CORE CURRICULUM IN NEPHROLOGY

Palliative Care

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BACKGROUND

Components of Renal Palliative Care
- Pain and symptom management.
- Advance care planning.
- Psychosocial and spiritual support to patients and families.
- Ethical issues in dialysis decision-making.

World Health Organization Definition
- Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

End-of-Life Care
- A subset of palliative care.

RELEVANCE TO END-STAGE RENAL DISEASE PATIENTS

Life Expectancy
- Patients are now living longer with better care of cardiac disease, diabetes, cancer, and hypertension, and older patients with considerable comorbidities who previously would not have lived are now presenting for dialysis.
- Limited life expectancy: Dialysis patients live one quarter as long as age-matched patients without renal disease (Table 1).

Survival
- 1-year unadjusted, all incident patients: 78%.
- 5-year unadjusted, all incident patients: 33%.
- 10-year unadjusted, all incident patients: 9%.
- Survival comparable or worse than patients with many types of cancer.
- Increasing number of incident patients with worse survival (median age, 64.5 years for incident patients in US Renal Data System [USRDS] Annual Data Report 2003).
- Younger patients without comorbidities may survive for 30 years with dialysis.

High Gross Mortality
- About 23% of dialysis patients in the United States die per year.
- More than 72,000 end-stage renal disease (ESRD) patients in the United States die per year.
- Considerable burden of comorbid conditions:
  - Diabetes, including retinopathy and neuropathy.
  - Coronary artery disease.
  - Congestive heart failure.
  - Hypertension.
  - Anemia.
  - Peripheral vascular disease.

Table 1. Expected Remaining Years of Life of the Dialysis Population (USRDS Annual Data Report 2002)

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0272-6386/04/4301-0031$30.00/0
Depression.
Dementia.
Cerebrovascular disease.

Considerable burden of symptoms:
- Pain.
- Fatigue and tiredness.
- Difficulty with sleep.
- Pruritus.

High frequency of death, including dialysis withdrawal, in dialysis units.
Average of 17 deaths per dialysis unit per year.
Most nephrologists have at least 1 patient per year (range, 0 to 10) who withdraws from dialysis.
Calculating from the USRDS Annual Data Report 2002, Table H.13, 18% of deaths are caused by dialysis withdrawal, but there are considerably fewer withdrawals for African-American patients.
Dialysis withdrawal more likely in the elderly.
Reasons for dialysis withdrawal:
- Acute medical or surgical complication.
- Chronic failure to thrive.
- Dementia.
- Stroke.
- Cancer.
- Unacceptable quality of life.
- Depression.

REFERENCES

INCORPORATION INTO DIALYSIS UNITS

A palliative care focus:
- Quality improvement activities.
- Inclusion of quality of death in morbidity and mortality conferences.
- Rounds to include question, “Would you be surprised if this patient died in the next year?”
- Educational in-services for dialysis personnel.

Pain and symptom assessment and management protocols (see outlines on pain and symptom management).
Advance care planning incorporated into semi-annual and annual care planning sessions (see outline on advance care planning).
Psychosocial and spiritual support for patients and families.
Terminal care protocols including hospice or a palliative care approach.
A bereavement program including a memorial service (see outline on referral to hospice, and grief and bereavement support).

REFERENCES

ADVANCE CARE PLANNING (ACP) AND CARDIOPULMONARY RESUSCITATION (CPR)

Definition and Components of ACP
ACP is a process of communication among patients, families, health care providers, and other important individuals about the patient’s preferred decision-maker and appropriate future medical care if and when a