Leveraging Patient Activation to Improve Kidney Health in High-Risk Patients

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ABSTRACT

Objectives: In the US, an estimated 37 million adults have chronic kidney disease (CKD). However, many lack awareness about CKD, which can be a factor in delayed diagnosis and treatment. CKD, when diagnosed late, is expensive to manage and often is fatal, killing thousands of individuals each year. The purpose of this study is to identify awareness gaps, understand how high-risk patients manage their health, and determine opportunities for prevention.

Study Design: Between May 25 and June 20, 2023, Phreesia, Inc, and the National Kidney Foundation conducted a survey completed by 4445 patients with a diagnosis of diabetes and/or hypertension but without a diagnosis of kidney disease. Survey respondents' diagnoses were derived from information in their electronic health records, and surveys were administered digitally to these patients during the check-in process for their doctors' appointments using the Phreesia platform.

Methods: Patients who agreed to participate received a survey featuring 40 questions with both single-choice and multiple-choice formats. To understand the degree to which high-risk patients engage in preventive behaviors, we created an index, which was used in multivariate regression analysis to identify predictors of index scores for each patient group. Ordinary least squares regressions were employed.

Results: Frequency of patient-provider conversations and patient activation are the 2 most significant predictors of a patient's behaviors in preventing kidney disease.

Conclusions: Intervening early to encourage more frequent conversations and support activation in patients may go a long way in bridging the awareness gap and encouraging behaviors that promote kidney health, helping to improve outcomes and lower costs.

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n the US, an estimated 37 million adults have chronic kidney disease (CKD). However, only 10% know they have it.1 CKD is asymptomatic at its onset and is characterized by increased cardiovascular morbidity, mortality, and progression into end-stage kidney disease requiring dialysis or transplant.²⁻⁴ Significant gaps in CKD testing exist among individuals at risk for CKD (those with diabetes and high blood pressure) receiving care in primary care settings.5,6 Most patients with CKD remain undiagnosed in primary care, including as many as 40% of those whose kidneys have already failed, limiting any opportunity to prevent the disease's progression and reduce the associated rising cardiovascular risk.^{6,7} Delays in testing and diagnosis are associated with limited use of guideline-recommended medications8; elevated risk of progression into end-stage kidney failure; and the composite of myocardial infarction, stroke, and hospitalization for heart failure.9 Without increased investment in prevention, it is estimated that the number of patients with kidney failure will likely exceed 1 million by 2030.10

To better understand how individuals at risk for CKD can play a more active role in managing that risk, Phreesia, Inc (Phreesia), and the National Kidney Foundation (NKF) conducted a survey to understand how patients manage their health and to identify key opportunities to detect kidney disease earlier. We sought to answer the following research questions:

- How aware are high-risk patients of their risk for kidney disease?
- Do patients report that providers discuss kidney health with them?
- What factors predict these discussions?
- What factors predict behaviors to prevent kidney disease among high-risk patients?
- What type of preventive behaviors are high-risk patients likely to take to prevent kidney disease?

STUDY DESIGN

This article draws on results from a survey conducted by Phreesia and NKF between May 25 and June 20, 2023, which was completed by 4445 patients with a diagnosis of diabetes and/or hypertension but without a diagnosis of kidney disease. Fifty-nine percent of the study population were women and 41% were men. The mean age of the study population was 58.8 years; 74% were White, 9% were Black, 3% were Asian, and 14% identified as other/unknown race. Ten percent identified as Hispanic, 79% as not Hispanic, and 11% as other/unknown. Eighty-six percent lived in urban areas, 10% in suburban areas, and 3% in rural areas.

Survey respondents' diagnoses were derived from information in their electronic health record and confirmed with a segmenting question in the survey. The survey was administered digitally using the Phreesia platform to patients during the check-in process for their doctors' appointments. Patients were presented with an optional Health Insurance Portability and Accountability Act authorization (form to release health information) to which they had to consent to be shown the survey; participation was voluntary, and they could exit the survey at any time.

The survey used a sampling approach that included elements of random sampling as well as convenience sampling and volunteer sampling. The survey was offered to a random sample of 10% of eligible patients with hypertension and 30% of eligible patients with diabetes. Ten percent of patients who were offered the survey agreed to participate, and two-thirds of those completed the survey. Although a small percentage of patients who were offered the survey completed it, the demographics of those who agreed to participate were not significantly different from those of patients who declined.

