INTRODUCTION:

Acceptance rates of patients onto dialysis have risen steeply in those aged over 65 in the last 10 years. Increased age is associated with increased co-morbidity and both are associated with increased risk of death on dialysis. (Figure 1).

The importance of end of life care for those with advanced kidney disease is acknowledged in The National Service Framework for Renal Services and a Framework for Implementation of End of Life Care in Advanced Kidney Disease is now available through the National End of Life Care Programme. The aim is to support people with established kidney failure to live as fully as possible and enable them to die with dignity in a setting of their own choice. 

Identifying patients with end of life care needs may be facilitated by tools such as the Gold Standards Framework prognostic indicator. This identifies both general (comorbidity, weight loss, poor and/or deteriorating performance status, low albumin and recurrent hospital admissions) and renal specific triggers (CKD stage 5, symptomatic renal failure and increasingly severe symptoms from comorbid conditions) for consideration of a palliative approach. 

A patient’s supportive and palliative needs require particular consideration:

- At the onset of “conservative kidney management”
- If a patient is deteriorating despite dialysis
- At times of crisis – e.g. new diagnosis
- If renal failure is consequent to other life-threatening conditions
- Following renal transplant failure if there is a decision not to pursue dialysis
- Around the decision to withdraw dialysis

This audit aimed to review the history, management and outcomes of patients who died, or were identified as dying, in the RIE renal unit.

METHOD:

A retrospective case notes analysis was undertaken of all patients who died under the care of the RIE renal team, or were discharged from the renal unit to die elsewhere, over a 9 months period.

The data collected included that in the Liverpool Care Programme, 2009 and both are associated with increased risk of death on dialysis. (Figure 1).

RESULTS:

During the audit period, 50 patients either died in the unit or were discharged for end of life care elsewhere. This represents 36% of the total number of deaths in patients known to the renal unit over the same time period. Only 23 patients could be included for audit analysis due to missing and incomplete case records.

Breathlessness (50%) and agitation (58%) were present in the 12 unexpected deaths around the time of death, but symptomatic management of these patients was suboptimal.

DISCUSSION:

This audit demonstrates that approximately 15 patients known to the Edinburgh Renal Unit die per month, supporting the requirement to review current procedures for end of life care planning.

Poor prognostic indicators were evident for those that died (poor performance status, comorbidity, recurrent admissions, CKD 5, increasing symptom burden), however, it was not evident that this information was being collated or responded to in a systematic manner. Clinical decision-making and formal advanced care planning could be better informed if admission documentation were to facilitate recording of this data.

Decisions and discussions around withdrawing treatments such as RRT can be challenging but necessary for effective advance care planning. Having a written document in place before instigating treatment can help remind patient, family and clinical team, and inform future discussions and decisions. Current end of life care on the unit for those identified as dying is in line with the goals identified in the Liverpool Care Pathway but may be improved with formal implementation of such a document as is planned.

In circumstances where CPR would be a medically unsuccessful intervention but ongoing active management continues, pre-emptive prescribing for end of life symptoms should be considered alongside active interventions in order to reduce the risk of a potentially distressing death.

While evidence clear of end of life care planning prior to terminal admission for those patients included in this audit was lacking, it has to be acknowledged that this may not have been the case for the significant number of patients who died at home or elsewhere.

REFERENCES:


