Dying with dignity

Initiative Type

Model of Care

Service Improvement

Status

Deliver

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Summary

Patients with Chronic Kidney Disease (CKD) have complex clinical needs and multiple co-morbid conditions. Only a few of these patients receive dialysis, however with or without dialysis, there are high rates of death, predominantly due to cardiovascular conditions. The last year of life is crucial for

these patients, having multiple hospital admissions, issues of frailty and displacement from their home environment. Unwillingly, the majority die at hospital and recurrent clinic visits are very distressful for patients, carers and family members. This project plans to resolve these issues and bring back dignity for those who are dying from CKD. The Renal Support Care Clinic (RSCC) provides multidisciplinary care for patients via a core team consisting of a Nephrologist, CKD Nurse, Social worker, Dietitian, pharmacist and other opportunistic allied health team members as and when required. The project has successfully navigated healthcare system challenges to deliver change, improvement and innovation in their own health service and was presented at the Clinical Excellence Queensland Showcase 2019.

Key dates

Mar 2018

Implementation sites

Darling Downs Hospital and Health Service

Partnerships

Current partnership is between multiple departments/services within Toowoomba Hospital. It is planned to involve PHN to better coordinate the care and improve communications.

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Aim

The main aim of the Renal Support Care Clinic (RSCC) is to support the patients with advanced kidney disease with multidisciplinary holistic care during the last year of their life.

Benefits

- Holistic care of the patient with focus on symptom management.
- Involvement of carer/family in the care and discussions.
- Attention to social and family needs.
- End of life care essentials like preparation of Advanced Health Directive, family will and financial issues.
- Early attention to services including ACAT assessment for higher care.
- Timely referral to palliative care, either at hospital or at community level.
- Decision making regarding place of terminal event-death at home, hospice or hospital.
- Avoidance of unnecessary hospital admissions.
- Reduced length of stay as an in-patient when admitted for specific reasons like heart failure, infections or electrolyte disturbances.
- Elimination of unnecessary procedures like dialysis or complex surgeries.
- Medication optimisation and elimination of polypharmacy.
- Attention to diet and improvement in nutritional status.
- Timely referrals to other services like psychology, occupational therapist.

Background

Chronic kidney disease is a debilitating chronic disease in its own right, but can also contribute to, or be impacted by, other prominent chronic diseases, including cardiovascular disease and diabetes mellitus.

Solutions Implemented

IPOS-Renal is a short measure, combining the most common symptoms renal patients experience plus additional items from IPOS on concerns beyond symptoms, such as information needs, practical issues, family anxiety. IPOS has been validated in a mixed population of those with cancer and non-cancer diagnosis, including renal patients, and shows good content and construct validity, reliability, and responsiveness to change. Patients are also asked to complete hospital anxiety and depression scale (HAAD scale) to evaluate their mental and emotional status and stability. Each measure is re-evaluated at review to see any improvement or worsening of status. Letters were sent to primary renal physician and to their GP. Patients and carers were given opportunity to contact any members of the team out of clinic times to clarify any doubts and arrange for services or documents. Accompanying carer if available was asked to complete carer strain index form. The Caregiver Strain Index is a screening instrument which can be used to identify strain of carers, assess their ability to go on caring and to identify areas where support may be needed. Strain was defined as ‘those enduring problems that have the potential for arousing threat’. All patients were given information about advanced care planning (ACP)

Evaluation and Results

The average age is 70.1 years with 4 people 80 years or above. 12 male and 3 females. All patients were informed of advanced care planning. 12 patients has either Enduring Power of Attorney (EPOA) or Advanced Health Directive (AHD) 4 patients died (1 at home, 1 Hospice 1 Nursing Home and 1 at local hospital) 11 patients are still under follow up. in the surviving patients 3 had hospital a total of 6 admissions (2 for upper GI bleed, 1 for chest infection, 1 for high potassium, 2 for fluid overload, hyperglycaemia).

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