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Conservative Kidney Management Practice Patterns and Resources in the United States: A Cross-Sectional Analysis of CKDopps (Chronic Kidney Disease Outcomes and Practice Patterns Study) Data

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Rationale & Objective: Conservative kidney management (CKM) is a viable treatment option for many patients with chronic kidney disease. However, CKM practices and resources in the United States are not well described. We undertook this study to gain a better understanding of factors influencing uptake of CKM by describing: (1) characteristics of patients who choose CKM, (2) provider practice patterns relevant to CKM, and (3) CKM resources available to providers.

Study Design: Cross-sectional study.

Setting & Participants: This study is a cross-sectional analysis of data from US nephrology clinics enrolled in the chronic kidney disease Outcomes and Practice Patterns Study (CKDopps) collected between 2014 and 2020. Data for this study includes chart-abstracted characteristics of patients with an estimated glomerular filtration rate $\leq 30\text{mL}/\text{min}/1.73\text{m}^2$ (n=1018) and available information on whether a decision had been made to pursue CKM at the time of kidney failure, patient (n=407) reports of discussions about forgoing dialysis, and provider (n=26) responses about CKM delivery and available resources in their health systems.

Analytical Approach: Descriptive statistics were used to report patient demographics, clinical information, provider demographics, and clinic characteristics.

Results: Among data from 1018 patients, 68 (7%) were recorded as planning for CKM. These patients were older, had more comorbidities, and were more likely to require assistance with transfers. Of the 407 patient surveys, 18% reported a conversation about forgoing dialysis with their nephrologist. A majority of providers felt comfortable discussing CKM; however, no clinics had a dedicated clinic or protocol for CKM.

Limitations: Inconsistent survey terminology and unlinked patient and provider responses.

Conclusions: Few patients reported discussion of forgoing dialysis with their providers and even fewer anticipated a choice of CKM on reaching kidney failure. Most providers were comfortable discussing CKM, but practiced in clinics that lacked dedicated resources. Further research is needed to improve the implementation of a CKM pathway.

Visual Abstract included

Complete author and article information provided before references.

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The decision to initiate kidney replacement therapy (KRT) is complex, particularly for older comorbid adults. For these individuals, KRT can be associated with loss of functional independence¹ and high mortality.² An alternative choice, conservative kidney management

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(CKM), defined as a holistic approach to kidney failure with goals of maximizing quality of life and preventing progression of chronic kidney disease (CKD) without initiation of dialysis,³ is a viable treatment option for many individuals. For older comorbid adults, there is increasing evidence for the potential of CKM to maintain quality of life without necessarily decreasing life expectancy.³⁻⁸ Given these data, an increasing number of people with CKD are likely to choose CKM for management of their kidney failure. In response, United States (US) nephrologists and CKD clinics will need to evolve to optimally deliver this care pathway.

Nephrologists have cited a lack of clinical guidelines, evidence, training, and system-level infrastructure as challenges to providing CKM.^{9,10} Individuals with CKD in the US report limited understanding and minimal discussion of CKM with their doctors.^{11,12} These trends, however, are not universal. A small number of US clinics have demonstrated successful delivery of CKM, more often those with access to palliative care expertise.^{13,14} This approach is not sustainable given the shortage of palliative care providers in the US and the lack of palliative care training for US nephrology fellows.^{15,16} In contrast, several non-US health systems have adapted to include structured care pathways for CKM^{17,18} that lower barriers to implementation.

We analyzed data from the Chronic Kidney Disease Outcomes and Practice Patterns Study (CKDopps) to gain a better understanding of the factors that influence the choice of CKM from provider and patient perspectives and resources available to support CKM delivery. CKDopps is a large nationally representative dataset that includes metrics

PLAIN-LANGUAGE SUMMARY

For older comorbid adults with kidney failure, conservative kidney management (CKM) can be an appropriate treatment choice. CKM is a holistic approach with treatment goals of maximizing quality of life and preventing progression of chronic kidney disease (CKD) without initiation of dialysis. We investigated US CKM practices and found that among 1018 people with CKD, only 7% were planning for CKM. Of 407 surveyed patients, 18% reported a conversation with their provider about forgoing dialysis. In contrast, most providers felt comfortable discussing CKM; however, none reported working in an environment with a dedicated CKM clinic or protocol. Our data show the need for further CKM education in the United States as well as dedicated resources for its delivery.

and clinical characteristics of a sample of CKD clinics, provider report of clinical practices, and a range of patient reported data. Our specific objectives were to describe: (1) patients with advanced CKD who plan on CKM at the time of kidney failure, (2) CKM resources available to clinics, including involvement of palliative care resources and providers, and (3) nephrology provider practices relevant to CKM.

