Disclosure Information

An Insider's View to Palliative Medicine for Nephology Providers
Sara Combs, MD

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I will not discuss off label use/or investigational use in my presentation.

An Insider's View to Palliative Medicine for Nephology Providers

Sara Combs, M.D.
Fellow, Palliative Medicine

University of Washington

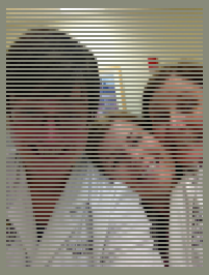
Objectives

- Define Palliative Medicine
- Define Shared Decision-Making
- Discuss strategies for effective shared decision-making in CKD patients
- Describe when and how to incorporate palliative care services into your nephrology practice

Objectives

- List five renal-specific clinical scenarios in which effective shared decision-making is important.
- Describe the "Ask-Tell-Ask" principle.
- Describe the "Respond to emotion" principle.
- Identify when and how palliative medicine might be helpful to your practice.

Nephrology Fellowship



The "real" medical experiences

Palliative Medicine

- The philosophy
- Primary palliative care
- Secondary palliative care
- Tertiary palliative care

Palliative Medicine

The philosophy :

Provide quality, patient-centered healthcare to patients with serious illness.

- Elicit patients' goals and values.
- Provide care in line with those values.
- Effectively communicate what's to come in the future.
- Elicit and manage symptoms.
- Elicit and address emotional distress.

Primary palliative care

- Basic skills in palliative medicine required of all providers (in all fields of medicine)
- Good medical care!!!
  - Communication
  - Symptom control

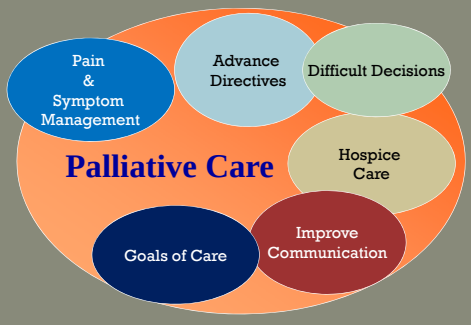
Secondary Palliative Medicine (Subspecialty palliative care)

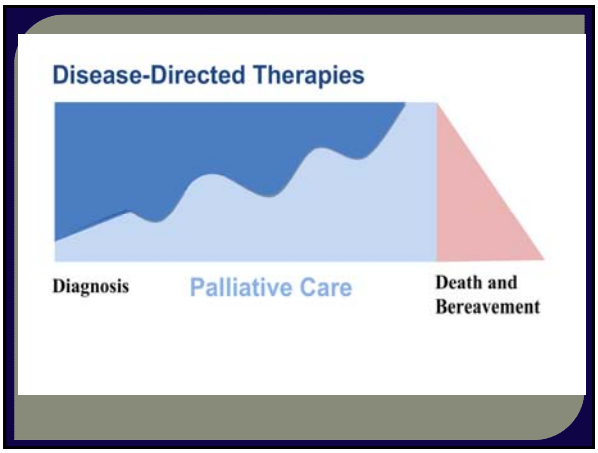
- Specialized medical care for people with serious illnesses.
- Provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.
- Goal is to improve quality of life for the patient and their family.
- Focused on providing patients with relief from symptoms, pain, and stress of a serious illness.
- Appropriate at any age and at any stage in a serious illness.
- Can be provided together with curative treatment.

Common Reasons for Palliative Care Consultation

- Clarification of patient and family care goals
- Pain and other symptom management
- Emotional, social, and spiritual support
- Figuring out the next steps

Hospice is One Component of Palliative Care





Models of subspecialty palliative care

- Inpatient consultation service
- Outpatient consultation service
  - Subspecialty palliative care clinic
  - Home visits
- Integrated palliative care (tertiary)
  - Imbedded in other subspecialty clinics

What are the benefits of Palliative Medicine

- Improves quality of healthcare delivered
  - Improved quality of life
  - Better symptom control
  - Improved patient and family satisfaction with care
  - Similar or improved survival of patients
- Lowers healthcare costs
  - Decreased healthcare utilization

Shared Decision-Making

- "A collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and practices"

Informed Medical Decisions Foundation

Key points about shared decision-making

- Medical decision-making should not be done in isolation. Identify and involve the surrogate decision-maker.
- Decisions are not "forever." Patients' goals and values may change over time.
- These conversations can take place over multiple visits.

Topics for shared decision-making in patients with kidney disease

- Renal replacement therapy decisions
- Choosing between renal replacement therapy and non-dialytic management of kidney disease
- Choosing dialysis modality and access
- Advance care planning
- Cessation of dialysis

Opportunities to communicate and reconfirm prior decisions

- Progression of kidney disease
- At dialysis initiation
- During or after acute illness/hospitalization
  - Acute kidney injury
  - Cardiac event
  - Infection
- At patient/family request
- Clear decline in patient's medical or functional status

Why is shared decision-making important?

Patients with progressive kidney disease do not feel they are making informed decisions about their healthcare.

