MJHS
INSTITUTE FOR INNOVATION IN PALLIATIVE CARE

Case Conference: Goals Discussions and Chronic Kidney Disease

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Case Conference: Goals Discussions and Chronic Kidney Disease

- A 76-year-old man with chronic kidney disease due to diabetes and hypertension returns to primary care clinic for a routine follow-up visit
- A quick review of his chart prior to the visit reveals a recent evaluation by his nephrologist
  - The summary: *"**Declining renal function, very distressed and confused about options. Still uncertain about dialysis**."*

Case Conference: Goals Discussions and Chronic Kidney Disease

- The quick review of the chart also reveals recent labs ordered by the nephrologist
  - eGFR is 25 ml/min/1.73m^2 (down from 35 ml/min/1.73m^2 two months earlier)
  - Hemoglobin declined from 10.5 gm/dl to 9.6 gm/dl
  - Hemoglobin A1c was stable at 7%

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- The patient starts the visit by stating that he is generally feeling poorly, and he complains about the conversation he has had with his nephrologist
  - His nephrologist said that he needed dialysis, but he also said that the decision about having or not having dialysis was the patient's
    - *"I don't get this. I have to have dialysis, right?"*
  - He was not clear about what dialysis would mean to his quality of life and his life expectancy

Background to the Case

- Medical history
  - NIDDM began 30 years ago; hypertension diagnosed at the same time
    - Treatment over years was moderately effective
    - Both disorders have been better controlled during the past 5 years

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - Estimated glomerular filtration rate (eGFR) began to decline at least 15 years ago
  - 3 years ago, eGFR became <40 ml/min/1.73m^2, and the possibility of dialysis or kidney transplant was discussed for the first time

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - During the past 3 years, eGFR varied between 30 ml/min/1.73m^2 and 40 ml/min/1.73m^2
  - The nephrologist raised the possibility of dialysis during this time but indicated that there was no need to rush into it
  - Anemia and hyperphosphatemia have required treatment

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - History of CAD
    - Three myocardial infarctions—15 years ago, 5 years ago, and 3 years ago
    - Coronary stent placement 1 year ago
    - Occasional angina continues
    - Cardiac EF at 45%

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - History of PVD
    - Balloon angioplasty for femoral-popliteal arterial disease 3 years ago
    - Amputation of a toe for gangrene 6 months ago

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - History of peripheral neuropathy
    - Burning paresthesias in the feet and distal legs also noted during the past 3 years
    - Impaired proprioception, pain and light touch sensation in the feet
    - Positive Romberg's sign and mild-to-moderate gait ataxia

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - Hyperuricemia with no gouty attacks
  - Episode of moderate depression 4 years ago, resolving with medication

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - Gradual worsening of symptoms including:
    - Burning in feet, particularly at night
    - Restlessness, particularly at night
    - Episodes of itch, usually arms and anterior legs
    - Insomnia related to symptoms
    - Fatigue
    - Dysphoria

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - Gradual worsening of function
    - Independent in ADLs; wife manages other activities
    - Spending most of the day in a chair
    - Reads the newspaper daily; most of the day watches television
    - Sees his children regularly, but no longer attends church services

A 76-Year-Old Man with Chronic Kidney Disease

- Medical history
  - No recent change in medications or OTC drugs
  - No change in diet, recent travel, or exposures
  - No fever or weight change

A 76-Year-Old Man with Chronic Kidney Disease

Medications

- Metoprolol 150 mg BID
- Amlodipine 5 mg BID
- HCTZ 25 mg/day
- Losartan 100 mg/day
- Atorvastatin 40 mg/day
- Allopurinol 100 mg/day
- Metformin 2000 mg/day
- Repaglinide 2 mg TID
- Aspirin 81 mg/day
- Calcium acetate 2001 mg TID
- Erythropoietin 10,000 units TIW
- Senna and docusate PRN

A 76-Year-Old Man with Chronic Kidney Disease

- Social history
  - Quit smoking 25 years ago; approximately 100 pack-years before quitting
  - No alcohol use now or in the past
  - No other use of drugs and no problems reported with prescription drugs

