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Original Investigation

System-Level Barriers and Facilitators for Foregoing or Withdrawing Dialysis: A Qualitative Study of Nephrologists in the United States and England

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Background: Despite a growing body of literature suggesting that dialysis does not confer morbidity or mortality benefits for all patients with chronic kidney failure, the initiation and continuation of dialysis therapy in patients with poor prognosis is commonplace. Our goal was to elicit nephrologists' perspectives on factors that affect decision making regarding end-stage renal disease.

Study Design: Semistructured, individual, qualitative interviews.

Methodology: Participants were purposively sampled based on age, race, sex, geographic location, and practice type. Each was asked about his or her perspectives and experiences related to foregoing and withdrawing dialysis therapy.

Analytical Approach: Interviews were audiotaped, transcribed, and analyzed using narrative and thematic analysis.

Results: We conducted 59 semistructured interviews with nephrologists from the United States (n = 41) and England (n = 18). Most participants were 45 years or younger, men, and white. Average time since completing nephrology training was 14.2 ± 11.6 (SD) years. Identified system-level facilitators and barriers for foregoing and withdrawing dialysis therapy stemmed from national and institutional policies and structural factors, how providers practice medicine (the culture of medicine), and beliefs and behaviors of the public (societal culture). In both countries, the predominant barriers described included lack of training in end-of-life conversations and expectations for aggressive care among non-nephrologists and the general public. Primary differences included financial incentives to dialyze in the United States and widespread outpatient conservative management programs in England.

Limitations: Participants' views may not fully capture those of all American or English nephrologists.

Conclusions: Nephrologists in the United States and England identified several system-level factors that both facilitated and interfered with decision making around foregoing and withdrawing dialysis therapy. Efforts to expand facilitators while reducing barriers could lead to care practices more in keeping with patient prognosis.

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INDEX WORDS: Dialysis withdrawal; foregoing dialysis; qualitative methodology; conservative management; end-stage renal disease (ESRD); ESRD decision-making; chronic kidney failure; end-of-life issues; conservative care; quality of life (QoL); palliative care; end-of-life care; survival benefit; financial disincentives; systemic barriers; culture of medicine; nephrology practice; purposive sampling; semi-structured interview.

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With the emergence and subsequent widespread availability of dialysis therapy in recent decades, its use for the treatment of chronic kidney failure has transformed from an option extended to carefully selected candidates to a routine medical procedure made available to an increasingly aging and medically complex population.[1,2] Initiation and continuation of dialysis therapy in patients with poor prognosis is commonplace in the United States.[1,3]

A growing literature suggests that a subset of patients (eg, aged >75 years with dementia or ischemic heart disease) may not derive a survival benefit from dialysis and that it may worsen quality of life and functional status.[4-11] Therefore, decisions to forego or withdraw from dialysis therapy may

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be needed. Prior survey-based studies suggest variability in decision making related to foregoing or withdrawing dialysis therapy among providers from different countries and over time, but they do not fully capture the underlying factors driving differences in dialysis practice patterns.[12-14] Understanding these factors may help identify facilitators and barriers to optimal care of patients with chronic kidney failure. In this qualitative study, we explored the perspectives underlying nephrologists' approaches to discussions about foregoing or withdrawing dialysis therapy in the United States and England, which has established conservative management programs.

METHODS

Study Design and Conduct

We used a comparative narrative design of nephrologists' beliefs and practices in the United States and England as related to dialysis decision making.[15-17] We developed an interview guide using practical knowledge of the clinical arena and existing literature, with the intention of capturing the factors influencing nephrologists' beliefs and practices (Box 1). The University of California, San Francisco Institutional Review Board approved the study (#13-11184).

Participant Selection

One investigator from England (D.O.) identified lead nephrologists who cared for adult patients with end-stage renal disease (ESRD) from dialysis units around the country to participate in the study. They in turn were asked to identify other nephrologists representing maximum variation between nephrologists by age, race, sex, and geographic location.

Similarly, in the United States, one investigator (N.R.P.) identified nephrologists who cared for adult patients with ESRD in various settings around the country. Using purposive sampling, we asked that they in turn identify nephrologists who varied in the aforementioned characteristics in addition to practice types and payment structures, which vary considerably in the United States. We also directly recruited nephrologists at a clinically focused national nephrology meeting who were similarly asked to identify others in their networks. We did not enroll nephrology trainees, nephrologists without a clinical practice, or pediatric nephrologists.

Data Collection

One investigator (V.G.), a nephrologist with 4 years' clinical practice beyond fellowship at the time of the study, conducted individual semistructured interviews from June 2013 through June 2014 at a time and by means (eg, in person or by telephone) convenient for each participant. After providing written informed consent, participants were asked to provide basic demographic and practice characteristics and were then asked about their experiences with regard to treatment decisions for patients with chronic kidney failure, which included a focus on situations involving foregoing dialysis and dialysis therapy withdrawal. Interviews were recorded and transcribed verbatim.

Analysis

Narrative and thematic analyses were systematically conducted by 2 investigators (V.G. and D.S.T.) using constant comparative analysis of text within and between interviews. Codes regarding the central themes were decided by consensus after independent analysis of 9 cases, 6 from the United States and 3 from England, selected randomly to represent both countries. Subsequent interviews were then coded according to these themes using ATLAS.ti version 7.0 to discover the range and variability in the subthemes and scan for new themes. Saturation of themes was achieved after half the interviews were analyzed; all remaining interviews were thoroughly examined and provided evidence confirming our findings.

Box 1. Interview Guide

1) Can you describe the process by which a patient outside of the hospital starts receiving dialysis? Who are the key individuals involved in making that happen? What are the local or national policies that help guide the process?
2) What about for the patient in the hospital? How is the process different?
3) Are there clinical situations when dialysis is not routinely offered to patients? Do you agree/disagree? Are there other clinical situations when you think dialysis should not be offered? Can you tell me more about your nephrology practice in relation to not offering dialysis? Is this a topic that you discuss regularly with your colleagues?
4) How do you usually approach discussions about dialysis with patients? How does your approach vary from patient to patient? Do you offer your opinion? If so, how?
5) Tell me about a time when you didn't offer dialysis (or wished you hadn't offered dialysis). How did this affect you at the time? Did this experience affect how you approached clinical situations going forward?
   a. If you always offer dialysis, why do you think that is?
6) Tell me about a time when you managed a patient without dialysis. Whose idea was it (yours, patient's, family member's)? Did you suggest this option? How did this affect you at the time? Did this experience affect how you approached clinical situations going forward?
   a. If you've never managed a patient without dialysis, why do you think that is?
7) Tell me about a time when you withdrew a patient from dialysis. Whose idea was it (yours, patient's, family member's)? Did you suggest this option? How did this affect you at the time? Did this experience affect how you approached clinical situations going forward?
   a. If you've never withdrawn a patient from dialysis, why do you think that is?
8) What are the challenges and facilitators of coming to a reasonable decision regarding dialysis? Are there ways that we could overcome those challenges to enhance the practice of dialysis in this country? In an ideal world, what would you like to see changed regarding the practice of dialysis in this country?

RESULTS

Participant Characteristics

A total of 59 interviews were completed among 18 English nephrologists and 41 American nephrologists. The average duration of interviews was 34 (range, 13.5-60) minutes. All interviews with English nephrologists were in person. Ten interviews with American nephrologists were in person, 10 were by videoconference (eg, Skype or FaceTime), and 21 were by speakerphone.