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## Timing of Initiation of Maintenance Dialysis:

### A Qualitative Analysis of the Electronic Medical Records of a National Cohort of Patients From the Department of Veterans Affairs

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#### Abstract

**IMPORTANCE**—There is often considerable uncertainty about the optimal time to initiate maintenance dialysis in individual patients and little medical evidence to guide this decision.

**OBJECTIVE**—To gain a better understanding of the factors influencing the timing of initiation of dialysis in clinical practice.

**DESIGN, SETTING, AND PARTICIPANTS**—A qualitative analysis was conducted using the electronic medical records from the Department of Veterans Affairs (VA) of a national random sample of 1691 patients for whom the decision to initiate maintenance dialysis occurred in the VA between January 1, 2000, and December 31, 2009. Data analysis took place from June 1 to November 30, 2014.

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*Study concept and design:* Wong, Liu, Williams, Hebert, O'Hare.

*Acquisition, analysis, or interpretation of data:* All authors.

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**MAIN OUTCOMES AND MEASURES**—Central themes related to the timing of initiation of dialysis as documented in patients' electronic medical records.

**RESULTS**—Of the 1691 patients, 1264 (74.7%) initiated dialysis as inpatients and 1228 (72.6%) initiated dialysis with a hemodialysis catheter. Cohort members met with a nephrologist during an outpatient clinic visit a median of 3 times (interquartile range, 0–6) in the year prior to initiation of dialysis. The mean (SD) estimated glomerular filtration rate at the time of initiation for cohort members was 10.4 (5.7) mL/min/1.73m<sup>2</sup>. The timing of initiation of dialysis reflected the complex interplay of at least 3 interrelated and dynamic processes. The first was physician practices, which ranged from practices intended to prepare patients for dialysis to those intended to forestall the need for dialysis by managing the signs and symptoms of uremia with medical interventions. The second process was sources of momentum. Initiation of dialysis was often precipitated by clinical events involving acute illness or medical procedures. In these settings, the imperative to treat often seemed to override patient choice. The third process was patient-physician dynamics. Interactions between patients and physicians were sometimes adversarial, and physician recommendations to initiate dialysis sometimes seemed to conflict with patient priorities.

**CONCLUSIONS AND RELEVANCE**—The initiation of maintenance dialysis reflects the care practices of individual physicians, sources of momentum for initiation of dialysis, interactions between patients and physicians, and the complex interplay of these dynamic processes over time. Our findings suggest opportunities to improve communication between patients and physicians and to better align these processes with patients' values, goals, and preferences.

In recent decades, maintenance dialysis has been initiated progressively earlier in the course of chronic kidney disease (CKD).<sup>1–5</sup> The reasons for this trend are not well understood. Although there are recognized indications for dialysis, such as life-threatening electrolyte abnormalities and signs and symptoms of uremia, in practice, there is often considerable uncertainty about the optimal time to initiate dialysis in individual patients and little evidence to guide this decision.<sup>6</sup>

Observational studies examining the association between the timing of initiation of dialysis and subsequent outcomes have contradictory findings. Most studies have reported higher mortality when dialysis is started earlier in the course of CKD or at a higher estimated glomerular filtration rate.<sup>7–14</sup> This finding may be partially explained by the older age<sup>14</sup> and higher prevalence of complex comorbid conditions and signs of malnutrition<sup>8,9,11,14</sup> among patients who initiate dialysis at a higher estimated glomerular filtration rate, but higher mortality also has been variously attributed to myocardial stunning, accelerated loss of native kidney function, and a systemic inflammatory state associated with dialysis.<sup>11</sup> Other studies, however, have reported no difference<sup>15</sup> or improved survival<sup>16–18</sup> when dialysis is started earlier in the course of CKD. The putative benefits of dialysis, such as better control of volume status, increased clearance of uremic toxins, and avoidance of severe uremic complications, also have been cited as a rationale for early initiation.<sup>19,20</sup> The Initiating Dialysis Early and Late (IDEAL) trial, in which patients were randomized to start dialysis at either a higher (10–15 mL/min/1.73m<sup>2</sup>) or lower (5–7 mL/min/1.73m<sup>2</sup>) targeted, estimated glomerular filtration rate, found no difference in survival or other clinical outcomes between the 2 study arms,<sup>21</sup> but patients randomized to start early spent more of their remaining lifetime receiving dialysis and incurred higher total health care costs.<sup>22</sup>

Prior work has focused primarily on associations between estimated glomerular filtration rate at initiation of dialysis and measured patient characteristics and outcomes.<sup>7–18,21,22</sup> These studies do not address with sufficient granularity how decisions about when to start dialysis are made in clinical practice. An earlier study used the medical records of a national cohort of patients receiving care within the Department of Veterans Affairs (VA) to examine patients' clinical presentation around the time maintenance dialysis was initiated.<sup>5</sup> Among members of this cohort, a trend toward earlier initiation of dialysis from 2000 to 2009 was not explained by changes in clinical indications, such as signs and symptoms consistent with advanced CKD or presentation with acute illness around the time of initiation of dialysis during the same 10-year period. To better understand the driving forces behind decisions about timing of dialysis, we performed an in-depth qualitative analysis of the medical records of the members of this same cohort.