The sample included only patients with hypertension and diabetes, and it included only patients using the Phreesia platform. Although it is not a random sample of all patients with hypertension and diabetes, the Phreesia platform enables patient check-ins for 10% (approximately 150 million) of visits each year, so it supports a broad swath of patients seeking care. Participants from 48 states were included in the sample. The patients who participated received no prompting information from Phreesia's online platform about kidney health, nor did they receive prompts about communicating with their provider about kidney health.

METHODS

The survey featured 40 questions with both single-choice and multiple-choice formats. Some questions were selectively shown to patients depending on their current condition and responses within the survey. Patients were required to answer every question before continuing, and a "decline to answer"

response option was included on every page. Partial responses were collected and included in the study. In designing this survey, our team conducted web-based research and incorporated expert input as well as feedback from a patient work group at the NKF.

To understand how patient activation (an individual's knowledge, skills, and confidence in managing their health) impacts kidney disease awareness and behaviors, our study included the PAM-10, a 10-question survey that identifies where an individual falls on a scale of 0 to 100. The Patient Activation Measure (PAM) is used in the analysis as a key predictor variable, predicting a patient's awareness of kidney disease risk and engagement in preventive behaviors. The 4 PAM levels are based on empirically derived cut points in the 0-100 scale. The levels range from "overwhelmed and disengaged" (level 1) to "proactive and goal oriented" (level 4).

To determine awareness of the risk of kidney disease, we assessed the distribution of responses to items on perceived risk for respondents with diabetes and separately for patients with hypertension. We then moved on to assess the bivariate relationship between risk awareness and the frequency with which providers had discussed kidney disease with them. We did this analysis for each disease group. We used bivariate analyses to explore the relationships among patient activation, frequency of discussions with providers, and awareness of risk.

To understand the degree to which high-risk patients engaged in preventive behaviors, we created an index, which is used in multivariate analysis. The Kidney Health Behavior Index (**eAppendix A** [eAppendices available at **ajmc.com**]) was created using a simple summated index. Scores ranged from 0 to 12 for diabetes or hypertension only and 0 to 14 for both conditions. Reliability was high: Cronbach α values for the indexes were 0.8322 (diabetes only), 0.8407 (hypertension only), and 0.8501 (both conditions).

We used multivariate regression analysis to identify predictors of index scores for each patient group. Ordinary least squares regressions were employed using Stata (StataCorp LLC). The models included control variables such as age, sex, race, ethnicity, and time since condition diagnosis to account for patients who have had diabetes or hypertension for longer periods of time.

RESULTS

How Aware Are High-Risk Patients of Their Risk of Kidney Disease?

Results of our analysis show that high-risk patients—those with diabetes and/or hypertension—often lack awareness about their heightened risk for CKD, do not understand its link to their diabetes and/or hypertension for many years after the primary condition is diagnosed, and are not engaging with

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their health care providers about this issue. Two in 3 high-risk patients are not aware of their risk for kidney disease (51% of patients with diabetes and 83% of patients with hypertension). The awareness gap is much larger for patients with hypertension than patients with diabetes: Awareness is nearly 3 times higher among those with diabetes.

When responses were analyzed by time since diagnosis of the primary condition, we found that 8 or more years after diagnosis of diabetes and/or hypertension, many high-risk patients remained unable to identify their risk for kidney disease (43% of patients with diabetes and 78% of patients with hypertension).

Stratifying responses by PAM level showed that patients who are more activated are more aware of how their condition, kidney health, and CKD are linked (**Table 1**). Fifty-five percent of PAM level 4 patients with diabetes understand the link between their condition and CKD, compared with 11% of PAM level 1 patients (P<.05). For patients with hypertension, understanding of the link between their condition and CKD is even lower: 40% of PAM level 4 patients and 7% of PAM level 1 patients (P<.05).

Do Providers Discuss Kidney Disease Risk With High-Risk Patients? What Factors Predict These Discussions?

Only 40% of patients with hypertension said they had ever discussed kidney health with their provider, significantly lower

than the 58% of patients with diabetes who reported kidney health discussions (P<.05) (**Table 2**). Patients with higher PAM levels were more likely to have discussed kidney health with their provider compared with those with lower activation levels (P<.05). Seventy percent of PAM level 4 patients with diabetes had discussed kidney health with their health care provider, compared with 38% of PAM level 1 patients (P<.05). Fifty-one percent of PAM level 4 patients with hypertension had discussed kidney health with their health care provider, compared with 7% of PAM level 1 patients (P<.05).

What Are the Main Factors Predicting Preventive Behaviors?

