

CORE CURRICULUM IN NEPHROLOGY

Palliative Care

Alvin H. Moss, MD, Jean L. Holley, MD, Sara N. Davison, MD, Richard A. Dart, MD,
Michael J. Germain, MD, Lewis Cohen, MD, and Richard D. Swartz, MD

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).

From Robert C. Byrd Health Sciences Center, West Virginia University, Morgantown, WV.

Address reprint requests to Alvin H. Moss, MD, Robert C. Byrd Health Sciences Center, West Virginia University, Morgantown, WV 26506. E-mail: amoss@hsc.wvu.edu

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

Age (y)	Black Male	Black Female	White Male	White Female
20-24	16.9	14.7	14.2	13.1
30-34	12.6	11.2	9.8	9.2
40-44	9.4	8.6	7.2	6.9
50-54	6.9	6.4	5.3	5.1
60-64	4.8	4.8	3.8	3.8
70-74	3.4	3.4	2.7	2.7
85+	1.9	1.9	1.6	1.6

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.

- 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

1. United States Renal Data System: USRDS 2002 Annual Data Report: Atlas of End-Stage Renal Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2002
2. Sekkarie MA, Moss AH: Withholding and withdrawing dialysis: The role of physician specialty and education and patient functional status. *Am J Kidney Dis* 31:464-472, 1995
3. Billings JA: Palliative care. Recent advances. *BMJ* 321:555-558, 2000
4. Neu S, Kjellstrand CM: Stopping long-term dialysis: An empirical study of withdrawal of life-supporting treatment. *N Engl J Med* 314:14-20, 1986
5. Leggat JE Jr, Bloembergen WE, Levine G, Hulbert-Shearon TE, Port FK: An analysis of risk factors for withdrawal from dialysis before death. *J Am Soc Nephrol* 8:1755-1763, 1997
6. Cohen LM, Dobscha SK, Hails KC, Morris JE, Pekow PS, Chochinov HM: Depression and suicidal ideation in patients who discontinue the life-support treatment of dialysis. *Psychosomatic Med* 64:889-896, 2002
7. United States Renal Data System: USRDS 2003 An-

nual Data Report: Atlas of End-Stage Renal Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2003

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

1. Cohen LM, Reiter GS, Poppel DM, Germain MJ: Renal palliative care, in Addington-Hall JM, Higginson IJ (eds): *Palliative Care for Non-Cancer Patients*. New York, NY, Oxford University, 2001
2. End-Stage Renal Disease Peer Workgroup of the Robert Wood Johnson Foundation’s Promoting Excellence in End-of-Life Care National Program: Completing the Continuum of Nephrology Care. Available at: <http://promotingexcellence.org/esrd/index.html> Accessed: July 21, 2003

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

patient is unable to make his or her own decisions.

- Advance directives are written documents completed by a capable person. An advance directive may identify a surrogate decision-maker or medical durable power of attorney (a proxy directive) or outline decisions to be made (instruction directive, eg, a living will or a do-not-resuscitate order).
- Components of ACP can be categorized into 3 areas:
 - *The Document*: Instruction directives are developed in accord with the person's wishes, values, life goals, and experiences and are influenced by cultural, spiritual, and religious views. Instruction directives are more useful if health states such as coma or severe dementia, rather than treatment interventions, are considered.
 - *The Participants*: ACP should be centered within the patient-family sphere rather than simply in the domain of the patient-physician relationship. Patients expect their physicians and/or dialysis unit staff to initiate discussions of ACP and advance directives. Such discussions should be considered part of the long-term care of those with kidney disease; these topics should be introduced early in the course of kidney disease and can be discussed whenever prognosis and/or the expected course of chronic kidney disease is considered.
 - *The Purpose*: The purpose of ACP is not merely the completion of a written advance directive. Patients and families view ACP as a way to prepare for death, strengthen interpersonal and interfamily relationships, relieve burdens on loved ones, and allow patients to maintain control over present and future health care.

REFERENCES

1. Singer PA: Advance care planning in dialysis. *Am J Kidney Dis* 33:980-991, 1999
2. Renal Physicians Association and American Society of Nephrology: *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*. Washington, DC, RPA, 2000, pp 28-30
3. Hines SC, Glover JJ, Holley JL, Babrow AS, Badzek LA, Moss AH: Dialysis patients' preferences for family-

based advance care planning. *Ann Intern Med* 130:825-828, 1999

4. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA: Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 284:2476-2482, 2000

Usefulness of ACP in the ESRD Population

- Survey studies have shown that ACP facilitates decision-making related to initiating and withdrawing dialysis. Nephrologists, as well as patients and families, find decision-making easier if ACP has occurred and advance directives exist.
- There is limited, but some, information suggesting that patients who have advance directives experience better, more reconciled deaths and avoid end-of-life therapeutic interventions that have little chance of benefit.