## Methods

### Study Design

We conducted a post hoc qualitative analysis of the electronic medical records of a national random sample of 1691 patients receiving care within the VA who initiated maintenance dialysis from January 1, 2000, to December 31, 2009. We identified members of the cohort using a combination of administrative data and information from the medical record collected within the year prior to initiation of dialysis, as described previously.<sup>5</sup> Patients were included in this cohort only if the decision to initiate dialysis occurred within the VA and if there was sufficient documentation in their medical record to understand the clinical context in which dialysis was initiated. The VA Puget Sound Healthcare System Institutional Review Board approved this study and waived the requirement to obtain informed consent from patients.

### Data Collection

The VA maintains a comprehensive, nationwide, electronic medical record system for all patients who receive care at any of its facilities; the records include progress notes for all inpatient and outpatient clinical encounters. One of us (A.M.O., a nephrologist with >15 years of clinical experience) reviewed the medical record of each patient around the time of initiation of dialysis and abstracted passages from progress notes containing information relevant to the decision to initiate dialysis, as previously described.<sup>5</sup> To assess the completeness of medical record abstraction for ascertaining information relevant to decisions about dialysis, a second investigator (S.P.Y.W., a senior nephrology fellow) independently abstracted passages from the medical records of a randomly selected sample of 50 patients. Side-by-side comparison indicated that passages independently abstracted by both investigators were largely similar (identical passages were retrieved for 42 of the 50 patients).

### Qualitative Analysis

Using inductive content analysis (an unstructured method of inquiry that facilitates discovery of previously unidentified factors pertaining to a phenomenon),<sup>23</sup> the 2 investigators then independently reviewed abstracted passages from all patients, coding for

factors that seemed relevant to decisions about the timing of initiation of dialysis in individual patients. Together, the investigators reviewed all codes and their corresponding passages for discrepancies in interpretation of the passages, and assignment of codes was deliberated until consensus was reached. The investigators then iteratively examined codes for patterns and trends and combined related codes into larger thematic categories. A third investigator (E.K.V., a geriatrician, palliative care physician, and ethicist) independently reviewed thematic categories for consistency and whether they were well grounded in their constituent codes and passages.<sup>24</sup> All 3 investigators then collectively refined the final thematic schema. We used Atlas.ti qualitative analysis software, version 7 (GmbH), to facilitate organization of codes and passages. Data analysis took place from June 1 to November 30, 2014.

## Results

Most of the 1691 patients initiated dialysis as inpatients (1264 [74.7%]) and with a hemodialysis catheter (1228 [72.6%]) (Table 1).<sup>5</sup> In qualitative analysis, we identified 3 dominant, overlapping themes relevant to understanding the timing of initiation of dialysis: physician practices, sources of momentum, and patient-physician dynamics. To illustrate each of these themes, Tables 2, 3, and 4 provide, respectively, exemplary quotes abstracted from the medical records of individual patients.

### Physician Practices

Timing of initiation of dialysis reflected differing physician practices, ranging from those directed at preparing patients for dialysis to those focused on forestalling the need for dialysis by using more conservative medical therapies to reverse or halt the loss of renal function and manage the signs and symptoms of advanced CKD (Table 2).

### Preparing for Dialysis

The decision to pursue dialysis usually involved a series of interdependent steps to prepare patients for dialysis. Examples include steps to help patients select a dialysis modality (hemodialysis or peritoneal dialysis) and secure permanent dialysis access (eg, arteriovenous fistula or graft or peritoneal catheter).

Aligning the timing of preparation with patients' trajectories of illness was a common challenge (Table 2). Although some patients were able to smoothly transition to dialysis after completing key preparatory steps (quote 1a), most were faced with the decision to initiate dialysis earlier than anticipated (quote 1b). Where patients were in the course of preparation sometimes influenced the timing of initiation. In some instances, initiation of dialysis was deferred until permanent access was ready (quote 1c). In other patients, the presence of functional access for dialysis seemed to have an almost disinhibitory effect, tipping the balance in favor of initiation of dialysis in situations in which there did not seem to be pressing clinical indications (quote 1d).

## Forestalling Dialysis

Often, dialysis was initiated after physicians had attempted a series of medical interventions intended to reverse or halt the loss of kidney function and/or treat the signs and symptoms of advanced CKD. Dietary changes and titration of diuretics, ion-binding resins, and alkali therapy were frequently prescribed with the intent to manage signs and symptoms until dialysis could be arranged or to postpone the need for dialysis.

A plan for when dialysis would be initiated was often made based on how patients responded to these interventions (quote 1e) (Table 2). The time frame for evaluating the effect of medical interventions seemed to vary depending on clinical context. In the outpatient setting, patients' response was usually reassessed during clinic visits over the course of weeks to months. In the inpatient setting, the time frame was often compressed to hours or days before a determination was made regarding whether to start dialysis.

