

Coalition for Supportive Care of Kidney Patients Bibliography

Clinical Practice Guideline

Renal Physicians Association. *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis, 2nd ed.* Rockville, MD: Renal Physicians Association, 2010.

Moss AH. Revised Dialysis Clinical Practice Guideline Promotes More Informed Decision-Making. *Clin J Am Soc Nephrol* 2010;5(12):2380-2383

RPA/ASN Position Statement

Renal Physicians Association. American Society of Nephrology: Position Paper on Quality Care at the End of Life. Rockville, MD: Renal Physicians Association, 2002.

Book

Chambers EJ, Germain M, Brown E, eds. *Supportive Care for the Renal Patient, 2nd ed.* Oxford: Oxford University Press, 2010.

Core Curriculum

Moss AH, Holley JL, Davison SN, Dart RA, Germain MJ, Cohen LM, Swartz RD. Core Curriculum in Nephrology: Palliative Care. *Am J Kidney Dis* 2004;43:172-185.

Fellows Training

Holley JL, Carmody SS, Moss AH, Sullivan AM, Cohen LM, Block SD, Arnold RM. The Need for End-of-Life Care Training in Nephrology: National Survey Results of Nephrology Fellows. *Am J Kidney Dis* 2003;42:813-820.

Advance Care Planning

Holley JL. Advance Care Planning in CKD/ESRD: An Evolving Process. *Clin J Am Soc Nephrol* 2012;7(6):1033-1038

Schmidt RJ. Informing Our Elders About Dialysis: Is an Age-Attuned Approach Warranted? *Clin J Am Soc Nephrol* 2012;7:185-189

Davison SN, Simpson C. Hope and Advance Care Planning in Patients with End Stage Renal Disease: Qualitative Interview Study. *BMJ*. 2006 Oct 28;333(7574):886. Epub 2006 Sep 21.

Davison SN. Facilitating Advance Care Planning for Patients with End Stage Renal Disease: the Patient Perspective. Clin J Am Soc Nephrol Sep 2006, 1:1023-1028

Davison SN, Torgunrud C. The Creation of an Advance Care Planning Process for Patients with ESRD. Am J Kidney Dis 2007;49:27-36.

Holley JL, Hines SC, Glover JJ, Babrow AS, Badzek LA, Moss AH. Failure of Advance Care Planning to Elicit Patients' Preferences for Withdrawal from Dialysis. Am J Kidney Dis 1999;33:688-693.

Hines SC, Glover JJ, Holley JL, Babrow AS, Badzek LA, Moss AH. Dialysis Patients' Preferences for Family-Based Advance Care Planning. Ann Intern Med 1999;130:825-828.

Holley JL. Palliative Care in End-Stage Renal Disease: Focus on Advance Care Planning, Hospice Referral, and Bereavement. Sem Dial 2005;18:154-156.

Holley JL. Advance Directives and Advance Care Planning in Patients with End-Stage Renal Disease. In: Chambers J, Germain M, Brown E, eds. Supportive Care for the Renal Patient. Oxford: Oxford University Press 2004: 35-43.

Hines SC, Glover JJ, Babrow AS, Holley JL, Badzek LA, Moss AH. Improving advance care planning by accommodating family preferences. J Palliat Med 2001; 4:481-489.

Chronic Kidney Disease

Murtagh FEM, Addington-Hall JM, Higginson IJ. End-Stage Renal Disease: A New Trajectory of Functional Decline in the Last Year of Life. J Am Geriatr Soc 2011;59:304-308

Da Silva-Gane M, Wellsted D, Greenshields H, Norton S, Chandna SM, Farrington K. Quality of Life and Survival in Patients with Advanced Kidney Failure Managed Conservatively or by Dialysis. Clin J Am Soc Nephrol 2012;7: 2002–2009

Carson R. Deny Dialysis or “D-NI” Dialysis? The Case for “Do Not Initiate; Do Not Ignore” Orders. Clin J Am Soc Nephrol 2012; 7: 1924–1926

Bowling CB, O'Hare AM. Managing Older Adults with CKD: Individualized Versus Disease-Based Approaches. Am J Kidney Dis 2012;59(2):293-302

Communication

Schell JO, Germain MJ, Finkelstein FO, Tulsy JA, Cohen LM. An integrative approach to advanced kidney disease in the elderly. Adv Chronic Kidney Dis 2010;17(4): 368-77

Schell JO, Patel UD, Steinhauer KE, Ammarell N, Tulksy JA. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *Am J Kidney Dis* 2012;59(4): 495-503

Schell JO, Green JA, Tulsky JA, Arnold RM. Communication skills training for dialysis decision-making and end-of-life care in nephrology. *Clin J Am Soc Nephrol*. 2013 Apr;8(4):675-80

CPR

Moss AH, Holley JL, Upton MB. Outcomes of Cardiopulmonary Resuscitation in Dialysis Patients. *J Am Soc Nephrol* 1992; 3:238-43.