Frequency of patient-provider conversations and patient activation are the 2 most significant predictors of a patient's score on the index (**Table 3**). These 2 factors are more powerful in predicting preventive behaviors than age, whether the condition is managed by a specialist, length of diagnosis, or frequency of provider visits. Surprisingly, we found that race, ethnicity, and sex were not significant predictors. The predictors of engaging in preventive behaviors were largely the same for both patient groups.

Patient-provider conversations about kidney health generally occur during routine clinician encounters, and in our survey, we asked patients to self-report the occurrence and frequency

Table 1. Awareness Findings										
Patients who understand their condition's link to CKD very or extremely well	Total	PAM level 1	PAM level 2	PAM level 3	PAM level 4					
Patients with diabetes*	37%	11%	30%	32%	55%					
Patients with hypertension*	27%	7%	20%	22%	40%					
CKD, chronic kidney disease; PAM, Patient Activation Measure. *P<.05 between level 1 and level 4.										

Table 2. Provider Discussion Findings										
Patients who have discussed kidney health with their providers	Total	PAM level 1	PAM level 2	PAM level 3	PAM level 4					
Patients with diabetes*	58%	38%	52%	59%	70%					
Patients with hypertension*	40%	7%	34%	37%	51%					
PAM, Patient Activation Measure. *P<.05 between level 1 and level 4.										

Table 3. Predicto	rs of Kidney Health Behavior
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		Diabetes	Н	ypertension		Both conditions			
	Overall	Standard coefficient	SE	Overall	Standard coefficient	SE	Overall	Standard coefficient	SE
Variables									
Age	0.0280***	0.146	0.005	0.0113**	0.060	0.005	0.0246**	0.089	0.011
Women	-0.059		0.131	-0.306**	-0.057	0.126	-0.405		0.239
White	-0.194		0.134	0.0498		0.135	0.04		0.262
Black	0.189		0.275	-0.149		0.250	0.0002		0.532
Hispanic	-0.35		0.223	-0.359		0.290	0.2473		0.501
PAM score	0.0191***	0.111	0.004	0.0228***	0.146	0.004	0.027***	0.141	0.007
Time since condition diagnosis	0.142		0.131	0.296**	0.056	0.130	0.2165		0.253
Frequency of kidney health discussions	0.744***	0.410	0.042	0.738***	0.420	0.042	0.9542***	0.427	0.083
Frequency of primary condition visits	0.168***	0.080	0.048	0.1516***	0.073	0.048	0.2756***	0.103	0.095
Specialist	0.432***	0.070	0.142	0.493***	0.066	0.177	0.7821***	0.094	0.297
Constant	-1.287***		0.436	-0.594		0.438	-1.133		0.885
Observations	1516			1378			583		
R^2	0.26			0.27			0.3		

PAM, Patient Activation Measure.

P<.05; *P<.01.

of these conversations. Importantly, however, these conversations were unrelated to the frequency of provider visits. Our survey found that most patients with either or both conditions visit their physician in accordance with clinical guidelines. This is true whether they are having kidney health discussions with their provider or not. Sixty-two percent of patients with diabetes visit their provider 3 or more times per year, which aligns with American Diabetes Association guidelines. Seventy percent of patients with hypertension visit their provider twice a year or more, which aligns with American College of Cardiology/ American Heart Association guidelines.

Which Preventive Behaviors Are High-Risk Patients Taking?

We found that PAM levels were highly correlated with index scores. Patients with a higher PAM level also received a higher score on the index. Patients in the top quartile of index scores are much more likely to be at PAM level 4 compared with those in the bottom quartile (44% vs 11% in diabetes and 49% vs 8% in hypertension).

These patients (who are more activated and have higher index scores) are more likely to engage in the full range of behaviors, including complex self-management behaviors, whereas those who are less activated and score lower on the index are more likely to report only behaviors that require less effort, such as basic testing as part of a wellness visit (eAppendices **A** and **B**). Eighty-nine percent of patients with diabetes with an index score of 1 regularly test their hemoglobin $A_{\rm 1C}$ levels. Ninety-six percent of patients with hypertension with an index score of 1 regularly undergo cholesterol testing. However, patients with higher index scores are significantly more likely to undertake more complex self-management behaviors daily: All of the patients with diabetes and hypertension with an index score of 11 or 12 managed their salt intake. Less than 2% of these patients with an index score of 0 to 3 managed their salt

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intake (see eAppendix B for detailed scores). The results of this analysis may help us understand what behaviors a patient with lower activation may be able to take on successfully and inform interventions aimed at patients at different levels of activation.

DISCUSSION

In the period between when a patient first receives a diagnosis of diabetes and/or hypertension and when they develop kidney disease (which is often years), their awareness and behaviors directly impact their health outcomes. If patient-provider conversations around kidney health took place more frequently and at an earlier stage, this would enable earlier diagnosis and treatment, and the patient could adopt preventive behaviors. 11,12

Most patients with either or both conditions are seeing their provider in accordance with clinical guidelines. However, regular provider visits are insufficient for encouraging behaviors related to kidney health because many patients (40% with diabetes, 60% with hypertension) do not discuss kidney health with their providers. Because the patient is already attending regular appointments with their provider, interventions that encourage patient-provider conversations around kidney health during these visits could be implemented easily and at a low cost. Such interventions, aimed at both patients and providers, require little effort relative to the intensive and expensive treatment for CKD and could save thousands of lives.

For high-risk patients, targeted education campaigns through digital outreach before or between visits with their provider would raise awareness and could prompt more frequent patient-provider discussions at an earlier point after diagnosis of diabetes¹³ and/or hypertension.¹⁴

A patient's activation level matters: Less-activated patients often do not know or understand that they need to play an active role in their health; they may see the provider as the only relevant actor. Helping patients see the importance of their role is key. In addition, an intervention as simple as training less-activated patients on how to ask questions during the medical encounter has been shown to improve doctor-patient communications and increase activation scores.¹⁵

Developing discussion guides and similar tools that are tailored to the patient's level of activation would help patients feel empowered and confident to have more frequent and meaningful conversations with providers, which would lead them to better understand their condition and its effect on kidney function.

PAM and Patient-Provider Conversations Are Closely Linked

Providers would benefit from automated prompts and supportive materials to initiate more frequent conversations about kidney risk with high-risk patients. These materials must be tailored to the activation level because it is not enough for a conversation about kidney health to take place; it must be at the appropriate level for each patient.

For patients who are overwhelmed, providers may not want to burden them with conversations about additional risks. Providers may put off discussions about CKD with these patients because the risk is not as immediate as other ones. Further, the provider's communication may not be delivered in a way the patient can understand: Even if a conversation about kidney health took place, a less-activated patient may not retain it. This has health equity implications because it results in patients with low activation remaining less informed and trapped in a vicious cycle of poor outcomes.

Avoiding kidney health discussions is a missed opportunity for more-activated patients, who may not be overwhelmed by multiple issues. Patients with higher PAM levels are more likely to retain information from a conversation with their provider and be receptive to adopting new behaviors to preserve kidney function. Giving providers prompts and materials to engage patients at different levels of activation at the right starting point is critical to making sure conversations happen often and occur in a way the patient can retain.

We know from the results of previous studies that higher levels of activation are associated with better health outcomes. ¹⁶ Once a provider knows a patient's activation level, they can take a realistic approach and target interventions to encourage behaviors the patient may be likely to be successful at, thereby engaging patients in their care. For patients with lower PAM levels, providers can focus on helping them adopt the easiest behaviors—such as testing—and educating them about the link between their condition and kidney health. Patients with higher PAM levels are likely ready to adopt self-management behaviors that require more self-management skill, such as diet and exercise modifications, and to make lifestyle changes that require daily vigilance.

Why Patients With Diabetes and Those With Hypertension Differ Significantly in Their Awareness

One possible explanation for why the awareness gap is much larger for patients with hypertension than those with diabetes is related to quality metrics. The Healthcare Effectiveness Data and Information Set (HEDIS) quality measure for Medical Attention to Diabetic Nephropathy, which included CKD testing, was included in the Comprehensive Diabetes Care measure set for over a decade. The availability of the new Kidney Health Evaluation for Patients With Diabetes HEDIS measure, which focuses exclusively on increased CKD testing, may be prompting providers to speak with patients with diabetes more frequently about kidney health. Because such a measure does not exist for

patients with hypertension, providers may be less likely to bring up kidney health with them. Still, higher-activated patients with hypertension are more confident they know how to prevent CKD. Thirty-five percent of PAM level 4 patients say they are very confident they understand how to prevent CKD, compared with only 5% at PAM level 1.

Limitations

The sample, although drawn from a national population, is not a random sample of eligible patients. Only patients with scheduled physician appointments on the Phreesia platform had the opportunity to participate in this survey. There could be nonresponse bias; however, although many patients declined to participate, their demographic characteristics were no different from participants'. Patients who do not or are not able to access health care did not have the opportunity to participate; therefore, the results are likely understated because these patients are likely even less aware and take fewer preventive behaviors than those receiving care.