Physicians seemed to vary in their willingness to offer alternatives to dialysis. Some physicians tried to accommodate patients' preference to continue with medical therapies rather than to start dialysis (quote 1f) (Table 2). One physician spoke of trade-offs between using medical therapies vs starting dialysis (quote 1g). Other physicians seemed to view the signs and symptoms of advanced CKD more as "indications" signaling the "need" for dialysis rather than as treatment targets in their own right (quote 1h).

## Sources of Momentum

Although known triggers for initiation of dialysis, such as electrolyte abnormalities and signs and symptoms consistent with uremia, were documented in the medical records of most cohort members around the time dialysis was started,<sup>5</sup> we also identified other sources of momentum for initiation of dialysis (Table 3).

## Acute Illness

Acute illness was the most prominent source of momentum for initiation of dialysis. For patients with life-threatening illness, physicians often described an urgent "need" for dialysis, and the imperative to treat appeared to supplant patients' choice in the matter (quote 2a) (Table 3).

Even in the absence of urgent clinical indications, simply being in the hospital seemed to increase the likelihood of initiation of dialysis. Patients with advanced CKD who were admitted to the hospital were often labeled by inpatient health care teams as "predialysis" or "approaching dialysis," and the question of when to initiate dialysis was routinely considered as part of the assessment and care plan. Hospitalization for an illness unrelated to kidney disease was sometimes explicitly viewed by physicians as an "opportunity" to coordinate the initiation of dialysis for patients who experienced obstacles to accessing routine medical care. For instance, for one patient who was hospitalized for treatment of psychiatric illness and who had an unstable housing situation, physicians recommended that dialysis access be placed during the hospitalization because "placement will be easier from an inpatient status." This patient ultimately started dialysis during the same hospitalization. We also found examples in which physicians seemed to seize the "opportunity" to initiate

dialysis during a hospital admission in patients who had been reluctant to start dialysis (quote 2b) (Table 3).

### Medical Optimization

Another source of momentum was physicians' perceived need to optimize patients' clinical status for an upcoming high-risk procedure, such as surgery or angiography, with the assumption that outcomes would be more favorable if dialysis were started in advance of the procedure (quote 2c) (Table 3). In some patients, dialysis was "required" by physicians before the relevant procedure would be performed (quote 2d).

Certain preparatory interventions sometimes had the unintended effect of precipitating initiation of dialysis. For example, several patients experienced worsening renal function or symptoms after surgery to place a dialysis access, prompting initiation of dialysis (quote 2e) (Table 3).

### Patient-Physician Dynamics

Timing of the initiation of dialysis also seemed to be shaped by the complex interactions between patients and physicians. There often appeared to be a push-pull relationship between patients and physicians, in which patients were described in progress notes as being "resistant" or "reluctant" to prepare for or start dialysis (Table 4). Physicians seemed most concerned about safety and survival, seeing any delay in initiation of dialysis as potentially hazardous, while patients seemed to have a range of priorities and concerns.

### Resistance

Although some patients were described as "ambivalent" toward or "accepting" of dialysis when physicians indicated it was time to start, many more patients viewed dialysis as a treatment of "last resort" and asked to postpone dialysis when physicians recommended initiation (quote 3a) (Table 4). Family members sometimes seemed more eager for patients to start dialysis than the patients themselves (quote 3b).

Physicians documented a range of pragmatic concerns cited by patients as reasons for postponing initiation of dialysis, which included competing social or family obligations, financial problems, or transportation difficulties (quote 3c) (Table 4). Although some physicians made note of significant barriers to dialysis for individual patients, these concerns did not always seem to affect their recommendation (quote 3d). At times, physicians pressed patients to start dialysis despite patients' clear reluctance (quote 3e).

For many patients, timing of initiation of dialysis was tied to a broader decision about whether to initiate dialysis at all. It was not uncommon for patients to have "refused" or "declined" offers to initiate dialysis on multiple occasions before eventually starting treatment. Patients' willingness to start dialysis seemed to be shaped by their changing experience of illness over time (quote 3f) (Table 4). Some patients seemed to need to become very sick before agreeing to start dialysis (quote 3g). Physicians described using various arguments to "persuade" or "convince" patients to start dialysis (quote 3h). One

patient refused treatment altogether when his physician would not give him the time to consider his choices (quote 3i).

### Paternalism

Most physicians seemed to view dialysis as a beneficial treatment and were skeptical when patients said they did not want to start dialysis (quote 3j) (Table 4). Some physicians perceived their patients to be “in denial” about or have “poor insight” into the severity of their kidney failure and the “inevitable need” for dialysis (quote 3k). Missing appointments with nephrologists and vascular surgeons for placement of dialysis access was often cast by physicians as “noncompliant” behavior or a means of “avoiding” dialysis. Other patients seemed to defer decisions about initiation of dialysis to their physicians (quote 3l). The question of whether patients were “competent” to make decisions about dialysis seemed to arise most often in situations in which patients rejected recommendations to start dialysis (quote 3m). In situations in which patients presented with cognitive impairment, it was more common to find documentation of concerns about whether patients had uremic encephalopathy as a compelling indication for dialysis than it was to find documented concerns about their capacity to participate in decisions about dialysis (quote 3n).