REFERENCES

1. Holley JL, Foulks CJ, Moss AH: Nephrologists' reported attitudes about factors influencing recommendations to initiate or withdraw dialysis. *J Am Soc Nephrol* 1:1284-1299, 1991
2. Swartz RD, Perry E: Advance directives are associated with "good deaths" in chronic dialysis patients. *J Am Soc Nephrol* 3:1623-1630, 1993
3. Cohen LM, Germain MJ, Poppel DM, Woods AL, Pekow PS, Kjellstrand CM: Dying well after discontinuing the life-support treatment of dialysis. *Arch Intern Med* 160:2513-2518, 2000

Strategies to Increase ACP in ESRD Patients

- Nephrologists should initiate discussions of ACP early in their relationship with patients. Learning some communication skills and language to use in these discussions will increase physicians' comfort with this aspect of medical care. Encouraging other members of the health care team (eg, dialysis unit social workers and peer counselors) to participate in ACP may increase the chances of success.
- Centering the ACP process within the patient-family relationship is important.

REFERENCES

1. Buckman R: *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore, MD, The Johns Hopkins University Press, 1992
2. Quill TE: Perspectives on care at the close of life: Initiating end-of-life discussions with seriously ill patients.

Addressing the “elephant in the room.” *JAMA* 284:2502-2507, 2002

3. Perry E, Swartz R, Smith-Wheelock L, Westbrook J, Buck C: Why is it difficult for staff to discuss advance directives with chronic dialysis patients? *J Am Soc Nephrol* 4:2160-2168, 1996

4. Swartz RD, Perry E: Medical family: A new view of the relationship between chronic dialysis patients and staff arising from discussions about advance directives. *J Womens Health Gen Based Med* 8:1147-1153, 1999

CPR in Dialysis Patients

- Although successful ACP does not require that a written advance directive be completed, a do-not-resuscitate order is a specific instruction directive that should be considered by ESRD patients. Nephrologists have an obligation to educate ESRD patients about the risks and outcome of CPR in dialysis patients (8% survival to hospital discharge). Patients’ choices should be honored.
- In a discussion about patients’ preferences regarding CPR, nephrologists should clarify patients’ preferences in their present condition and in conditions of severe comorbid illness such as coma, vegetative state, and ventilator-dependence.
- Development of dialysis unit policies about CPR requires consideration of patients’ desire to maintain control and the overall purpose of ACP in general.

REFERENCES

1. Renal Physicians Association and American Society of Nephrology: *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*. Washington, DC, RPA, 2000, pp 28-30

2. Moss AH, Holley JL, Upton MB: Outcome of cardiopulmonary resuscitation in dialysis patients. *J Am Soc Nephrol* 3:1238-1243, 1992

3. Moss AH, Hozayen O, King K, Holley JL, Schmidt RJ: Attitudes of patients toward cardiopulmonary resuscitation in the dialysis unit. *Am J Kidney Dis* 38:847-852, 2001

4. Hijazi F, Holley JL: Cardiopulmonary resuscitation and dialysis: Outcome and patient’s views. *Semin Dial* 16:51-53, 2003

COMMUNICATION ISSUES

Communication: The “Achilles Heel” of End-of-Life Care

- Impacted by cultural and ethnic issues, religious (spiritual) beliefs, and personal understanding of chronic illness and prognosis.

- Requires identification of decision-makers according to state law who possess capacity to give informed consent or refusal.
- Requires identification of patients’ values and treatment preferences if known.
- Addresses need of patients and families to know what to expect and when to expect it and desire of patients and families to participate in decision-making.

Patient-Family Conferences or Meetings

- Provide format to discuss a patient’s current medical condition and options for treatment and to decide on plan of care.
- Dialysis unit semi-annual and annual care planning meetings provide a venue for stable patients.
- Impromptu meetings often in the hospital and when a patient’s condition worsens are required to establish the goals of care.
- Format for patient-family conferences:
 - Introduction of self and others and establish meeting goal.
 - Review patient’s current medical condition and prognosis.
 - Ask for patient/family questions to ensure understanding.
 - Determine what patient’s values would be for the situation, if known.
 - Identify possible options for treatment.
 - Decide based on patient’s preferences, if known, or patient’s best interest.
 - Summarize decisions reached and plan.

6-Step Protocol for Communication of Bad News

- Getting started.
- What does the patient/family know?
- How much does the patient/family want to know?
- Sharing the information.
- Responding to feelings.
- Planning and follow-up.

Importance of Questions to Determine Patient/Family Needs

- “How much do you want to know?”
- “How specific do you want me to be?”

- “Is there someone you would like to have here for this discussion?”

Importance of Using Language in a Positive Way

- “I want to ensure that your father receives the kind of treatment he wants.”
- “Your father’s comfort and dignity will be my top priority.”
- “We want to help you live meaningfully in the time you have.”

