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COMMENTARY

Patient and Clinician Perspectives: To Create a Better Future for Chronic Kidney Disease, We Need to Talk About Our Kidneys

Pamela R. Kushner · Jane DeMeis · Petrina Stevens · Ana Marija Gjurovic · Elmas Malvolti · Navdeep Tangri

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Abstract: Chronic kidney disease (CKD) affects more than one in ten people worldwide. However, results from the REVEAL-CKD study suggest that it is often not diagnosed. Many patients are therefore unaware that they have CKD, putting them at increased risk of disease progression and complications. Empowering patients with knowledge about CKD will allow them to become active participants in their own care, driving improvements in diagnosis rates and changing patient outcomes for the better. In this article, we provide patient and clinician perspectives on the importance of early CKD diagnosis and management. We present an overview of the tests commonly used to diagnose CKD in clinical practice, as well as actionable suggestions for patients, clinicians, and health policymakers that could help improve disease detection and treatment.

Keywords: Patient author; Chronic kidney disease; Epidemiology; Observational study; Patient perspective; Primary care

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P. R. Kushner (✉)
Department of Family Medicine, University of California Irvine Medical Center, Orange, CA, USA
e-mail: pamkushner@hotmail.com

J. DeMeis
Patient Author, Fairport, NY, USA

P. Stevens
Global Patient Engagement, BioPharmaceuticals Medical, AstraZeneca, Cambridge, UK

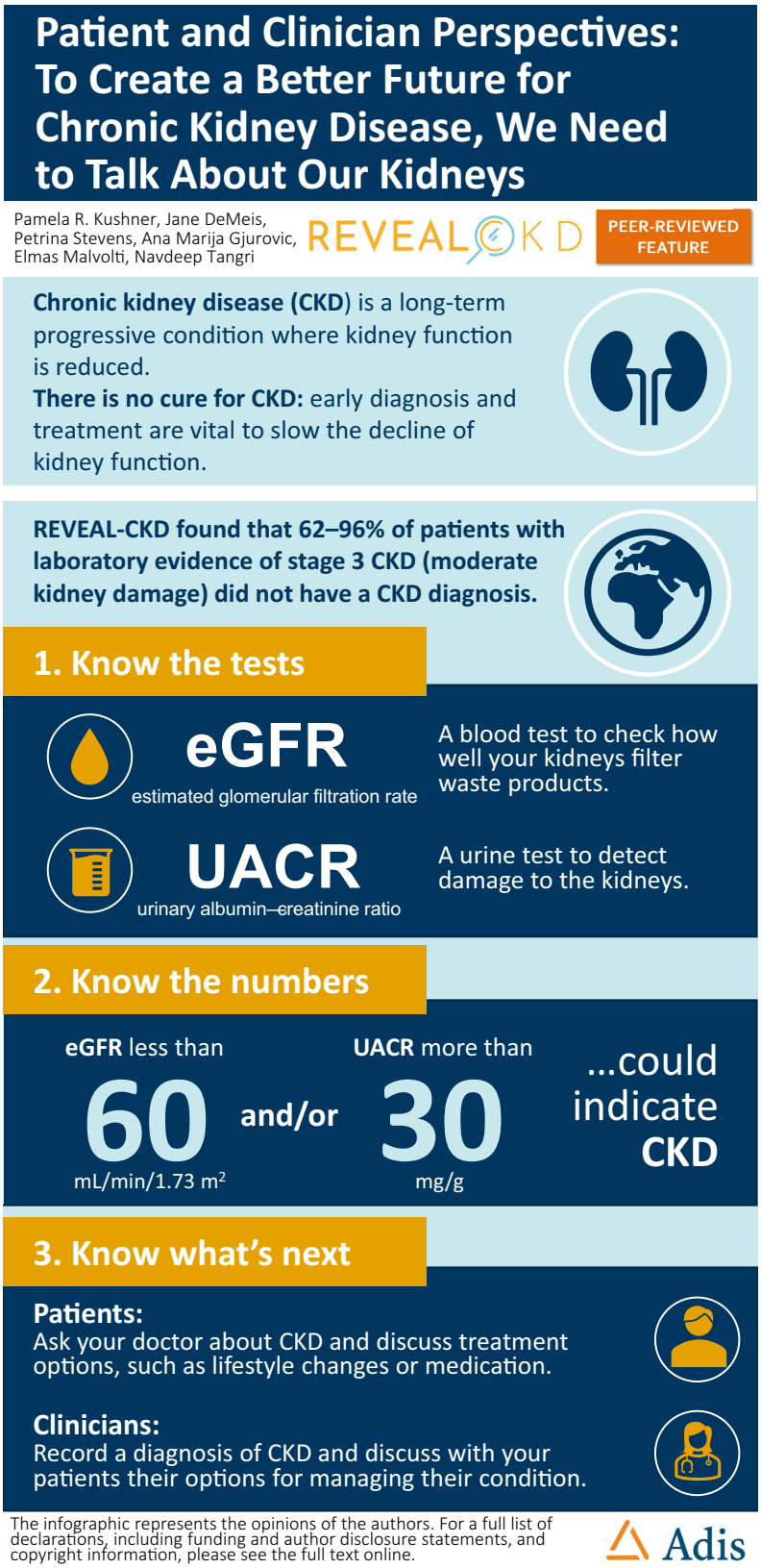
A. M. Gjurovic
Global Patient Engagement, BioPharmaceuticals Medical, AstraZeneca, Dubai, UAE