Patients’ treatment goals and values were rarely documented in the medical record. When they were documented, many patients emphasized quality of life and autonomy. In contrast with patients, physicians tended to have a safety-conscious approach toward initiation of dialysis and focused on the perceived hazards of delaying dialysis. Although patients were typically asked to provide informed consent before dialysis was initiated, the decision was frequently cast by physicians as one of “dialysis vs death” or grave disability (Table 4) (quote 3o). One physician documented that his patient felt that “he ‘has no choice’ if his other alternative is ‘dying.’”

### Discussion

The medical record serves as important documentation of health care interactions, accountability, and communication; it provides a unique vantage point from which to examine how treatment decisions are made about the timing of initiation of dialysis. Our analysis suggests that the initiation of maintenance dialysis reflects the complex interplay of at least 3 interrelated and dynamic processes: the care practices of individual physicians, sources of momentum for dialysis initiation, and interactions between patients and physicians.

Dialysis is associated with distinct benefits and harms for individual patients; clinical practice guidelines recommend that decisions about whether and when to initiate dialysis be shared between patients and physicians.<sup>6,25,26</sup> In a shared decision-making model, treatment decisions integrate patients’ values, goals, and preferences with physicians’ expertise on prognosis and the risks and benefits of available treatments. Our findings spotlight the substantial challenges to achieving this ideal in real-world clinical settings.

These findings are in accord with studies suggesting that decisions about dialysis seem to be driven much more by physician-level factors, such as regional practice style, than by

individual patient characteristics.<sup>27,28</sup> Qualitative interviews with patients and ethnographic work conducted in renal clinics have also indicated that physicians tend to frame dialysis as an inevitable treatment rather than as an explicit treatment choice with associated benefits and harms.<sup>29–32</sup> Documentation in the medical record tended not to focus on patient concerns and priorities. Instead, physicians emphasized achieving biomedical targets (ie, level of kidney function, signs and symptoms of uremia), coordinating procedures, keeping patients safe, and prolonging life. In situations in which patients did not start dialysis when recommended or started only when they became very sick, physicians tended to view this course of action as maladaptive behavior rather than as an implicit treatment choice. Taken together, our findings call for stronger efforts to improve patient-physician communication with a view to clarifying patients' health care values, goals, and preferences and better aligning treatment recommendations with patients' priorities. Our findings also suggest that there is work to be done to better understand how to best support patients' readiness to face serious illness and engage in treatment decisions about initiation of dialysis.

We used patients' medical records to analyze decisions about dialysis. Prior qualitative studies examining decisions about dialysis have been based on information gathered from one-time interviews with patients and physicians<sup>33–35</sup> or ethnographic work conducted in renal clinics.<sup>29,30</sup> Interviews do not provide direct information on how these decisions occur in a clinical context or on patient-physician interactions. Direct observation may alter the behaviors of patients and physicians<sup>36</sup> and does not always capture decisions about treatment at the time they occur. Nevertheless, our study has limitations. First, owing to the complexity of the themes identified, our findings do not lend themselves to dichotomous categorization that would be needed to quantify the frequency of each theme among cohort members. Documentation was also not uniform across all patients and physicians; therefore, we could not be certain that a particular theme was not present in individual cases. Second, we selectively presented only dominant themes; our results are not exhaustive of all themes related to the timing of initiation of dialysis. Themes also reflect interactions with the health care system and what physicians chose to document in the medical record and thus provide only indirect and limited insight on the perspectives and experience of patients. Third, our analysis examines factors relevant to understanding the timing of initiation of dialysis among patients who initiated dialysis and was not intended to address decisions about whether to initiate dialysis in patients with advanced CKD. Fourth, our study findings within the VA may not be generalizable to other health care settings or populations (especially women). Nevertheless, the VA is the largest integrated health care system in the United States, and available evidence suggests that dialysis initiation practices in the VA parallel, and are more conservative than, those found in the wider US population.<sup>2</sup> Last, there is some evidence that the trend toward earlier initiation of dialysis may be leveling off in recent years.<sup>1,2</sup> Thus, it is possible that our results may not reflect current practice.

## Conclusions

Our findings offer insight into the complex processes that shape the timing of maintenance dialysis in real-world clinical settings and suggest that there may be opportunities to make these processes more patient centered.



