

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 Health Care Professionals (HCP) 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: HCP identified from the mailing list of special interest groups in hepatology and gastroenterology (liver), general practice (GP) and specialist palliative care (SPC) across the UK.

Results Of the 6181 potential contacts identified, 517 HCP 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 GPs felt unable to manage advanced cirrhosis in the community. There were differences in the optimal trigger for SPC referral with liver HCP 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 both the role of SPC in caring for those dying with cirrhosis and needs for further training to improve confidence and enable joint working between SPC, GP 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 United Kingdom (UK)¹ and accounts for 2% of deaths in England². The increases in alcohol consumption, viral hepatitis and obesity in the UK suggest that liver disease is a growing public health problem³. People with end stage liver disease (cirrhosis) have supportive and palliative care needs⁴⁻⁷. The recent Lancet Commission report on improving liver care acknowledges the importance of both primary care and hospital services in providing high quality care for people with cirrhosis¹. Nevertheless it skims over the care issues arising for those who are dying of liver disease. At present, this care is poor⁸, most deaths from cirrhosis occur in hospital² 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 Appendix ii – see Supplementary file) to explore a) referrals to specialist palliative care – numbers, reasons, timing; b) health professionals' training needs; c) ideas for improved end of life care in cirrhosis; d) areas for future research.

The link to the survey and an invitational e-mail were sent to (i) those working in liver teams; (ii) those working in specialist palliative care; (iii) General Practitioners (GP) with an interest in gastroenterology. To identify potential participants, we gained the co-operation of key professional organisations who contacted their members with two reminders at three week intervals (Appendix ii – see Supplementary file):

- 1) Liver teams: a) the British Society for Gastroenterology (Liver section); b) the British Association for the Study of the Liver (Doctors and Nurses); c) the British Liver Trust Nurses Forum; d) Royal College of Nurses (Gastroenterology Forum) and e) the London Liver group.
- 2) Specialist palliative care 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 specialist palliative care 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 specialist palliative care, 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 13⁹.

Research ethics approval was received from UCL Ethics committee (3552/002).

Results

A maximum of 6,181 contacts received the online survey and we received data from 514 respondents: 195 liver professionals, 273 SPC and 46 GP professionals (response rates 4%, 23% and 10% respectively; overall response rate 8%). A breakdown of responders by speciality and discipline (see Appendix iii – see Supplementary file) showed that most were from a medical background (306/514) and worked in specialist palliative care (273/514). Analysis by NHS Region (see Appendix iv – see Supplementary file) showed responses across the UK, with most from the North of England.

Provision of specialist palliative care (SPC)

Referrals to SPC

Nearly all SPC professionals (97%; 262/269) had accepted referrals from liver teams for patients with cirrhosis near the end of life; 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 in-patients than out-patients (Table 1). Referrals from General Practice (GP) were equally low, with only 19% (44/228) of SPC professionals receiving referrals for patients with cirrhosis, and no more than 5 patients per year.

Insert Table 1

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 end of life 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).

Insert Table 2

End-of-life 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 specialist palliative care 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 and GP professionals identified symptom control and training in end of life 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 and GP personnel 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 both primary care and SPC needed specific training in understanding the 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).

Insert Table 3

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 (33/39; 85%), more educational opportunities in specialist liver units (26/39; 67%) and improved provision of specialist palliative care (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, both 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 out-patient 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 both 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. (i) 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); (ii) Service models -both 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 both 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.

Insert Table 4 here

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 specialist palliative care are relatively uncommon and usually made late in the illness when death is very close. Understanding of the role of specialist palliative care was poor. All health professionals, irrespective of speciality, 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 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 specialist palliative care and the identification of potential triggers for palliative care

consultations⁴. Our work also supports recommendations from the Lancet Commission report on the role primary care in liver disease and the need for community hepatology posts for GPs to work more closely with liver professionals¹.

