

British Association for the Study of the Liver (BASL) special interest group (SIG) position statement on palliative and supportive care in patients with chronic liver disease.

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Introduction

There have never been more patients with chronic liver disease in the UK than there are now; an inevitable consequence of the increasing levels of obesity in parallel with increasing numbers with excess alcohol consumption. Whilst hepatologists and patients will applaud recent advances in managing patients with viral hepatitis, the reality is that the prevalence of chronic liver disease remains at an unprecedented level in the United Kingdom, and continues to increase.

Both the Lancet Commission¹⁻⁴ and the Atlas of Liver Disease⁵ have drawn recent attention to the trends in mortality for the most common conditions causing death in the UK. While standardised mortality rates from cardiovascular, cerebrovascular, respiratory and neoplastic disease are all *falling*, the mortality from liver disease continues to *rise* inexorably. Notably, the median age of death from liver disease is significantly younger than other major causes of mortality (with huge implications for years of life lost). Furthermore, mortality rates from liver disease correlate significantly with socio-economic deprivation. This may reflect the disproportionate impact of obesity and excess alcohol consumption on those in the lowest quintile for the 'index of multiple deprivation'⁵.

While in some cases death may be sudden, it is much more likely that death from liver disease will occur after an extended period of ill health, during which the poor prognosis will have been clear to most or indeed all of those involved. As such, in almost all cases, there *should* be a window of time where prognosis can be discussed, and patients and their families can be afforded opportunities to discuss preferences for care towards the end of life.

Patients with liver disease have a high physical symptom burden with increased deterioration in health-related quality of life scores compared to other life limiting diseases⁶. In addition to features of decompensation, they experience higher incidence of symptoms unrelated to decompensation (cramps, fatigue, dyspnoea, sexual dysfunction) and higher levels of psychological distress compared to other organ failure trajectories. There is a high caregiver burden with carers more likely to rate overall quality of care as poor and less likely to rate as outstanding when liver disease was mentioned⁷. Death commonly occurs in hospital which at least gives an opportunity for advance care planning, but often palliative care is not considered until the last few days of life if at all⁸⁻¹⁰, after many invasive procedures.

End of life care “ helps those with advanced, progressive, incurable illness to live as well as possible until they die.” Traditionally in the UK, palliative care has been considered integral to the late management of malignancy, however, extensive and unresolved supportive and palliative care needs have also been widely reported among patients dying from non-malignant organ failures. Whilst there has been an increased focus in recent years on palliative care for non-malignant disease, inequities in the availability of specialist palliative care services are recognised, and a disproportionately low percentage of such deaths occur in a hospice environment¹¹. Specifically palliative care services are seldom accessed by patients with non-malignant liver disease, with interventions typically limited to inpatient end-of-life care for a minority of patients^{8,9}. A recent analysis of healthcare use in the last year of life among patients who died from liver disease in England has demonstrated the downstream consequences of this, with deaths caused by hepatocellular carcinoma associated with lower healthcare costs, fewer inpatient bed days, and a significant reduction in the probability death occurring in a hospital environment, when compared with deaths caused by decompensated cirrhosis alone in matched patients¹².

The purpose of this special interest group is to review the current status of end of life care within hepatological practice in the UK, to identify those areas where improvements might be made to previous guidance, and to disseminate these observations to clinicians involved in the care of such patients, both from gastroenterology/hepatology and also palliative care. A series of workshops with intentionally small but broad representation from all relevant bodies (Appendix 1) has been set up to achieve this.

This review focuses on the main themes that evolved through two workshops in February 2017 and March 2018 and is intended as a discussion document prior to the introduction of a pragmatic toolkit to implement care.

Terminology

One striking observation that arose during the meetings was that the terminology used to describe the care needed for patients dying with or from liver disease differed both between individuals and between professional specialities, probably because the terms lack specificity. Thus, 'palliative care', 'supportive care', 'best supportive care' and 'end of life care' were used interchangeably in particular by hepatologists. The level of care on offer with each 'term' could differ and vary substantially according to where the patient was located on the path from the first recognition of cirrhosis to death.