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## References

1. Saran R, Li Y, Robinson B, et al. US Renal Data System 2014 annual data report: epidemiology of kidney disease in the United States. *Am J Kidney Dis.* 2015; 66 suppl 1(1):S1–S305.
2. Yu MK, O'Hare AM, Batten A, et al. Trends in timing of dialysis initiation within versus outside the Department of Veterans Affairs. *Clin J Am Soc Nephrol.* 2015; 10(8):1418–1427. [PubMed: 26206891]
3. Stel VS, Tomson C, Ansell D, et al. Level of renal function in patients starting dialysis: an ERA-EDTA Registry study. *Nephrol Dial Transplant.* 2010; 25(10):3315–3325. [PubMed: 20400449]
4. Rosansky SJ, Clark WF, Eggers P, Glasscock RJ. Initiation of dialysis at higher GFRs: is the apparent rising tide of early dialysis harmful or helpful? *Kidney Int.* 2009; 76(3):257–261. [PubMed: 19455195]
5. O'Hare AM, Wong SP, Yu MK, et al. Trends in the timing and clinical context of maintenance dialysis initiation. *J Am Soc Nephrol.* 2015; 26(8):1975–1981. [PubMed: 25700539]
6. National Kidney Foundation. KDOQI clinical practice guidelines and clinical practice recommendations for 2006 updates: hemodialysis adequacy, peritoneal dialysis adequacy and vascular access. *Am J Kidney Dis.* 2006; 48(suppl 1):S1–S322. [PubMed: 17045862]
7. Traynor JP, Simpson K, Geddes CC, Deighan CJ, Fox JG. Early initiation of dialysis fails to prolong survival in patients with end-stage renal failure. *J Am Soc Nephrol.* 2002; 13(8):2125–2132. [PubMed: 12138145]
8. Beddhu S, Samore MH, Roberts MS, et al. Impact of timing of initiation of dialysis on mortality. *J Am Soc Nephrol.* 2003; 14(9):2305–2312. [PubMed: 12937307]
9. Kazmi WH, Gilbertson DT, Obrador GT, et al. Effect of comorbidity on the increased mortality associated with early initiation of dialysis. *Am J Kidney Dis.* 2005; 46(5):887–896. [PubMed: 16253729]
10. Wright S, Klausner D, Baird B, et al. Timing of dialysis initiation and survival in ESRD. *Clin J Am Soc Nephrol.* 2010; 5(10):1828–1835. [PubMed: 20634325]
11. Rosansky SJ, Eggers P, Jackson K, Glasscock R, Clark WF. Early start of hemodialysis may be harmful. *Arch Intern Med.* 2011; 171(5):396–403. [PubMed: 21059968]
12. Crews DC, Scialla JJ, Boulware LE, et al. DEcIDE Network Patient Outcomes in End Stage Renal Disease Study Investigators. Comparative effectiveness of early versus conventional timing of dialysis initiation in advanced CKD. *Am J Kidney Dis.* 2014; 63(5):806–815. [PubMed: 24508475]
13. Sawhney S, Djurdjev O, Simpson K, Macleod A, Levin A. Survival and dialysis initiation: comparing British Columbia and Scotland registries. *Nephrol Dial Transplant.* 2009; 24(10):3186–3192. [PubMed: 19390120]
14. Lassalle M, Labeeuw M, Frimat L, et al. Age and comorbidity may explain the paradoxical association of an early dialysis start with poor survival. *Kidney Int.* 2010; 77(8):700–707. [PubMed: 20147886]
15. Sjölander A, Nyrén O, Bellocco R, Evans M. Comparing different strategies for timing of dialysis initiation through inverse probability weighting. *Am J Epidemiol.* 2011; 174(10):1204–1210. [PubMed: 21984655]
16. Korevaar JC, Jansen MA, Dekker FW, et al. Netherlands Cooperative Study on the Adequacy of Dialysis Study Group. When to initiate dialysis: effect of proposed US guidelines on survival. *Lancet.* 2001; 358(9287):1046–1050. [PubMed: 11589934]

