HONORING PATIENT WISHES

Advance Care Planning for Patients with Late Stage Kidney Disease

Network 18 Conference July 18, 2017

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Disclosures

None of the faculty or planners for this educational activity have any relevant financial relationships with commercial interests to disclose. There was no commercial support provided for this activity.
Objectives

• Describe hospice eligibility for patients with advanced renal disease.
• List the basic elements and goals of Palliative Care.
• Understand basic Palliative Care principles for patients with chronic kidney disease.
Overview

• Describe the continuum of advance care planning (ACP)
• Explain the importance of planning for end of life for patients with late stage kidney disease (LSKD)
• Learn strategies for integrating principles of Palliative Care into routine care for those with LSKD
• Describe how Hospice Care transitions work for LSKD patients
Who we are

Coalition for Compassionate Care of California

• Nonprofit organization founded in 1998 with diverse membership of healthcare providers, systems, consumers and government agencies

Our mission is to promote high-quality, compassionate care for everyone who is seriously ill or nearing the end of life.
## What we do

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The Issue.
Caring and Conversations

It is about the people

FreeVideo
https://www.youtube.com/watch?v=JJaVqJc6_OQ&list=UUkHdreM5xdow0iGvCNOV2RQ
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It’s a FACT

• Patient’s want to plan for end of life
• Providers agree it is very important
• Majority of healthcare settings have no formal system for assessing patient goals of care
• ACP leads to patient provider and system benefits

(Data from CHCF 2012, Hartford, Cambia, CHCF 2016)
We want to:

• Assist healthcare professionals to guide patients in exploring their options for care during a serious illness at end of life

• Help patients express their informed choices, and

• **Strengthen the healthcare environment where those personal choices will be honored.**
Definition of ACP

"Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."

Patient Perspective

Wishes Explored

Wishes Expressed

Wishes Honored
Healthcare Perspective

COMPETENT COMMUNITIES

COMPETENT PROFESSIONALS

COMPETENT SYSTEMS

PUBLIC POLICY & COMMON VISION

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Complete an Advance Directive

Update Advance Directive Periodically

Diagnosed with Serious or Chronic, Progressive Illness (*at any age*)

End-of-Life Care Planning

Complete a POLST Form

Treatment Wishes Honored

**Observations**

*CCC perspective on Advance Care Planning*
Current conditions

• Quality person-centered end-of-life care is lacking for this population
• Systematic advance care planning (ACP) is not widespread
• More than ½ of patients starting dialysis are >60 y and have comorbid conditions resulting in higher morbidity and greater mortality
• Hospice enrollment is often late not equitable across the U.S. leading to poor quality of life as end of life approaches

Center for Disease Control, 2012 California Healthcare Foundation, Kaiser Family Foundation Poll 2015, Center for Medicare Medicaid Services Dartmouth Atlas Project, Institute of Medicine © 2016 COALITION FOR COMPASSIONATE CARE OF CALIFORNIA
End stage renal disease & survival

- Unique illness without cure
- Survival varies widely
  - some may live decades on dialysis or following renal transplant (young, no comorbidities)
  - others will face end of life in a few months or years

Care cannot be One Size Fits All
Findings from the Dartmouth Atlas:
Patients with Chronic or Serious Illness

More intensive inpatient care at end of life does not lead to

• improved survival,
• better quality of life, or
• better access to care
Findings from the Dartmouth Atlas

Patients’ experiences differ dramatically; those with chronic illness nearing end of life

- receive much more aggressive care,
- see medical specialists more frequently,
- spend more days in the hospital, and
- die in an ICU more often than those in other regions
Geographic Variation at End of Life
High Medical Expenditures Make Planning Important

Healthcare costs at end of life are high and increasing.

Medical costs are the #1 cause of personal bankruptcy.

Planning for Care in Serious Illness

Washington on his Deathbed by Junius Brutus Stearns, 1851
Planning for care: Goals

- Help the patient (family/friend) understand condition
- Identify patient’s goals for care
- Name a trusted decision-maker in the event of incapacity
- Prepare for decisions that may have to be made over time
Elements of planning for care at end-of-life.

