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Living with Chronic Kidney Disease and Type 2 Diabetes Mellitus: The Patient and Clinician Perspective

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ABSTRACT

Comorbid type 2 diabetes mellitus (T2D) and chronic kidney disease (CKD) is associated with poor health outcomes and a high economic burden. Management of these conditions remains a significant challenge for current healthcare systems. The objective of this article is to describe the experiences of patients living with T2D and CKD and their thoughts on how communication between patients and their clinicians could be improved despite the multiple comorbidities that need to be addressed. We present the individual perspectives of three patient authors, followed by relevant discussion

around the management of CKD in patients with T2D by clinician authors.

Audio abstract available for this article.

PLAIN LANGUAGE SUMMARY

People living with type 2 diabetes mellitus (T2D for short) and chronic kidney disease (CKD for short) may have worse health over time. Managing long-term health conditions can be expensive for those living with the conditions and for healthcare systems. To optimize their quality of life, people with T2D and CKD need the necessary resources to better manage their conditions. Healthcare professionals desire the

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best outcomes for their patients. Currently, communication between healthcare professionals and their patients is suboptimal, and ineffective communication creates a barrier to effective optimal care. The aim of this article is to describe the experiences of three people living with T2D and CKD (patients), who are also authors of the article. They outline their thoughts on how communication between patients and healthcare professionals might be improved when managing multiple conditions. We also present responses from three healthcare professionals (clinicians), who are co-authors of this article, to the points made by the patients, as well as their views on how to manage these long-term conditions.

Keywords: Chronic kidney disease; Diabetes mellitus; Patient perspective; Clinician perspective

Key Summary Points

Managing chronic conditions such as type 2 diabetes mellitus (T2D) and chronic kidney disease (CKD) remains challenging.

We present the perspectives of three patient authors who are living with T2D and CKD and three consultant clinician authors who give their perspectives on the management of CKD in patients with T2D in the context of the patients' experiences.

The patients noted that they desired the latest treatment and innovations. They also wanted more readily accessible, easy-to-understand educational materials explaining these medical innovations to be provided to the patient community.

After reviewing the patients' perspectives, the clinicians noted an opportunity to improve communication between clinicians and their patients at clinic visits; these communication opportunities specifically relate to issues around CKD, such as diagnosis, treatment, and prognosis, which are often not directly addressed, and the connection between T2D and CKD, as well as ways to help prevent CKD that are typically not discussed.

Additionally, the clinicians noted the existence of newer therapies/treatment approaches for the management of CKD that can help prevent CKD progression in patients who are diagnosed with CKD, i.e., secondary prevention rather than primary prevention.

Practical approaches are urgently required to improve communications/educational materials and management activities between patients and clinicians that can help address care gaps and improve the quality of care for all patients with CKD and T2D.

DIGITAL FEATURES

This article is published with digital features, including an audio introduction to the article by two of the article authors and a graphical abstract. To view digital features for this article go to <https://doi.org/10.6084/m9.figshare.21120646>.

INTRODUCTION

Because patients have first-hand lived experience of a condition, they bring an expertise and

greater understanding of living with their condition and may help to identify areas of unmet need. Furthermore, partnering with their clinician (and/or healthcare team) to provide practical information on self-management of their condition is welcomed by patients [1, 2]. The patient experience is therefore integral to patient-centered care and is likely associated with improved clinical safety, effectiveness, and health outcomes. Shared information, deliberation, and mindset are at the heart of patient-centered interactions.

Juggling multiple complicated chronic conditions such as type 2 diabetes mellitus (T2D) and chronic kidney disease (CKD) remains challenging for current healthcare systems. As a result of the poly-organ system pathology of these conditions and limited visit time, primary healthcare providers may focus on just one or two of the multiple morbidities associated with T2D per visit, and thus the attention to CKD, given its insidious nature, could be overlooked.