Moss AH, Hozayen O, King K, Holley JL, Schmidt RJ. Attitudes of Patients Toward Cardiopulmonary Resuscitation in the Dialysis Unit. *Am J Kidney Dis* 2001;38:847-852.

Karnik JA, Young BS, Lew NL, Herget M, Dubinsky C, Lazarus JM, Chertow CM. Cardiac Arrest and Sudden Death in Dialysis Units. *Kid Int* 2001;60:350-57.

Hijazi F, Holley JL. Cardiopulmonary Resuscitation and Dialysis: Outcome and Patients' Views. *Sem Dial* 2003;16:51-53.

Lehrich RW, Pun PH, Tanenbaum ND, Smith SR, Middleton JP. Automated External Defibrillators and Survival from Cardiac Arrest in the Outpatient Hemodialysis Clinic. *J Am Soc Nephrol* 2007;18:312-320.

Hospice

Murray AM, Arko C, Chen S-C, Gilbertson DT, Moss AH. Use of Hospice in the United States Dialysis Population. *Clinical J Am Soc Nephrol* 2006;1:1248-1255.

Pain and Symptoms

Davison SN, Jhangri G, Johnson J. Longitudinal Validation of a Modified Edmonton Symptom Assessment System (ESAS) in Hemodialysis Patients. *Nephrol Dial Transplant*. 2006 Nov; 21(11): 3189-95. Epub Sep 6 2006

Davison SN, Jhangri G, Johnson JA. Cross Sectional Validity of a Modified Edmonton Symptom Assessment System in Dialysis Patients: A Simple Assessment of a Symptom Burden. *Kidney Int*. May 2006, 69(9):1621-1625.

Davison SN, Jhangri G. The impact of Chronic Pain on Depression, Sleep and the Desire to Withdraw from Dialysis in Hemodialysis Patients. *J Pain Symptom Manage*. Nov 2005;30(5):465-73.

Davison SN. Chronic Pain in End-Stage Renal Disease. *Advances in Chronic Kidney Disease*. 2005;12(3):326-334.

Barakzoy AS, Moss AH. Efficacy of the World Health Organization Analgesic Ladder to Treat Pain in End-Stage Renal Disease. *J Am Soc Nephrol* 2006;17:3198-3203.

Davison SN. Pain in Hemodialysis Patients: Prevalence, Cause, Severity, and Management. *Am J Kidney Dis* 2003;42:1239-1247.

Dean M. Opioids in Renal Failure and Dialysis Patients. *J Pain Symptom Manage* 2004;28:497-504.

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* 2003;42:713-721.

Cohen LM, Tessier EG, Germain MJ, Levy NB. Update on Psychotropic Medication Use in Renal Disease. *Psychosomatics* 2004;45:34-48.

Weisbord SD, Fried LF, Arnold RM, Fine MJ, Leveson DJ, Peterson RA, Switzer GE. Prevalence, Severity, Importance of Physical and Emotional Symptoms in Chronic Hemodialysis Patients. *J Am Soc Nephrol* 2005;16:2487-2494.

Murphy EJ. Acute Pain Management Pharmacology for the Patient with Concurrent Renal or Hepatic Disease. *Anaesthesia and Intensive Care*. 2005;33:311-322.

Pasero C, McCaffery M. Ketamine. *Am J Nursing* 2005;105:60-64.

Weisbord SD, Fried LF, Mor MK, Resnick AL, Unruh ML, Palevsky PM, Levenson DJ, Cooksey SH, Fine MJ, Kimmel PL, Arnold RM. Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2007;2:960-967.

Davison SN. The prevalence and management of chronic pain in end-stage renal disease. *J Palliat Med* 2007;10:1277-1287.

Murtagh FEM, Addington-Hall JM, Edmonds PM, et al. Symptoms in advanced renal disease: A cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. *J Palliat Med* 2007;10:1266-1276.

Palliative Care Overview

Davison SN. The ethics of end-of-life care for patients with ESRD. *Clin J Am Soc Nephrol* 2012; 7(12):2049-2057

Wong SPY, Kreuter W, O'Hare AM. Treatment Intensity at the End of Life in Older Adults Receiving Long-term Dialysis. *Arch Intern Med* 2012;172:661-663

Germain MJ, Kurella Tamura M, Davison SN. Palliative Care in CKD: The Earlier the Better. *Am J Kidney Dis* 2011;57(3):378-380

Holley JL. Palliative Care in End-Stage Renal Disease: Illness Trajectories, Communication, and Hospice Use. *Adv Chronic Kidney Dis* 2007;14 (4):402-408.

Cohen LM, Moss AH, Weisbord SD, Germain MJ. Renal palliative care. *J Palliat Med* 2006;9:977-992.2006;977-992

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*, 2nd Edition. Philadelphia: W. B. Saunders, Co, 2003: 753-756.

Moss AH. Kidney Failure. In: Emanuel L, Librach SL, eds. *Palliative Care: Core Skills and Clinical Competencies*. Philadelphia: W.B. Saunders, 2007, pp. 354-368.

