Performance Excellence and Accountability in Kidney Care

QUALITY PARTNERS OF RHODE ISLAND

BROWN

FAMILY "TOOLS OF ENGAGEMENT"
BEST PRACTICE 2

BEST PRACTICE

Provide support and resources to guide patients/families in patient centered advance care planning.

HOW DO YOU ACHIEVE THIS BEST PRACTICE?

1) Improve communication between patient/families and health care professionals
   a) Assess readiness to learn about this topic and health literacy
   b) Assess perceptions about dialysis and their quality of life
   c) Encourage expression of fears, cultural beliefs, wishes and preferences
      i) Gain insight into their understanding of ESRD and kidney replacement therapies
   d) Assess families role in the decision making process and relationship with patient
   e) Assess current knowledge and/or advance care planning activities that may have been completed

2) Empower the family to discuss advance care planning with the patient through education about the importance of advance care planning and the pros and cons of specific components, including:
   a) Advance Directive (including Living Will, Durable Power of Attorney, and Surrogate)
   b) Cardiopulmonary resuscitation
   c) Hospice
   d) Palliative Care
   e) End-of-life care (e.g., symptom management, pain, and uremic symptoms)
   f) Making decisions
      i) Appreciate the level of difficulty in making choices
      ii) Assess congruence between patient/family (surrogate) treatment preferences
      iii) Ethical and legal issues

3) Encourage family to engage advance care planning activities with patient by providing psychosocial, spiritual, and cultural support

4) Respect the role of family/primary caregiver as part of the healthcare team by providing support and involving them in the decision making process
   a) Understand what it means to be a caregiver
   b) Provide emotional and spiritual comfort
   c) Encourage and assist in the development of caregiver stress reduction strategies

FAMILY ENGAGEMENT BEST PRACTICE 2: TOOLS AND RESOURCES	
Web-Based Tools and Resources	
Advance Care Planning Information	Caring Connections http://www.caringinfo.org/PlanningAhead.htm The Maryland Commission of Kidney Disease http://dhmh.maryland.gov/mdckd/marc.html#adcare National Hospice and Palliative Care Organization www.nhpco.org
Caring Connections	Caring Connections http://www.caringinfo.org/Home.htm
Kidney End-of-Life Coalition	Kidney End-of-Life Coalition http://www.kidneyeol.org/
Physician Orders for Life Sustaining Treatment Paradigm (POLST)	Physician Orders for Life Sustaining Treatment http://www.ohsu.edu/polst/
Planning for End-of-Life Care Decisions	National Institute on Aging http://www.nia.nih.gov/HealthInformation/Publications/endoflife/08_planning.htm
Printed Tools and Resources	
Caregiver Booklet	Caring Connections http://www.caringinfo.org/userfiles/File/EOL_Caregiver_booklet.pdf
End of Life Decisions Booklet	Caring Connections http://www.caringinfo.org/userfiles/File/PDFs/End-of-Life_Decisions.pdf
Five Wishes Booklet	Aging With Dignity http://www.agingwithdignity.org/five-wishes.php
If You Choose Not to Start Dialysis Treatment	National Kidney Foundation http://www.kidney.org/atoz/pdf/IfYouChoose.pdf
Initiation or Withdrawal of Dialysis in End Stage Renal Disease: Guidelines for the Health Care Team	National Kidney Foundation http://www.kidney.org/members/source/catalog/index.cfm?section=unknown&task=3&CATEGORY=P&PRODUCT_TYPE=SALES&SKU=12-10-0334 (Book; $20.00 for non-members)
Myths and Facts about Health Care Advance Directives.	American Bar Association http://www.abanet.org/aging/pdfs/myths_and_fact_about_HC_AD.pdf

When Stopping Dialysis Treatment Is Your Choice: A Guide for Patients	National Kidney Foundation http://www.kidney.org/atoz/atozcopy.cfm?pdflink=StopDialysis.pdf (Click on "I accept" and brochure will open)

Supporting Literature:

Mogg A, Bartlett A. **Refusal of treatment in a patient with fluctuating capacity: theory and practice.** *J Forens Psychiatry Psychol.* 2005 16(1):60-69. http://www.informaworld.com/smpp/1584559447-743/content~db=all~content=a713735089

Song MK, et al. **Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease.** *Appl Nurs Res.* 2010 23:65-72. http://linkinghub.elsevier.com/retrieve/pii/S0897189708000475

Werth JL, et al. **Psychosocial issues near the end of life.** *Aging Ment Health.* 2002 6(4):402-412. http://www.ncbi.nlm.nih.gov/pubmed/12425774

All links last accessed on October 31, 2010