Presenting the Option of Refusing Dialysis

- Estimate the patient’s prognosis prior to conversation, taking into account age and comorbid conditions (USRDS Annual Data Reports and prognostic tables in Renal Physicians Association/American Society of Nephrology clinical practice guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis).
- Explain survival with and without dialysis.
- Describe burdens of dialysis, including surgery for access, length and timing of treatments, and complications including infections and hospitalizations.
- Present palliative care approach as an alternative, and promise patient will be kept comfortable and not abandoned.
- Describe that death from uremia is often more comfortable than deaths from other types of diseases: cancer, congestive heart failure, and end-stage lung disease.
- Offer hospice, and explain services provided by hospice.
- Allow time for patient/family to reach decision.

REFERENCES

1. Ambuel B, Weissman D: Conducting a Family Conference. End-of-Life Palliative Education Resource Center. Available at: <http://www.eperc.mcw.edu/> Accessed: July 21, 2003
2. Emanuel LL, von Gunten CF, Ferris FD: Communicating Bad News, in American Medical Association’s Education for Physicians on End-of-Life Care. Chicago, The Robert Wood Johnson Foundation, 1999. Available at: www.epec.net Accessed: July 24, 2003
3. Buckman R: How to Break Bad News: A Guide for Health Care Professionals. Baltimore, MD, The Johns Hopkins University Press, 1992

PAIN MANAGEMENT IN RENAL PATIENTS

Background

- Pain is most common symptom in dialysis patients (50% of patients).
- Undertreatment is widespread and negatively impacts quality of life.
- May occur for any number of causes at any time.
- Patients often won’t admit to nor seek relief from it.

Basic Mechanisms of Pain

Pain types

Acute.

- Identifiable event, resolves in days-weeks.
- Usually nociceptive.

Chronic.

- Cause not easily identifiable.
- Multifactorial, indeterminate duration.
- Nociceptive and/or neuropathic.

Neuropathic.

- Pathophysiology:
 - Disorder of central or peripheral nerves.
- Multiple factors involved in causation.
- May exceed observable injury.
- Often tingling, shooting, stabbing, electrical.
- Treatment with anticonvulsants, tricyclic antidepressants, and opioids depending on severity.

Nociceptive.

- Pathophysiology:
 - Direct stimulation of intact nociceptors.
 - Sharp, aching, throbbing.
 - Somatic, easy to describe and localize.
 - Visceral, difficult to describe and localize.
- Treatment with opioids and adjuvants depending on severity.

Assessment of the Patient With Pain

Agency for Health Care Policy and Research Clinical Practice Guideline ABCDE recommendations for pain assessment and management

- Ask about pain regularly. Assess pain systematically.
- Believe the patient and family in their reports of pain and what relieves it.

- Choose pain control options appropriate for the patient, family, and setting.
- Deliver interventions in a timely, logical, and coordinated fashion.
- Empower patients and families. Enable them to control their course to the greatest extent possible.

Physical Examination and Assessment

- Look for etiologic factors.
- Character: burning, steady, aching, dull, etc.
- Location.
- Relief.
- Aggravating factors.
- Intensity.
 - Scoring systems: Usually 0 to 10, where 0 = no pain at all and 10 = worst pain imaginable.
 - Descriptive scale: Mild-moderate-severe or use of faces.

Psychological Assessment

- Principally to assess effect on quality of life.
- Depression often a comorbid condition.

Causes of Pain

- Musculoskeletal pain:
 - Osteoarthritis.
 - Osteoporosis.
 - Renal osteodystrophy.
 - Diskitis/osteomyelitis.
- Related to dialysis procedure.
- Neuropathic pain from peripheral neuropathy.
- Ischemic pain from peripheral vascular disease.
- Carpal tunnel syndrome.
- Angina.
- Other:
 - Polycystic kidney disease.
 - Malignancy.
 - Calciphylaxis.
 - Trauma.

Therapeutic Intervention

- Learn a few drugs in each category.
- Learn weaknesses, limitations, and “best” situations in which the drugs apply.
- Learn doses and how to reassess.

- Adjust and /or change therapy as needs dictate.
- Learn variety of routes available to give: orally, intravenously, subcutaneous, sublingual, transdermal patch.

World Health Organization 3-Step Ladder for Pain: Evidence-Based

- Convenient and allows progressive levels of intervention as needed by pain level.

Step 1 (mild), pain rated 1-4

- Adjuvants: medications used to counteract an opioid side effect or analgesics added to enhance analgesia.
 - Examples: gabapentin, valproic acid, steroids.
- Analgesics: non-narcotic.
 - Acetylsalicylic acid (aspirin).
 - Acetaminophen (Tylenol).
 - Nonsteroidal anti-inflammatory drugs: numerous examples.