A 76-Year-Old Man with Chronic Kidney Disease

- Social history
  - English-Spanish bilingual, with English as preferred language
  - Married for 35 years; two sons live nearby
  - Supportive relationship with his family
  - Receiving social security disability; wife recently retired from work as a licensed practical nurse
  - Observant Catholic

A 76-Year-Old Man with Chronic Kidney Disease

- Advance care planning
  - No advance directive in the chart
  - In a prior conversation, he indicated that he would want his wife to make decisions if he were unable to speak for himself

A 76-Year-Old Man with Chronic Kidney Disease

- Family history
  - Mother died of lung cancer at age 72
  - Father died of myocardial infarction at age 61; history of early Alzheimer's disease at the time of death
  - Brother is 65 years old and has a history of stroke and amputation of a leg due to "poor flow of blood"
  - Wife and sons are healthy

Back to the Visit

- The patient is a 76-year-old man with Stage 4 CKD, multimorbidity, and multiple sources of illness burden and distress
  - On presentation, no urgent medical concerns are noted
  - Confusion about treatment options and the lack of an advance directive are important contributors to distress and will complicate management going forward
- The PCP decides that the visit would be a good opportunity to address goals of care

What Does the Case Reveal About Goals Discussions in Primary Care?

- The processes and outcomes are complex and multifaceted
- The process should be unfold over time and be framed by specific objectives
- There is a need for a framework and a guideline for best practices appropriate to the primary care setting

What Are Goals Discussions?

- A type of communication between patients or families and health professionals, which focuses on present or future expectations or preferences about health care
- Advance care planning is a ***type*** of goals discussion
- Goals discussions are also called 'serious illness discussions'

Goals of Care Discussions

- According to the Institute of Medicine (2014) and the American College of Physicians (2014)
  - Improvement is needed in the ***quality*** and ***quantity*** of discussions about goals, values, and care preferences with patients who have serious illnesses
  - Discussions should
    - Be iterative and elicit patient's goals, values, fears, and preferences over time
    - Increasingly focus on treatment decisions and advance care planning as the illness advances

Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academies Press; 2014: Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med*. 2014;174(12):1994-2003.

2014 ACP Review

- End-of-life conversations are associated with
  - Better quality of life
  - Reduced use of life-sustaining treatments near death
  - Earlier hospice referrals
  - Care that is more consistent with patient preferences
- Patients who engaged in advance care planning are more likely to have their wishes known and followed
- Preparation for the end of life is associated with improved bereavement outcomes for family

Bernacki RE et al. Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Intern Med*. 2014;174(12):1994-2003.

2016 Review of Primary Care Practices

- Qualities of primary care—continuity, duration, trust, and the ability to coordinate care—are well-suited to conversations about serious illness
- But only 14% to 35% of seriously ill older adults have advance care planning, and when goals are discussed, the focus tends to be on biomedical issues
- Primary care clinicians describe a lack of knowledge and confidence about goals conversations

Lakin JR et al. Improving communication about serious illness in primary care: A review. *JAMA Intern Med*. 2016;176(9):1380-1387.

2016 Review of Primary Care Practices

- 57% of internists report inadequate training in prognostication
- Prognostication is complex because of multimorbidity and social determinants of illness, and the changing plans of specialists

Lakin JR et al. Improving communication about serious illness in primary care: A review. *JAMA Intern Med*. 2016;176(9):1380-1387.

2016 Review of Primary Care Practices

- When PCPs are surveyed, they report
  - Very busy practices, increasing number of mandates, and EHR's that may complicate documentation
  - No simple approach to care coordination with specialists who are seeing the patient
  - Quality improvement in this area usually focuses on a narrow issue, e.g., increased number of health care proxies, and there is no focus on communication itself

Lakin JR et al. Improving communication about serious illness in primary care: A review. *JAMA Intern Med*. 2016;176(9):1380-1387.