METHODS

Study Design and Setting

To provide a brief overview, CKDopps is a prospective cohort study conducted across multiple centers, focusing on adult patients with CKD who are not on maintenance dialysis or have undergone kidney transplantation. Recruitment took place at 34 nephrology clinic sites throughout the US. The study began recruiting participants in 2013 and is currently ongoing. For our analysis, we utilized data from the US cohort collected between 2014 and 2020. The CKDopps study rationale and protocol design have been previously described.¹⁹

The sampling scheme for participating CKDopps clinics was designed to ensure a nationally representative cohort in terms of geographical region, clinic size, and health system status (public vs private). Eligibility criteria included patients with an estimated glomerular filtration rate (eGFR) <60 mL/min/1.73m. We enriched the enrollment for patients with advanced CKD, aiming for a target enrollment ratio of 2:1 between patients with eGFR <30 mL/min/1.73m and those with eGFR between 30–59 mL/min/1.73m.

Baseline demographic information and comorbidity data were collected on enrollment by extracting relevant data from the medical records. Longitudinal data, including laboratory values and incidents of kidney failure or death, were obtained from nephrology follow-up visits conducted as part of routine care at each clinic site.

The CKDopps study protocol received approval from an independent institutional review board, and all study participants provided written informed consent for their participation.

Study Data

We analyzed 3 different CKDopps US data sources: (1) patient demographic and clinical data, including treatment choice, as recorded by a study coordinator through chart abstraction, (2) data from a survey administered directly to patients, and (3) data from a survey administered to practicing clinicians at each enrolled CKD clinic, supplemented with data describing clinic demographics. [Items S1](#) and [S2](#) show all the questions that provided the data used for this study.

A research coordinator used chart abstraction to obtain patient demographics and clinical information, including anticipated treatment choice at the time of kidney failure, from the first data record of enrolled patients with an eGFR ≤ 30 mL/min/1.73m² (measured by the CKD-Epi equation). Patients were categorized by the answer to the following question of interest, “Has a decision been made for conservative management without dialysis or transplant, at the time when dialysis or transplant would otherwise be initiated for kidney failure?” Data that answered this question was abstracted from the charts only if research coordinators had identified an answer of no to the question, “Has the initial modality of renal replacement been planned?”, therefore allowing us to exclude those who had decided on KRT or transplant. We categorized patients who were recorded as having chosen an initial modality of KRT as not choosing CKM. We excluded all surveys missing an answer to both questions (n=793, 44%). We used univariate analysis to compare patients with excluded surveys to the final study cohort to evaluate for differences in patient characteristics ([Fig 1A](#)).

For patient responses, we analyzed the first participant survey from those with an eGFR ≤ 30 mL/min/1.73m². We categorized survey responses by the answer (yes/no) to the question, “Has your provider discussed not starting any therapy at all?” We used this question to determine whether there had been a discussion of the option of forgoing dialysis therapies and as representative of a choice of CKM ([Fig 1B](#)).

For provider responses, we analyzed the initial practice survey as filled out by providers (representing unique clinics) for practice patterns, resources, and clinic characteristics (refer to [Items S1–S2](#) for full questionnaires). Questions were about the providers’ practice patterns and clinic resources. One sample question was “Do you have a written protocol or guideline for how to manage End Stage Renal Disease (ESRD) patients on conservative care without dialysis?” Answers were no; no, but in preparation; or yes. Another sample question was “How comfortable are you with discussing palliative or conservative care (ie, no dialysis or transplant) with patients?” Answers ranged from not comfortable at all to extremely comfortable (Likert scale).