It became clear that phrases including 'end of life care', 'palliative care' and 'hospice care' carried connotations to patients and physicians of imminent mortality, which is not necessarily the case. It was recognised that inappropriate use by professionals or interpretation of such phrases by patients and professionals might act as a barrier to optimal management, or even direct patients down an inappropriate clinical pathway. Palliative care colleagues were keen to refer to this phase of treatment as *early* palliative care or supportive care, rather than end of life care which implies only that.

Uncertainty regarding prognosis

It was agreed that patients with cirrhosis can be divided broadly into three prognostic groups, which can be defined on clinical grounds.

The diagnosis of cirrhosis in the absence of any clinical features of hepatic decompensation places the patient in the *first phase*. There is a substantially increased risk of liver-related mortality in the long-term, but not in the short-term, unless due to superimposed malignancy.

The *second phase* is defined by the onset of hepatic decompensation and has many manifestations including variceal haemorrhage, hepatic encephalopathy, the development of ascites, or the evolution of hepato-renal or hepato-pulmonary syndromes or porto-pulmonary hypertension. Depending upon the complication, the level of background liver function at this stage and the evolution (or not) of additional organ failure, the prognosis is very variable, though any form of decompensation establishes the patient on a very different mortality curve, with a significant mortality risk over the subsequent 1-2 years¹³.

There is a wealth of prognostic models in liver disease, which have value once a patient has developed hepatic decompensation. These models have been developed almost exclusively to estimate survival in order to optimise selection of patients for liver surgery in the past or more recently, shunt procedures to treat variceal haemorrhage. More recently these scoring systems have been used in the prioritisation and selection of patients for liver transplantation. Given that a number of the established prognostic algorithms have been tested and validated in a number of settings over a period of time, does not mean that they should not also be used to aid in identifying patients who stand to benefit from end of life care planning and supportive care interventions. Such models most often look at survival over a two year period and it was agreed that a future research focus of the BASL special interest group should be improved modelling to identify those patients at high risk of death from liver disease within one year. This should include those patients listed for liver transplantation, since up to 20% of those listed do not survive long enough or become too ill to undergo liver transplantation.

This would allow appropriate timing of discussions with the patient and their next of kin, informing them of prognostic expectations in order that patients and their families can be actively involved in planning personalised treatment escalation plans, as well as in advance care planning. This may include places where patients would ideally wish to die (home, care-home, hospice or hospital). Such an approach would also facilitate parallel planning for those where liver-death is not an inevitability (ie. where re-compensation and/or transplantation are possible).

It is important to identify people in the *final phase* and who are in the process of dying. Recognition of the need for palliative care in patients with advanced liver disease often occurs very late in the clinical course across most hospitals in the UK^{8,9}, and is often prompted by exhaustion of all other therapeutic options.

It is likely that minor modifications to established liver disease prognostic algorithms can be constructed to identify those in the final phase, although none are used widely at present. A pragmatic and sensible approach is to consider the question “would you be surprised if the patient died in the next 12 months or during this admission?”. This simple consideration, used widely in other organ failure trajectories¹⁴, should trigger an honest conversation with the patient and carers, and an opportunity to express preferences around future care.

Helpful tools to answer these questions include: a global impression, more than one unplanned admission with hepatic decompensation in the previous 12 months, high UKELD or MELD scores, deteriorating performance status, refractory ascites (especially if the ascites is infected), refractory or recurrent encephalopathy, deteriorating renal function, progressive HCC and continued alcohol consumption in those surviving an episode of alcohol-related hepatitis^{13,15-18}.

One recent formal and validated approach is the use of a screening tool based on 5 simple parameters: Child-Pugh-Turcotte C, more than two admissions in the last six months, continued use of alcohol, patient considered unsuitable for liver transplantation and a pre-admission WHO performance status >2. A score of 3 or more triggered end of life discussions followed by the introduction of appropriate supportive and palliative care measures. The model had a positive predictive value for death within one year of admission of 81% (sensitivity 72, specificity 84)¹⁹.

