Introduction

Owing perhaps to the potential for liver transplantation and uncertainty of prognosis, it is known that patients with end stage liver disease (ESLD) are less likely to access palliative care services than other disease groups. Because of this, and the frequency of acute decompensation resulting in death, the majority of deaths due to cirrhosis occur in the hospital setting. It is well documented, however, that given the choice, most people would prefer to die at home, rather than in hospital (National VOICES survey 2012). There is very little data on the patterns of dying in patient with cirrhosis and whether this can be managed at home.

Aim

To document the experiences of patients with ESLD dying at home.
To identify ways to make home deaths more available to patient with ESLD if that is their preference.

Method

Case note review of all patients referred to St Barnabas House Hospice in 2015 with a primary diagnosis of cirrhosis (of all causes). Particular attention was paid to symptoms present on referral and throughout their care under St Barnabas, symptoms present throughout the last days of life and how these were managed. Place of death and frequency of attendance by healthcare professionals was documented.

Results

Six patients were referred to our services through the 12 month period. Four patients were male with an average age of 75 years.

Cause of cirrhosis:

<table>
<thead>
<tr>
<th>Cause of Cirrhosis</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary biliary cirrhosis</td>
<td>2</td>
</tr>
<tr>
<td>NASH</td>
<td>1</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
</tr>
<tr>
<td>Alcohol</td>
<td>1</td>
</tr>
<tr>
<td>Alpha 1 antitrypsin deficiency</td>
<td>1</td>
</tr>
</tbody>
</table>

On average, patients were referred to our services approx. one month before death – mean 40 days (range 6-92 days).

All patients preferred place of death was home and all achieved this.

Frequency of symptoms during their time under our care is recorded visually in the word cloud (centre). Abdominal pain and profound fatigue were the most common and most troublesome symptoms. Although confusion and mild agitation was fairly common, it was not difficult to manage and settled with low doses of medication.

Two patients had acute decompensations within the last month of life but the patients declined hospital admissions despite this being recommended by their GPs. Both these patients preferred to stay at home for end of life care, being aware of palliative care services that could be provided at home.

One patient had melaena 4 days prior to death, but there were no deaths due to haemorrhage (despite several patients having thrombocytoopenia and varices).

Conclusion

It is possible for patients dying of liver failure to achieve their preference of dying at home, although it does require significant medical and nursing support. Patients need to be aware of their likely prognosis in order to make choices about their treatment, but estimating prognosis in liver disease is difficult and often uncertain. Other studies looking at the palliative care needs of patients with ESLD highlight the overwhelming uncertainty that surrounds prognosis, compared with other advanced diseases.

Only a small number of patients with ESLD are accessing community palliative care in our area – the 6 referrals in 2015 represent approximately 1/10th of the estimated population with advanced liver disease. The reason for this is likely to be multifactorial, but is certainly influenced by the uncertainty of prognosis, and possible recovery of individual patients making discussing referral to palliative care difficult.

To try and increase access to palliative care services and give patients and families opportunity to consider advance care planning, we have created an innovative ESLD palliative care nurse post, based at St Barnabas House, but able to review patients in community and hospital settings. We hope that this nurse will be able to provide emotional support to patients and families, as well as opportunities for advance care planning, accepting that prognosis is uncertain and indeed, some of these patients may yet recover.

Outcomes from this project will be available next year.

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Poster presentation for BASL 2016

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