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| **Name** | **'Thinking Ahead' Advance Care Planning Clinic** |
| **Type of project** | Service quality improvement project |
| **Aims/objectives** | To improve management of patients with end-stage cirrhosis unsuitable for liver-transplantation, taking into account unpredictable disease trajectory, complex psychosocial needs of patients, and lack of experience in primary care. |
| **Inclusion/exclusion criteria** | Patients identified after discussion at liver MDT<br>• Considered to be in the last 12-24 months of life<br>• Not candidates for liver transplant<br>• Not candidates for HCC surveillance<br>• Active untreatable HCC<br>• Child Pugh B/C<br>• Recurrent admissions with decompensation<br>• Frailty |
| **Description of intervention** | • Patients appropriate for ACP identified by liver MDT<br>• Patients seen in 'Thinking Ahead Clinic' (TAC) run by Consultant Nurse<br>• Clinic provides a holistic care pathway for patients with advanced cirrhosis, from recognition of incurable illness, to planning for end-of-life care and providing support post-bereavement.<br>• GP receives letter with agreed plan of care<br>• Risk of Admission Patient Alerts (RAPA) system activated (Email notification of admission)<br>• District Nurses / Community Matrons notified<br>• Domiciliary home visits commenced if appropriate (69% of patients)<br>• Hepatology team remain actively involved with patients and community partners until death. |
| **Measures used to assess progress** | Pattern of healthcare usage recorded post consultation including emergency admissions, need for domiciliary visits and place of death |
| **Resources required** | Provided using existing departmental resources<br>MDT quorate requires presence of at least 2 Consultants and 3 Clinical Nurse Specialists<br>Dedicated hour in liver MDT to discuss ACP patients |
| **Progress** | 39 patients seen in clinic over 2-year period<br>37/39 patients since died (mean survival from THC date to death (1 to 11 months)<br>2/37(6%) deaths occurred in hospital (non-preferred place of death) 35/39 died at home |
| **Lessons learnt** | Whilst patients wished to discuss what will happen to them, they also wished to reconcile with their life's decisions and these topics were labelled as:<br>*I wish……..*<br>*Not good enough……..*<br>*Belonging……..*<br>*I need to……*<br>*I didn't Know……..*<br>*I was told to often……..*<br>*How long……..*<br><br>In selected patients, with appropriate support, Rocket drains provided symptom control and reduced admissions (46% of patients had Rocket drain inserted) |
| **Future plans** | |
| **Resources available** | Thinking Ahead – Advance Care Planning GP letter<br>Thinking ahead - Advance Care Planning Document |
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