Patient groups on which to focus

There is growing use of tools to identify patients who may benefit from early palliative care. The “surprise question” and the simple checklist described by Hudson et al¹⁹ is a good place to start. Certain patient groups, such as those undergoing regular paracentesis, those with HCC and those referred for transplant have an obvious need.

The (mis)perception that chronic liver disease is a special case

For many, managing liver disease is considered a challenge because of the complex multi-system nature of the disease, especially in the later stages and hence specialist input is recommended. Less experienced medical and nursing staff may be less confident about interventions or prescriptions, especially when facing issues regarding pain relief or sedation in the presence of liver failure. Recent questionnaire-based studies of physicians in primary, secondary and tertiary care in the UK have

emphasised a perceived lack of the requisite skills and training to deal with the palliative needs of advanced liver disease, with an acknowledgement that delivery of such care is inadequate²⁰.

Patients, *per se*, may be challenging or have challenging circumstances such as deprivation, isolation and poverty²¹. The practicalities of managing ascites, gastrointestinal haemorrhage and lack of mental capacity (for example due to encephalopathy) are also considered especially difficult issues which frequently mandate hospital admission, contributing to the low proportion of deaths from liver disease that occur at home or in hospice environments. Patients have however, (including those with end stage liver disease) when directly asked about their preferences, have expressed a preference for “a palliative care approach that focuses on morbidity”²².

Hepatologists may consider the management of end of life care in advanced liver disease a part of their own exclusive domain and so become reluctant to refer. The reality, however, is that palliative care teams consider complex cases as part of everyday practice. One oft-cited barrier to managing death in the community is the possibility of fatal variceal haemorrhage, but there are precedents, including spontaneous rupture of the carotid artery in head and neck cancers or massive haemoptysis with lung metastases, which are managed effectively in a community setting with pre-emptive prescription of sedatives as required, and proportional to the likely distress caused.

Managing ascites in those with liver disease is another area often considered complex in the palliative setting, but which is a common complication of malignant disease that is also managed effectively in the community.

Specific manifestations of decompensation of chronic liver disease

There was discussion about each of the specific manifestations of chronic liver disease, considering how they were currently managed and how this might be improved upon, taking into consideration the prognostic implications of the decompensation events and the role and timing of palliative care input. For each form of decompensation, gastroenterologists and hepatologists are used to looking for precipitants, including infection, portal vein thrombosis, development of hepatocellular carcinoma, as well as in some instances ongoing/return to alcohol consumption. The search for a cause for the clinical deterioration should not, however, deflect the clinician from the fact that the patient's liver disease has reached a stage where they are starting to get features indicative of end-stage disease, and that the management plan needs to take into consideration the short-, medium- and long-term implications of this.

Recognition that decompensation can occur without a clear precipitant, possibly due to progression of the underlying disease process may avoid the need for progressively more invasive investigations. Unless there is clearly an anticipated reversible element to the underlying liver disease, through such measures as abstinence from alcohol or treating hepatitis B or C virus infection, the clinician needs to be mindful of the trajectory of the liver disease and the anticipated mortality associated with this. Once a patient develops manifestations of advanced liver disease, gastroenterologists and hepatologists may seek an opinion from a liver transplant unit as to whether the patient needs, and is suitable for, liver transplantation. This process follows from the recognition that the patient's liver disease is now likely to impact their longevity. For the same reason, the input of palliative care could

appropriately be instituted at this stage, irrespective of whether the patient is a candidate for transplantation or not.

