BASL End of Life Care in Liver Disease Special Interest Group

6th March 2018

Main points and further actions

Terms

Terminology is important, palliative care colleagues were keen to refer to this phase of treatment as EARLY Palliative care rather than end of life care which implies only that, or enhanced supportive care which is possibly unclear in meaning.

Multi-disciplinary working for patients with advanced liver disease

The MDT is essential to produce individualised advanced care plans which can then be made available to community teams (GP, district nurses, paramedics and hospice care) and families where appropriate. Typical make up of an MDT would include a palliative care consultant and specialist nurse, hepatology consultant and advanced liver nurse, alcohol liaison nurse, possible also a pharmacist.

Examples of advanced liver disease clinics with palliative care focus were also presented showing early benefit.

Actions

Presentations from the meeting have been circulated detailing examples of how this works in practice.

Please share examples of advanced care plans for local adoption.

Please share any business cases/ proposal documents etc.

Information sharing

There should be a universal document summarising status where possible this should not be too liver specific to facilitate use by palliative care teams and allow them to integrate care with other conditions. This should be linked in with available technology eg. EPACS and other information sharing sites as they become rolled out

Actions

BASL may be able to pay for a working group to get these set up. Try to link with EPACS and other information sharing sites. Volunteers to form this working group required.

Patient groups on which to focus

There is growing use of tools to identify patients who may benefit from early palliative care. Certain patient groups are those undergoing regular paracentesis, those with HCC and those referred for transplant.

Nurse led paracentesis units can lead the way here as they are 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 was stressed, especially in light of Hudson et al's work. Business cases for advanced liver nurse practitioners will be needed, but should be financially robust based on available data.

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.

Actions

Addition of a section on transplantation to the position statement.

Need to share financial models for business cases for advanced liver nurse practitioners.

Share successful business cases where available.

Assessing outcomes- what does good early palliative care look like?

In assessing services we need to measure outcomes, but we need to decide 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/ bed days in last year of life. The concept of dying friendly hospitals was raised- looking at what happens to those arriving in hospital with an end of life care plan in place to avoid unnecessary interventions.

Actions

NHS Voices Data asks carers about their experience of a relatives death we will see if possible to extract liver specific data from this.

Share existing study endpoints looking at good dying.

Preaching to the Choir

Clearly there was great enthusiasm and examples of excellent practice in the meeting but it was acknowledged that this expertise and willingness to develop services may not be universal across the health service.

Actions

Complete the BASL position statement for publication on the website. Currently awaiting comments from a couple of palliative care consultants and a section on transplant patients. Produce a document relevant to all areas of the UK.

Raise awareness by incorporating palliative care into national liver and gastroenterology meetings.

Submission of abstracts and publications demonstrating good practice to conferences.

Incorporation of palliative care training into SpR training days and core curriculum.

Any volunteers with access to the curriculum?

Link with the decompensated liver disease care bundle, to ensure that those in whom palliative care have been involved, receive care in line with their advanced care plans.

Financial Constraints

Much of the excellent work presented had been funded charitably, through research or by interested clinicians doing things in their own time. Moving finite palliative care resource into this new area creates problems elsewhere.

It was discussed that much of what we are doing is definitely (or at least probably cost effective) in terms of reduced bed days, acute resource use, but expensive in terms of time. We recognised that much palliative care could be delivered by the hepatologists and advanced liver nurses already involved,with input from palliative care via MDTs and later in the patients illness.

Actions

Share successful business cases- eg. For advanced liver nurses, PAs of palliative care consultant time.

Incorporate health economic analyses into research.

A tool kit?

It was obvious that a tool kit like the decompensated liver disease care bundle would be far too simplistic, but rather what was needed was a multidisciplinary approach and to ensure that individualised care plans were produced and adhered to.

Actions

Lessons from other disease areas would be useful here-Conservative management in advanced renal disease may be transferable to liver disease. We will contact Dr Emma Murphy who has done a lot of the work in this area.

Circulation of advanced care planning documents.