E. Malvolti
Global Medical Cardiovascular, Renal and Metabolism, BioPharmaceuticals Medical, AstraZeneca, Cambridge, UK

N. Tangri
Department of Internal Medicine, University of Manitoba, Winnipeg, MB, Canada

N. Tangri
Seven Oaks General Hospital, Winnipeg, MB, Canada

Infographic



Key Summary Points

Chronic kidney disease (CKD) is a long-term progressive condition characterized by reduced kidney function that affects an estimated one in ten people worldwide.

Despite the widespread nature of the disease, the REVEAL-CKD study found that, across five countries, 62–96% of patients with laboratory evidence of stage 3 CKD (moderate kidney damage) lacked a CKD diagnosis in their medical records.

This article summarizes findings from REVEAL-CKD and offers patient and clinician perspectives on the importance of early CKD diagnosis and management.

Providing patients with a simple and clear understanding of key kidney function tests could empower them to engage in meaningful conversations about kidney health with their clinicians.

Together, patients, clinicians, and health policymakers all have a role to play to improve the rates of CKD diagnosis and management, and ultimately improve patient outcomes.

DIGITAL FEATURES

This article is published with digital features, including an Infographic and a Video Abstract, to facilitate understanding of the article. To view digital features for this article, go to https://doi.org/10.6084/m9.figshare.25000109.

INTRODUCTION

Chronic kidney disease (CKD) is a long-term condition in which the function of the kidneys is reduced. CKD affects an estimated one in ten people [1] and is one of the leading causes of death worldwide [2, 3]. CKD is a progressive disease, meaning that kidney function declines over time [4]. Research has identified shortcomings in early identification and treatment of CKD, despite clinicians and policymakers shining a spotlight on the importance of these actions [5]. However, this growing problem needs to be tackled not just by clinicians and policymakers but through empowering patients themselves.

There are two tests used to diagnose CKD. Estimated glomerular filtration rate (eGFR) is a blood test to estimate the kidneys' ability to filter waste products from the blood. Urinary albumin–creatinine ratio (UACR) is a test to investigate the level of a protein called albumin in a sample of urine. UACR measures structural damage to the kidneys. The results of these tests are used to divide the severity of CKD into stages from 1 to 5, with stage 1 being mostly normal kidney function and stage 5 being kidney failure [6]. Early in the course of the disease (stages 1–3), patients will often not experience any symptoms [7]. As kidney function continues to decline, patients may experience symptoms such as tiredness, nausea, insomnia, cramps, pain, and itching [8]. If CKD progresses to stage 5, or kidney failure, the kidneys can no longer function well enough for a patient to survive without kidney transplant or dialysis (a medical procedure to remove waste products from the blood) [9]. However, kidney failure is not the only negative outcome of unmanaged CKD—even in the early stages, CKD is associated with an elevated risk of high blood pressure, heart failure, and stroke, and an increased risk of premature death [4, 10].