- Patient concerns, values and priorities,
- Family perspective and concerns,
- Unacceptable states of health,
- Palliative care, hospice care
- Risks/Burdens/Benefits
- Place of care
- Transfer/no-transfer
- Life sustaining treatments & POLST
- Cultural, Social, Logistical, Financial issues
Shared Decision Making in LSKD

The Advance Health Care Directive Act
Also Known as the Health Care Decisions Law

A Guide for Chronic Dialysis Patients

Photo courtesy of CreativeCommons/Flickr
Shared Decision Making in LSKD

Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Clinical Practice Guideline
Second Edition

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Elements of ACP Conversations

- Patient understanding of their illness
- Patient preferences for information
- Patient preferences for family involvement or decision-making
- Personal life goals
- Fears and anxieties
- Tradeoffs they are willing to accept
Other Tools and Resources

For patients and families
• Caringinfo.org
• GetPalliativeCare.org
• CoalitionCCC.org
• TheConversationProject.org

For healthcare providers and staff
• CoalitionCCC.org
• CSUPalliativeCare.org
• National Institute on Aging
• American Bar Association
CMS definition of Palliative Care

“Patient- and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering.”

Only a patient can define for themselves what they experience as suffering.
In the details, Palliative Care.

Palliative care is a multidisciplinary approach to specialized medical care for people with serious illnesses.

It focuses on providing patients with relief from symptoms including, pain, physical stress, and mental/emotional stress such as arise in serious illness.

All the care you need, only the treatments you want.
Patient Centered Care = Palliative Care

Principles of Palliative Care

- Any age, any illness, any stage of disease
- All patients are eligible
- Concurrent with specific disease management
- Focusses on maximizing patient quality of life
The heart of palliative care

- Advance care planning
- Skilled conversations
- Symptom management
- Support

Image courtesy of CreativeCommons/Flickr
Hospice care

• **Comprehensive care at the end of life**
  - Multidisciplinary team of healthcare providers
  - Focused on symptoms, comfort, quality of life
  - Support patient and family
  - Care is most often in the home
  - Includes bereavement care

“Palliative Care without focus on extending life.”
MediCare hospice benefit

To be eligible for Medicare Hospice benefit:

• Six months prognosis
• Forego specific curative treatment
Palliative care model (present)
Palliative and hospice care for patients with advanced renal disease

• Any patient with symptom burden from renal disease is appropriate for palliative care.

• Patients on dialysis may be eligible for and wish to have hospice care.
Advance planning promotes hospice use and out-of-hospital death

Schmidt RJ et al The Power of Advance Care Planning in Promoting Hospice and Out-of-Hospital Death in a Dialysis Unit. J Pall Med Volume 18, Number 1, 2015
DOI: 10.1089/jpm.2014.0031

*CFTT= Chronic Failure to Thrive
Dialysis patients and Hospice

Patient selection for a discussion about hospice of possible non-start of or withdrawal from dialysis is determined by patient characteristics.

In addition:

• Patients with terminal illness other than advanced renal disease may be referred for hospice evaluation, and
• May even be able to continue dialysis while on hospice.
Palliative Approach to Dialysis Care
Systematic approach to palliative care for ALL LSKD patients: Basic Elements

- Pain & symptom management
- Full complement of ACP activities
- Shared decision-making for informed consent
- Patient specific prognosis discussions
- Regular reassessment of prognosis, burdens and wishes
- POLST form
- Timely hospice referral
PC in the dialysis facilities: Process

1. Palliative care focus
   a. Educational activities, including dialysis unit in-service trainings
   b. Quality improvement activities, including morbidity and mortality conferences
   c. Use of the “Would you be surprised if this patient died within the next year?” question or other method to identify patients appropriate for palliative care
   d. Collaboration with local hospice programs to coordinate a smooth transition to end-of-life care
PC in the dialysis facilities: Process