Too often, patient care does not match patient preferences

Why is shared decision-making important for CKD and ESRD patients?

Studies repeatedly demonstrate that:

1. Patients feel unprepared for what to expect in the future.
2. Patients are shocked about the realities of their disease trajectory when they experience it.
3. The majority of patients feel they have no choice about starting dialysis nor about dialysis modality.
4. Many patients perceive that the physician had already made these choices for them prior to discussing it in person.

Song et al. NDT. 2013;28(11)
Schell et al. AJKD. 2012; 59(4)

Why is shared decision-making important?

Survey of patients with ESRD on hemodialysis conducted in Alberta, Canada:

- 61% of patients regretted their decision to start dialysis.
- 5.8% of patients felt informed about their medical condition and how it might change over time.
- 85% of patients thought it was extremely/somewhat important to be informed about this.
- 36% of patients preferred to die at home
- 27% preferred to die in a hospital

Davison. CJASN 5: 2010, 195-204

Intensity of care during the final month of life of patients with chronic illness

	Medicare Beneficiaries		
	Dialysis	**Cancer**	**Heart Failure**
Death in a hospital (%)	45	29	35
Hospice use (%)	20	55	39
Intensive care unit admission (%)	49	24	19

Wong et al. Arch Intern Med 2012;172(8):661-663.

Choosing Wisely
An initiative of the ABIM Foundation

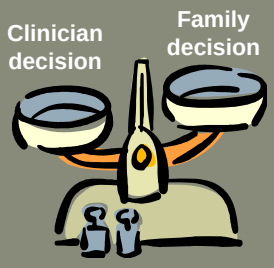
American Society of Nephrology
ASN

Five Things Physicians and Patients Should Question

5 **Don't initiate chronic dialysis without ensuring a shared decision-making process between patients, their families, and their physicians.**

The decision to initiate chronic dialysis should be part of an individualized, shared decision-making process between patients, their families, and their physicians. This process includes eliciting individual patient goals and preferences and providing information on prognosis and expected benefits and harms of dialysis within the context of these goals and preferences. Limited observational data suggest that survival may not differ substantially for older adults with a high burden of comorbidity who initiate chronic dialysis versus those managed conservatively.

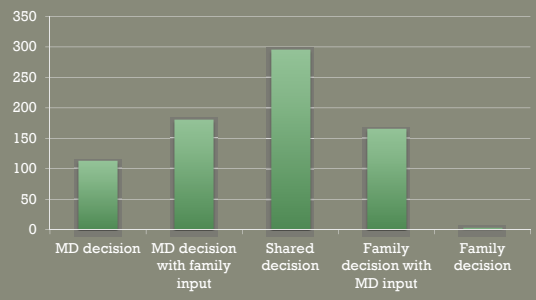
Shared Decision-Making



- Key factors
  - Prognosis
  - Level of certainty
  - Family preferences
- Roles
  - Patient/family: patient values and preferences
  - Clinician: treatments that are indicated

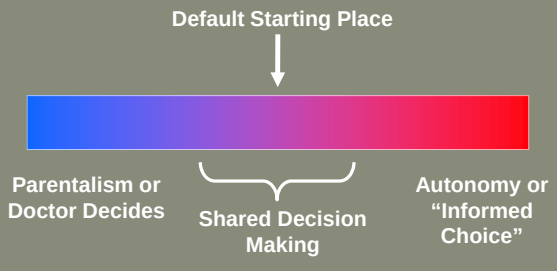
Carlet, Intensive Care Med 2004; 30:770

Surrogate decision maker preferences in medical decision-making



Heyland et al, Intensive Care Med (2003) 29: 75

The "Right Approach" to Decision-Making: Parentalism vs. Autonomy



Curtis/White, Chest, 2008; 134:835
Curtis/Vincent, Lancet, 2010; 375:1347

How do you know what role the patient/family wants you to play?

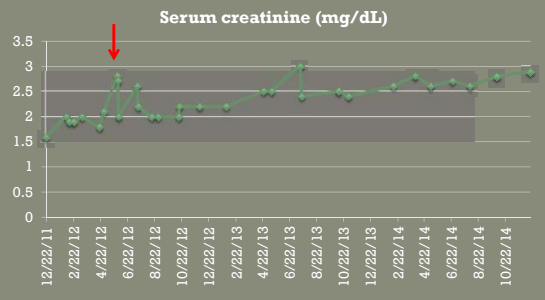
- Use what you know about the patient from previous interactions.
- Listen for their decision-making style.
- Explore statements about decision-making in previous situations.
- Generate hypotheses for their role and explore that hypothesis.

Case #1: Mr. Rodriguez

54 year-old Mexican-American man with diabetic nephropathy returns to clinic for follow-up.

- Known patient for 2 years
- Blood pressure, diabetes now well controlled
- Kidney disease continues to progress, now with eGFR 24mL/min, 2.5 grams/24h proteinuria

Kidney disease progression



What you know about the patient

- Married. Wife often comes to visits, doesn't say much but clearly involved in his healthcare.
- They have two children, 17 and 19, who live at home with them.
- Works full time in construction.
- Really enjoys riding his motorcycle and spends time working on it at home in his free time.

