Advanced Organ Disease Nurse Specialist Community Posts – A Pioneering Approach to Increase Access to Palliative Care for those with Advanced Liver and Renal Disease

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Background - It is well recognised that the palliative care needs of patients with advanced organ failure are similar to those with advanced cancer, yet the numbers of patients with organ failure being referred to palliative care services (including our own unit) remains low (< 10% of all referrals). Our hospice looked for an innovative solution to increase access to palliative care for patients with organ failure.

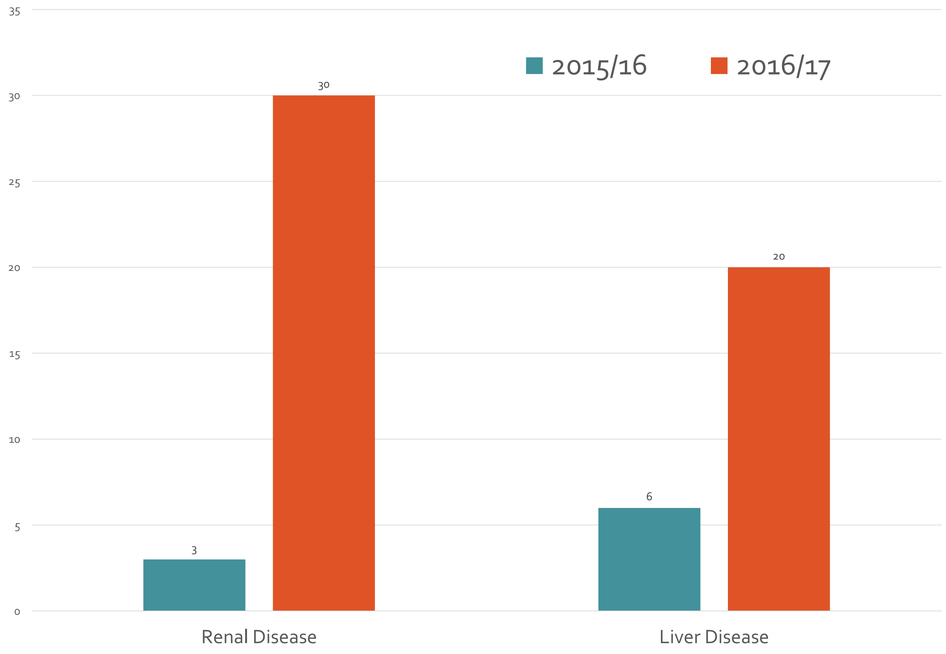
Aim - To increase the numbers of patients with advanced liver and renal disease having their supportive needs assessed.
To increase access to palliative care services for people with advanced liver and renal disease.
To provide opportunities for advance care planning for patients with advanced liver and renal disease.

Method - We created innovative clinical nurse specialist posts in advanced liver disease and advanced renal disease, to work in the community setting (but able to review patients in the hospital and hospice settings). These nurses created new patient pathways, working with the hospital liver and renal teams, resulting in joint clinics, MDMs and new routes for referral in to palliative care.

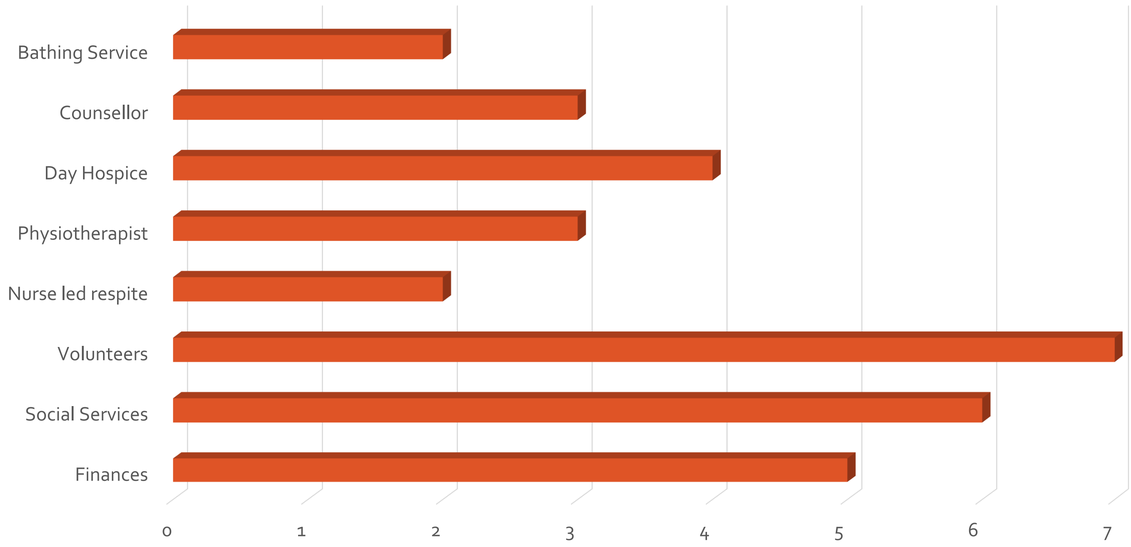
Results
Referrals to the service have increased significantly in the first 12 months of the service. Renal referrals 30 vs 3 in the previous 12 months, Liver referrals 20 vs 6 in the previous 12 months (see graph 1). Advance Care Planning discussions have been offered to 50-85% with a similar percentage completing an Advance Care plan. 90% of patients have achieved their preferred place of death. Symptom burden for these patients is heavy – see word cloud for diagrammatic representation of symptom burden in the liver patients, and patients have been referred to many aspects of the palliative care service – see graph 2.

Word cloud representing symptom burden in liver patients

Graph 1: Number of patients referred to hospice services



Graph 2: Additional hospice services accessed by patients with renal disease



Conclusion: Advanced Organ Disease CNS posts can significantly increase access to palliative care services for patients with advanced renal disease and advanced liver disease. We now intend to evaluate further outcomes such as quality of life and carer burden to further assess the benefits of these posts.

References
NHS Kidney Care End of Life Care Programme. End of life care in advanced kidney disease: a framework for implementation. 2010
NHS Liver Care End of Life Care Programme. Getting it right: Improving end of life care for people living with liver disease. 2013

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