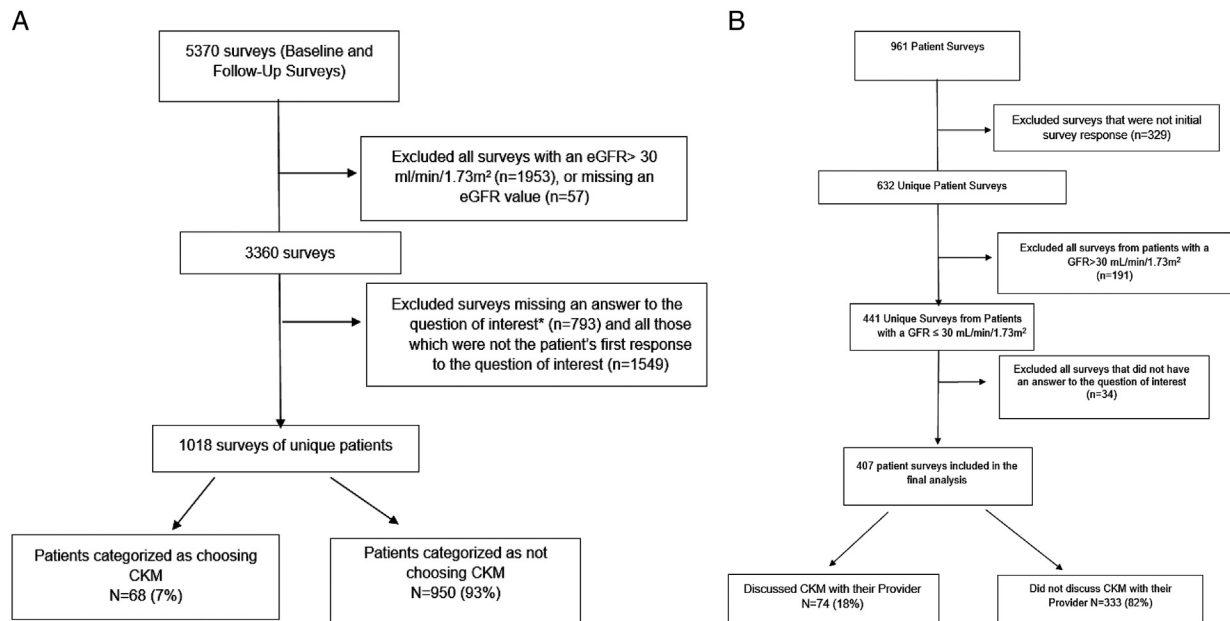


Figure 1. (A) Derivation of dataset abstracted describing patient choice of conservative kidney management (CKM). Abbreviations: eGFR: estimated glomerular filtration rate; CKM: conservative kidney management. Note: * Question of Interest: “Has a decision been made for conservative management without dialysis or transplant, at the time when dialysis or transplant would otherwise be initiated for kidney failure?” (B) Derivation of the Patient Response Cohort. Abbreviations: PQMQ, Patient questionnaire medical questionnaire; CKM, conservative kidney management; GFR, glomerular filtration rate

Statistical Analysis

We used descriptive statistics to report patient demographics, disease status, provider demographics, and clinic characteristics. We used multivariable logistic regression analysis of complete cases ($n=957$) to examine clinical characteristics associated with choice of CKM (Table S1). Covariates included clinical and demographic characteristics hypothesized to be predictors of patient choice on the basis of prior literature and clinical experience including age, gender, race, ethnicity, living situation, ability to transfer independently, and comorbidities (eg, coronary artery disease, cerebrovascular disease, peripheral vascular disease, and neurological disease). Education level was hypothesized to be important, but was excluded from the model because of a high number of “unknown” responses. $P \leq 0.05$ was considered significant. All analyses were completed in Stata version BE 17 (College Station, TX).

For the primary CKDopps study, ethics approval and informed patient consent were obtained as required by national and local regulations. Additional details regarding the CKDopps study design have been described previously.¹⁹

RESULTS

Characteristics of Patients Who Chose CKM

Among the 1018 patients in our final cohort, 68 (7%) were recorded as choosing CKM at the time of kidney

failure. Compared with those who did not chose CKM, these patients were older (mean 79 vs 68 years) and lived more often in the central region of the US (40% vs 27%); married (55% vs 51%), living with someone (67% vs 64%), more were retired or disabled (67% vs 61%), and having comorbid illnesses, with the exception of diabetes or hypertension. Fewer patients who chose CKM were able to ambulate independently (95% vs 98%), transfer independently (90% vs 97%), or had received education about KRT options, either through a class or one-on-one session (22% vs 40%). The eGFR distributions were similar between groups, as were the proportions who were female or Black. Most patients were classified as “full code.” Although a higher proportion in the CKM group had a status of do-not-resuscitate, many of those who had not chosen CKM were missing this data element (Table 1).

In adjusted models (Table S1) age (adjusted odds ratio [aOR] 4.01, 95% Confidence Interval [CI] 2.52-7.15, $P < 0.001$ for patients >75 years) and the need for assistance when transferring (aOR 2.71, 95% CI 1.01-7.26, $P = 0.05$) were significantly associated with choosing CKM. No other characteristics were independently associated with the choice of CKM.

Patient Survey Responses

Among 407 patient surveys analyzed, 74 (18%) reported a discussion of “no therapy” or forgoing dialysis with their provider. A higher proportion of patients who reported having this conversation were White (79% vs 72%), not

Table 1. Demographics and Clinical Characteristics of Patients^a (N=1018)

Patient Choice	CKM (n=68, 7%)	No CKM (n=950, 93%)
GFR, mL/min/1.73m ²	19 (6)	20 (6)
Age	79 (10)	68 (13)
Age Categorized		
≤ 75 y	24 (35%)	657 (69%)
> 75 y	44 (65%)	293 (31%)
Sex		
Male	36 (53%)	481 (51%)
Female	32 (47%)	469 (49%)
Race	n = 68	n = 944
White	50 (74%)	657 (70%)
Black	16 (24%)	207 (22%)
Other	2 (%)	82 (9%)
Ethnicity	n = 67	n = 949
Non-Hispanic/ /unknown	65 (97%)	885 (93%)
Hispanic	2 (3%)	64 (7%)
Region		
West	13 (19%)	187 (20%)
Central	27 (40%)	256 (27%)
Northeast	15 (22%)	306 (32%)
South Atlantic	13 (19%)	201 (21%)
Marital Status	n=67	n=936
Married	37 (55%)	484 (51%)
Not married	17 (25%)	357 (38%)
Unknown	13 (19%)	95 (10%)
Living Situation, n (%)	n=66	n=929
Alone	22 (33%)	339 (36%)
Not alone	44 (67%)	590 (64%)
Education Level	n=62	n=873
High school or below	8 (13%)	185 (21%)
College or advanced degree	8 (13%)	115 (13%)
Unknown	46 (74%)	573 (66%)
Employment	n=64	n=907
Employed	1 (2%)	153 (17%)
Not employed	0 (0%)	60 (7%)
Retired or disabled	43 (67%)	556 (61%)
Unknown or other	20 (31%)	138 (15%)
	n=63	n=907
Ambulate independently or with some assistance	60 (95%)	886 (98%)
	n=62	n = 928
Transfer independently	56 (90%)	896 (97%)
	n=58	n=761
Do not resuscitate	7 (12%)	15 (2%)
Diabetes	38 (56%)	547 (58%)
	n=67	n=946
Congestive heart failure	16 (24%)	159 (17%)
	n=67	n=940
Hypertension	59 (88%)	873 (93%)
Lung disease	12 (18%)	109 (12%)
	n=67	n=947
Coronary heart disease	30 (45%)	284 (30%)