Step 2 (moderate), pain rated 5-6

- Opioids
 - Codeine.
 - Oxycodone.
 - Hydrocodone.
 - Dihydrocodeine.
 - Tramadol.
 - +/- Adjuvants.

Step 3 (severe), pain rated 7-10

- Opioids
 - Morphine.
 - Hydromorphone.
 - Methadone.
 - Levorphanol.
 - Fentanyl.
 - Oxycodone.
 - +/- Adjuvants.
- Adjustment for decreasing glomerular filtration rate (GFR) needed for morphine and hydromorphone since glucuronide metabolites accumulate in renal failure.
- No adjustments for decreased GFR needed for oxycodone, fentanyl, and methadone.
- Start low and titrate dose upwards based on subsequent pain rating.
 - For pain that persists as mild to moderate, increase dose 25% to 50%.

- For severe/uncontrolled pain, increase dose 50% to 100%.
 - Adjust faster for worse pain.
- Immediate-release formulations, oral.
 - Codeine, hydrocodone, morphine, hydromorphone, oxycodone.
- Sustained-release formulations, oral.
 - Improve compliance, adherence, and pain control for chronic pain.
 - Dose every 8, 12, or 24 hours depending on formulation.
 - Adjust every 48 to 96 hours (once steady state reached).
- Adverse drug effects.
 - Drugs to avoid in renal failure and elderly because of metabolites:
 - Propoxyphene, meperidine.
- Morphine, unless life expectancy is short because of build up of metabolites causing opioid neurotoxicity.
- Common, expected adverse drug reactions to opioids:
 - Constipation.
 - Dry mouth.
 - Nausea/vomiting.
 - Sedation.
- Management of adverse drug reactions (ADRs) and side-effects:
 - Constipation by far the most common ADR, and patients do not develop tolerance to it unlike other opioid ADRs.
- Bowel preparations:
 - Bulk forming agents such as psyllium do not work and should not be used.
 - Stimulant laxatives required (senna, bisacodyl, glycerine, casanthranol).
 - Prokinetic agents (metoclopramide, cisapride).
 - Osmotic laxatives (lactulose or sorbitol).
- Summary of opioid pharmacotherapy for chronic pain:
 - By the mouth, since 80% of time pain can be controlled with oral medications.
 - By the World Health Organization ladder.
 - By the clock, ie, around-the-clock prescribing.
 - For the individual.
 - With attention to detail.

REFERENCES

1. Emanuel LL, von Gunten CF, Ferris FD: Pain management, in American Medical Association's Education for Physicians on End-of-Life Care. Chicago, The Robert Wood Johnson Foundation, 1999. Available at: www.epec.net Accessed: July 24, 2003
2. Aronoff GR, Berns JS, Brier ME, Golper TA: Drug Prescribing in Renal Failure: Dosing Guidelines for Adults (ed 4). Philadelphia, PA, ACP, 1998
3. Schetz M, Ferdinande P, Van den Berghe G, Verwaest C, Lauwers P: Pharmacokinetics of continuous renal replacement therapy. *Intensive Care Med* 21:612-620, 1995
4. Giacomini KM, Gibson TP, Levy G: Effect of hemodialysis on propoxyphene and norpropoxyphene concentrations in blood of anephric patients. *Clin Pharmacol Ther* 27:508, 1980
5. Schrier RW, Gottschalk CW (eds): Diseases of the Kidney (ed 6). Boston, MA, Little, Brown, 1997, pp 2978-2981
6. Kappel J, Calissi P: Nephrology 3: Safe drug prescribing for patients with renal insufficiency. *CMAJ* 166:473-477, 2002
7. Chernow B: Pocket Book of Critical Care Pharmacotherapy, Philadelphia, PA, Lippincott, Williams & Wilkins, 1995
8. Management of Cancer Pain. Clinical Practice Guideline Number 9. Rockville, MD, US Department of Health and Human Services, March 1994
9. Davison SN: Pain in hemodialysis patients: Prevalence, cause, severity, and management. *Am J Kidney Dis* 42:1239-1247, 2003

SYMPTOMS IN RENAL DISEASE

Background

- ESRD patients are amongst the most symptomatic of any chronic disease group.
- The greater the number of troublesome symptoms ESRD patients report, the lower they rate their quality of life.
- Pain, weakness, difficulty sleeping, pruritus, fatigue, anorexia, and sexual dysfunction are common symptoms. Erythropoietin can improve some but not all of these symptoms.
- Experience with nocturnal dialysis has demonstrated a significant reduction in hemodialysis-related symptoms, and peritoneal dialysis eliminates the direct hemodialysis-related symptoms such as intradialytic hypotension, vomiting, cramps, and postdialysis "washout."
- There are no ongoing, evidence-based symptom treatment protocols in dialysis units.