With early CKD detection, kidney function can often be preserved through lifestyle changes. These include improving diet, managing weight, reducing alcohol consumption, and eliminating tobacco use. It is also important to ensure that other conditions, such as hypertension and type 2 diabetes, are managed appropriately, and that medications for those conditions are taken as prescribed [11, 12]. Eventually, specific medications may be needed to slow kidney function decline [6]. CKD cannot be cured, and it is not possible to reverse the damage already done to the kidneys [4, 13]. Early and effective management is therefore

crucial to slow disease progression and delay the development of complications.

The first step towards managing and treating CKD is for patients and clinicians to recognize the condition and treat it as a distinct disease that must be addressed. Patients should feel comfortable with initiating discussions about kidney health with their healthcare team. Such discussions can prompt proper recording of a CKD diagnosis, an essential step to trigger lifestyle adjustments and begin required treatments.

THE REVEAL-CKD STUDY

A patient with undiagnosed CKD is more likely to be a patient with untreated CKD. The REVEAL-CKD study was designed to investigate rates of diagnosis of stage 3 CKD (moderate kidney damage), and to identify shortcomings in CKD diagnosis and management across the globe.

An article from REVEAL-CKD reporting findings from France, Germany, Italy, Japan, and the USA was published in May 2023 [14]. In this article, the authors found that the proportion of patients with available laboratory evidence of stage 3 CKD, but who did not have a CKD diagnosis in their medical records, ranged from 62% in the USA to 96% in France. In addition to this, the authors found that UACR tests were often unavailable, with over 94% of patients in each country having no record of UACR [15]. These low rates are particularly concerning considering that guidelines recommend UACR testing in patients at risk of CKD [6], and that UACR values are useful both for the accurate staging of CKD and assessing the risk of CKD progression [16]. It should be noted that REVEAL-CKD investigated CKD diagnosis in high-income countries, and the results may therefore not be directly translatable to low- and middle-income countries. However, limited healthcare resources in lower-income countries are likely to result in similar or lower rates of CKD diagnosis and testing than those seen in high-income countries. Therefore, it is still important to raise awareness of the importance of early CKD diagnosis in these countries.

Another article from REVEAL-CKD that investigated patient management and clinical outcomes associated with receiving a CKD diagnosis was also published in May 2023 [15]. This article looked at over 26,000 patients from the USA. The authors found that, after a CKD diagnosis was made, the rate of prescribing of guideline-recommended medications to treat CKD increased substantially (an increase of 62–123% in the 180 days after [versus the 180 days before] CKD diagnosis). In addition, the rate of monitoring for blood pressure, kidney function, and blood sugar levels also increased after a CKD diagnosis. The authors found that, on average, yearly decline of kidney function was around four times slower after a CKD diagnosis compared with before. Finally, a delayed diagnosis was seen to increase risks of progression to stage 4/5 CKD, kidney failure, or cardiovascular events including heart attack, stroke, or hospitalization for heart failure.

WHAT NEEDS TO CHANGE: IT'S TIME TO TALK ABOUT OUR KIDNEYS

REVEAL-CKD highlights substantial shortcomings in CKD diagnosis across the globe. Blood tests showing that patients have CKD are being performed, but a diagnosis of CKD is not being recorded. Patients may therefore be missing opportunities to manage their disease. Similarly, UACR testing is rarely performed, meaning that the severity of the disease often remains unknown.

It appears that patients and clinicians are not talking about CKD in the same way that they would talk about blood pressure or diabetes. Patients need to be empowered to ask about their kidneys, especially because there are often no symptoms in the early stages of CKD. If a person relies on symptoms alone to identify the disease, then they may only be diagnosed after their kidney function has declined to a point where kidney failure is very close. Acting upon earlier opportunities to foster self-care and improve health behaviour will help to avoid negative outcomes and mitigate the burden of living with CKD.