(Continued)

Table 1 (Cont'd). Demographics and Clinical Characteristics of Patients^a (N=1018)

Patient Choice	CKM (n=67)	No CKM (n=946)
Cerebrovascular disease	12 (18%)	108 (11%)
Peripheral vascular disease	17 (25%)	140 (15%)
Cancer	15 (22%)	142 (15%)
Neurologic disease, n (%)	7 (11%)	37 (4%)
Psychiatric disorder	12 (18%)	151 (16%)
Received education about kidney replacement treatment options	15 (22%)	371 (40%)

Note: Values are presented as number (percentage) and continuous variables as mean (SD).

Abbreviations: CKM, conservative kidney management; GFR, glomerular filtration rate; SD, standard deviation.

^aDemographics and Clinical Characteristics of patients with eGFR < 30 mL/min/1.73m² according to chart abstracted plan for conservative kidney management (CKM) or not at the time of kidney failure.

married (53% vs 44%), not employed (90% vs 85%), living alone (34% vs 23%), and had low-income levels. When the survey asked, “If your kidneys were to fail completely in the next month, do you know which treatment you would choose.” Overall, 7% of those who did discuss “no therapy” would choose “no treatment,” compared with 3% of those who did not discuss forgoing dialysis. Those who discussed “no therapy” reported fewer discussions of other treatment options compared with those who reported not having a conversation of “no treatment” (Table 2). Similar proportions of patients in both groups would choose “in-center hemodialysis;” however, a majority in both groups did not know what treatment option they would choose.

Clinic or Provider Surveys

Surveys from 26 unique clinics (76% of all included clinics) describing resources and practice patterns were analyzed in our final cohort. Of the providers who answered these surveys, there was a near even distribution of ages (above or below 50 years). A majority of respondents were male (77%) and board-certified nephrologists (92%). A majority (54%) of respondents were clinic directors, while 35% were staff nephrologists and 12% categorized themselves as “other”. When describing their clinics, providers reported that the population served was on average 67% White (standard deviation [SD] = 30; range, 0-98) and 24% Black (SD = 27; range, 0-100). A total of 10 clinics (38%) were located in the northeast, 8 (31%) in the South Atlantic, 6 (23%) in the central region of the US, and 2 (8%) in the Western region. A total of 11 clinics (42%) were practices that consisted of ≥7

Table 2. Survey responses of Patients^a (N=407)

Variable or question	Discussed “not starting therapy”	Did not discuss “not starting therapy”
	n=74 (18%)	n=333 (82%)
Enrollment eGFR	21 (6)	20 (6)
Age (y)	70 (12)	68 (13)
Race	n=72	n=321
White	57 (79%)	232 (72%)
Black	13 (18%)	63 (20%)
Asian or other or Indian	2 (3%)	26 (8%)
Marital Status	n=74	n=327
Married	35 (47%)	182 (56%)
Not married	39 (53%)	145 (44%)
Education Level	n=68	n=319
High school/ below	39 (57%)	182 (57%)
College, below, advanced degree, or unknown	29 (43%)	137 (43%)
Employment	n=63	n=308
Employed	6 (10%)	47 (15%)
Not employed*	57 (90%)	261 (85%)
Household income in the last year (\$)	n=69	n=291
5000-20,000 or don't know	30 (43%)	111 (38%)
20,000-75,000	34 (49%)	146 (50%)
> 75,000	5 (7%)	24 (12%)
Living situation	n=74	n=329
Alone or other	25 (34%)	77 (23%)
Not alone	48 (65%)	247 (75%)
Facility	1 (1%)	5 (2%)
	n=65	n=273
CES-D	7 (6)	7 (6)
	n=67	n=282
Mental component score ^b	50 (12)	49 (13)
Physical component score ^c	36 (13)	36 (12)
Ability to transfer	n=73	n=322
Independent	72 (99%)	309 (96%)
With assistance	1 (1%)	13 (4%)
If your kidneys were to fail completely in the next month, do you know what treatment option you would choose?	n=71	n=307
In-center hemodialysis	14 (20%)	68 (22%)
Home hemodialysis	5 (7%)	16 (5%)
Peritoneal dialysis	4 (6%)	24 (8%)
Transplant	0 (0%)	12 (4%)

(Continued)

Table 2 (Cont'd). Survey responses of Patients^a (N=407)

Variable or question	Discussed “not starting therapy”	Did not discuss “not starting therapy”
No treatment	5 (7%)	8 (3%)
Doesn't know	43 (61%)	179 (58%)
Discussed in-center HD with provider	15 (20%)	125 (38%)
Discussed home HD with provider	13 (18%)	73 (22%)
Discussed PD with provider	10 (14%)	74 (22%)
Discussed transplant with provider	11 (15%)	80 (24%)
Have not discussed any treatment option with their provider	7 (9%)	163 (49%)

Note. Values are presented as number (percentage) and continuous variables as mean (SD).

