Barriers to referral to palliative care for patients with Kidney Disease

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Outline

- ESKD population
- Dialysis patients
- Prognostication
- Supportive care
- Trajectories of illness
- Symptoms
- Referral to palliative care - lack of clarity about referral point, use of predictive tools
- Palliation for dialysis patients - relatively straightforward and predictable?
- Barriers to referral to palliative care
Chronic kidney disease

1 in 10
Australian adults (10%)—approximately 1.7 million people in 2011–12—had biomedical signs of chronic kidney disease (CKD).

1.6 million
Hospitalisations—17% of all hospitalisations in 2013–14—where chronic kidney disease was the principal and/or additional diagnosis. 80% of which were for regular dialysis.

1 in 10
or 15,900 deaths in 2013 recorded chronic kidney disease as an underlying or associated cause of death.

3 to 5 times as high
Among Aboriginal and Torres Strait Islander Australians compared with non-Indigenous people when looking at death and hospitalisation rates.

3 times as high
in Remote and very remote areas compared with Major cities for CKD hospitalisation rates including dialysis.
Prevalence of ESKD

For every person who commences dialysis or has a transplant, there is another who does not.

(AIHW, 2011)
Prevalent RRT Patients - Australia
31 December 2014

2015 ANZDATA Annual Report, Figure 2.1
Comorbid conditions at RRT entry

Australia


Suspected cases included

Coronary
Peripheral vascular
Lung
Cerebrovascular

2015 ANZDATA Annual Report, Figure 1.8
Mortality in elderly ESKD on dialysis

Elderly ESKD patients who commence dialysis have considerable mortality. An Australasian study showed:

- 1-year survival of 77%,
- 2-year survival of 59%
- 3-year survival of 45%
- Late referral and lack of dialysis access are independent predictors of mortality
- Survival on dialysis for an average 60-year-old patient is worse than for most cancers.

Frank Brennan, Palliative care physician, Department of Nephrology, St George Hospital, Sydney
ANZSN Renal Supportive Care Guidelines 2013, Nephrology 18 (2013) 401–454
Prognosis

Five year survival of patients aged 60 years with common cancers compared with kidney transplant and dialysis

- Testicular: 95%
- Breast: 85%
- Bladder: 75%
- Kidney Transplant: 75%
- Rectal Diagnosis: 62%
- Cervical: 60%
- Colon: 54%
- Stage 5 CKD on dialysis: 46%
- Ovarian: 44%

Nat. Rev Nephrol 2011; 7:578-589
For patients aged over 80 years, with a poor performance status or high co-morbidity scores, the survival advantage of renal replacement therapy over conservative management was lost at all levels of disease severity \(^1, 2\).

Those accessing a conservative management pathway had greater access to palliative care services and were less likely to be admitted to or die in hospital. \(^1, 2\)

1. Jamilla A Hussain, Andrew Mooney, Lynne Russon, Sue Ryder, 2013, Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease, Palliative Medicine 27(9) 829–839

Supportive Care - survival prognostication

“Elderly patients who choose not to have dialysis as part of shared decision making survive a median of 16 months. About one-third survive 12 months past a time when dialysis might have otherwise been indicated.”

Patient-reported measures including symptom scores and quality of life are useful in detecting issues to be addressed.

Demographic and laboratory data, vascular comorbidities including peripheral vascular disease (PVD), foot ulcers, cardiovascular disease and dementia, appear the most consistent clinical co-morbidities determining poor prognosis.

Surprise question accurate and useful for physicians who know patient.

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CARI guidelines recommend that ‘an expectation of survival with an acceptable quality of life’ is a useful starting point for recommending dialysis…..

A ‘conservative’ pathway is an important option for the management of end-stage kidney disease (ESKD) patients who are elderly, have significant comorbidity, poor functional status, malnutrition or who reside in a nursing home.

A conservative approach should be underpinned by a specific renal supportive care programme in each unit.

Nephrologists need to lead realistic discussions about likely survival before dialysis is instituted.

A renal supportive care programme is a positive way of offering holistic care for patients and their families; many of these patients live much longer without dialysis than might have been expected.
2014 KDIGO Summary - what should renal supportive care look like

- Includes interventions to delay progression of kidney disease
- Minimize risk of adverse events or complications
- Supports shared decision making,
- Active symptom management
- Detailed communication
  - advance care planning
  - psychological support
  - social and family support
  - cultural and spiritual domains of care

Supportive and palliative care patient cohort

Three main patient groups who may benefit from palliative and supportive care.

1. No renal replacement therapy – supportive care pathway.
   • Emphasis is on slowing the decline in existing kidney function
   • treating the symptoms and complications of renal failure.
   • The palliative phase may last for 1–2 years
   • The challenge is as much about optimising quality of life as planning for later death.