Goal: communicate the need for dialysis/transplant in the near future

Communication Framework:
Ask-Tell-Ask

- Communication as a two-way process:
  - Assess patient's perceptions and preferences (Ask)
  - Before telling the information (Tell)
  - Checking in for understanding (Ask)

Goal: communicate the need for dialysis/transplant in the near future

How to start the discussion
Ask-Tell-Ask

- The first Ask:
  - Assess whether they're ready to talk
  - Understand what they already know
  - Negotiate how the information will be given

Ask: The Invitation

- Prepares the patient and their family for the discussion to follow
- Gives them a sense of control in a time when their life is increasingly more medically complicated

Ask: The Invitation

He says, "doc, I'm worried because my numbers keep getting worse."

"Yes, I'm also concerned. Is it OK if we spend our time today talking about this and what to expect in the future?"

"Yes, of course."

Ask: Explore patient's understanding

- Allows you to know what he knows and his perspective on his illness
- Facilitates conversation between the patient, their caretaker/family, and any other parties involved.

Ask: Explore patient's understanding

- *"Before we do that, it would help me to hear from you what you know about what's going on with your kidneys and how they're functioning."*

Ask: Explore patient's understanding

"Well, I know my numbers keep getting worse and that means my kidneys are getting worse. I just don't understand because I feel like I'm doing everything I can. I'm worried about needing dialysis. My cousin was on dialysis and he hated it. Going to dialysis three days a week? I can't do that. I have to support my family."

What did you learn that you didn't know before?

- Patient knows that renal replacement therapy is in his future.
- He is worried about financial stability and being able to support his family.
- He has an unfavorable impression of dialysis.

Ask: Negotiating the content

Goals:

- Determine what type of information they would like to hear.
- Determine how they would like to hear the information.
- Elicit any fears or concerns.

Ask: Negotiating the content

Goal:	Question:
Determine what type of information they would like to hear	It sounds like you're concerned about needing dialysis and how it will impact your lifestyle. Would it help to hear about what to expect in the next months?
Determine how they would like to hear the information	Based on our previous interactions, you seem like the kind of person who prefers hearing statistics rather than general information. Do I have that correct?
Elicit fears or concerns	It sounds like finances are a concern of yours. Is there anything else looking forward that worries you?

Ask-**Tell**-Ask

Tell:

- Be straightforward
- Provide information in short, digestible chunks
- Avoid medical talk

Ask-Tell-**Ask**

Ask

- "I've just delivered a lot of new information. What are your thoughts?"
- "Tell me what you're going to tell your wife about this visit when you get home today."
- "What questions do you have?"

Case #2: Ms. Williams

Later in the day you are making rounds at your hemodialysis unit. You stop by Ms. Williams. She is a 75 year-old woman who has been on HD for 6 years for ESRD from hypertensive nephropathy. You note she's been hospitalized three times in the last four months. The last admit was two weeks ago for PEA arrest of unclear etiology. You're hoping to finish up in five minutes because you have an obligation in an hour and a lot of dictation to do.

Case #2: Ms. Williams

You ask her how she's doing.

"Terrible. I honestly don't see the point in it all anymore."

Teaching points

- When you're stuck, ask for more information.
- Don't forget the power of silence.
- Nothing can be accomplished until you acknowledge and respond to patient's/family's emotions.

Case #2: Ms. Williams

"Tell me more."

I feel terrible, all I do is sleep and then go to dialysis. I don't have energy to do anything. I hate living like this.

Responding to emotions: Mnemonic: NURSE

- Naming: "It sounds like you're frustrated" or "I wonder if you might be feeling angry."
- Understanding: "I cannot imagine what it must feel like to be in your situation."
- Respecting (verbal and nonverbal): "These are excellent questions and I'm glad we're talking about this."
- Supporting: "I want you to know that we are all here for you and want the best for you."
- Exploring: "You've been through a lot in the last few months. Tell me how you and Bob have been dealing with all of this."

Case #2: Ms. Williams

"I'm really glad you brought this up. It sounds like we should talk more about how things are going for you. I want to be able to dedicate more time to this discussion than I have right now. How about I come back on Wednesday and we can talk further. I think it would be really helpful if Bob could be part of the discussion as well."

When might palliative care be helpful

- Choosing between renal replacement therapy and non-dialytic management of progressive kidney disease, especially in older patients with comorbidities
- Addressing or re-addressing goals of care and code status
  - Sentinel events
  - Decline in functional or medical status
- Advance care planning
- ESRD patients in the ICU
- Withdrawing or withholding dialysis (acute or chronic)
- Difficult patient/family/care team dynamics
- Difficult symptom management

When do I involve palliative care?

- Know what resources are available for your patients
- Outpatient palliative care: use us when you get stuck and/or time is an issue.
  - Most outpatient services do not take on pain management for CKD/ESRD patients.
- Inpatient palliative care:
  - Sentinel events
  - ICU patients on dialysis
  - Outpatient palliative care not available

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