Abbreviations: eGFR, estimated Glomerular Filtration Rate; SD, Standard Deviation; CES-D, Center for Epidemiologic Studies Depression Score; HD, home hemodialysis; PD, peritoneal dialysis.

*Survey response of patients with eGFR < 30 mL/min/1.73m² categorized by patient response to “Has your provider discussed not starting therapy at all?”^bPart of the Kidney Disease Quality of Life questionnaire.

^cGiven that the question is phrased in a manner that implies forgoing dialysis, we have analyzed these answers as representative of a choice of conservative kidney management.

nephrologists, 5 had between 3 and 7 nephrologists, and 10 (38%) had ≤3 nephrologists.

Of the 18 clinics that answered the question of ability to routinely offer CKM, 100% confirmed that they were able to offer this option. A majority (93%) of clinics said they offer the option of CKM for patients aged >75 approaching kidney failure at least half the time. However, a majority of clinics (58%) also reported that only 0% to 5% of their clinic population choose CKM on kidney failure, with the rest of responding clinics reporting that 10% to 20% of their patients choose CKM. Most reported that the attending nephrologist (82%) or a nephrology trainee (6%) is responsible for delivering kidney failure treatment option education and planning in their clinics. One clinic said palliative care is usually or always involved in kidney failure education and planning, and 6 (35%) said they are sometimes involved. Among 18 responses (69%) to questions about availability of CKM resources, none had an established CKM protocol or guideline, 4 (22%) had a dedicated nephrologist serving as the CKM clinician, and none had a dedicated CKM clinic. There was no consensus on nomenclature for CKM with descriptions including the words “conservative”, “palliative or supportive”, or “non-dialysis or other” (Table 3). Among the 26 respondents, only 1 respondent said they were not comfortable discussing palliative care or CKM and 100% of respondents (n=25) said they typically discuss CKM as a treatment option for kidney failure.

The characteristics that most influenced provider contemplation of CKM suitability were frailty (77%

Table 3. Characteristics of Included Clinics (N=26)

Variable	Values
Respondent Age	n=22
≤ 50 y	9 (41%)
51-60 y	6 (27%)
> 60 y	7 (32%)
Respondent gender	n=26
Female	6 (23%)
Male	20 (77%)
Respondent title	n=26
Clinic director	14 (54%)
Staff nephrologist	9 (35%)
Other	3 (12%)
Board Certified in Nephrology	n=25
	23 (92%)
Are you comfortable discussing Palliative Care or CKM?	n=26
Not comfortable	1 (4%)
Fairly comfortable	9 (35%)
Extremely comfortable	16 (62%)
Do you typically discuss CKM as a treatment option for kidney failure?	n=25
	25 (100%)
Race breakdown of clinic population	n=26
White	67% (30; 0-98)
Black	24% (27; 0-100)
Region	n=26
West	2 (8%)
Central	6 (23%)
Northeast	10 (38%)
South Atlantic	8 (31%)
No. of nephrologists	n = 26
≤ 3	10 (38%)
3-7	5 (19%)
≥ 7	11 (42%)
No. of registered nurses	n=17
≤ 2	14 (82%)
3-4	3 (18%)
No. of physician assistants	n = 18
0	15 (83%)
1-4	3 (17%)
Does your clinic have the ability to routinely offer CKM?	n=18
Yes	18 (100%)
In your clinic, do you discuss the option of CKM with all CKD stage V patients aged > 75 y?	n=26
Yes	22 (85%)
For patients aged >75 y approaching KF, how often does your team offer the option of CKM?	n=26
Never	2 (8%)
Seldom or half the time	9 (35%)
Usually or always	15 (58%)
Estimate of the percent of patients from your clinic who use CKM when they transition to KF	n=26

(Continued)

Table 3 (Cont'd). Characteristics of Included Clinics (N=26)

Variable	Values
0%-5%	15 (58%)
10%-20%	11 (42%)
Main person responsible for delivering education about KF treatment options and planning	n=17
Nephrology Fellow	1 (6%)
Nephrology attending	14 (82%)
Advance practice nurse or nurse practitioner	1 (6%)
Other, nurse	1 (6%)
For patients seen by a nephrologist for at least 3 months before starting dialysis, are palliative care specialists typically involved in educating about and planning for KF (dialysis, transplant, or conservative care)?	n=17
No	10 (59%)
Yes, sometimes	6 (35%)
Yes, usually or always	1 (6%)
Written protocol or guideline for CKM	n=18
No	17 (94%)
No, but in preparation	1 (6%)
Dedicated CKM Clinician	n=18
Yes	4 (22%) ^a
Dedicated CKM Clinic	n=18
Yes	0 (0%)
If conservative care is chosen and the patient does not start dialysis, how often do you (the nephrologist) continue to provide some care?	n=25
Seldom	1 (4%)
Usually	10 (40%)
Always	12 (48%)
Skipped/no	2 (8%)
If CKM is chosen and the patient does not start dialysis, how often does a palliative care team become involved with the patient's care?	n=24
Seldom	3 (13%)
About half the time	7 (29%)
Usually	9 (38%)
Always	5 (21%)
Words used in your clinic to describe CKM	n=26
Conservative management or CKM or conservative care	16 (62%)
Palliative or supportive	6 (23%)
Non-dialysis or other	4 (15%)

Note. Values are presented as number (percentage) and continuous variables as mean (SD) and mean % (SD; range).