Improving patients' understanding of the laboratory tests used to diagnose CKD could help to normalize the discussion of kidney health. If patients understand these tests, they

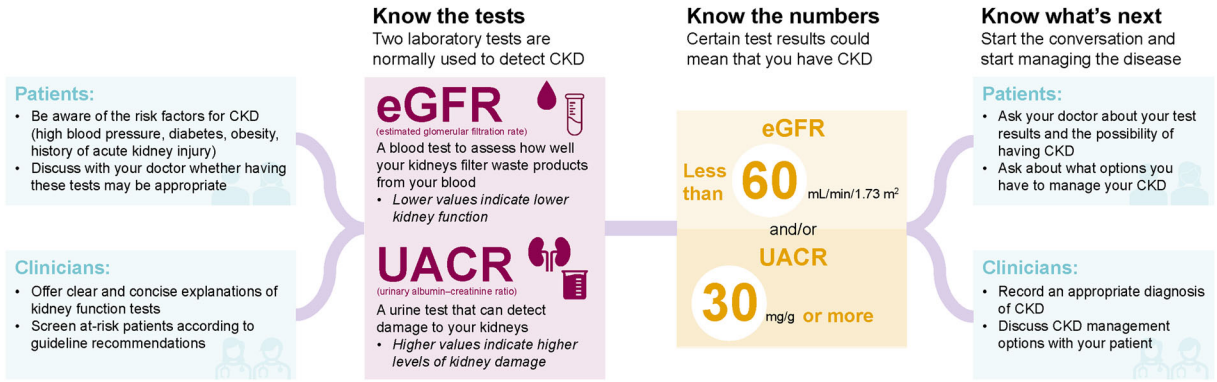


Fig. 1 Empowering patients with knowledge of kidney function tests and the meaning of their results could help to improve CKD diagnosis rates. *CKD* chronic kidney disease, *eGFR* estimated glomerular filtration rate, *UACR* urinary albumin–creatinine ratio

may feel comfortable requesting them and discussing the results with their clinician. Simply understanding that lower eGFR corresponds to reduced kidney function, or high UACR indicates kidney damage, could help patients to engage in conversations about kidney health. A clear and concise understanding of some threshold values for CKD may also help prompt a conversation: eGFR less than 60 mL/min/1.73 m^2 and/or UACR of 30 mg/g or more (Fig. 1). For example, if their eGFR is 45 mL/min/1.73 m^2, patients should feel comfortable asking their doctor about this, just as they might ask about a high blood pressure reading. Furthermore, if a patient has an eGFR that could indicate CKD, they should be confident in asking their clinician for a UACR test so that the disease can be staged accurately.

Awareness of these tests could prompt patients to start conversations about CKD, but clinicians still have an important role to play. In recent years, focus has been placed on early CKD diagnosis and treatment [5], although results from REVEAL-CKD show that there is still much to be done. Clinicians may still be hesitant to diagnose patients with CKD because they are afraid of overwhelming them with the diagnosis of a lifelong condition [17]. However, research has shown that patients want to know about their CKD, and they want to know early [18]. Clinicians should follow guideline recommendations for screening at-risk individuals using both eGFR and UACR tests.

Healthcare systems and policymakers also have an important role to play, and public awareness of CKD could be increased through broad national campaigns. Policymakers should implement changes in the care pathway to incentivize screening and diagnosis of CKD at earlier stages, and increase accessibility of blood and urine tests for CKD.

Early-stage CKD should not be ignored. Patients with undiagnosed CKD may be missing out on lifestyle changes or medical treatments that could prevent further damage to their kidneys. The benefits of early diagnosis are clear, not only from REVEAL-CKD [15] but from a wide array of research that outlines the high burden of late-stage CKD in terms of both symptoms and financial costs [10, 19, 20].

CONCLUSIONS

It is time for patients and clinicians to talk about kidney health. These conversations can spark meaningful changes in the management of diet, lifestyle, and medications [21, 22]. Patients should be empowered with knowledge: an understanding of kidney function tests could help them to become active participants in decisions affecting their own care. Similarly, clinicians should be comfortable in diagnosing CKD as early as possible and helping patients to understand their options. Efforts on the part of health policymakers to increase public

awareness of CKD, incentivize early CKD diagnosis, and enable adequate screening practices are also needed to tackle the problem. Together, these changes could drive earlier diagnosis and improve outcomes for patients with CKD. Patients want to know, and they deserve to know: know the tests, know their numbers, and know how to manage their CKD.

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Declarations

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