Brown EA. Epidemiology of renal palliative care. *J Palliat Med* 2007;10:1248-1252.

Patient Perspectives

Davison SN. End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease. *Clin J Am Soc Nephrol* 2010;5(2):195-204.

Prognosis

Kurella Tamura M, Covinsky KE, Chertow GM, *et al*. Functional Status of Elderly Adults Before and After Initiation of Dialysis. *N Engl J Med* 2009; 361:1539–1547

Moss AH, Ganjoo J, Sharma S, *et al*. Utility of the “Surprise” Question to Identify Dialysis Patients with High Mortality. *Clin J Am Soc Nephrol* 2008;3(5):1379-1384

Cohen LM, Ruthazer R, Moss AH, Germain MJ. Predicting six-month mortality in patients maintained with hemodialysis. *Clin J Am Soc Nephrol* 2010; 5(1):72-79

Kurella M, Covinsky KE, Collins AJ, *et al*. Octogenarians and Nonagenarians Starting Dialysis in the United States. *Ann Intern Med* 2007;146:177–183

Vascular Access Considerations

Kaufman SR, Shim JK, Russ AJ: Old age, life extension, and the character of medical choice. *The journals of gerontology. Series B, Psychological sciences and social sciences* 2006; 61:S175-184

Moist LM, Lok CE, Vachharajani TJ, *et al*: Optimal hemodialysis vascular access in the elderly patient. *Seminars in dialysis* 2012; 25:640-648

Richardson AI, 2nd, Leake A, Schmieder GC, et al: Should fistulas really be first in the elderly patient? *The journal of vascular access* 2009; 10:199-202

Tamura MK, Tan JC, O'Hare AM: Optimizing renal replacement therapy in older adults: a framework for making individualized decisions. *Kidney Int* 2012; 82:261-269

Vachharajani TJ, Moossavi S, Jordan JR, et al: Re-evaluating the Fistula First Initiative in Octogenarians on Hemodialysis. *Clinical journal of the American Society of Nephrology : CJASN* 2011; 6:1663-1667

Xi W, Harwood L, Diamant MJ, et al: Patient attitudes towards the arteriovenous fistula: a qualitative study on vascular access decision making. *Nephrol Dial Transplant* 2011; 26:3302-3308

Withdrawal of Dialysis and End-of-Life Decision-Making

Germain MJ, Davison SN, Moss AH. When Enough Is Enough: The Nephrologist's Responsibility in Ordering Dialysis Treatment. *Am J Kidney Dis* 2011;58 (1): 135-143.

Moss AH. Ethical Principles and Processes Guiding Dialysis Decision-Making. *Clin J Am Soc Nephrol* 2011;6(9);2313-2317

Cohen LM, Germain MJ, Woods AL, Mirot A, Burleson JA. The Family Perspective of ESRD Deaths. *Am J Kidney Dis* 2005;45(1):154-161.

Cohen LM, Germain M, Poppel DM, Pekow PS, Woods A, Kjellstrand CM. Dying Well After Discontinuing the Life-Support Treatment of Dialysis. *Arch Intern Med* 2000;160:2513-2518.

Cohen LM, Germain MJ, Poppel DM. Practical Considerations in Dialysis Withdrawal: "To have the option is a blessing." *JAMA* 2003;289:2113-2119.

Cohen LM, Bostwick JM, Mirot A, Garb J, Braden G, Germain M. A psychiatric perspective of dialysis discontinuation. *J Palliat Med* 2007;10:1262-1265.

Moss AH. Patient Selection for Dialysis, the Decision to Withdraw Dialysis, and Palliative Care. In: Brady HR, Wilcox CS, eds. *Therapy in Nephrology and Hypertension*, 2nd edition. Philadelphia: W. B. Saunders, Co., 2003:875-882.

Davison SN, Jhangri GS, Holley JL, Moss AH. Nephrologists' Comfort with End-of-Life Decision-Making. *Clin J Am Soc Neph* 2006;1:1256-1262.

Holley JL, Davison SN, Moss AH. Nephrologists' Changing Practices in Reported End-of-Life Decision-Making. *Clin J Am Soc Neph* 2007;2:107-111.

Sekkarie, MA, Moss, AH. Withholding and Withdrawing Dialysis: The Role of Physician Specialty and Education and Patient Functional Status. *Am J Kidney Dis* 1998;31:464-472.

Patient-Friendly

Callanan, M., Kelley, P. (1993). *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*. New York: Bantam.

Dunn, H. (2001). *Hard Choices For Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness*.
http://www.hnehealth.nsw.gov.au/__data/assets/pdf_file/0016/54250/HardChoices.pdf.

Okun, B., Nowinski, J. (2011). *Saying Goodbye: How Families Can Find Renewal Through Loss*. New York: The Berkley Publishing Group.

Webb, M. (1997). *The Good Death: The New American Search to Reshape the End of Life*. New York: Bantam.