Opportunities for Further Research

Because our survey was completed by individuals with scheduled physician appointments, the sample does not include patients with diabetes and/or hypertension who are not seeking care for their condition but are still at risk for kidney disease. Studies that utilize a nationally representative sample that includes both those seeking care and those who are not accessing the system are needed. Further research should also examine whether, over the long term, increasing the frequency of patient-provider conversations around kidney health and supporting activation in patients leads to better kidney health outcomes. Finally, given that 8 or more years after diagnosis of diabetes and/or hypertension, the majority of high-risk patients remain unable to identify their risk for kidney disease, delays in diagnosis of kidney disease are likely common. Further research should estimate the average time and clinical consequences of such delays.

CONCLUSIONS

This survey offers insights on how to identify key opportunities for timely intervention through the PAM's predictive value and our findings from the Kidney Health Behavior Index (eAppendices A and B). Increased patient awareness and early diagnosis of kidney disease have the potential to improve the quality of life for many patients, saving them from intensive treatments such as dialysis and reducing overall costs of care. If more providers were to support activation in their patients, this could help increase the frequency with which high-risk patients seek out information about the link between their condition and kidney disease, initiate frequent discussions about kidney health with their providers themselves, and undertake preventive behaviors.

Using PAM, providers can develop care plans tailored to the patient's activation level instead of expecting patients to take all the steps necessary to manage kidney disease at once. This can be applied to help patients with other severe health conditions by tailoring interventions that move a patient along the continuum of their care journey, encouraging them to adopt increasingly complex—but vital—preventive health measures.

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eAppendix A. The Kidney Health Behavior Index

Survey Question
How often do you get your A1C levels tested?*
How often do you get your cholesterol tested?**
Are you currently doing anything to manage your kidney health?
Which of the following are you doing to manage your kidney health?
Maintain healthy diet
Reduce salt intake
Exercise regularly
Control protein intake
Reduce or stop smoking
Reduce or stop drinking alcohol
Control blood sugar*
Avoid medications that affect the kidneys
Control blood pressure**
Maintain or lose weight
Have you ever had a lab test to check your kidney health?

eAppendix B. Results from the Kidney Health Behavior Index

Diabetes

	Test A1C	Manage Diet	Manage Salt	Manage Exercise	Manage Protein	Manage Smoking	Manage Alcohol	Manage Medications	Manage Weight	Manage Blood sugar	Blood Test KH	Urine Test KH
0	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
1	89%	1%	0%	0%	0%	0%	0%	0%	0%	0%	11%	7%
2	87%	1%	0%	0%	0%	0%	0%	0%	1%	1%	63%	54%
3	98%	6%	2%	22%	0%	0%	0%	1%	3%	7%	92%	90%
4	90%	26%	28%	15%	0%	4%	7%	13%	29%	71%	65%	58%
5	86%	37%	37%	29%	5%	8%	12%	22%	42%	82%	72%	70%
6	98%	58%	44%	38%	8%	7%	22%	26%	62%	91%	79%	70%
7	91%	70%	57%	50%	23%	15%	28%	39%	75%	95%	83%	75%
8	96%	91%	67%	54%	28%	17%	38%	49%	84%	99%	93%	86%
9	94%	90%	81%	73%	50%	29%	46%	71%	92%	98%	94%	85%
10	97%	97%	97%	97%	69%	28%	58%	89%	86%	100%	92%	89%
11	88%	100%	100%	89%	94%	61%	100%	94%	100%	100%	94%	83%
12	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

	Test Chol	Manage Diet	Manage Salt	Manage Exercise	Manage Protein	Manage Smoking	Manage Alcohol	Manage Medications	Manage Weight	Manage BP	Blood Test KH	Urine Test KH
0	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
1	96%	0%	0%	0%	0%	0%	0%	0%	0%	0%	8%	5%
2	97%	1%	0%	1%	0%	0%	0%	1%	1%	2%	71%	34%
3	99%	4%	2%	2%	0%	1%	1%	1%	2%	9%	91%	89%
4	91%	30%	34%	34%	4%	0%	12%	12%	18%	72%	58%	40%
5	89%	33%	41%	38%	5%	4%	16%	26%	43%	81%	67%	59%
6	99%	50%	60%	40%	2%	5%	17%	31%	64%	95%	79%	60%
7	97%	71%	81%	57%	14%	3%	29%	42%	71%	95%	86%	57%
8	99%	94%	88%	73%	23%	13%	32%	45%	77%	96%	86%	78%
9	100%	91%	89%	82%	44%	22%	56%	67%	80%	100%	89%	84%
10	95%	91%	100%	77%	64%	32%	73%	86%	95%	100%	91%	100%
11	91%	92%	100%	92%	83%	75%	92%	92%	100%	100%	100%	92%
12	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%