportunities in specialist liver units
- Other  Please specify what: \_\_\_\_\_

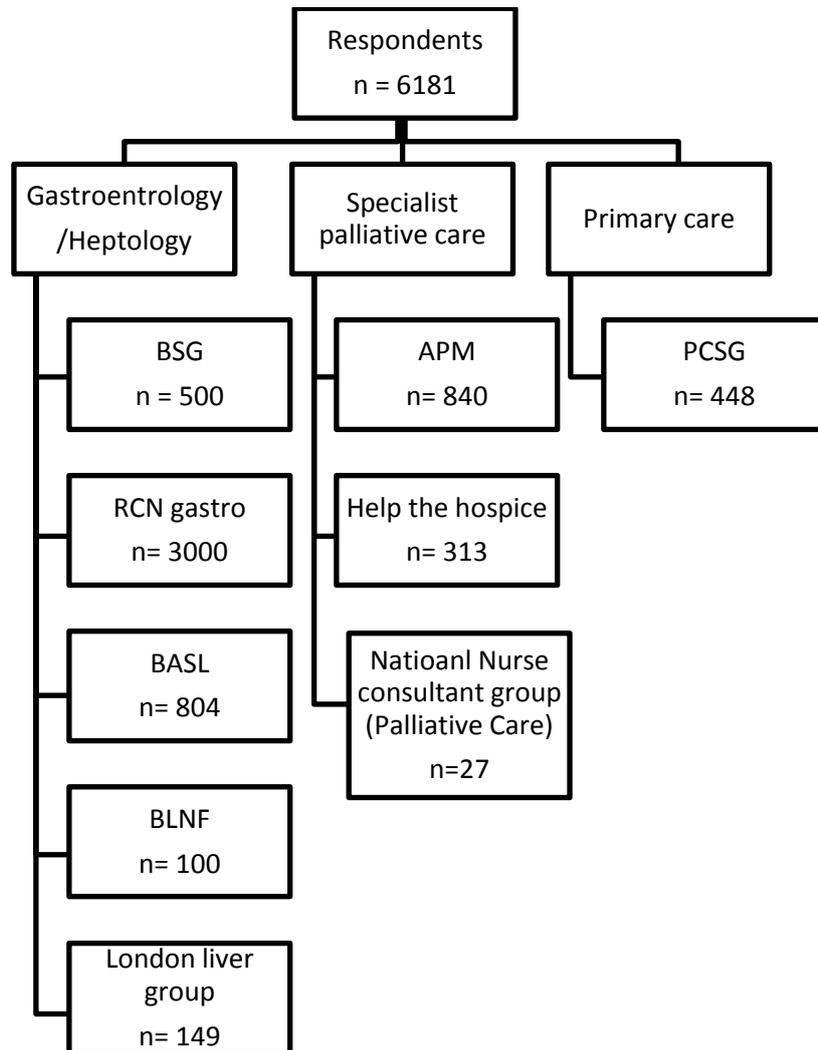
12. What are your key priorities for research in end stage liver disease?

OPEN TEXT

---

**Thank you for completing this questionnaire**

**Appendix ii: Number of potential respondents identified from each organisation by professional group.**



Key:

PCSG - Primary Care Society for Gastroenterology

BASL - British Association Study Liver

BSG - British Society of Gastroenterology – Liver section

BLTNF - British Liver Trust Nurses Forum

RCN - Royal College of Nursing gastro-enterology section

APM - Association for Palliative Medicine

### Appendix iii: Respondents professional background by speciality

Respondents professional background	Respondents Speciality				
	Gastro-entroylogy	Hepatology	Primary Care.	Specialist palliative care.	Total
AHP	0	1	1	5	7
Doctor	55	72	19	160	306
Nurse	42	25	25	106	198
Other	0	0	1	2	3
Total	97	98	46	273	514

#### Appendix iv: Respondents' speciality by site of NHS Region

In which geographical (NHS) Region do you work?	Number (percentage) of respondents				
	Gastro-entriology	Hepatology	Primary Care	Specialist palliative care	Total
London	15 (15)	31 (32)	5 (11)	43 (16)	94 (18)
Midlands and East of England	17 (18)	21 (21)	7 (15)	54 (20)	99 (19)
North of England	33 (34)	15 (15)	22 (48)	100 (37)	170 (33)
Northern Ireland	1 (1)	2 (2)	0 (0)	11 (4)	14 (3)
Scotland	7 (7)	9 (9)	5 (11)	19 (7)	40 (8)
South of England	20 (21)	15 (15)	6 (13)	33 (12)	74 (14)
Wales	4 (4)	5 (5)	1 (2)	13 (5)	23 (4)
Total	97 (100)	98 (100)	46 (100)	273 (100)	514 (100)