2. Pain & symptom assessment & management protocols
3. **Systematized advanced care planning**
4. Psychosocial and spiritual support to patients and families, *including the use of peer counselors*
5. Terminal care protocols that include hospice referral
6. Bereavement programs for families
Insights into life expectancy

Elderly patients with advanced comorbidities who start dialysis may have a similar survival and higher morbidity compared to patients who choose conservative management.
Prognosis, co-morbidity, survival

How do we measure it? When do we talk about it?
Prognostic factors for predicting renal progression & survival: **Lost in Numbers**

- eGFR
- Acute Kidney Injury
- Comorbidity status
  - An improved Comorbidity Index (Liu et al. Kid Int 2010;77:141-151), Charlson Comorbidity Index (CCI), Davies Comorbidity Index
- Functional status (e.g. Karnofsky)
- Geriatric syndromes (falls, cognitive decline)
- Other: Albumin, nutrition, inflammation markers

Schell JO et al Recent insights into life expectancy with and without dialysis Curr Op Neph Hypertens Vol 22 No 2 March 2013
Stop measuring start talking

How often do we leave it until it is too late?
Patient selection for palliative care referral or hospice evaluation

- Patient specific method of estimating prognosis
  - Prognosis calculator
  - Surprise question (validated)
  - Frailty (validated)
  - Chronic Failure to Thrive (CFTT) due to current conditions
Predicting Mortality for Dialysis Patients

HD MORTALITY PREDICTOR
Programmed by Stephen Z. Fadem, M.D., FASN and Joseph Fadem

Download iPhone App

Serum Albumin
3.5 g/dL

Surprise Question
- I would NOT be surprised if my patient died in the next 6 months.
- I would be surprised if my patient died in the next 6 months.

Age: 65 years

Dementia
- My patient HAS dementia.
- My patient does NOT have dementia.

Peripheral Vascular Disease
- My patient HAS peripheral vascular disease.
- My patient does NOT have peripheral vascular disease.

XBETA: -154.59
Predicted Six Month Survival: 89%
Predicted Twelve Month Survival: 74%
Predicted Eighteen Month Survival: 60%

Reference:

Supporting data table

http://touchcalc.com/calculators/sq
The Surprise Question

“Would I be surprised if this patient died within the next year?”


Frailty in Patients with Chronic KD…

Predicts higher morbidity and mortality.
Patients with Frailty: Higher risk of death

- Frailty alone is a reasonable prognostic tool in patients who receive dialysis.
- The prevalence of frailty in dialysis patients approximately 67% and bears twice the chance for death and hospitalization.

Patient selection for palliative care referral or hospice evaluation: Triggers

- Surprise question=No
- Accelerating co-morbid condition
- Poor patient-specific prognosis
- Increased frequency of hospitalizations
- Loss of drive
- Failure to thrive
- Diagnosis of non-renal terminal illness
- Loss of function
- Skilled facility admission
Goal directed plan of care with dialysis

Use of Time Trials, Milestones and Pause Points

Patients not deriving personal goal directed benefits from dialysis therapy should be offered an opportunity to discuss withdrawal.

*Dying on Dialysis: The Case for a Dignified Withdrawal.* R. J. Schmidt and A. H. Moss

- Patient-centered versus disease-centered approach to end-of-life care
- Suggested sequence (master checklist) for implementation of withdrawal in identified patients

Towards better care

• Advance care planning achieves the triple aim of person-centered, value driven, quality care.
• Patients, families, providers and systems benefit when informed shared decision-making guides care, both early and late in treatment.
• Tools, programs and trainings are available to support your efforts.
Healthcare Perspective

COMPETENT COMMUNITIES

COMPETENT PROFESSIONALS

COMPETENT SYSTEMS

PUBLIC POLICY & COMMON VISION
YOUR ROLE

• Be a patient-centered care champion
• Support ACP and end of life care planning
• Support skills training for having conversations about ACP, palliative care and hospice
• Promote palliative care in your area
• Implement processes to gather, track and retrieve goals-of-care information
• Facilitate palliative care and hospice referral when indicated
Questions?

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