17. Tang SC, Ho YW, Tang AW, et al. Hong Kong Peritoneal Dialysis Study Group. Delaying initiation of dialysis till symptomatic uraemia—is it too late? *Nephrol Dial Transplant*. 2007; 22(7):1926–1932. [PubMed: 17400562]
18. Coronel F, Cigarran S, Herrero JA. Early initiation of peritoneal dialysis in diabetic patients. *Scand J Urol Nephrol*. 2009; 43(2):148–153. [PubMed: 19085460]
19. Hakim RM, Lazarus JM. Initiation of dialysis. *J Am Soc Nephrol*. 1995; 6(5):1319–1328. [PubMed: 8589305]
20. Rosansky SJ, Cancarini G, Clark WF, et al. Dialysis initiation: what’s the rush? *Semin Dial*. 2013; 26(6):650–657. [PubMed: 24066675]
21. Cooper BA, Branley P, Bulfone L, et al. IDEAL Study. A randomized, controlled trial of early versus late initiation of dialysis. *N Engl J Med*. 2010; 363(7):609–619. [PubMed: 20581422]
22. Harris A, Cooper BA, Li JJ, et al. Cost-effectiveness of initiating dialysis early: a randomized controlled trial. *Am J Kidney Dis*. 2011; 57(5):707–715. [PubMed: 21349618]
23. Krippendorff, K. *Content Analysis: An Introduction to Its Methodology*. 3. Thousand Oaks, CA: Sage Publications; 2013.
24. Giacomini MK, Cook DJ. Evidence-Based Medicine Working Group. Users’ guides to the medical literature: XXIII: qualitative research in health care A: are the results of the study valid? *JAMA*. 2000; 284(3):357–362. [PubMed: 10891968]
25. Renal Physicians Association (RPA). *Shared Decision-Making in the Appropriate Initiation of Withdrawal From Dialysis*. 2. Rockville, MD: RPA; 2010.
26. United Kingdom Renal Association Clinical Practice Guidelines. *Planning, Initiating and Withdrawing of Renal Replacement Therapy*. 6. Hampshire, United Kingdom: Renal Association; 2014.
27. O’Hare AM, Rodriguez RA, Hailpern SM, Larson EB, Kurella Tamura M. Regional variation in health care intensity and treatment practices for end-stage renal disease in older adults. *JAMA*. 2010; 304(2):180–186. [PubMed: 20628131]
28. Treit K, Lam D, O’Hare AM. Timing of dialysis initiation in the geriatric population: toward a patient-centered approach. *Semin Dial*. 2013; 26(6):682–689. [PubMed: 24112631]
29. Kaufman SR, Shim JK, Russ AJ. Old age, life extension, and the character of medical choice. *J Gerontol B Psychol Sci Soc Sci*. 2006; 61(4):S175–S184. [PubMed: 16855038]
30. Russ AJ, Shim JK, Kaufman SR. “Is there life on dialysis?”: time and aging in a clinically sustained existence. *Med Anthropol*. 2005; 24(4):297–324. [PubMed: 16249136]
31. Song MK, Lin FC, Gilet CA, Arnold RM, Bridgman JC, Ward SE. Patient perspectives on informed decision-making surrounding dialysis initiation. *Nephrol Dial Transplant*. 2013; 28(11):2815–2823. [PubMed: 23901048]
32. Schell JO, Patel UD, Steinhauer KE, Ammarell N, Tulskey JA. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *Am J Kidney Dis*. 2012; 59(4):495–503. [PubMed: 22221483]
33. Hussain JA, Flemming K, Murtagh FE, Johnson MJ. Patient and health care professional decision-making to commence and withdraw from renal dialysis: a systematic review of qualitative research. *Clin J Am Soc Nephrol*. 2015; 10(7):1201–1215. [PubMed: 25943310]
34. Harwood L, Clark AM. Understanding pre-dialysis modality decision-making: ameta-synthesis of qualitative studies. *Int J Nurs Stud*. 2013; 50(1):109–120. [PubMed: 22560169]
35. Morton RL, Devitt J, Howard K, Anderson K, Snelling P, Cass A. Patient views about treatment of stage 5 CKD: a qualitative analysis of semistructured interviews. *Am J Kidney Dis*. 2010; 55(3):431–440. [PubMed: 20116914]
36. Patton, MQ. *Qualitative Research and Evaluation Methods*. 3. Thousand Oaks, CA: Sage Publications; 2002.

**Table 1**Characteristics of 1691 Patients at Time of Initiation of Dialysis<sup>a</sup>

Characteristic	Value <sup>b</sup>
Age, mean (SD), y	62.7 (11.3)
Sex	
Male	1663 (98.3)
Female	28 (1.7)
Race	
White	777 (45.9)
Black	740 (43.8)
Latino	128 (7.6)
Other	46 (2.7)
eGFR, mean (SD), mL/min/1.73 m <sup>2</sup>	10.4 (5.7)
Comorbidities	
Diabetes mellitus types 1 and 2	1042 (61.6)
Hypertension	1494 (88.4)
Coronary artery disease	520 (30.8)
Congestive heart failure	528 (31.2)
Peripheral arterial disease	103 (6.1)
Stroke	81 (4.8)
Chronic obstructive pulmonary disease	265 (15.7)
Dialysis modality	
Peritoneal dialysis	81 (4.8)
Hemodialysis	1610 (95.2)
Hemodialysis access	
Arteriovenous fistula or graft	382 (22.6)
Catheter	1228 (72.6)
Outpatient nephrology visits in the prior year, median (IQR), No.	3 (0–6)
<b>Clinical Presentation</b>	
Clinical setting	
Outpatient	427 (25.3)
Inpatient	1264 (74.7)
Elective admission	850 (50.3)
Signs and symptoms	
Any	1611 (95.3)
Gastrointestinal	860 (50.9)
Cardiopulmonary	823 (48.7)
Fatigue or weakness	640 (37.8)
Electrolyte abnormalities	307 (18.2)

Characteristic	Value <sup>b</sup>
Neurologic	281 (16.6)
Other	357 (21.1)

Abbreviations: eGFR, estimated glomerular filtration rate; IQR, interquartile range.