Intradialytic Symptoms

- Symptoms are common and problematic during dialysis. Approximately 40% of hemodialysis treatments are associated with symptomatic hypotension and/or symptoms such as cramps, nausea, and vomiting; and pruritus. Postdialysis hypotension and a “washed out” feeling or weakness lasting up to 24 hours are also common.
- Shorter dialysis treatments, high-efficiency dialysis, elderly patients, and high comorbid burden correlate with increased symptoms on dialysis. The majority of symptomatic treatments occur in a minority of patients who are recurrently symptomatic. Recent studies have supported the value of changes in the dialysis prescription in decreasing intradialytic symptoms. Blood volume monitoring, decreased dialysis temperature, and modeling of dialysate sodium and ultrafiltration rates are effective and inexpensive.

Pruritus

- Uremic pruritus is one of the most common and frustrating symptoms experienced by patients with ESRD. Up to 60% of dialysis patients experience pruritus, sometimes worse during the dialysis session. Secondary hyperparathyroidism, hyperphosphatemia, increased calcium-phosphate deposition in the skin, dry skin, inadequate dialysis, anemia, iron deficiency, and low-grade hypersensitivity to products used in the dialysis procedure have all been identified as possible causes of pruritus in the dialysis patient.

Anorexia

- A nonspecific symptom that may be an indication of inadequate dialysis and uremia. Depression, gastrointestinal disturbances, taste disorders, and mechanical causes may also contribute to anorexia.

Constipation

- A common complaint in the dialysis patient and the cause is multifactorial. Dietary restriction of high-potassium fruits and vegetables decreases the fiber content of food ingested. Fluid restriction, inactivity, and

medications such as phosphorous binders, iron supplements, and narcotics can cause constipation.

Insomnia

- Problems of sleep disturbances have been reported by 50% to 90% of dialysis patients surveyed. Research has also shown that these patients have a high incidence of specific primary sleep disorders such as sleep apnea syndrome, periodic leg movement disorder, and restless legs syndrome.

Lethargy

- Persistent fatigue and postdialysis fatigue have been attributed to a number of causes: ultrafiltration and its effect on blood pressure, blood-membrane interactions, acute reductions in serum potassium and phosphorous levels during dialysis, depression, insomnia, poor nutrition, anemia, medication, the rapid osmotic changes of the extracellular fluid space during hemodialysis, and depletion of specific substances such as carnitine.

Neuropathy

- Uremic neuropathy is a mixed motor and sensory polyneuropathy that is distal and symmetrical. Currently the condition is attributed to one or more toxins retained in uremia and not adequately removed by dialysis. Diabetic peripheral neuropathy is also a common cause of symptoms because of the high incidence of diabetes in the ESRD population. Medications such as gabapentin or tricyclic antidepressants are used to treat the painful burning sensation in hands and feet associated with this disorder.

Restless Legs

- The prevalence of uremia-associated restless leg syndrome is estimated to be between 20% and 40%, and it is unclear to what extent this condition is related to uremic neuropathy. Anemia, low serum ferritin levels, low serum levels of parathyroid hormone, and inadequate dialysis have been associated with the presence of restless leg syndrome in dialysis patients.

Nausea and Vomiting

- May be a manifestation of uremia, fluid and electrolyte changes, and hypotension during the dialysis procedure. Treatment for nausea and vomiting depends on the underlying cause.

Depression

- Subsyndromal depressive symptoms are found in 25% and major depression in 5% to 22% of ESRD patients. Although major depression can be effectively ameliorated with psychotherapy and/or selective serotonin reuptake inhibitors, in dialysis facilities depression is often unrecognized and untreated.

REFERENCES

1. Kimmel PL, Emont SL, Newmann JM, Danko H, Moss AH: ESRD patient quality of life: Symptoms, spiritual beliefs, psychological factors, and ethnicity. *Am J Kidney Dis* 42:713-721, 2003
2. Cohen LM, Reiter GS, Poppel DM, Germain MJ: Renal palliative care, in Addington-Hall JM, Higginson IJ (eds): *Palliative Care for Non-Cancer Patients*. New York, NY, Oxford University Press, 2001
3. Cohen LM, Germain MJ: Palliative and supportive care, in Brady HR, Wilcox CS (eds): *Therapy of Nephrology and Hypertension: A Companion to Brenner's The Kidney*. (ed 2). Philadelphia, PA, Elsevier Science, 2003, pp 753-756
4. Cohen LM, Germain MJ, Tessier EG: Neuropsychiatric complications and psychopharmacology of end-stage renal disease, in Brady HR, Wilcox CS (eds): *Therapy of Nephrology and Hypertension: A Companion to Brenner's The Kidney*. (ed 2). Philadelphia, PA, Elsevier Science, 2003, pp 731-746

REFERRAL TO HOSPICE, AND GRIEF AND BEREAVEMENT SUPPORT

Hospice

- Sees death as a natural part of life.
- Recognizes the patient *and* family as the unit of care.
- Requires prognosis of 6 months or less based on the physician's determination of the normal course of the patient's illness.
- Believes in treating symptoms, not prolonging life or hastening death.
- Focuses on pain and symptom management.
- Supports the patient and family during death and after.