Refractory ascites

A new presentation with ascites in conjunction with impaired hepatic and/or renal function is one of the most common manifestations of advancing liver disease. At some point the ascites will become less sensitive to diuretics. At this stage alternative strategies may be considered, including liver transplantation, a transjugular intrahepatic portosystemic shunt or regular planned paracentesis with concomitant infusion of albumin. Explicit recognition from physicians that all treatments short of liver transplantation are palliative is required. This should trigger a conversation with the patient about overall prognosis and advance care planning. It is recommended that in these circumstances paracentesis should be a planned procedure undertaken by appropriately trained clinicians or a specialist nurse trained in the procedure and the associated complications. A recent analysis of all deaths in England caused by cirrhosis with ascites in England between 2013-2015 demonstrated that patients enrolled in a day-case (i.e. planned) paracentesis service within their last year of life had lower overall healthcare costs (average £4240 less per patient), spent less time as a hospital inpatient (average 17 days less over the last year of life), and had a lower probability of dying in hospital (odds ratio = 0.31), when compared with patients who received exclusively unplanned care in their last year of life¹². The NIHR funded REDUCE trial (Repeated drainage, untreatable cirrhosis) is currently comparing outcomes among patients who have an indwelling peritoneal drainage catheter, vs those undergoing repeated large volume paracentesis among patients not suitable for liver transplantation. Longer term drains should also be considered in this patient group, where primary services are equipped to manage these drains in the community.

Development of facilities within GP treatment centres or community palliative care services (eg hospices), as an alternative to hospital based day-case care are an aspiration, although establishment of paracentesis services in all acute hospitals would be a good 1st step and also cost effective. Whatever location is used, a coordinated planned approach with clear pathways and guidelines are needed. An unplanned acute admission to hospital in these circumstances often results in an unnecessary and protracted stay and must be avoided. In general, as ascites and renal impairment progress, it often becomes appropriate to discontinue diuretics, lift dietary restrictions and opt for, symptomatic relief with a smaller volume paracentesis which does not mandate volume replacement with albumin, which is otherwise essential. Blood tests and analysis of ascitic fluid are not needed in the care of patients in the terminal phase. Further development of community hepatology services may improve care in this regard.

Long term, tunnelled drains and the use of devices such as alfa-pumps may be better for symptom management in advanced disease despite the clear risks described in trials and case series in terms of survival and renal dysfunction^{23,24}.

Nurse led paracentesis units can lead the way as a regular interface between specialist staff and patients (including those who tend to otherwise miss appointments). The importance of rolling these out across the NHS is stressed, especially in light of recent data¹². Business cases for advanced liver nurse practitioners will be needed, but can be financially robust based on available data¹².

Encephalopathy

Hepatic encephalopathy (HE) is the neurocognitive manifestation of hepatic decompensation with a prognosis that is poor and similar to that of refractory ascites. The development of an episode of clinically overt HE carries with it a significant 1 year mortality risk and should be a trigger for consideration of liver transplantation and/or end of life care conversations. In this context in particular it is important to consider advance care directives and the role of 'Power of Attorney' when the patient is lucid. Encephalopathy can be difficult to manage at home and is often a justification for hospital admission. In-patient treatment of HE then discharge can lead to a cycle of admission/discharge/re-admission. Home carers require education to treat constipation which could reduce re-admission rates, especially if GP services and District Nurses were also involved. Here too, community palliative care services can be of huge support to the patient, however also to the carer(s), who are left to deal with the psychological burden associated with neurocognitive and physical decline of a family member.

Variceal haemorrhage

There are clear guidelines for managing bleeding oesophageal varices in patients with cirrhosis and the emphasis should be on prophylaxis to reduce the risk of haemorrhage or recurrent haemorrhage. Optimal treatment of portal hypertension before advanced disease evolves will reduce suffering as a consequence of gastrointestinal haemorrhage in the terminal stages. The patient with advanced liver disease in the terminal or close to the terminal phase that then presents with bleeding varices represents a real challenge. In essence, the decision to undertake any treatment to halt gastrointestinal bleeding *must* be taken on the basis that the patient otherwise has an expectation of good quality of life, and after discussion with the patient and their carer(s). Interventions for active haemorrhage in patients with terminal liver disease often require sedation and the combination of severe disease with an intervention and sedation often exacerbates the situation and may lead to a final admission to ITU to manage the airway. Palliative care teams are comfortable managing active variceal haemorrhage conservatively, in contrast to hepatologists, who are interventionists by nature and who might feel that further endoscopic management might stop bleeding. The optimal situation is that the clinician has led a discussion with the patient and next of kin, anticipating this scenario and thereby allowing there to be a pre-agreed management plan in place should this eventuality arise.