As a step toward healthcare improvement, this review will explore perspectives from patients on the medical management of their T2D and CKD and of their personal experiences with seeking care for these conditions. The aim of this article, coauthored by patients living with T2D and CKD and consultant clinicians, is to describe the patients' experiences of these conditions and to obtain their perspectives on how communication between patients and their clinicians could be optimized despite the multiple comorbidities that need to be addressed. Our article seeks to inform and facilitate the diagnosis and management of patients with early rather than advanced stages of CKD and T2D and aims to encourage effective communication between healthcare professionals (HCPs) and patients regarding CKD. In response to the patients' perspectives, the consultant clinicians discuss management of CKD in patients with T2D in the context of the patients' experiences.

AUTHOR BIOGRAPHIES

Susanne B. Nicholas (clinician coauthor) is a tenured Professor of Medicine at the David Geffen School of Medicine at UCLA in the

Department of Medicine, Division of Nephrology. She received her medical degree from the University of California, San Diego; Master's in Public Health from San Diego State University; and PhD in Physiology from UCLA, after completing her training in clinical nephrology at UCLA. Her research interests focus on identifying new therapies for diabetic kidney disease and modifiable risk factors for CKD progression for future interventional studies, and increasing diversity in kidney-related clinical trials.

Eugene E. Wright's (clinician coauthor) clinical specialty is primary care internal medicine. He is currently the Medical Director for Performance Improvement at the Charlotte AHEC and holds appointment as a Consulting Associate in the Department of Medicine at Duke University Medical Center. Dr Wright's clinical experience includes private practice, academic medical practice, and time at the Care Clinic (a clinic for underserved and uninsured patients run by Catholic Charities and local community philanthropic efforts in Fayetteville, NC).

Liana K. Billings (clinician coauthor) is Vice Chair of Research and Education for the Department of Medicine at NorthShore University HealthSystem. She also directs a Clinical and Genetics Research program in Diabetes and Cardiometabolic disease. She is an adult endocrinologist in the NorthShore Endocrine Medical Group and a Clinical Associate Professor in Medicine at the University of Chicago Pritzker School of Medicine. Dr. Billings is focused on designing and implementing studies that increase our understanding of diabetes, medication response, and comprehensive therapy. She conducts both investigator-led and industry-sponsored clinical trials in diabetes, obesity, NASH/NAFLD, and cardiovascular and renal outcomes.

Estela Ambriz (EA) (patient coauthor [college educated]) is a teacher in California, USA. Estela has received a diagnosis of T2D, CKD, and hypercholesterolemia.

Patrick Gee (PG) (patient coauthor [age 58; educational level: PhD]) is a retired Major/Chief of Security from the Virginia Department of Corrections and is the founder of iAdvocate, Inc., a nonprofit faith-based health and wellness

organization. He is also a patient representative for the Diabetes Kidney Disease-Collaborative Task Force and an advocate for those living with CKD and the morbid conditions that contribute to this disease. Patrick was diagnosed with CKD in 2013 and was receiving dialysis by the end of the same year. He received a kidney transplant in 2017.

Terry Peeler (TP) (patient coauthor [age 58; college educated]) served as a firefighter and paramedic for 29 years in Livingston, Alabama, USA, until illness forced him to retire in 2016. Terry is currently serving six terms as Sumter County coroner. Terry had lived with T2D for 10 years until he was diagnosed with CKD. He has been undergoing dialysis since October 2016.

Compliance with Ethics Guidelines: This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

THE PATIENT PERSPECTIVE

Identification of Patient Authors

Each of the three patient authors has participated in patient advisory boards and/or meetings that focused on kidney disease. EA and PG were patient members of a Bayer-sponsored diversity in CKD care advisory board, and TP was a patient participant in a Bayer-sponsored American Association of Kidney Patients focus group. The patient authors were invited to be authors by Bayer corporation because of their individual perspectives on their experiences with T2D and CKD. Each patient author had the freedom to answer the interview questions as they wished without influence from Bayer corporation (interview questions and answers are below). The patient perspectives provided in this manuscript are individual to the patient authors and may not necessarily be representative of all patients.

