



## Person-Centered Care for Older Adults With Kidney Disease: Core Curriculum 2019

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This Core Curriculum article models a person-centered approach to care for older adults with kidney disease. We provide background information on the principles of person-centered care and outline ways in which this approach contrasts with the more disease-based approaches that dominate current medical education and practice. Using hypothetical cases, we discuss 3 clinical scenarios that arise commonly when caring for older adults with kidney disease: (1) a moderate reduction in estimated glomerular filtration rate, (2) new-onset nephrotic-range proteinuria, and (3) the prospect of starting dialysis. For each scenario, we summarize relevant available evidence and model what a person-centered approach might look like. In discussing each scenario, we highlight: (1) the considerable heterogeneity in clinical presentation, circumstances, priorities, and values that exist among older adults with kidney disease; (2) the importance of interpreting available evidence and clinical practice guidelines in the context of what is relevant to each patient; (3) methods for grounding discussions about care and treatment options in the realities of each patient's situation and what is most meaningful to them; and (4) the importance of setting aside one's own biases and practice style to ensure that patients' own values and goals guide their care.

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### Introduction

Available evidence suggests that for people with kidney disease, many of the treatment decisions that arise in the course of illness tend to be shaped more by provider- and system-level considerations than by the goals and values of individual patients. There is growing recognition that the narrow disease-based technologically focused approach to medicine that shapes much of contemporary clinical practice does not always address what matters most to individual patients. This is particularly true at older ages, when patients are more likely to have multiple different comorbid conditions and limited life expectancy. In such patients, a siloed approach to care that focuses on the management of individual diseases without consideration for the whole person can have unintended adverse consequences for patients' care and experiences of illness. For this reason, we and others have argued for a more person- or patient-centered approach to care, defined by the Institute of Medicine as "care that is respectful of and responsive to individual patient preferences, needs, and values and [ensures] that patient values guide all clinical decisions."

traditional disease-based model of health in which care is driven by an understanding of underlying biological mechanisms and population-based patterns of disease. Recommended care strategies and treatments are largely shaped by available evidence and the nature and severity of patients' underlying kidney disease. These generally focus on minimizing the risk for disease-related complications and preparing for the most likely clinical outcomes (eg, nephrology referral for high-risk patients, cardiovascular risk reduction, angiotensin-converting enzyme inhibition for patients with proteinuric diabetic chronic kidney disease [CKD], and advance placement of a fistula or peritoneal dialysis catheter for patients expected to start dialysis). However, the disease-based model has limitations, as summarized in [Box 1](#) and discussed in the following text.

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*The Core Curriculum aims to give trainees in nephrology a strong knowledge base in core topics in the specialty by providing an overview of the topic and citing key references, including the foundational literature that led to current clinical approaches.*

### Disease-Based Versus Patient-Centered Models

#### Disease-Based Model

##### Overview

Contemporary clinical practice guidelines for patients with kidney disease are grounded in a

#### Clinical Practice Guidelines

As is the case for all clinical practice guidelines, those dealing with kidney disease are intended as a road map for optimizing the care of most patients with this condition. Although it is understood that not all patients will want to follow these recommendations (patient preference can always trump the recommendations even under an evidence-based approach), the guidelines tend to assume some homogeneity in the characteristics of the target population and reasonable uniformity in the illness experience and frequency of relevant clinical outcomes. They also assume

**Box 1. Key Limitations of a Disease-Based Approach to Care**

1. Patients often have >1 comorbid condition and treatments may have diverse effects on each of these conditions.
2. Not all outcomes can be linked to a single underlying disease process.
3. Patients may place different values on a given outcome.
4. The evidence supporting clinical practice guidelines may not be relevant to all groups of patients.

that such outcomes will carry near-universal significance for members of the population, meaning that they are valued the same way and to the same extent by different patients.

Once established, clinical practice guidelines, particularly those that are supported by high-quality evidence (eg, use of renin-angiotensin system inhibition in diabetic kidney disease), strongly shape clinical practice. Research demonstrating less favorable clinical outcomes in patients who fail to “adhere” to the guidelines further bolsters the perceived importance of following guideline recommendations. When guideline adherence is linked to quality metrics and provider reimbursement, as occurs in some health care settings, this can add to the frustration that providers may experience when patients fail to follow treatment recommendations. Thus, although clinical practice guidelines are intended to improve patient care, they can have the unintended effect of pitting patients and providers against one another.