Hepatocellular carcinoma (HCC)

Patients with HCC on a background of cirrhosis are more likely to be offered palliative care than those dying from cirrhosis without a tumour¹². Patient needs in both scenarios are often identical. HCC may lead to terminal disease simply through tumour bulk, intrahepatic and/or extrahepatic vascular thrombosis often with tumour or metastatic disease (bones lungs, nodes, peritoneum or adrenal), all of which are difficult to manage effectively but employ approaches common to all malignancies. In most patients, however, the underlying process that dictates symptoms and prognosis is evolving liver failure, so management is the same as for those without HCC.

A balance needs to be struck between applying the new treatments becoming available and recognition that they are still ultimately palliative. Recent guidance does at least include recognition of this²⁵.

Patients on Liver transplant waiting lists

Hepatologists present who are involved in transplantation were in agreement that those assessed and on the waiting list were appropriate for palliative care, but there was discussion about the optimal timing of the conversation to avoid information overload and mixed messages.

Multi-disciplinary working for patients with advanced liver disease

The power of multi-disciplinary working in its widest sense in providing high quality care for these patients was acknowledged. As it is a "multi-dimensional disease", affecting people socially, psychologically and existentially, as well as physically, If we ignore the other aspects of their care needs, we don't give good care to people and their carers/close others in this group.

We should strive to establish multidisciplinary teams comprising a palliative care consultant and specialist nurse, hepatology consultant and advanced liver nurse, alcohol liaison nurse, possibly also a pharmacist, dietician and a social worker. The role of the MDT is to discuss the medical options available, which can then be discussed with the patient and an individualised advance care plan agreed which can then be made available to community teams (GP, district nurses, paramedics and hospice care) and families where appropriate.

The social and financial burdens of advanced disease need considering. It is important for example to make use of the benefits assessment team, who is able to make sure that people are on the appropriate level of personal support that they are entitled to on the basis of their terminal diagnosis.

Linking with community and primary care services

The vast majority of patients who die from liver disease do so in hospital. This situation may arise inevitably and may sometimes be unavoidable. We shouldn't always see this as a bad thing- aiming for a 'good hospital death' may be best practice.

Communication within and between teams is essential to ensure careful end of life care plans are executed efficiently, sympathetically and especially with families in mind with consistency. These issues are especially important following the changeover of clinical responsibility care between staff of all grades to avoid the scenario where the new team might recommend further endoscopy or admission to ITU.

Having had complex and sincere conversations with patients and their families it is mandatory that this information is communicated to all relevant services within and outside the hospital with a detailed written plan for the GP, community palliative care services, the patient and the family. Entry of the patient onto the community palliative care registry is an important component. Agreement of an Emergency Health care plan (EHCP) or anticipatory care plan facilitates out of hours care as well. Patient-held information may help patients and carers to participate actively in the coordination of their own care. Electronic palliative care co-ordination system (EPACCS) solutions and other electronic palliative care record systems are being developed throughout the UK and may help end of life

information to be shared electronically. There may not be the facility for the hepatologist and other hospital based healthcare professionals to enter data onto these platforms. The importance of timely information (written, via a discharge letter, or telephone contact in the context of an end of life discharge) is imperative to ensure seamless transitions of care between settings.

Recognition of each patients individual needs makes the prospect of a simple checklist similar to the decompensated liver disease care bundle unlikely. However a model is evolving and there is recognition that many existing care pathways are adaptable to chronic liver disease.

Conclusions- what does good, early palliative care in advanced liver disease look like?