Abbreviations: CKD, Chronic Kidney Disease; CKM, Conservative Kidney Management; KF, Kidney Failure; SD, standard deviation.

^aAll nephrologists

strongly or very strongly), patient reaction (65% strongly or very strongly), and uremic symptoms (46%) (Fig 2).

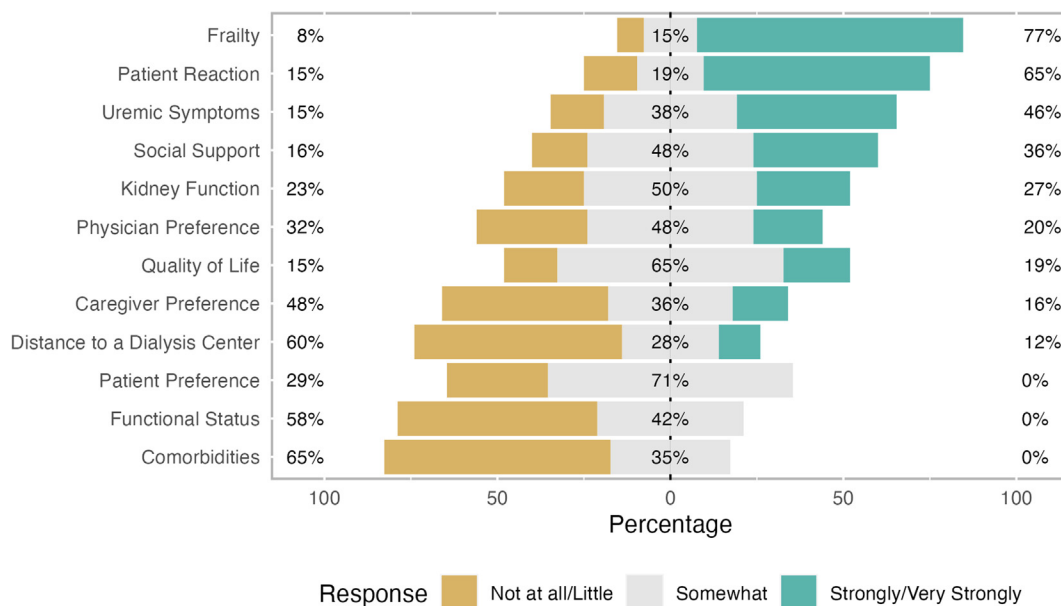


Figure 2. Influence of patient characteristics on providers' contemplating the suitability of conservative kidney management (CKM) for a patient (Data taken from provider surveys and represent estimates of nephrologists in their practice).

DISCUSSION

In this study we describe factors influencing the choice of CKM from provider and patient perspectives, and report on structural resources available for CKM delivery from 26 geographically diverse practices in the US. There were several key findings. Seven percent of patients with advanced CKD in our cohort planned for CKM at the time of kidney failure. These patients were older and more often functionally dependent and lived with someone. Most surveyed providers felt comfortable discussing CKM with their patients, but only 18% of patients reported having a conversation about not starting KRT with their nephrologist. Among factors that influenced surveyed providers to consider suitability for CKM, frailty and “patient reaction” were most important. Few clinics had dedicated support for CKM, and treatment option education was primarily the responsibility of nephrologists. A small number of clinics had early involvement of palliative care; however, often involved these providers once the patient had chosen CKM. Finally, we found that nomenclature for CKM was inconsistent across clinics.

Our findings are similar to a recently published paper from France. Hamroun et al²⁰ found similar results to ours in that an estimated 6% of included patients (N=1204) said they would not start “any therapy” at the time of kidney failure. Determining the reason for the similarity in our data would require further exploration; however, taken as a whole, our data shows that barriers to the uptake of CKM in the US likely exist at multiple points in clinical care.

One explanation for the low number of individuals choosing CKM is the physician report of lack of resources and infrastructure for delivering CKM in the US.^{21,22} Our findings contribute to previously reported data on this