**Limitations of a Disease-Based Approach**

A major limitation of this kind of evidence- or disease-based approach is that older people often have more than 1 chronic condition, for which different and sometimes conflicting treatments and targets may apply. Further, individual patients may value outcomes other than those tested in clinical trials and targeted in clinical practice guidelines, including some that cannot be linked to a single underlying disease process (eg, functional status, independence, and pain control). It thus stands to reason that the potential benefits and harms of a given treatment can vary drastically among patients, based not only on their risk for a given outcome, but also on their priorities and the value placed on that outcome.

**Lack of Evidence to Support Care of Older Adults With Kidney Disease**

Another limitation of a disease-based approach to care for older adults is that many of the assumptions underlying contemporary clinical practice guidelines and the evidence on which they are based may have limited relevance to this population. As for other practice areas, older adults with kidney disease are often excluded from clinical trials, and the outcomes that matter most to them are not always addressed by these trials. Among patients with kidney disease, there are also dramatic differences in the

frequency of key outcomes such as death and progression to end-stage kidney disease (ESKD) among patients of different ages with similar estimated glomerular filtration rates (eGFRs) that can alter the benefits and harms of guideline-recommended treatment strategies. It can be challenging for providers to communicate with patients about these complexities, particularly when it might seem inconsistent with the kinds of simplified messages that patients are hearing from other sources, such as professional societies, advocacy groups, and the media.

**Person-Centered Model****Overview**

Under a person- or patient-centered model, patients' goals, values, and preferences move to center stage (Box 2). Medical evidence and knowledge are still important, but under a person-centered approach, these serve to inform rather than dictate treatment decisions. This approach essentially shifts the locus of decision making away from guidelines and the evidence on which they are based toward what is important to each patient. Under this schema, patients are viewed as experts in their own experience of illness and what is important to them.

A shift from an evidence-based to a person-centered approach to care results in a seemingly subtle, but important, reframing of our role as health care providers. An evidence- or disease-based approach to care typically begins with the following question: “How should we care for patients like this?” whereas under a person-centered approach, we would instead ask: “How should we care for this person?” In other words, our role as health care providers is to share medical knowledge and provide expert guidance based on what we understand to be important to each patient. Medical evidence and knowledge are still important but must be evaluated in the unique context of the person we are caring for and applied judiciously so as to uphold what is important to them.

**Shared Decision Making**

Shared decision making is the cornerstone of person-centered care, which some have likened to a kind of “dance” between the patient and clinician. Patients share information about their experience of illness, values, and preferences while clinicians offer information and recommendations with these in mind. The model of shared decision making falls on a continuum between paternalistic decision making at one extreme (in which the provider makes recommendations based on what

**Box 2. Key Tenets of a Person-Centered Approach to Care**

1. Patients are experts in their values and experience of illness.
2. Evidence should be considered in the context of the individual patient and should guide rather than dictate care.
3. Providers use their expertise to make recommendations based on their knowledge of the evidence and what is important to each patient.

they think should be important to the patient) and informed decision making at the other (in which the provider offers information about the benefits and harms of different treatment strategies and leaves the patient to choose between these). Under a shared decision-making model, the patient and provider work together to identify the “right treatment” based on the patients’ unique circumstances and values.

### Nonadherence

Under a person-centered paradigm, failure of patients to follow provider recommendations and treatment guidelines ceases to be the source of frustration that it might be under a more disease-centered approach. Instead, such instances provide an opportunity to learn something more about the circumstances, goals, and priorities of the person under our care. When the primary goal becomes upholding the essence of who our patients are, instances of so-called nonadherence are transformed into real-time opportunities to grow in our understanding of our patients and strengthen our relationships with them.

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### Caring for an Older Adult With Kidney Disease

In the following, we discuss 3 clinical scenarios that arise commonly when caring for older adults with kidney disease to model what a person- or patient-centered approach

to care might look like. In each instance, we provide a detailed review of relevant evidence and model what we see as the key components of this approach.