Lessons can be learned from research on the management of people with other advanced non-malignant diseases. In the UK, in advanced heart failure¹⁰ and advanced kidney disease¹¹ shared care approaches have been developed involving multi-professional collaboration between primary care and specialist services, and specialist palliative care input when required. The key elements are sensitive communication with patients and their families especially earlier in the illness, holistic assessment and care involving multi-professional 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, general practice and specialist palliative care.

We note the very low response rate to our survey, which currently limits the generalizability 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. E-mail circulations may have been incomplete, and overlap in the membership of our targets groups (e.g. 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%¹² considered standard for on-line surveys. It is possible, but we cannot be certain that there is currently a reluctance to consider issues of end of life care amongst 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 e-mails 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 surveys¹³.

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 end of life. The financial challenges faced by the NHS over the next years as outlined by the NHS England Chief Executive¹⁴ 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.

References

1. 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(9958): 1953-1997.
2. National End of Life Care Intelligence Network. *Deaths from liver disease. Implications for end of life care in England*. Bristol. 2012.
3. 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 January 22, 2015).
4. Potosek J, Curry M, Buss M, Chittenden E. Integration of palliative care in end-stage liver disease and liver transplantation. *Journal of Palliative Medicine*. 2014; 17(11):1271-7.
5. Roth K, Lynn J, Zhong Z, Borum M, Dawson NV. (2000). Dying with end stage liver disease with cirrhosis: insights from SUPPORT. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Journal of the American Geriatrics Society*. 2000; 48(5 Suppl):S122-30.
6. Sanchez W, Talwalker JA. Palliative care for patients with end-stage liver disease ineligible for liver transplantation. *Gastroenterology Clinics of North America*. 2006;35(1):201-19,
7. Hansen L, Sasaki A; Zucker B. End-stage liver disease: challenges and practice implications. *Nursing Clinics of North America*. 2010; 45(3):411-26.
8. 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 February 13, 2015).
9. StataCorp. 2013. Stata Statistical Software: Release 13. College Station, TX: StataCorp LP.
10. Scottish Partnership for Palliative Care. *Living and dying with advanced heart failure: a palliative care approach*. Edinburgh. 2008.
11. NHS Kidney Care National End of Life Care Programme. *End of life care in advanced kidney disease: A framework for implementation*. 2010.
12. Nulty DD. The adequacy of response rates to online and paper surveys: what can be done? *Assessment & Evaluation in Higher Education* 2008; 33(3):301-314.
13. Edwards PJ, Roberts I, Clarke MJ, DiGuseppi C, Wentz R, Kwan I, Cooper R, Felix LM, Pratap S. Methods to increase response to postal and electronic questionnaires. *Cochrane Database of Systematic Reviews* 2009, Issue 3. Art. No.: MR000008. DOI:10.1002/14651858.MR000008.pub4.
14. NHS England. *Five year forward view 2014*. <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> (assessed 6th February 2015).

Table 1: The number of patients referred to specialist palliative care from liver professionals by type of care and diagnosis.

	Number referred by liver professionals to SPC				Number of referrals received by SPC	
	In-patient care		Outpatient care		Cirrhosis	
	N	%	N	%	N	%
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	%	N	%	N	%
<i>Reasons for referral to SPC by speciality</i>						
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			
<i>Most appropriate times for referral to SPC by speciality</i>						
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				0	
Total responses	177				245	

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

	Liver professionals		General Practice		Specialist Palliative Care	
	N	%	N	%	N	%
<i>Comparison of training needs of liver and GP professionals</i>						
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			
<i>Initiatives that would improve end of life care for patients with cirrhosis by speciality</i>						
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	

Table 4: Research themes identified by discipline

	SPC (n=114)	Liver HP (n=93)	GP (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
Psycho-social 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

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Competing interests

None required.

Contributorship statement

JL, VV and SD were responsible for the conception and design of this work, acquisition, analysis and interpretation of data, drafting the work and giving final approval. JB was responsible for the design of the work, data analysis and interpretation, drafting the work and giving final approval. LG, KH, AM, DT and LJ were responsible for the design of this work, revising it critically for important content, and giving final approval.

Data sharing statement

Extra data is available by emailing Dr Joe Low at joseph.low@ucl.ac.uk.

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