Good quality palliative care in liver disease need not be complex. Gastroenterologists and Hepatologists involved in the care of patients with these conditions need to firstly, consider the issue of the anticipated prognosis whenever they see a person with decompensated chronic liver disease and, second, lead the discussions with the patient and next of kin. It is important, that open, honest conversations take place in a timely fashion. The conversations cannot be rushed and a number of issues may need to be covered in more than one conversation, but any time spent will be rewarded in terms of improved patient dignity, comfort at end of life and avoidance of futile investigations or interventions. In assessing services we need to measure outcomes, but we need to define the most appropriate metrics what those outcomes are. Normally death in hospital (opposed to home or hospice) is seen as something to be avoided, but it was acknowledged that for some liver patients especially those suffering from poverty and deprivation, hospital may be desirable. What should be avoided is late referrals in the last few days of life. Rather than using place of death, instead look at whether a good death in hospital has been achieved, avoiding late inpatient referral, and other measures such as how many emergency admissions and their duration in the last year of life. Looking at what happens to those arriving in hospital with an end of life care plan in place to avoid unnecessary interventions may give rise to concept of 'dying friendly' hospitals.

Scoring systems, used currently to plan curative interventions should be re-purposed and then used to direct clinicians towards supportive palliative care interventions, before the point at which the maximal benefit of such interventions are lost.

Future work and implementation

The BASL Hepatology Clinical Network is in evolution; the expectation is that each hub will have a clear referral pathway to local palliative care services.

How to introduce these concepts into everyday practice?

The special interest group has commissioned a working group to produce a tool kit to assist in the management of those with advanced liver disease.

- Bring consideration of prognosis and role of advanced supportive care into 'Decompensated chronic liver disease care bundle'.
- Introduce symptom and frailty assessment into standard care of in-patients with cirrhosis^{26,27}.
- Use of tools such as of the SPICT summary page in Emergency Departments and Acute Medical Wards (www.spict.org.uk/).
- Standard format/ check list for communication with primary care.
- Toolkit for managing complex symptoms in advanced liver disease
- Roll out of a prognostic proforma¹⁹.
- Business cases for developing day case service models

The curriculum for hepatology and gastroenterology trainees including specific elements in eportfolio will need to be modified.

Raising awareness of this field through BASL BSG symposia/ communications with links on website to relevant sites.

Involvement with British Liver Trust, Liver 4 Life and other patient focussed liver charities to enhance patient awareness.

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Appendix 1. Workshop attendees February 2017.

John O'Malley; Jez Thompson; Graeme Alexander; Mike Allison; Alex Gimson; Mathis Heydtman; Ben Hudson; Aileen Marshall; Anne McCune; Doug Thorburn; Mark Wright. Jackie Jennings; Lynda Greenslade; Sharon Quinn; Karen Sikka; Sarah Tarff; Chris Bridges; Yvonne Cartwright; Carol Davis; Suzanne Ford-Dunn; David Gray; Joe Low; Maria McKenna; Colette Reid; Paddy Stone; Andrew Langford; Sarah Matthews; Julia Verne.

Appendix 2. Workshop attendees March 2018

Yvonne Cartwright; Barbara Kimbell; Lucy Bernard; Fiona Thompson; Kara Rye; Pooja Khanna; Fiona Finlay; Hazel Woodland; Jo Tod; Charlotte Smith; Lucia Macken; Sumita Verma; Suzanne Ford-Dunn; Virginia Cambell; Joe Low; Ben Hudson; Nathan Hall; Jill Lockhart; JackieParr; Wendy Prentice; Anne McCune; Heather Lewis; Katherine Buxton; Sarah Smith; Aileen Marshall; Lynda Greenslade; Catherine Carroll; Mathis Heydtmann; San Thompson; Rebecca West; Carol Davis, Graeme Alexander; Sara Tarff; Michael Allison; Amelia Stockley; Jackie Swabe; Mark Wright; Andrew Jenks; Sarah Baurez; Louisa Grant; Jon Thomas; Jayne Dillon; Brian Hogan; Lucy Bemand- Qureshi; Kim Batchelor; Ruth Yates; Nina Stafford.