<sup>a</sup> Further description on the cohort and how variables were ascertained have been previously reported.<sup>5</sup>

<sup>b</sup> Data are presented as number (percentage) of patients unless otherwise indicated.

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**Table 2**

Theme 1: Physician Practices<sup>a</sup>

Subtheme	Exemplary Quotes	Clinical Service and Setting	Time Before Dialysis Initiation, d
Preparing for dialysis	1a. "Patient appears uremic with nausea and vomiting. He has a good fistula and ready to be used. Plan is to initiate dialysis today. Risks (bleeding, hypotension, stroke, myocardial infarction, seizure, air emboli, death) and benefits of dialysis were explained to [patient] and his wife, and both agreed to start dialysis."	Renal inpatient	2
	1b. "[Dialysis] access in place; however, not ready for use...we need another 6–8 weeks for access to be ready for use. Patient experiencing uremic symptoms and states she cannot hold on any longer...Plan to arrange [hemodialysis catheter] placement and initiate dialysis this week."	Renal clinic	2
	1c. "Evidence of mild uremic symptoms. Electrolytes stable. Will await until placement of [dialysis] fistula to start hemodialysis unless worsening of uremic symptoms or electrolytes."	Renal inpatient	25
	1d. "No overt signs and symptoms of uremia; however, would benefit from initiation of renal replacement therapy chronically given mature access and current GFR and diminished appetite."	Renal clinic	8
Forestalling dialysis	1e. "If nausea does not improve over the next 2 days (would try a histamine receptor-2 blocker), hemodialysis treatment would be the next logical step."	Renal inpatient	2
	1f. "He had about 1680 cc urine output today with current diuretic regimen... Patient does not want to go on hemodialysis if [he] does not absolutely have to. I still think we can still delay any hemodialysis with close follow-up for a few more weeks, months, even though volume status could be easily controlled via hemodialysis."	Renal inpatient	10
	1g. "Patient has lost approximately 15 pounds, 206 to 191, since addition of metolazone. During same period he fainted twice...It is difficult [to] balance the treatment of all pressing issues in this case. If the patient is too wet, some of the extracellular volume accumulates in the chest, and the patient has dyspnea. If he is too dry, as he is at present, lungs and legs are in good shape, but orthostatic hypotension and probably renal perfusion are unacceptable...we agreed to proceed to dialysis...I think that the need for extracellular fluid volume control warrants an early start."	Renal clinic	16
	1h. "Patient's blood chemistries are consistent with ESRD, and his need to start dialysis is clear. Although he is not overtly uremic, any further delay on his part to initiate dialysis will most surely compromise his health at a minimum and his life expectancy at a maximum. I have arranged for him to have a [dialysis] catheter placed on July 13 with dialysis initiation to follow."	Renal clinic	3

Abbreviations: ESRD, end-stage renal disease; GFR, glomerular filtration rate.

<sup>a</sup>Timing of dialysis is tied to physicians' approaches to preparing patients for and forestalling the need for dialysis.

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**Table 3**Theme 2: Sources of Momentum<sup>a</sup>

Subtheme	Exemplary Quotes	Clinical Service and Setting	Time Before Dialysis Initiation, d
Acute illness	2a. "Patient seen as an emergency at the request of [another physician]...She is now end-stage with creatinine >11 mg/dL, potassium 6.1 mEq/L, and hematocrit 24%. She has some nausea but no other uremic symptoms...She prefers peritoneal dialysis but will need a course of hemodialysis first until she has a functional peritoneal catheter placed."	Renal clinic	5
	2b. "...Near ESRD, refusing hemodialysis initiation in [the] past, presents with epistaxis and bright red blood per rectum...Although no urgent indication for initiation, it would be best to take this admission as an opportunity to establish hemodialysis access...I will contact vascular surgery about placing [dialysis] access, then will initiate hemodialysis."	Renal inpatient	3
Medical optimization	2c. "Patient was admitted with chest pain, and cardiology plans a cardiac catheterization...Will dialyze patient tomorrow and Wednesday; after 2 dialysis treatments [he] will be in [an] optimal state for repeat cardiac catheterization."	Renal inpatient	1
	2d. "I really feel pretty good, do I have to start dialysis?" Denied nausea, vomiting, anorexia, insomnia, dyspnea, orthopnea, chest pain, headache, numbness/tingling, mental status changes...advised dialysis is needed at this time and surgery for carotid stenosis will be considered after he is adequately dialyzed."	Renal clinic	1
	2e. "Two weeks ago, he had a peritoneal dialysis [catheter] placed in his lower left abdomen. The following day, patient developed red, hot, swollen bilateral knees consistent with previous gout flares...Patient also presents for treatment today to receive dialysis. Since [catheter] placement, he reports additional symptoms of diarrhea 4–5 times per day, anorexia, a bitter taste in his mouth, muscle weakness with minimal activity, pedal edema, and vomiting with all oral intake...Hemodialysis in the morning."	Medicine inpatient	0

Abbreviation: ESRD, end-stage renal disease.