Interview Questions and Answers

What did you know about kidney disease and its relationship with diabetes when you were first diagnosed with T2D?

EA: When I was first diagnosed with T2D, I really did not take my condition that seriously. I was never informed that if I did not take care of myself it could lead to more serious conditions, so I just went about my life as usual, without making any lifestyle changes.

PG: Nothing at all. The time that I was diagnosed is when I found out the correlation between diabetes and kidney disease. I had not had a clue before then.

TP: I did not have any idea that diabetes and hypertension were related to CKD when I was first diagnosed. At the time I was being treated for heart failure.

How did your diagnosis for CKD come about? Did you have any additional symptoms that led to your diagnosis?

EA: It was actually a nurse practitioner who initially diagnosed my CKD. He ran some blood and urine tests and said that my numbers were not what they should be. After a few weeks and some follow-up tests, he confirmed that I had stage 3 CKD. He said that he was going to refer me to a nephrologist, and at that point I did not even know what kind of doctor that was.

PG: I was diagnosed with CKD in April 2013 and had progressed to receiving dialysis by December the same year. My endocrinologist was also my primary care physician, and I had been visiting her since 2003 when I was first diagnosed with T2D. It was only when I was first found out that I had CKD that she told me that I had already progressed to stage 3b and that my kidney function was between 30% and 35%. My endocrinologist referred me to a nephrologist, and it was only then that I started receiving information about kidney disease. Although I had been living with diabetes for 10 years, at no time was I ever told that diabetes was the number one leading cause for CKD.

TP: I had diabetes and hypertension for almost 10 years but had no idea of the correlation with kidney disease. I started experiencing a metallic taste, itching, and other symptoms associated with kidney disease, but up to that

point I did not know anything about CKD and its association with hypertension or blood pressure. One nephrologist checked my creatinine level and said that it did not merit starting dialysis at that time, but another nephrologist was aware that my mom and my younger brother were receiving dialysis and, because of my family history, said that I needed to initiate dialysis immediately.

Once you had your diagnosis, were you then provided with information about kidney disease? Do you feel you received enough information then? Were you happy with the amount and type of information you received?

EA: I visited several physicians, but since I was obese, their advice was always focused on losing weight and very little else. I felt that they lacked empathy. When I asked for referral to a nutritionist, my doctor was adamant that I did not need that and that I could Google information and find out for myself. I would change my eating habits and still not see anything happening. There was so much information out there, but I did not know which way to go or what to do. It was so frustrating. Finally, I broke down and gave up on myself because everybody kept telling me to lose weight like that was the solution to everything. It was really only the love and support of my husband that kept me going. He told me not to give up and to speak up for myself.

PG: Based on what I know now, I would say no. The only thing I was told was that I needed to refrain from eating certain foods like dairy, nuts, and chocolate, and that eventually I would require dialysis—that was the only information I was given. I wish that at the time I was diagnosed I was provided with literature to let me know the risk factors associated with having T2D, but I never received any of that. It was not until I started receiving dialysis and joining a number of patient advocacy organizations that I really learned about kidney disease and T2D. When it came to CKD, I was able to take a kidney education class, which helped me understand the different modalities of dialysis and make better lifestyle choices.

TP: I wish that they had talked to me earlier about the relationship between diabetes and

kidney disease and, in the end, the association with heart failure. The doctors were treating me for heart failure, not kidney disease, and I did not appreciate that these conditions all tie in together. CKD is not talked about in your doctor's office. They focus on hypertension and diabetes—CKD is an afterthought until you get it. I would have liked to have known when I had stage 1 CKD what I could do to prevent me from progressing to stage 5. By the time I found out that I had kidney disease, I was already at stage 5. Family doctors are generally focused on trying to get blood sugar and blood pressure under control. Screening for kidney disease at an early stage is often way down on the list of priorities, so many do not even consider it. If a patient is more educated and knows about appropriate tests, this could help. However, it is difficult because some physicians become offended when we ask questions about our health and additional tests that we could have.

