PREPARING PATIENTS AND FAMILIES FOR THE CKD TRAJECTORY

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LEARNING OBJECTIVES

- Outline communication skills that prepare patients for the kidney disease trajectory with an experiential and values-based perspective.
- Introduce follow-up opportunities to respond to, assess, and modify the treatment plan over time.
- Use these conversations to trigger an action plan to improve patient experience.

QUESTIONS FOR DISCUSSION

- What does a prepared patient look like?
- What are some ways you help these patients prepare?
  - (emphasis on communication!)

Meet 'Moira'

- Initial Consult: RJH ER July 2014
  - 72 y/o mother of two daughters, divorced, retired, lives independently with her dog
    - RFA: 'Acute Kidney Injury' – eGFR 11 ml/min
    - PMHx:
      - Hemicolectomy/Ileostomy ('High output')
      - CKD
      - Smoker (no intention of quitting)
      - Alcohol abuse
    - Declines hospital admission today – needs to find care for her dog (was in the car!!); agrees to return tomorrow

Meet 'Moira'

- Renal function improves with IV fluids, strategies to reduce ostomy output; GFR 22 ml/min at discharge
- Agrees to referral to KCC for 'modality education'
- 'Overwhelmed with decision'; 'scared to death of dialysis'
- Dog dies -→ severe depression -→ Etoh intake increases
- New dog, feeling better; BUT, remains anxious/depressed re: **'THE DECISION'**
- **Acute unilateral visual loss due to macular hemorrhage**
  - **"If I can't drive, I'm not doing dialysis"**

THE CHALLENGE

- We've been trained to extend lifespan
- We perceive end of disease-oriented treatment as 'failure'
- Invested in our expertise
- Hope often based on the 'next treatment'

Traditional approach to treatment preparation

- Focus is on decision to be made
  - Convey the risks, benefits and prognostic factors
- Make an informed decision
  - Based on the evidence, clinical and patient-specific data

Focusing on the initial decision is difficult

- Patients can't prepare for something they have never experienced
  - Similar to being a new parent
  - Words are inadequate to the lived experience
- Uncertainty exists regarding how a patient will do
  - Clinicians have difficulty predicting time course
  - Patients respond to uncertainty with emotion

Focusing on the initial decision is difficult

- Experience shapes how patients view the future
  - Symptoms and preparation needs may change
  - Perception about dialysis and EOL may change

A NOVEL APPROACH

- Change how we prepare patients by shifting our focus from ‘the decision’ to the patient experience

The Patient Experience

- Symptom burden comparable to those on dialysis
- Overlapping coexisting conditions influence morbidity/mortality
- Uncertain renal trajectories challenge EOL preparation
- Less opportunity for timely advance care planning

An Opportunity

- Focus on the patient perspective
- Elicit goals and values to guide treatment decisions
- Proactively reassess and modify treatment plan over time

Gaining the patient perspective

- Core communication skills
  - Open-ended questions
  - Reflections
  - Affirmations
    - Acknowledgement of struggles/difficulties, skill/strengths, emotions
- Skills to:
  - Establish rapport
  - Elicit patient-specific concerns
  - Outline patients' values
  - Guide patient-centered treatment plans

Use ‘Ask-Tell-Ask’ to define treatment plan

- Framework and skill that promotes informed discussion
  - Assessing what the patient understands (**Ask**)
  - Before giving information (**Tell**)
  - Checking for understanding after giving information (**Ask**)

Starting the conversation

- Agenda setting
  - "As we talk about how best to care for you, it's helpful to understand what's important to you…."
  - "What are you thinking about your kidney management?"

Ask what the patient understands

- "What's your sense of where things stand as far as your kidney condition goes?"

- **Explore what's important**
  - "As you think about the future, what things do you hope for? What do you want to do?"

  - "What things do you worry about? What else?"

Tell

- Reflections to align with patient goals and values
  - "You worry about being a burden…."
- Insights tailor management plan
  - Goals and values
  - Quality vs Quantity
  - Health conditions that signal reassessment in plans
  - Reflections guide recommendations

Affirmations: Responding to emotion

- Patients respond to bad news/uncertainty with emotion
- Providers often respond with cognitive information
- Emotion serves as a barrier to understanding; to help overcome this:
  - Name the emotion "I can see you are worried…"
  - Understand the emotion "These decisions are hard…"
  - Respect the patient "You are making the right choice for you."
  - Support the patient "We'll be with you…"
  - Sit with emotion (Silence)

Dealing with uncertainty

- Variable trajectory of chronic illness
- Fluctuation between hope for the future and fear of dying
- Acknowledging uncertainty allows opportunity to discuss what may happen if things do not go as expected

Check in for understanding

- Assess patient understanding
  - "We talked about a lot of information. Can you tell me what you will take away today?"
- Assume they have questions
  - "What questions do you have?"
  - "What concerns do you have?"

Follow-up

- "It's been 3 months since our last visit. Can we check in to see how things have been going?"
- "What would be helpful for us to talk about today?"

Follow-up

- Encourages the opportunity to explore:
  - Symptoms/needs
  - ACP (goals of care)
  - Reassess treatment plan (dialysis concerns)
  - Caregiver needs

Action steps

- Utilizing the renal care team
  - Symptom scales
  - Further exploration of concerns
  - Psychosocial support for patient and family
- Resources
  - HCC
  - Counseling/psychiatric resources
  - Chaplain referral
  - Symptom management (palliative care, pain clinic)

Discussing Advance Care Planning

- ACP – dynamic process of defining patient care goals based on values, treatment preferences and overall goals
- Timely ACP discussions prepare patients and caregivers to make 'in the moment' decisions
- ACP is a series of discussions
  - Preferences change over time based on experiences

Benefits of timely ACP
(Wright et al JAMA 2008)

- Patients whose doctor asked them goals should they become sicker:
  - Are **NOT more distressed**
  - Are less likely to have CPR or die in the ICU
  - Are more likely to receive Hospice care
- Bereaved family members
  - Are more prepared
  - Are less likely to have regret
  - Are more likely to have better mental health

Check-ins to address EOL needs

- "As we prepare for your care at the end of life:
  - What is most important to you?"
  - What is important for us to help you do before that time comes?"
  - What worries do you have?"
- Role of affirmations:
  - Support statement
  - Non-abandonment
  - Responding to emotion

CONCLUSIONS

- Shift preparation from the decision to patient perspective
- Core communication skills can explore the patient perspective and guide treatment
- Use **Ask-Tell-Ask** as a framework for discussing information
- Check-ins encourage opportunities for symptom management, ACP and quality EOL care

HOW WILL THIS CHANGE PRACTICE?

What one new skill will you try with your patients/families in the next 2 weeks?

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