SI conversion factors: To convert creatinine to micromoles per liter, multiply by 88.4; to convert potassium to millimoles per liter, multiply by 1.0; and to convert hematocrit to proportion of 1.0, multiply by 0.01.

<sup>a</sup>Triggers that appeared to hasten initiation of dialysis.

Table 4

Theme 3: Push-Pull Dynamics<sup>a</sup>

Subtheme	Exemplary Quotes	Clinical Service and Setting	Time Before Dialysis Initiation, d
Resistance	3a. "He does not want a [dialysis catheter] insertion/trial of hemodialysis unless it is deemed an absolute emergency (which it is not currently). I have discussed the many complications as his uremia progresses, including pericarditis, encephalopathy, platelet dysfunction, hyperkalemia, metabolic acidosis, hypocalcemia—he understands the risk and still wants to hold off on hemodialysis initiation at this time."	Renal inpatient	83
	3b. "In the past, patient told me that he is satisfied with the life he had and prefers a conservative treatment at this point. However, he has second thoughts now. His family, especially his grandson, would prefer him to start on hemodialysis."	Renal clinic	1
	3c. "Patient is uremic and should be admitted for [dialysis catheter] placement and hemodialysis initiation... Patient refusing admit for now because he has issues to resolve at home. States he will return November 3 for elective admit."	Renal clinic	5
	3d. "...Discussed dialysis initiation. Patient very hesitant due to travel arrangements and family life. Patient's wife with Alzheimer [disease] and patient is primary caretaker. When patient is on dialysis, there will be no one with his wife... We would like to start dialysis next week."	Renal clinic	8
	3e. "I have explained the risks, including death, of waiting until Tuesday to come here for dialysis considering his recent history of seizures. [Patient] verbalized the understanding; however, he refused to come here before Tuesday and says that 'if you push further, I even won't make it on Tuesday.'"	Renal clinic	5
	3f. "Feeling much better, no longer with nausea or fatigue... requesting to hold on starting dialysis for another 30 days."	Renal clinic	49
	"Presented to the emergency room with complaints of nausea and palpitations... He will think about the option of dialysis."	Emergency medicine	7
	"Patient called [his nephrologist] and stated that he was ready to start dialysis."	Renal clinic	2
	3g. In the past, the patient and his wife were against starting dialysis. Now, however, he is feeling poorly and he has change[d] his mind. [He] is willing to try dialysis."	Renal clinic	0
	3h. "Initially patient refused hemodialysis, saying he wanted to die with dignity and did not want to feel like a machine. After further discussion, he consented to dialysis treatment... Patient was told that if, after a period of time, he was dissatisfied with his quality of life, dialysis could be terminated at any time."	Renal inpatient	0
3i. "Patient stated that he does not want dialysis at this point, and that he has to think about it further. He wants to discuss it with his son but refused to let us call his son. I explained to him that although death is not imminent today, it could become imminent within the next week if he does not start dialysis... The patient stated 'Then I will just die.' I asked him if he would want us to dialyze him if it were a life and death situation, and he said 'Just let me die then.'"	Renal inpatient	1	
Paternalism	3j. "I am not convinced that when the time for a life and death decision needs to be made whether to do or not do dialysis, [the patient] or his family will be steadfast in deferring dialysis."	Renal inpatient	6
	3k. "He was offered to start renal replacement therapy [5 and 4 months ago] to which he declined. Patient is now not able to grasp the concept that he needs to start dialysis or else come to terms with his demise... We spoke to the patient again and told him it is time to start. He doesn't seem to be able to grasp the reality of his situation."	Renal inpatient	1
	3l. "[Patient] stated that 'he did not care when he started.' Told him that [dialysis] would drastically change his life, and he stated that he does not do anything so it did not matter."	Renal clinic	29
	3m. "'I'm an 80-year-old man and I am not sure I want to do that 3 times a week for the rest of my life. I feel fine now.' ... Has no urgent/emergent indications to start hemodialysis. We feel that he is competent to make the decision not to start dialysis today."	Renal inpatient	14

Subtheme	Exemplary Quotes	Clinical Service and Setting	Time Before Dialysis Initiation, d
	3n. “[Patient’s] wife is reporting worsening of his behavior at home, so in view of these symptoms we have to assume that uremic encephalopathy may be contributing to some of these symptoms. Today, patient is being initiated on hemodialysis.”	Renal clinic	0
	3o. “I reviewed the risk of bleeding, infection, small chance of death on dialysis with patient. Alternative will be no dialysis, which will risk the patient’s life with development of frank pulmonary edema, respiratory failure, and need for ventilator support. Patient understood the above and consented to [dialysis catheter] placement and dialysis procedure.”	Renal inpatient	0

<sup>a</sup> An oppositional relationship between patients and physicians leading up to dialysis initiation.

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