What about additional medications for your kidney disease? Did you receive any when you received your CKD diagnosis, and have you received any subsequently?

EA: I was initially given metformin for my diabetes and was later prescribed semaglutide. I have not received any medications for kidney disease.

PG: I was not prescribed any medications for kidney disease until I started dialysis, when I received potassium and phosphorus binders. I was also given additional hypertension medication and treatment for anemia.

TP: I have never been on any medications for kidney disease. Just for diabetes and hypertension.

In terms of disease awareness, is it your impression that things have improved since your original diagnosis?

EA: One thing I have learned is that nobody knows me better than I know myself. I do not consider that my health issues are only related to my weight. I believe that other factors are involved. Of course, my obesity contributes, but I am sick and tired of just being told to lose weight. I had been seen by four or five doctors, but my situation improved when I visited a

nurse practitioner. We did not see eye-to-eye on everything, but he listened and worked with me and did not dismiss me as I felt the other doctors had. He is the one who brought me down to earth and told me that I need to start taking better care of myself, that I was not always going to be young, and that if I did not change my lifestyle, it would catch up with me sooner or later.

PG: I am going to say not in all communities. In communities of color, there is still not a lot of health literacy regarding CKD, diabetes, and hypertension.

TP: The situation has improved, but it is still not where we need to be. We have got to get the doctors to talk to us more about kidney disease and the different stages and how it is associated with your blood pressure and diabetes. My main aim would be to educate doctors on the different levels of kidney failure and to stress how important it is to transfer that knowledge to patients. As I said previously, I did not even know that there were different stages of kidney disease until I got put on dialysis. If I could have known when I was at stage 1, I could have modified my diet and lifestyle to avoid or at least slow further progression. If they are monitoring my hypertension and my diabetes, they could have monitored my kidney function at the same time.

What, if any, are the challenges associated with your treatment? Is there anything in particular that you do to look after your health?

EA: My biggest challenge continues to be my weight. I have tried various diets, but it tends to be yo-yo dieting. I went to see a weight loss specialist, but after I waited for many months, he told me that my only option was to have surgery, but I was not prepared to do that. I do exercise regularly and walk around my neighborhood at least four times a week; I also love aqua Zumba.

PG: Initially, it was a lack of knowledge. The only thing my endocrinologist would say was to exercise, and, of course, I was on two different types of insulin and that was all. Now, I am good at managing my health, so I guess a barrier would be just for me to overcome various

obstacles to finding a way to exercise in inclement weather and staying abreast of any new innovations around CKD and diabetes. COVID-19 is also having a large impact and is currently probably the biggest challenge for people with diabetes. The need to self-quarantine is creating more stress, so people tend to binge eat out of frustration and worry.

TP: The cost of insulin and other medicines has been a challenge. I am not working because of disability, and so purchasing my medication is a big financial burden. I was paying almost \$300 a month on insulin, and sometimes I would need to halve my dose to make it last longer. I live in a poor, rural area in which healthcare is often inadequate, and many people do not even have a primary physician. I have to make a 72-mile round trip three times a week to a dialysis center, which is an additional challenge and obviously incurs further costs.

What were your main sources of education and information when you first started looking into CKD, and where did you get those materials?

EA: None of my healthcare providers gave me any patient education materials about CKD or mentioned any organizations that might help. I was only able to get information by looking online. I even used Google to find my nephrologist. I had not had good experiences with local doctors, so when I was diagnosed with CKD I decided I would go to a nephrologist in San Diego, which was 106 miles away.

PG: I saw a flyer on the wall at the dialysis center for the patient advisory committee, and that is where I really learned about kidney disease and how to manage it. I was inundated with information, and one of the good things was that I was also among peers, so I was not alone. All of us were going through the same process and were able to share our experiences, good and bad. It was really beneficial. From that starting point, I then began joining other organizations because I was keen to learn more, and I also wanted to take knowledge back to the community. I am now the chairman of the patient advisory committee, and we present patient perspectives at various dialysis facilities so that we can all help each other. The goal is to

form a partnership between facilities and patients so that they can work together to bridge the gap in promoting quality care for everybody.

TP: It was only after I started dialysis that I really became educated about kidney disease. During dialysis, I have a lot of time to sit and read and learn more about CKD, and I try to spread my knowledge to different people who will listen. I am a paramedic, so I am familiar with some of the medical terms, but my biggest concern is that the patient needs to be an advocate for their own health instead of relying on the staff to inform them. You need to be your own spokesperson for your own health. The social worker at the dialysis center knew my background as a firefighter and a paramedic in the community, and he asked me if I would be an advocate for the patient organization. I am now a member of the Dialysis Patient Citizens and of the Association of Kidney Patient Advocates; the more I got involved, the more interested I became, and the more I felt that I was not on this island by myself. There needs to be more advocacy to keep people from needing dialysis, and that has to start with your primary doctor. The organization I am with is in the process of developing a toolkit for doctors' offices describing the different stages of kidney disease. I tell all of my friends to have their creatinine and glomerular filtration rate levels checked to assess their kidney function instead of waiting until it is too late. I probably had some symptoms and did not realize it.

What means do you use to reach out to patients who are not members of the groups yet? What are the main vehicles for getting new members and reaching them so they can benefit from your group?

PG: With the permission of the social worker, I started a support group. Once I started dialysis, we would meet every month, and I would bring in information that I gathered from the patient advocacy organizations that I was with to share with the patients in the support group. The social workers in the facility here at the dialysis center were a bit hesitant at first, but then they understood how beneficial this was. The more education a patient has, the

better they can manage their disabilities. It really worked out well.

TP: We have a website, but being from a rural area, there are issues with the internet, so I try to do most of my talking in the clinics. Since I have been an advocate, I talk to families about the risk factors associated with kidney disease and tell them what I did not know: that the two causes of being on dialysis are diabetes and hypertension. I also encourage people to study their family history. I know that my mom has been on dialysis for almost 30 years and my brother has been on for about 15 years, but I found out that there is also kidney disease on my dad's side of the family.

What is your relationship like with the medical clinical staff involved in your treatment?

EA: When I was diagnosed with diabetes, I was told to watch my weight and then dismissed. As I previously mentioned, I had visited a number of doctors before I found somebody that I could relate to: a nurse practitioner. He is the only person who took the time to talk to me about diabetes. He did not refer me to an educator or nutritionist, but he actually took the time to test my blood and urine. He is the one who diagnosed my CKD. I have now been visiting my nurse practitioner for 5 years without ever seeing a physician. Recently, I have been told that I need to see a doctor at least annually, but I question what they can do for me if I only have one consultation a year, compared with the nurse practitioner whom I visit every three months.

PG: I have an excellent relationship with my care team. I am also working with a nutritionist in a weight loss clinic right in the same hospital where I underwent my transplant. Those two departments working together has really helped me with improving my quality of life. It is important to me to be able to have an informal conversation with the clinical staff and for them to ask about my interests and what I am doing in terms of my advocacy before we get to the dialysis. It allows me to see the humanity that had been missing in my healthcare and to know that, at any given time, I can have access to my

care team, whether by phone or through messaging via the patient portal.

TP: I have a good relationship with the clinical team, although I think that they could be more empathetic at times. I know that the staff are under a lot of pressure, but sometimes it feels like a production line, in that they have to put you on and take you off dialysis by certain times. More interaction during dialysis would be appreciated.

How do you think the communications between physicians and patients can be improved?

EA: I definitely think that the physicians I have seen need to learn how to be more empathetic. I work with children with special needs. Their behavior is often erratic, and I do get frustrated, but I do not show them that. I put myself in their shoes and work harder to try to understand them and help them through when they have a crisis. I just feel that the doctors I have seen could have shown a little bit more empathy too.