### 1. The Older Adult With a Moderate Reduction in eGFR

**Case 1:** The patient is a 78-year-old man who was referred to your clinic by his primary care provider because a recent laboratory test showed that he had an eGFR of 50 mL/min/1.73 m<sup>2</sup>. He has long-standing hypertension that is well controlled on treatment with 2 medications. He lives independently, is an avid gardener, and takes long walks every Sunday with friends. Both the patient and his daughter were alarmed to hear about his kidney disease and ask you whether this means that he will have to start dialysis. You review the patient’s prior creatinine levels and see that for the last 10 years, his eGFR has been in the 50– to 60–mL/min/1.73 m<sup>2</sup> range without evidence for a downward trend. You obtain a urine protein-creatinine ratio and find this to be within the normal range (<200 mg/dL). You look at his urine under the microscope and the sediment is bland.

### Relevant Evidence

Clinical practice guidelines define kidney disease based on uniform cut points in eGFR and urinary albumin values. At the population level, the prevalence of both low eGFR and albuminuria, and thus by definition, CKD, increases with age. Almost 40% of adults 70 years or older meet criteria for CKD. These older adults account for almost half the adult US population with kidney disease. Contemporary clinical practice guidelines for patients with this level of eGFR focus on cardiovascular risk reduction and, as for all patients with kidney disease, efforts to prevent or slow progression to ESKD.

### Clinical Significance of Moderate Reductions in eGFR in Older Adults

Like this patient, many older adults who meet criteria for CKD have only a moderate reduction in eGFR in the 45– to 59–mL/min/1.73 m<sup>2</sup> range. Because there is a large degree of heterogeneity in the clinical implications of CKD among patients of the same age with similar eGFRs, attempts to provide a unified message around the clinical significance and preferred management of CKD stage 3 in older adults may be at best uninformative and at worst misleading. Additional information, such as eGFR trajectory, presence and level of proteinuria, functional status, and the presence of other comorbid conditions, is of critical importance in judging the clinical significance of a low eGFR and identifying the subset of older adults who may benefit from the kinds of diagnostic and therapeutic interventions that are recommended in clinical practice guidelines.

For older adults like this patient with little or no proteinuria and no evidence for ongoing loss of eGFR, the presence of a moderate reduction in eGFR in this range is

unlikely to be clinically meaningful. The absolute risk for death is much higher than the risk for ESKD for patients with this level of eGFR among patients of all ages. However, the relationship of eGFR with mortality varies systematically with age. While younger adults with very moderate reductions in eGFRs (eg, 50-59 mL/min/1.73 m<sup>2</sup>) are at increased risk for death compared with their peers with higher eGFRs, older adults (>65 years) with eGFRs just below 60 mL/min/1.73 m<sup>2</sup> are at no greater risk for death than their peers with higher eGFRs who, according to current definitions, do not meet criteria for CKD. This observation, along with the very high prevalence of moderate reductions in eGFR at older ages, has led to controversy within the renal community about whether isolated moderate reductions in eGFR to levels just below 60 mL/min/1.73 m<sup>2</sup> should even be considered a disease in older adults. Because the vast majority of adults who meet criteria for CKD are elderly and have eGFRs in this range, this debate has substantial implications both for clinical practice and for estimating the size of the population with CKD.

### Person-Centered Approach

From reviewing the patient's medical record, we know that his eGFR has been stable over time and that he does not have significant proteinuria. We know from our review of the literature that for a man of his age, his risk for adverse outcomes such as progression of CKD, death, and cardiovascular events are essentially no different than if he did not meet criteria for CKD. We quickly learn when we meet him that he and his daughter are worried about his kidney disease and whether this might mean that he needs dialysis.

In structuring the conversation with the patient and his daughter, we might initially focus on learning more about how he sees his health, what is most important to him, what he knows and does not know about kidney disease, and what concerns he might have about the future. This will allow us to use the information we have gathered from his chart and from the literature to address the matters that are of greatest concern to the patient and his daughter.

We might begin by orienting the patient and his daughter to the stability of his eGFR and lack of proteinuria and explain that together, these observations suggest that he is unlikely to experience progressive loss of kidney function. In explaining abnormalities in his kidney function, it may be helpful to anchor the discussion to the kinds of things the patient has told us are important to him. For example, we might reassure him that his kidney disease is unlikely to affect his ability to hike with friends or spend time gardening.

Depending on the patient's interest level and/or that of his daughter, we might situate his experience within the broader controversy that exists within the renal community over whether patients with his level of kidney function should be labeled as having kidney disease. It would

also be important to make a distinction between what we know from populations and what we can know about the course of illness in an individual patient, cautioning that we cannot be completely certain about whether or how his eGFR will change in the future. This conversation might then pave the way for open dialogue and formulation of a care plan that reflects the patient's main concerns and goals, followed by redirection if outcomes do not turn out as initially expected. In this patient's case, we might discuss the option of referring him back to primary care with nephrology follow-up as needed versus follow-up in the nephrology clinic.

Box 3 summarizes the main considerations to keep in mind with a person-centered approach to caring for an older adult with a moderate reduction in eGFR.

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### Box 3. Take Home Points in the Person-Centered Care of an Older Patient With a Moderate Reduction in eGFR

- The older adult population with CKD is large and extremely heterogeneous.
- The majority of older adults who meet criteria for kidney disease have very moderate reductions in eGFRs.
- The risk for progression to ESKD with moderate reductions in eGFRs is very low for most older adults but will vary depending on other aspects of their presentation.
- The relationship between eGFR and mortality varies systematically with age, such that many older adults with eGFRs just <60 mL/min/1.73 m<sup>2</sup> are at no greater risk for death than their peers with higher eGFRs (who do not meet criteria for CKD).
- A nuanced approach is needed when discussing the clinical implications of such moderate reductions in eGFR in an older adult that is tailored to the specifics of each person's situation while addressing what is foremost in his or her mind.
- Conversations with patients with kidney disease should respond not only to their information needs but also to their emotional needs.

Abbreviations: CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; ESKD, end-stage kidney disease.



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## 2. The Older Adult With Nephrotic-Range Proteinuria

**Case 2:** The patient is an 80-year-old man with stage 4 CKD who has had diabetes and hypertension for 15 years; he does not have diabetic retinopathy. He has severe osteoarthritis and needs a wheelchair to get around at home. He had coronary bypass surgery 8 years ago. He lives in an assisted-living facility with his wife. He started feeling poorly 2 weeks ago with shortness of breath and leg swelling. You examine him and notice that he appears volume overloaded; he has 3+ swelling to the mid thigh and crackles at both lung bases. On urinalysis, he has 5 to 10 dysmorphic red blood cells per high-power field. He has a serum creatinine level of 3.5 mg/dL, with a baseline of ~3.0 mg/dL for the last several years. Urinary protein-creatinine ratio is 7 mg/mg, compared with <1 mg/mg previously.

### Relevant Evidence

Diagnostic evaluation to identify the underlying cause of proteinuria is best viewed as a process comprising a series of interrelated decisions about whether to obtain diagnostic testing to identify possible underlying conditions that can be associated with kidney disease, what tests to obtain, and whether to recommend treatment based on the results of testing. Whether to pursue workup to determine the cause of kidney disease requires forethought about the safety and harms of testing itself, the likelihood that testing will yield a diagnosis, whether there are effective treatments for the diagnosed entity, and whether the benefits of treatment are likely to exceed the harms in an individual patient.

Decisions about whether, when, and for whom to pursue a diagnostic evaluation to identify the underlying cause of kidney disease are among the most challenging encountered in nephrology practice, yet clinical practice guidelines have little to say on this matter. Decisions about diagnostic evaluation are often especially difficult in older adults with complex comorbidity and limited life expectancy for whom the benefits of standard disease-based practices directed at identifying and treating underlying pathophysiologic processes are often least certain.

### Potential Pitfalls of Diagnostic Evaluation of Proteinuria in Older Adults

Given the large number of potential causes of proteinuric kidney disease, numerous different laboratory tests can be

obtained as part of the initial evaluation. This testing can be costly and potentially burdensome for patients and can lead to a cascade of additional diagnostic testing that is not always beneficial, especially when test results are falsely positive. For instance, tests to evaluate for monoclonal gammopathy (urine and serum electrophoresis and immunofixation and  $\kappa:\lambda$  light chain ratio) are often ordered as part of the diagnostic evaluation for proteinuric kidney disease. Minor abnormalities in these test results are extremely common in older adults, both with and without kidney disease, but their presence is rarely clinically significant. It is estimated that only 1% to 2% of patients who test positive for monoclonal gammopathy are subsequently found to have a related kidney condition or new multiple myeloma.

### Kidney Biopsy in Older Adults

Not uncommonly, laboratory testing alone fails to provide a definitive diagnosis or sufficient information to formulate a disease-based treatment plan. Next steps in the diagnostic workup may thus include a kidney biopsy, which is considered to be the gold-standard method for diagnosing the underlying cause(s) of kidney disease and assessing its severity and likely responsiveness to treatment. However, risks for complications with biopsy, such as bleeding, increase with age and burden of comorbid conditions. These potential harms should be weighed against the likelihood that biopsy results will lead to a diagnosis for which targeted therapy is available and likely to be effective in a given patient.

### Treatment Considerations in Older Adults

In older patients with a high burden of comorbid conditions, there is little evidence to support the efficacy of most treatments for conditions requiring confirmation by kidney biopsy (eg, glomerulonephritis and interstitial nephritis), either because trial data are not available or trials have excluded older adults. Further, the kinds of treatments (ie, cytotoxic and immunomodulatory agents) that might be offered based on the results of kidney biopsy are more likely to lead to serious complications, such as infection, muscle atrophy, heart failure, and death, in older patients with multiple comorbid conditions. For instance, observational studies reporting outcomes of older patients (>80 years) aggressively treated with immunosuppression for severe renal involvement in ANCA-associated vasculitis suggest that approximately half will die within 1 year of treatment, one-third will not recover kidney function and will go on to start maintenance dialysis, and one-third will develop an infectious complication.

### Person-Centered Approach

This patient's case reflects the clinical complexity present in many older patients with underlying kidney disease. He has evidence of long-standing advanced kidney disease and proteinuria that is most likely due to

his underlying diabetes and hypertension, but this has not been confirmed with biopsy. Whether the recent onset of nephrotic-range proteinuria reflects a new process or evolution of a pre-existing process is unclear. Certainly the absence of retinopathy, presence of dysmorphic red blood cells on urinalysis, and rapid increase in proteinuria raise concern that the patient's clinical presentation may be due to something other than diabetic kidney disease.

It is important to recognize that there are myriad possible approaches to caring for this patient. Individual clinicians would likely differ in their preferred approach and specifically in their willingness to recommend a kidney biopsy. However, under a person-centered paradigm, how we proceed should be strongly shaped not by our own "practices," but by how individual patients weigh the benefits and harms of different possible approaches. It is not uncommon for us to hear from our patients, "Doctor, if this were you, what would you do?" or "I'll do it if you think it will help me." These sorts of statements may make us want to offer what we might consider the best possible treatment plan regardless of the expected benefits and harms in an individual patient. Put to the test, we can acknowledge our patient's anxiety, explain that there is no "right" approach, and help them understand that our goal is to help them identify the right approach for them based on their goals and how they view the potential benefits and harms of testing and treatment.

Strong communication skills are critical in supporting these kinds of discussions. Such skills can help us elicit how patients perceive their illness, understand how it has affected their life, and learn about their values, goals, and preferences. These skills can also help us communicate information with compassion and understanding and offer guidance in a way that gives patients the confidence to make health care decisions that reflect what is most important to them. Conversely, poor communication can lead to mistrust between patients, families, and health care providers and limit the benefits of the therapeutic relationship and any treatments that might be offered.

In discussing diagnostic and treatment options with the patient, we might begin with open-ended questions that allow us to gain an understanding of his concerns and priorities as we develop a diagnostic and treatment plan (Box 4). Although these questions have little to do with the specific diagnostic and treatment decisions at hand, beginning with an open-ended approach will help us understand what treatment options might be reasonable to discuss and to tailor our discussion of the benefits and harms of different treatment options to what is most important to the patient. In nephrology practice, we often have an opportunity to build relationships with our patients and get to know them as people, often over long periods. This can provide an extraordinarily strong foundation for discussions about complex diagnostic and

#### Box 4. Examples of Open-Ended Questions to Elicit Patient's Goals, Values, and Preferences

1. How do you see the situation you are facing with your kidney disease?
2. What prior experiences have you had with illness and/or health care that might inform the way you see your current situation with your kidney disease?
3. Can you tell me a little about yourself and the kinds of things that are most important to you?
4. What worries you the most about your illness and/or care?
5. What do you hope we can preserve or achieve with your illness?
6. Who or what do you rely on for help in making decisions about your illness and/or care?
7. Where do you find support/strength as you face your illness?
8. What else do I need to know about you so that I can help to make sure you get the care that is right for you?

treatment strategies, for which an iterative approach and high levels of trust are often needed.

Box 5 summarizes the main considerations to keep in mind with a person-centered approach to an older adult with nephrotic-range proteinuria.

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#### Box 5. Take Home Points Related to Person-Centered Care of an Older Patient With Nephrotic-Range Proteinuria

- Decisions about diagnostic evaluation of kidney disease should be based on the expected benefits and harms in an individual patient.
- Diagnostic testing to identify the cause of kidney disease can sometimes lead to a cascade of downstream testing and treatment that may be associated with benefits, but also harms.
- While questions about the utility of diagnostic testing and kidney biopsy often come up in the care of patients with kidney disease, there is little evidence to guide decisions about diagnostic evaluation, especially in older adults.
- Strong communication skills, including asking open-ended questions to elicit a patient's goals, values, and preferences, are needed to develop an individualized diagnostic and treatment plan.

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### 3. The Older Adult Faced With the Prospect of Starting Dialysis

**Case 3:** The patient is an 85-year-old African American woman with diabetes, hypertension, and advanced heart failure (ejection fraction < 20%). She lives in an upstairs apartment with her daughter and needs assistance negotiating the stairs. She is independent in most activities of daily living but needs a wheelchair when venturing outside her apartment. She came to the hospital with shortness of breath and volume overload and was found to be in new-onset atrial fibrillation. During the admission, her eGFR decreased from her prior baseline of 15 to ~7 mL/min/1.73 m<sup>2</sup>. Although she has diuresed well and no longer feels short of breath, she has started to feel nauseated and now has asterixis. You ask about what her conversations have been so far about dialysis and she explains that she had been talking with her nephrologist about starting dialysis at some point in the future but would only want to do this if she had to.

#### Relevant Evidence

Approximately 1 in 4 patients treated with maintenance dialysis in this country is older than 75 years. These older patients currently represent one of the fastest growing demographic groups starting dialysis. On average, life expectancy for patients receiving dialysis is about one-quarter that for a patient of the same age who does not have ESKD. Survival is especially limited for older adults with ESKD and those with a higher burden of comorbid conditions and disability. For example, among US patients 75 years and older, median life expectancy after initiation of maintenance dialysis is approximately 3 years as compared with approximately 11 years in the general population.

#### Outcomes Among Older Adults Treated With Dialysis

Although it is often assumed that dialysis initiation will restore health for patients with advanced kidney disease,

several studies have reported that among disabled and older adults, functional status and level of independence decrease after dialysis initiation. Up to one-third of adults 80 years and older living independently in the community at the time of dialysis initiation require community or private caregiver support or transfer to a nursing home within 6 months. Also, the vast majority of nursing home residents who start dialysis either die or experience worsening functional status within the first year after dialysis initiation. There can also be substantial escalation of care after dialysis is started and particularly as patients approach the end of life. Many older adults receiving maintenance dialysis are hospitalized and receive interventions intended to prolong life, such as intensive care unit admission, mechanical ventilation, and cardiopulmonary resuscitation during the final months of life. For some older patients with advanced kidney disease, any survival benefit that dialysis might confer may be outweighed by the additional treatment burden and time spent in health care settings.

#### Conservative Care for Advanced Kidney Disease

Several countries outside the United States have established conservative care programs to support patients who do not wish to receive maintenance dialysis. Conservative management, which typically involves the formulation of a multidisciplinary care plan that is individualized to support patients' goals with a focus on quality of life, can provide a strong positive alternative to dialysis for some patients. Limited observational data suggest that in very elderly patients with a high burden of comorbid conditions and/or disability, survival and quality of life may be no better for those treated with dialysis than for those who decide to pursue a more conservative approach.

It is important to keep in mind that these results come from studies conducted outside the United States, where there are well-developed conservative care programs and a more proactive approach to helping patients choose between dialysis and conservative care relatively early in the illness trajectory. While there is growing interest in conservative care within the US nephrology community, formal conservative care programs have been slow to develop in this country and dialysis continues to be a powerful default. When US patients choose not to pursue dialysis, this tends to occur very late in the illness trajectory only after all other options have been exhausted.

#### Supporting Patients Who Are Ambivalent About Dialysis or Want to Delay This as Long as Possible

Although relatively few US patients ultimately choose not to initiate dialysis, many express a desire to avoid this for as long as possible or until they can envision a benefit. Not uncommonly, clinical decision making for patients with advanced kidney disease is severely hampered by the substantial uncertainty that can exist around the expected course of illness. Some patients may need to become very sick before they can reasonably make decisions about dialysis (or even take steps to prepare for this).

Evidence from the IDEAL trial, a large randomized controlled trial of early versus late dialysis initiation, suggests that patients with advanced kidney disease followed closely by a nephrologist can gain approximately 6 months of dialysis-free time with no increased risk for mortality or other adverse events (and at lower cost). A willingness to manage patients conservatively until they feel able to reach a decision about dialysis (and other upstream care processes such as modality selection and access placement) may offer a useful “middle ground” for patients who find themselves unable to move along existing clinical pathways. That is, patients with advanced kidney disease who do not feel ready to either prepare for dialysis or commit to a formal conservative care pathway with a clear plan not to pursue dialysis.

### **More Flexible Models of Dialysis Care**

In addition to supporting a more individualized approach to decisions about dialysis initiation, some have also argued for greater flexibility in how we prescribe dialysis treatments for those receiving this therapy, which can of course shape patients’ upstream decisions about whether and when to start dialysis. For example, there is growing interest in alternatives to standard thrice-weekly dialysis for patients who do not need or want the level of clearance that this would provide. Incremental hemodialysis has been suggested as an alternative to thrice-weekly dialysis for patients who retain significant residual kidney function, and a palliative approach to dialysis delivery has been suggested for patients with limited life expectancy who wish to limit the burdens of treatment. There is also interest in providing concurrent access to palliative care and hospice services to patients receiving dialysis, although regulatory processes are not optimally configured to support concurrent hospice for most US dialysis patients.

### **Person-Centered Approach**

The question of dialysis initiation often comes up when patients with advanced kidney disease are admitted to the hospital. Under these circumstances, there can be considerable clinical momentum favoring initiation. These situations also tend to expose large differences in the practices of individual nephrologists. For example, some providers might see this patient’s asterixis and nausea as sufficient reason to recommend dialysis initiation while she is in the hospital. Others might see these as “less urgent” indications for dialysis and advise delaying dialysis initiation until she develops more compelling indications for dialysis, or perhaps until she has a functional fistula. Other providers may believe that patients like this patient, who are elderly and have a significant burden of comorbidity, would be better served by not starting dialysis and recommend conservative care. However, under a person-centered paradigm, this decision should be shaped not by providers and what they think is important but by the patient and what is important to her.

Recall that the patient had initially stated that she would be willing to start dialysis if she had to. This kind of statement (which is common to hear from patients) seems to imply a belief that there is a “right” time to start dialysis and that providers will ultimately let her know when this time has arrived. However, under a person-centered paradigm, decisions about whether and when to start dialysis should ideally be shaped by the patient herself, with the nephrologist serving in a supportive and/or facilitative role. Thus, our initial task is to help the patient understand that our role is to help her identify the treatment strategy that is best for her, and that the right time for her to start dialysis (if there is a right time) would be when she feels ready.

Under a person-centered approach, whether and when dialysis should be initiated depends on how individual patients judge the trade-offs that starting versus not starting dialysis may involve. Often, the “devil” is in the “details” when it comes to these kinds of decisions. That is, how patients weigh the benefits and harms of dialysis (and its alternatives) might vary substantially depending on the type of dialysis, the circumstances under which it might be offered, and how it is prescribed (trial of dialysis, incremental dialysis, and home vs in-center), as well as their own life circumstances (eg, transportation difficulties, living situation, significant life events, and competing priorities). It would be impossible to know any of this or what might constitute reasonable treatment options for the patient without first engaging in a shared decision-making process.