Goals Discussions: Practical Considerations

- Introducing the…

"When, What, How (OPUS) Model" for Goals Discussions in Primary Care

  - For patients with any type of serious chronic illness
  - To support best practices to communication, particularly ***when signs indicate advanced disease or prognosis is 1-2 years***

"When, What, How (OPUS)" Model

- **WHEN** to have a goals discussion?
  - At least once during a ***stable*** period
  - Repeatedly after '***triggers***'
    - Medical complication or accelerated decline
    - Signs consistent with death within a year or positive "surprise question"
    - Need for specific treatment decisions
    - Need for an advance directive or to amend one
    - Patient or family request

"When, What, How (OPUS)" Model

- **WHAT** should be discussed?
  - Key point
    - Plan for ***each*** discussion by having ***specific objectives*** in mind

What Are the Objectives of Goals Discussions?

- Objectives may be general or specific
  - General
    - Impediments to communication
    - Patient's or family's values and preferences
  - Specific
    - Prognostic awareness
    - Specific treatment decisions
    - Advance care planning

Values and Preferences

- 'Decisional control preferences'
- Desire for information
- Quality vs. quantity of life
- Views about specific interventions, e.g., hospitalization, ICU stays, artificial ventilation, or nutrition

Prognostic Awareness

- Life expectancy
  - Expressed without a time horizon, e.g., 'terminal illness'
  - Expressed with a time horizon, e.g., 'maybe a few months'
- Expected course of illness
  - Symptoms
  - Physical functioning
  - Cognitive functioning

Specific Treatment Decisions

- Many examples
  - Beginning dialysis
  - Another chemotherapy
  - Feeding tube placement
  - Returning to the hospital

Advance Care Planning

- Key objective: legal, actionable advance directives
- Two types of advance directives
  - Selecting a person or persons (Health Care Proxy or Power of Attorney for Health Decisions)
  - Giving instructions ("instructional directive")
    - Oral or written living will
    - Nonhospital (home) DNR
    - MOLST/POLST

"When, What, How (OPUS)" Model

- WHAT should be discussed during a stable period?
  - Patient's or family's values and preferences
  - Prognostic awareness
  - Advance care planning

"When, What, How (OPUS)" Model

- WHAT should be discussed after a trigger?
  - Prognostic awareness
  - Specific treatment decision
  - Advance care planning
  - Values and preferences

"When, What, How (OPUS)" Model

- **HOW** to meet these objectives?
  - A structured approach with the mnemonic ***OPUS***

O = *"**O**pener"*
P = *"**P**ermission"*
U = *"**U**nderstanding"*
S = *"**S**upport"*

"When, What, How (OPUS)" Model

***O* = "Opener"**
- **Setting the stage**
- **Neutral opening statement**
- **Main objective, in general terms**

- ***O*** = *"Opener"*
  - Setting the stage
    - » Time, adequate space, privacy, seating
  - Neutral opening statement
    - » Example: "I would like to talk to you about your illness, make sure that your questions are answered and that I understand a few things."

"When, What, How (OPUS)" Model

***O* = "Opener"**

- **Setting the stage**
- **Neutral opening statement**
- **Main objective, in general terms**

- ***O*** = *"Opener"*
  - Main objective, in general terms
    - » Example: "I want to know what you heard from the nephrologist and also discuss the treatments that were suggested; I want to make sure that you understand before deciding about next steps."
    - » Example: "I want to talk about how decisions regarding your treatment would be made if it ever happened that you became very ill and couldn't speak for yourself."

"When, What, How (OPUS)" Model

***P* = "Permission"**

- **Decision-making preferences?**
- **Who gets information and is it OK to proceed?**

- ***P*** = *"Permission"*
  - Decision-making and information preferences
    - » Example: "Is it OK to have this discussion now, or should we schedule an appointment when someone in your family can come in? Who do you want to be involved in the discussion?"