2. Those who begin dialysis in somewhat good health and decline over time,
   • They become more symptomatic and less well able to tolerate dialysis.
   • The focus moves to symptom control, may include a reduction in tablet burden or even in dialysis frequency
   • priorities move to those of quality of life while planning for end-of-life

3. Those with relentlessly progressive conditions causing renal failure
   • While dialysis may be offered, prognosis is very poor.
   • A combined approach of supportive symptom control and palliative care is offered.
Figure 3: Trajectories at the end of life

- **Sudden Death (A)**: Function remains high until death occurs.
- **Terminal Illness (B)**: Function declines over time until death.
- **Organ Failure (C)**: Function decreases in stages until death.
- **Frailty (D)**: Function slowly declines until death.
Trajectories in ESKD

- In the 2 months before death, patients reported a sharp increase in symptom distress and health-related concerns.
- Health care should anticipate and address this increase, which may indicate the patients is approaching death.
- Considerable individual variation and flexibility/responsiveness of care is important: one size of service does not fit all.

Trajectory of functional status

![Graph showing the trajectory of functional status over time before death. The graph plots KPS (%) against time in months, with a downward trend indicating a decline in functional status. The graph includes error bars for 95% confidence intervals and a red circle highlighting a significant change near the end of the timeline.]
Symptoms

- 50% of ESKD patients of all ages have moderate to severe pain. (Davison, 2003; Davison et al, 2006 & Murtagh et al, 2007)

- 5-50% of dialysis patients are depressed. (Davison & Jhangri, 2005; McDade-Montez, 2006)

- In one study (n=388 dialysis patients) 73% had either moderate or severe cognitive impairment. (Murray et al, 2006)
Symptom burden, Stage 3-5 CKD

Symptoms, moderate, severe or overwhelming severity as described on POS-S Renal

- Weakness/lack of... (25%)
- Difficulty sleeping (30%)
- Poor mobility (40%)
- Pain (35%)
- Drowsiness (25%)
- Shortness of breath (20%)
- Poor appetite (15%)
- Feeling anxious (25%)
- Restless legs (10%)
- Feeling depressed (15%)
- Constipation (5%)
- Itching (10%)
- Changes in skin (5%)
- Nausea (2%)
- Mouth problems (2%)
- Diarrhoea (2%)
- Vomiting (1%)

Kerry Linton, 2015, unpublished data
Symptom burden in the terminal phase of life

Despite the commonly held belief that death from uraemia is relatively symptom free, ESKD patients experience a significant symptom burden in the 24 h preceding death.

40% of patients experienced pain,
30% suffered agitation
25% were breathless.

Palliative care can significantly improve the quality of dying with reductions in pain, agitation and dyspnoea.

Referral to palliative care

- Nephrologists comfortable to refer for dialysis patients
- More likely to liaise with GP for supportive care patient
- In one study, primary care providers have been identified as being a possible barrier for referring to hospice with a discrepancy between provider attitudes toward hospice and their actual referral practices
- Referral to palliative care from hospital inpatient setting relatively smooth
- Accessing palliative care from outpatient clinic logistically difficult
Barriers to palliative care – renal perceptions

Prognostication
- Lack of clarity of referral criteria to palliative care
- Effective communication between all stakeholders difficult

Unrealistic expectations
- Especially (but not exclusively) in general medicine
- Lack of confidence in chronic disease clinicians to talk about death – variable

Patient and family resistance to the concept of palliative care
- Lack of recognition palliative care support can be appropriate for symptom management
Barriers to palliative care – renal perceptions

Lack of clear collaborative models between agencies

Capacity within palliative care services

- Referral process relatively clear but long, difficult to do in clinic
- Discharge if no immediate care needs
- Wait time for service, up to 30 days before Palliative Care can enrol patient
- Concern regarding clinical expertise in palliative care services around chronic disease management, especially when services are outsourced
Barriers to referral to palliative care

- Care providers who have completed their own Advance Care Plan more likely to engage in discussion about palliative care.

- Primary care providers have been identified as being a possible barrier for referring to hospice with a discrepancy between provider attitudes toward hospice and their actual referral practices.

- Primary care providers become invested in curative treatment and have difficulty shifting to palliative care.

- Education for family practice providers may need to focus on establishing goals of care and end-of-life issues with patients before a crisis.

- Nurse Practitioners may be the best option for communicating end-of-life issues.

Questions

What are your learning needs regarding care of people with ESKD - is lack of clinical expertise an issue?

What does palliative care have to share regarding care of renal patients that we can learn from - what works well in other disease models, services?

Can you foresee a change in the model of care/ funding model to include people who have chronic disease and a long disease trajectory- an “inactive” category?

How do you see the place of palliative care in the multidisciplinary/ multispecialty disease clinic?