Delivering supportive and palliative care in advanced liver disease across the UK. A mixed methods study of Hepatologists' perceptions, current service provision and future challenges.

Public Health England

Protecting and improving the nation's health

B Hudson [1,2] , CA McCune [1] , K Forbes [1,2] and Julia Verne [3] (Presenting) – julia.verne@phe.gov.uk
University Hospitals Bristol NHS Trust [1], University of Bristol [2], Public Health England [3]

Liver Medicine
Bristol Royal Infirmary

INTRODUCTION

- The Lancet Standing Commission on Liver Disease highlighted the dual role of hepatologists in providing high quality supportive and palliative care, in parallel to disease focussed treatments for patients with advanced liver disease[1].
- Data from the annual VOICES study of bereaved relatives indicate that patients with liver disease receive an inferior quality of care when compared to similar life limiting conditions towards the end of life, although the reasons for this are unclear[2].
- We aimed to investigate the attitudes of the UK hepatology community towards the use of supportive and palliative care in advanced liver disease, the current availability and distribution of services across the UK, and the barriers and challenges faced in improving supportive and palliative care for patients with end stage liver disease.

METHODS

- An electronic questionnaire was piloted locally and subsequently distributed to all members of the BSG liver section and BASL. The questionnaire aimed to assess attitudes towards the optimum timing of supportive and palliative care discussions and interventions in liver disease, the current availability of specialist supportive and palliative care services to patients with liver disease, and the clinical and resource barriers faced in improving supportive and palliative care services.
- 10 questionnaire respondents were purposively selected to represent the breadth of hepatology services across the UK (DGH gastroenterologists to quaternary transplant consultants), and invited to take part in an in depth recorded interview addressing the same themes.
- Interviews were digitally recorded, transcribed, and analysed using grounded theory. Analysis was aided by Nvivo™ qualitative analysis software.

RESULTS

Questionnaire

- 308 of 908 questionnaire were returned (33.9% response rate)
- With respect to timing of supportive and palliative care interventions (in response to a series of clinical vignettes – figure 1):
    - Over 90% of respondents considered supportive and palliative care referral and interventions appropriate in cases of diuretic resistant ascites and HCC outside transplant criteria.
    - A minority of respondents considered supportive and palliative care interventions and discussions appropriate in cases where disease trajectory was uncertain (e.g. decompensated HCV cirrhosis or alcoholic hepatitis). This included patients at the point of listing for transplantation.
- With respect to availability of supportive and palliative care services:
    - When comparing cases of severe decompensated disease to advanced hepatocellular carcinoma (HCC), despite similar proportions of respondents considering it clinically appropriate, referral to specialist supportive and palliative care services in routine practice was significantly more common in HCC.
- With respect to barriers to improving supportive and palliative care services (figure 2)
    - Across all respondents, the absence of routine consideration amongst physicians, was considered the most important barrier.
    - Lack of resources and the absence of an established referral framework were more commonly considered a significant barrier amongst physicians working outside transplant centres.
    - The unpredictable clinical trajectory of liver disease was a commonly cited reason for reluctance to introducing supportive and palliative care at an earlier stage in disease management (e.g. at point of decompensation).

Qualitative Analysis

- Five key themes emerged from qualitative analysis of interview transcriptions (figure 3). Amongst these concern regarding patients' understanding of the term "palliative care" and a difficulty in predicting trajectory in liver disease stood out as a key reasons why timely supportive and palliative care interventions remain rare in the context of advanced liver disease.

CONCLUSIONS AND FURTHER WORK

- Hepatologists' attitudes towards integrating supportive and palliative care in the management of advanced liver disease are broadly positive, however the primacy of malignant disease, difficulties in managing the uncertain trajectory of decompensation, and a paucity of evidence based models of care are demonstrated.
- Development of evidence based interventions which facilitate parallel integration of supportive and palliative care with ongoing active management are required.

REFERENCES

1. Implementation of the Lancet Standing Commission on Liver Disease in the UK. 2015. Lancet. 386 (2098-2111)
2. National survey of bereaved people (VOICES – Views of Informal Carers – Evaluation of Services). 2014. Office for National Statistics, UK.

Figure 1 - For given clinical vignettes, percentage of respondents considering supportive and palliative care input clinically appropriate vs percentage that WOULD refer in routine practice

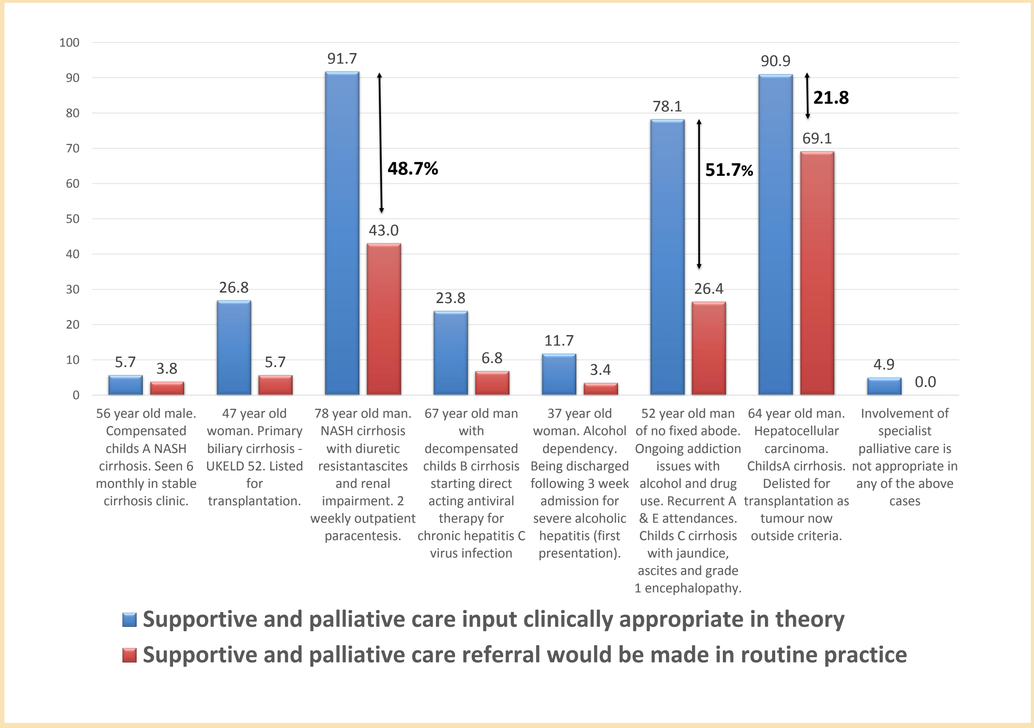

Figure 2 – Ranked importance of cited barriers to palliative care in liver disease by consultant place of work

Barrier to involvement of supportive and palliative care	Overall		DGH Consultants		Tertiary Consultants		Transplant Consultants	
	Rank	% agree	Rank	% agree	Rank	% agree	Rank	% agree
Palliative care of value but referral not routinely considered	1	81.8	2	78.6	4	76.6	1	91.3
No clearly established referral framework for liver disease.	2	80.2	1	80.3	2	84.4	4	54.6
Liver disease has potential for improvement. Physicians reluctant to refer when disease potentially reversible.	3	79.4	3	74.7	1	87.3	3	60.9
The illness trajectory is uncertain and identification of a clear "terminal phase" difficult.	4	72.1	5	65.7	5	71.9	2	69.6
Insufficient resources.	5	64.7	4	71.8	3	78.1	5	54.5
Involvement of palliative care risks patients not being managed aggressively/appropriately by other specialties (eg. ITU/A&E)	6	61.4	6	55.7	6	61.9	6	47.8
Palliative care and the hospice movement are not set up for patients with liver disease	7	46.0	7	55.2	7	45.3	7	52.1
There is no need for specialist palliative care input for most patients	8	14.2	8	21.1	8	12.5	8	13.0

Figure 3 – Emergent themes from qualitative analysis with representative quotations

CONFLICTS OF INTEREST - NONE