- Covered by most insurance including Medicare.
- Provides, coordinates, and pays for all services related to the terminal condition.
- Despite serving over 700,000 dying persons and their families each year, hospice recognizes that there are barriers to access, and it wants to provide care to ESRD patients and those with disorders other than cancer and acquired immunodeficiency syndrome.

Services Provided

- Nursing.
- Pastoral care.
- Psychosocial support.
- Volunteers.
- Home care aides.
- Hospitalization for acute management of uncontrolled pain and symptoms.
- Out-patient services.
- Supplies, medications, equipment.
- Bereavement services for 1 year after the death.
- Provides care when patient is in home, hospital, or nursing home.

ESRD Patients on Dialysis

- Because of Medicare payment regulations, if patient were referred to hospice with ESRD as the terminal diagnosis, the hospice would be financially responsible for payment of dialysis on the \$115/day they receive from Medicare. Medicare would not pay for dialysis and hospice. Hospices cannot afford to pay for thrice-weekly dialysis.
- Dialysis would be viewed as life prolonging and would be outside of the scope of most hospice philosophies.
- Therefore, most hospices will rarely accept a patient on maintenance dialysis with a renal diagnosis as the reason for hospice referral.
- ESRD patients who are referred must have a nonrenal terminal diagnosis, eg, end-stage heart disease, pulmonary disease, cancer. If the terminal diagnosis for hospice is nonrenal, then the costs for dialysis are not charged to the hospice.

When to Refer to Hospice

- Referral should be considered for *all* renal patients discontinuing dialysis and made for all patients who want to die at home or in a nursing home. Acute hospice care is possible in some hospitals.
- ESRD patients with other nonrenal diseases in advanced stages may selectively be referred.
 - Determine that patients have prognosis of 6 months or less by using the Local Medical Review Policies (LMRP) website listed below.

Bereavement Services

- Should be provided to all families and loved ones following ESRD patient deaths whether or not referral is made to hospice.
- Condolence letter and/or call from the nephrologist or other staff.
- Attendance by staff at funeral or wake encouraged.
- Notification of death announced at the dialysis clinic, eg, display obituary, place a flower in a vase, or some other ritual.
- Renal social worker contact.
- Annual renal memorial service.

REFERENCES AND RESOURCES

1. Description of LMRP prognostic criteria. Available at: www.DraftLMRP.net.
2. National Hospice and Palliative Care website. Available at: www.nhpco.org. Accessed: July 21, 2003
3. American Academy of Hospice and Palliative Medicine website. Available at: www.aahpm.org. Accessed: July 21, 2003
4. Jennings B, Ryndes T, D'Onofrio C, Baily MA: Access to hospice care: Expanding boundaries, overcoming barriers. *Hastings Cent Rep* March-April:S3-S7, S9-S13, S15-S21, 2003
5. Braveman C, Cohen, LM: Discontinuation of dialysis: The role of hospice and palliative care. *AAHPM Bull* 3:1,16-17, 2002
6. Poppel D, Cohen L, Germain M: The renal palliative care initiative. *J Palliative Med* 6:321-326, 2003
7. Cohen LM, Germain MJ: Palliative and supportive care, in Brady HR, Wilcox CS (eds): *Therapy of Nephrology and Hypertension: A Companion to Brenner's The Kidney*. (ed 2). Philadelphia, PA, Elsevier Science, 2003, pp 753-756
8. Cohen LM, Reiter G, Poppel D, Germain M: Renal palliative care, in Addington-Hall J, Higginson I (eds): *Palliative Care for Non-Cancer Patients*. London, Oxford University Press, 2001, pp 103-113

CLINICAL, ETHICAL, AND LEGAL ISSUES IN WITHHOLDING AND WITHDRAWING DIALYSIS**The Ethical and Legal Right of Competent Patients to Have Dialysis Withheld or Withdrawn***Clinical considerations*

- Responding to a patient's request to stop dialysis, determine why.
 - Identify provider(s) who will coordinate communication with the patient or legal agent (eg, nephrologist in conjunction with the primary care provider for ESRD patients).
 - Assess patient decision-making capacity and whether it is diminished by major depression, encephalopathy, or other disorder. Obtain psychiatric and/or neurological consultation as appropriate, and institute treatment for conditions impairing decision-making capacity.
 - Are the patient's perceptions about dialysis accurate? Does the patient know what to expect if dialysis is not started or discontinued?
 - Does the patient really mean what he/she says or is the decision to refuse or stop dialysis made to get attention, help, or control?
 - Are there changes that might improve quality of life and would the patient be willing to start or continue dialysis while the factors responsible for the patient's request are addressed?
 - Are there persons (eg, social worker, chaplain) with whom the patient would be willing to discuss the decision?