subject through concrete examples of limited resources from 26 different health systems. Given the necessity of clinical delivery support, this is likely an important barrier. We found that most providers in our cohort work in systems that do not provide resources for delivery of CKM. Few clinics in our cohort had a dedicated protocol or workforce to deliver CKM, and none had a dedicated clinic. In the majority of clinics, patients with advanced CKD did not have access to early palliative care, but a majority often did interact with palliative care providers once CKM is chosen. Our low uptake of CKM contrasts with those from countries who have integrated infrastructure for kidney palliative care and CKM. We can examine these successful programs to help us better understand the gaps in our system. For example, the number of patients in our cohort planning for CKM is in sharp contrast to the 14%-29% reported from Australia or the United Kingdom, both countries that have established renal supportive (or palliative care) services.²³⁻²⁵ Australia and New Zealand²⁶ have national guidelines for delivering kidney supportive care with specific details regarding CKM. Another example is Alberta, Canada, which has a well-established kidney supportive care effort²⁷ that studies and clarifies practices for implementation of CKM. Although the health care system in the US differs in important ways from these countries, these data suggest that adopting practices from other countries, or emulating their coordinated, system-level approach could possibly influence the use of CKM in the US. Two groups from the US have reported on successful delivery of CKM in a clinic setting that has access to palliative care and a dedicated clinical pathway for CKM.^{13,28} However, these examples are single-centered and preliminary, but do suggest that

when resources are available, patients and providers may be more comfortable with the choice of CKM.

We found several discrepancies concerning discussions of CKM. First, we found inconsistent nomenclature used to describe CKM across practice settings. Variable nomenclature may reflect the lack of a standardized approach to CKM in the US or differences in how clinicians themselves understand and discuss CKM. This can confuse patients and collaborating providers. Furthermore, words like palliative or nondialysis can be seen as “no-care”, a common misconception that can influence patient choice. This is important because we found that nearly all the provider respondents felt comfortable discussing CKM and reported regularity of these conversations. This means that throughout the country, there may be frequent conversations about CKM, but no consistent message of what the choice represents. Our data shows the importance of these conversations, as we also found that nephrologists listed “patient reaction” as the second most influential factor when contemplating CKM for a patient. We can infer that this choice represents a nephrologist’s assumption or anticipation of their patient’s reaction and subsequently will use this to determine whether or not they engage in a conversation with their patients about CKM. Although the survey does not specify what patient reaction means, it does suggest that a provider may have a perception that this choice represents a lack of hope for the patients with whom they choose to discuss CKM. This perspective may limit the number of individuals educated about CKM. This is striking, because research shows the opposite when considering hope. In a qualitative study of 19 dialysis patients, Davison et al²⁹ showed that hope is unique for each individual and is shaped by their values and beliefs,²⁹ therefore, assumptions of taking away one’s hope cannot be made universally. Beyond that, research examining the patient perspectives of this topic show that realistic conversations about choices, prognosis, and the future can not only foster hope in general, but allows for patients to center this hope on realistic and attainable goals, often resulting in empowerment.²⁹ In aggregate, these findings highlight the need to teach practicing and training nephrologists communication skills around these complex, yet common, discussions.

Second, we observed conflicting findings in the patient accounts of CKM discussions compared with provider accounts. Frequent discussions of CKM were reported by nephrologists; however, only 18% of surveyed patients reported these conversations. One explanation for the discrepancy is that discussing CKM as a future option is different from actually supporting a patient through acceptance of this option. A provider who is comfortable discussing this treatment option may actually not be comfortable managing the symptoms or the increasingly complex discussions needed as the CKD trajectory evolves in CKM treatment pathway. In addition, providers also report having limited resources to turn to for supporting this population. An alternative explanation may be that

although surveyed providers reported comfort discussing CKM, these discussions may not be conveyed to the patients effectively. This can result in few patients choosing this pathway or even recognizing that it has been discussed. Although our findings are quantitative and cannot explain the nuances of the shared decision-making process, these data suggest that shared decision making around KRT is not always complete or systematically approached by providers. This variation in practice patterns does support the need for a better understanding of the clinical discussions of CKM and suggests that standardized CKM education and communication training in nephrology training programs, as well as standardized patient education materials, may be beneficial.

Our findings of factors influencing a provider’s consideration of CKM are concerning. We found that a provider’s perception of a patient’s frailty and reaction had greater influence than the patient’s functional status, comorbidities, and patient preference. Functional status and comorbidity burden are clinical elements that have evidence-based impact on mortality in available prognostic models for individuals on maintenance dialysis.^{30,31} Although these tools are not validated in CKD, they are evidence-based approaches that can be used by providers to risk stratify CKD patients. It is notable that no providers said that functional status and comorbidity burden were strongly or very strongly influential in their decision of suitability of CKM. This comes in the context that the known evidence based tools to help guide clinicians in decision making for kidney failure treatment, as well as data supporting benefits of CKM, come for older comorbid adults, a population which has functional impairments.^{3,4,7,8} In addition, while we cannot say if the survey answer “frailty” was associated with a formal assessment of frailty by the respondent, we do know that nephrology providers are often not trained to assess frailty, and instead make this decision based on subjective conclusions, or a general gestalt. These findings suggest that better integration of prognostic tools into clinical practice, increased education in application of these tools, and in communication training can provide clinicians with evidence and practical skills to support their clinical decision-making, something which is currently lacking.