"When, What, How (OPUS)" Model

***U* = "Understanding"**

- **What does the patient or family <u>know</u>?**
- **What does the patient or family <u>want to know</u>?**

- ***U*** = *"Understanding"*
  - What does the patient or family know?
    - » Example: "What is your understanding about where you are with this illness?"
    - » Example: "Do you know what to expect from dialysis?"
    - » Example: "Does your spouse know your feelings about dialysis?"

"When, What, How (OPUS)" Model

***U* = "Understanding"**

- **What information <u>should be provided</u>?**

- ***U*** = *"Understanding"*
  - What information should be provided?
    - » Prognostic disclosure:
      - Example: "It is true that you would probably die sooner without dialysis, but your kidneys still have some function and no one can be sure how long this would last."
      - Example: "You know that you have declined recently. The doctors do not expect this to improve, and we are concerned that you may get worse during the next weeks or months."

"When, What, How (OPUS)" Model

***U* = "Understanding"**

- **What information should be provided?**

- ***U* = "Understanding"**
  - What information should be provided?
    - » Risks/benefits of a treatment
    - » New treatment option
      - Example: "I want to talk to you about getting more services at home by enrolling in a home hospice program."

"When, What, How (OPUS)" Model

***U* = "Understanding"**

- **What information should be elicited?**

- ***U* = "Understanding"**
  - What information should be elicited?
    - » Goals
      - Example: "If time is limited, what are your priorities for yourself and your family? What is most important?"
    - » Trade-offs
      - Example: "Some people believe that quality of life is most important, and they would rather not go back to the hospital, even if it meant they would not live quite as long. Other people believe the opposite. What do you think about this?"
    - » Fears and concerns
      - Example: "Many people have fears or worries when they are living with a serious illness. Do you want to share any of this with me?"

"When, What, How (OPUS)" Model

***S* = "Support"**

- **Allow emotion**
- **Empathize**
- **Offer a plan**

- ***S* = "Support"**
  - Allow emotion; empathize
    - » Example: "It's OK to be upset. You've been dealing with a lot I know."
  - Offer a plan
    - » Example: "It sounds like we would try to manage your symptoms for now and wait to see how you feel before deciding about dialysis"
    - » Example: "Let me schedule another visit with you and your family, so we can go over your health care proxy one more time."

Back to the Visit

- "When, What, How (OPUS) Model
  - The PCP decides that the recent decline in eGFR should be a trigger for several objectives of a goals discussion
    - Treatment decision about dialysis
    - Prognostic awareness
    - Advance care planning
  - The PCP realizes that this process also should yield more information about the patient's values, preferences, fears, and goals—all helpful in managing the case going forward

"When, What, How (OPUS)"

- The PCP's "Opener" and "Permission" statements set the stage about discussions covering dialysis and advance care planning
- The PCP asks the patient whether his wife or son should be present for a conversation about these issues, and he tells the patient that a second appointment will be needed within the month to have enough time
- The patient states that he and the physician can talk today and that he will bring his wife to the next visit

"When, What, HOW (O-P-U-S)"

- "Understanding" triggers the following questions/ comments by the physician
  - "What is your understanding about where you are with your illness?...Other than the issue of dialysis, do you have other questions?"
  - "Do you understand what to expect from dialysis?...how it might affect the quality of your life…what it would do in terms of how long you would have to live?"
  - "If dialysis would prolong your life but the quality of your life was poor, would you want to continue it?"

"When, What, How (O-P-U-S)"

- After the discussion, the patient indicates that he now understands that he can decide to start or delay dialysis, or start it and then stop it if he perceives the benefit to be less than the burden; he speaks openly about dying sooner if he never starts dialysis
  - He states that he will make an appointment with the nephrologist to make a plan—no dialysis until his symptoms worsen, then he will try it
  - He states that he wants to talk about this with his wife present at the next appointment

Case Conference: Goals Discussions and Chronic Kidney Disease

- Conclusion
  - Goals discussions (or serious illness discussions) are multifaceted, should be iterative, and should be guided by clear objectives
  - The "When, What, How (OPUS) Model" is an approach to timely and structured communication


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Q&A