Ethical considerations

- The right of competent patients to have dialysis withheld or withdrawn is grounded in the ethical principles of:
 - Autonomy: requires respect for patient's right to make free decisions about his/her health care.
 - Respect for persons: requires that health care professionals refrain from carrying out unwanted interventions and that they actively encourage autonomy and pro-

Initiation of and Withdrawal from Dialysis. Clinical Practice Guideline. Number 2. Washington, DC, Renal Physicians Association, 2000

6. Beauchamp TL, Childress JF: Principles of Biomedical Ethics (ed 4). New York, NY, Oxford University Press, 1994

When Patient Is No Longer Competent to Give Consent for Withdrawal or Initiation of Dialysis

Ethical considerations

- To respect patient autonomy, a substitute decision-maker must give consent to withhold or withdraw dialysis.

Who should make the decision?

- Person(s) with the best knowledge of the patient's specific wishes/values/beliefs/preferences as they pertain to the present situation.
- In various states, the appropriate legal agent is called a health care proxy or medical power of attorney or durable power of attorney for health care. Such agents are appointed by the patient while capacitated.
- In most states, if the patient has not appointed a decision-maker in an advance directive, state law allows the appointment of a health care surrogate to participate in decision-making with the physician.
- Nephrologists must be knowledgeable of the state law in the state in which they are practicing.

How should the decision be made?

- Decisions should reflect a patient's wishes, if known.
- If advance care planning has been done and/or an advance directive has been completed, a patient's expressed wishes should be honored.
- If a patient's wishes are unknown, a decision should be made based on the patient's best interest.
- Difficulties arise when family members request treatments that are contrary to the patient's previously expressed wishes or the health care team's assessment of the patient's best interest.
 - The family has no moral or legal authority to make medical decisions for the patient independent of the patient's wishes or best interest. By requesting such treat-

ment, they breach their fiduciary duty as surrogate decision-makers for the patient and in such cases there is no legal or ethical duty to provide the treatment. See below.

- Difficulties arise when there is disagreement as to what is in the patient's best interest or what his/her prior wishes were.
 - This situation often requires a process of conflict resolution to come to a common understanding of the values and beliefs of the patient and the goals of care (see conflict resolution below).

Legal considerations

- The law requires that a person authorized by law or mandate should replace the patient if the patient is not competent to make decisions.
- Most states and provinces have enacted legislation giving family members, or specific individuals previously designated by the patient, the right to make health care decisions on behalf of incompetent patients.
- If such a substitute decision-maker is not available, then a court-appointed guardian, or the court itself, will make the necessary health care decisions on behalf of the patient by exercising its *parens patriae* jurisdiction.
- The substitute decision-maker has a fiduciary duty to make decisions based on the known wishes of the patient or, if not known, in the patient's best interest. These decisions should take into account the known values and beliefs of the patient as well as the relative risks and benefits.

REFERENCES

1. Hare J, Pratt C, Nelson C: Agreement between patients and their self-selected surrogates on difficult medical decisions. *Arch Intern Med* 152:92-98, 1992
2. Lazar NM, Greiner GG, Robertson G, Singer PA: Bioethics for clinicians: 5. Substitute decision-making. *Can Med Assoc J* 155:1435-1437, 1996
3. Renal Physicians Association and American Society of Nephrology: Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. Clinical Practice Guideline. Number 2. Washington, DC, Renal Physicians Association, 2000
4. Singer PA, MacDonald N: Bioethics for clinicians: 15.

Quality end-of-life care. *Can Med Assoc J* 159:159-162, 1998

5. Weir RF, Gostin L: Decisions to abate life sustaining therapy for nonautonomous patients: Ethical standards and legal liability for physicians after Cruzan. *JAMA* 264:1846-1853, 1990

6. Cohen LM, Germain MJ, Poppel DM: Practical considerations in dialysis withdrawal: "To have the option is a blessing." *JAMA* 289:2113-2119, 2003