Shared decision making should generally begin with some assessment of patients’ readiness to enter the conversation (Box 6). This can be as simple as asking for the patient’s permission to have a conversation about dialysis and whether there are others she might want to involve in this conversation. Assuming that she feels ready to talk about possible treatments for her kidney disease, we might want to learn about earlier conversations that she may have had with her nephrologist. It may also be helpful to learn whether she knows anyone receiving dialysis and whether she has friends or family members who have been faced with decisions about dialysis. This can help us understand what kind of information she may need to support her decision-making process.

An important goal would be to learn about the patient’s daily life and what gives her life meaning to understand the implications of different treatment options for her. We might also try to elicit what she might consider “good” reasons to start dialysis. Perhaps she would prefer to try to control her nausea with medication rather than resorting to dialysis? Perhaps she would need to feel sicker than she does at present, even if this might mean repeat admissions and starting dialysis urgently with a catheter despite the known risks? Or perhaps she is concerned about being able to get to and from dialysis and would only consider starting treatment if she could maintain her current level of independence?



**Box 6.** Examples of Open-Ended Questions That Can Help Prepare for Shared Decision Making

1. Given where we are with your kidney disease, would it be all right if we talk about what to expect in the future and possible treatments?
2. Is there someone else (eg, family or friends) you would like to have with you when we talk about your kidney disease and possible treatments?
3. What have you been told so far about your kidney disease and what to expect in the future?
4. Has anyone talked with you about possible treatments for your kidney disease?
5. How did these conversations go? Was there anything that made talking about treatments for your kidney disease easier (or more difficult) for you?
6. As we talk about your kidney disease, is there anything in particular you want to make sure that we cover?

*If patient is not ready or wanting to have a conversation:*

I can understand why you might not want to talk about this right now. Perhaps we could revisit this next time we meet?

*If discussing at the next visit is not acceptable to the patient:*

Do you have a sense as to when might be the right time for us to have this conversation?

In planning the next steps, we might leverage the patient's current experience of acute illness and hospital admission to make this conversation more concrete. For example, we might try to learn whether (and if so, how) her experience during her current admission has changed her thinking about her kidney disease and possible treatments moving forward. We might try to learn what future experiences she is willing to tolerate (eg, more frequent clinic visits with symptom assessment and laboratory checks) or would like to avoid (eg, another hospitalization) that might influence her decision making.

Based on what we learn about the patient's understanding of her treatment options, we would want to make sure we educate her not only about the immediate option of in-center hemodialysis but also reasonable short- and long-term alternatives (eg, continued medical management, formal conservative care with no intention to start dialysis, home dialysis, and hospice) and the possibility of a trial approach to her chosen treatment. We would also want to be forthright with her about the treatment options that are unlikely to be realistic for her, given her advanced age and heart failure (ie, kidney transplantation).

Box 7 summarizes the main considerations to keep in mind with a person-centered approach to an older adult faced with the prospect of starting dialysis.

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**Box 7.** Take Home Points Related to Person-Centered Care of an Older Patient Faced With the Prospect of Starting Dialysis

- As much as possible, decisions about treatments for advanced kidney disease should be driven by patients and what is meaningful to them rather than medical parameters (eg, results of laboratory tests, clinical indications for dialysis) or provider practices.
- Decisions about treatment for advanced kidney disease often unfold over time and may call for flexibility in responding to patients' evolving preferences, readiness to engage in decision making, and the shifting realities of their situation.
- To arrive at a place at which person-centered recommendations can be made, ground work is needed to assess patients' understanding of their treatment options and learn how they value the risks and benefits of different options.
- Efforts should be made to avoid framing dialysis as the default treatment for advanced kidney disease and ensure that patients are educated about reasonable alternatives.

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## Conclusions

Using 3 common clinical scenarios, we have modeled what a person-centered approach to care might look like. In each instance, we reviewed the literature in a focused manner to extract what might be relevant to the person under our care. We took the time to learn about the patient, what is important to him or her, and the knowledge and concerns they bring to the encounter. We waited to learn about the practical realities of their situation, who they are, and what is important to them before making treatment recommendations. The recommendations we

make should ideally emerge from a shared decision-making process informed by the realities of each patient's situation and their goals and values.

## Article Information

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