We also found that a majority of patients had not received formal education in KRT options, and that most of the time, treatment education is the responsibility of the nephrologist. This is likely to be challenging in a busy clinic, because a thoughtful and supportive shared decision-making conversation may require significant time and several visits. We found that nephrologists also frequently stayed involved when the patient chooses CKM. Although this may be expected, we also noted that most clinics also involved palliative care at this point. Because of the absence of standardized protocols for CKM delivery, there can be a lack of clarity of roles when providing interdisciplinary team-based care for these patients. Although palliative care seems to be welcomed and

nephrology providers reported comfort with CKM, the late involvement of palliative care may reflect workforce limitations and availability of palliative care providers.³² As more patients choose CKM, our health care system will need to evolve to optimize the delivery of CKM. As proceeding with CKM requires nuanced decision making that balances a nephrologist's skills in complex conversations, lack of palliative care resources or training of palliative care skills for nephrologists may create missed opportunities to support patients and families earlier in the disease course. Furthermore, one's practice environment needs to be the one that has a workflow to facilitate the occurrence and normalization of these conversations and visits with palliative care, if necessary. Further research is needed to determine the optimal timing and overall need for palliative care involvement in the care of those with advanced CKD.

Strengths of our study include the geographic diversity of our cohort, the multiple perspectives reported, and the inquiry of CKM, an understudied topic. There are limitations as well. First, the vocabulary used in the survey was not consistent across all measures. It is possible that the categorizations used in our analysis do not fully represent patients' interpretations of the questions. For example, "not starting therapy" may not have been universally interpreted by participants as an active choice of CKM. Nevertheless, this question does clearly delineate the option of not commencing KRT. Second, assessment about choice of CKM were determined by study coordinators through review of clinical records rather than directly from patients. Third, our report focuses primarily on anticipated therapeutic options and plans. These anticipated treatment choices may not reflect the care the patients underwent at the time of kidney failure. Fourth, although the number of providers surveyed is small, each provider reports on unique health systems. Therefore, our study does report on 26 different health systems which we think is a strength. Fifth, our sample was majority White which limits the generalizability as CKD disproportionately affects racial and ethnic minorities. Finally, our data were collected between the years 2014 and 2020. It is important to place our findings in the context of the time of collection, because the field of kidney palliative care is dynamic and rapidly changing. For example, a PubMed search for "kidney palliative care" retrieved 58 results from 2012; yet 11 years later, in 2023, 160 results were retrieved. This large increase reflects the changing field and the corresponding discourse that influences practice.

Our analyses provide important information for advancing the delivery of CKM in the US, while also highlighting the need to obtain more comprehensive understanding of CKM practice. This information can provide a foundation to guide comprehensive practice change. As currently several policy initiatives are being implemented nationally to expand patient choice and to improve the quality of life for patients with kidney disease.³³ It is clear CKM is a large part of American Nephrology practice, and

one that more patients may continue to choose with higher frequency. However, it is a clinical pathway that is understudied, poorly understood, lacks vital resources in its delivery, and is heterogeneously implemented. In conclusion, our data suggests the need for a coordinated national effort to better support and to better study providers, patients, and health systems who strive to optimally deliver CKM for people with kidney failure.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Item S1. Survey questions used to abstract plan for conservative kidney management by the research coordinators.

Item S2. Survey questions asked to nephrologists about their clinics and practice patterns.

Table S1. Patient characteristics associated with choosing conservative kidney management (N=957).

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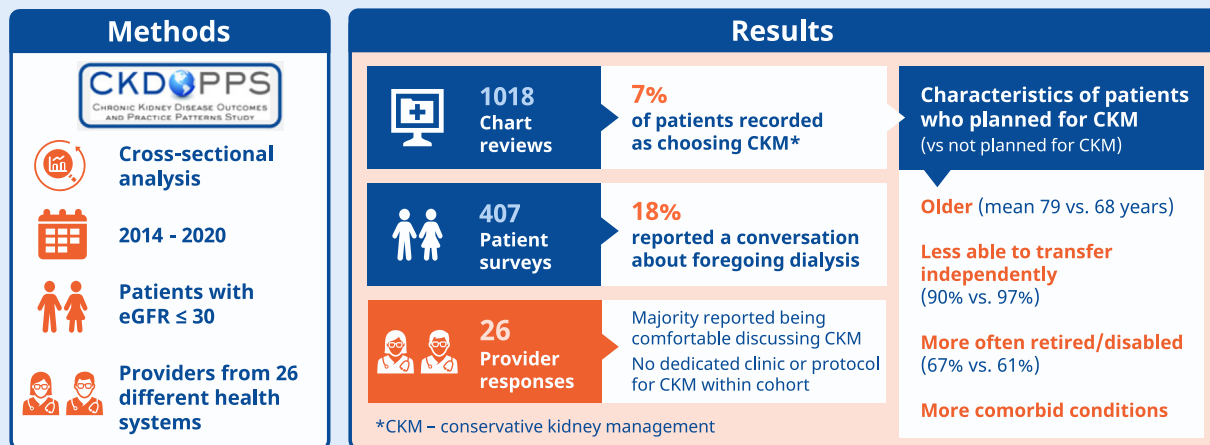
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What are conservative kidney management practice patterns in the United States?



Conclusion: Few patients report discussions of forgoing dialysis with their providers, and even fewer anticipate a choosing CKM. Most providers were comfortable discussing CKM but practiced in clinics that lacked dedicated resources. Further work is needed to improve CKM pathway implementation.

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