Demand for "Inappropriate" Initiation or Continuation of Dialysis

Ethical considerations

- The limits of patient autonomy have recently been challenged by demands from patients and families for medical intervention felt to be inappropriate by the medical team.
- Conflict between the ethical principles of autonomy versus beneficence: The physician's obligation to respect the wishes of the patient must be tempered by duties to consider the well-being of the patient and provide appropriate care. Appropriate care is that in which there is a reasonable expectation that the benefits of care will exceed the burdens. Patients' wishes cannot, on their own, become the standard for medical care.
- In most cases, dialysis treatment can be ethically withheld or withdrawn in patients who have irreversible, profound neurological impairment such that they lack signs of thought sensation, purposeful behavior, and awareness of self and environment, eg, patients in permanent unconsciousness.
- Two very different ethical issues:
 - Demand for ineffective treatment: can be dismissed because such treatments fall outside the bounds of standard medical care.
 - Demand for effective treatment supporting a controversial end (eg, dialysis for a patient with permanent unconsciousness):
 - Typically involve substantial value disagreements and cannot be addressed by the concept of "futility." Often the question "What sort of life is worth preserving?" is at their core. Most patients would not choose to prolong life in a profoundly diminished state but some have good reasons for doing so (relig-

ious or cultural beliefs). It is not ethical practice to arbitrarily discount patients' values. A unilateral decision to withhold or withdraw care in such cases violates the obligation to respect the wishes and values of the patient.

- Must consider social value for family and loved ones, appropriate use of scarce resources, suffering of the patient, and ethical burden on health care team.
- Ethical theories such as ethic of care and relational ethics may help approach these types of situations, at least at the level of the individual patient. Issues of appropriate use of resources need to be dealt with at a higher and ultimately a societal level.
- This type of conflict requires open communication and negotiation (conflict resolution) between the health care team and the patient or family.

Legal considerations

- Currently, the law does not adequately address the issue of whether physicians can refuse a patient's wish to receive life-sustaining treatment deemed medically inappropriate.
- There is a distinction between the negative right to refuse unwanted treatment and a positive right to demand specific treatment. "Autonomy is limited by the reach of the legal roots that established it: the constitutional right to privacy; the common law doctrine of informed consent; and the common law right to be free from unwanted bodily invasion. Each is a negative right from which no entitlement to medical care properly can be inferred." (*Brophy v. New England Sinai Hospital*).
- The courts have tried to balance concerns for ethical integrity of the medical profession against respect for patient autonomy.
 - There is nothing in the law "which would justify compelling medical professionals. . .to take active measures which are contrary to their view of their ethical duty toward their patients."
 - Within the context of withdrawing life-sustaining treatment, the court has stated that a physician "is under no duty to treat

... a patient where a large body of informed and responsible medical opinion is to the effect that no benefit would be confirmed by continuance.” (*Airedale NHS Trust v. Bland*).

- This does not mean that the medical community is free to abandon patients if their conscience does not allow them to participate in the patient’s care. They are expected to transfer the patient to another physician willing to comply with the patient’s wishes, if such a physician can be found.
- Even if the law may not oblige physicians to act contrary to conscience, it does not consistently support the withdrawal of life-sustaining treatment contrary to the wishes of the patient or family.
 - Historically, courts have not addressed *what* should be decided but *who* should decide and typically support the right of families to make decisions for their loved ones contrary to the advice given to them by the treating physician (eg, cases of Helga Wanglie and Baby K).

REFERENCES

1. Renal Physicians Association and American Society of Nephrology: Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. Clinical Practice Guideline. Number 2. Washington, DC, Renal Physicians Association, 2000
2. Singer PA, MacDonald N: Bioethics for clinicians: 15. Quality end-of-life care. *Can Med Assoc J* 159:159-162, 1998
3. Weijer C, Singer PA, Dickens BM, Workman S: Bioethics for clinicians: 16. Dealing with demands for inappropriate treatment. *Can Med Assoc J* 159:817-821, 1998
4. Weir RF, Gostin L: Decisions to abate life sustaining

therapy for nonautonomous patients: Ethical standards and legal liability for physicians after Cruzan. *JAMA* 264:1846-1853, 1990

5. Shiner K: Medical futility: A futile concept. *Wash & Lee L. Rev.* 53:803, 806 (1996)
6. Brophy v. New England Sinai Hospital: 398 Mass. App. Ct. 417; 497 N.E. 2d 626, 1986
7. *Airedale N.H.S. Trust v S* (1993) 1 All E.R. 821 at 861

Conflict Resolution

- The law and ethics attach considerable importance to communication and the process of care. When disagreement among the health care team and patient/family persists, the physician should seek a negotiated solution through the process of conflict resolution.
- Conflict resolution aims to de-escalate conflict and find a common ground. This often requires extensive exploration of values, beliefs, and expectations for care. This may require the services of someone trained in conflict resolution such as a bioethicist, social worker, or psychologist.
- Courts are *not* the place to achieve resolution as they are highly polarized venues for parties to address disputes.
- If conflict cannot be resolved through mediation, consultation with a lawyer may be necessary. The courts should only be sought as a last resort.

REFERENCES

1. Renal Physicians Association and American Society of Nephrology: Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. Clinical Practice Guideline. Number 2. Washington, DC, Renal Physicians Association, 2000
2. AMA Council on Ethical and Judicial Affairs: Medical futility in end-of-life care. *JAMA* 281:937-941, 1999