PG: As people with CKD, we all have an affliction, and we need those who care for us to see us as individuals. We may be fearful of the prognosis that we get because nobody likes bad news, but at the same time, we need to understand that physicians and healthcare workers are under tremendous scrutiny and pressure to provide better health outcomes. I think if there is more collaboration, if there is some sort of partnership when we go to medical appointments or when we are allowed to participate on certain workgroups and committees, then that would help to bridge the gap and enable us to communicate in a more humane manner.

TP: I like to receive information by word of mouth from my physicians and maybe follow up with an email. I am also a member of an organization (a dialysis patients' citizen group) that is trying to pass a bill (the Care Act) to make sure that your nephrologist and your doctor are on the same page when they are prescribing medicine. They are trying to make it mandatory for them to communicate more with each other. Currently, the nephrologist visits my clinic once a month, and I have an appointment with my primary doctor every

three months, which I do not believe is enough. I think more frequent consultations via teleconference is the way forward to improve communication and identify issues earlier.

The most important message to convey to those living with T2D and CKD

The consensus among the patient coauthors was that they are three people from different walks of life and different regions of the country, but they share similar stories. When patients read this, hopefully they will see themselves and recognize people who are dealing with the same afflictions that they are. The patient coauthors want people to be able to have access to the latest innovations and newer medications. This is what patients are craving for, and as long as people have hope, they can better persevere. If this can happen, it would really be a game changer, not only for people with CKD, but for those with heart disease and those newly diagnosed with diabetes. The American Society of Nephrology is trying to work on an initiative to get Congress to support making these innovations cost-effective because they know how beneficial this is. The patient coauthors would like to see more readily accessible, easy-to-understand educational materials explaining these medical innovations provided to the patient community so that they can have a relevant conversation with their primary healthcare providers before it is too late. We have come a long way in the past five years, but we still have a long way to go.

THE CLINICIAN PERSPECTIVE

Historical Perspective

Management of CKD associated with T2D requires a multifaceted approach, encompassing increased awareness by clinicians and patients, lifestyle modifications, glycemic control, cardiovascular risk mitigation, and blood pressure regulation with a renin-angiotensin-aldosterone system (RAAS) inhibitor, in addition to newer therapies that have been proven to reduce risks of CKD progression and kidney failure. It is also important to remember

that CKD and diabetes may be complicated by non-diabetic kidney diseases, such as minimal change disease or focal segmental glomerulosclerosis, so consideration of conditions that may run alongside CKD in T2D is needed [3].

Historically, the primary tools for reducing the risk of onset of CKD, CKD progression and CKD complications in T2D was adequate control of blood glucose, blood pressure, and cholesterol (lipid) levels [4–7]. Additionally, for many years, angiotensin-converting enzyme inhibitors (ACEis) and angiotensin receptor blockers (ARBs) have been used to prevent progression of kidney disease in people who have early signs of disease, such as elevated urine albumin-to-creatinine ratio (UACR), and elevated blood pressure [4, 5, 7]. With the drive to conduct longer-term clinical outcomes trials in diabetes, more recent studies have shown that additional agents, including sodium-glucose cotransporter 2 (SGLT-2) inhibitors and the nonsteroidal mineralocorticoid receptor antagonist (MRA) finerenone, provide risk reduction of CKD progression in patients on maximum-tolerated ACEi or ARB therapy or intolerance to ACEi or ARB therapy [8–11]. These additional available interventions have reinvigorated the medical community to treat and prevent progression of early CKD to end-stage kidney disease.

While the patient coauthors' experiences appear to be consistent with effective ways of reducing risk of CKD and CKD progression, including blood pressure and blood glucose control, solely controlling these parameters does not fully prevent CKD. The implementation of old and new pharmaceutical agents may reduce this residual risk further. Consistent with the patient stories in this article, it was perceived that the patients' CKD was not addressed at clinic visits; it was not effectively communicated to the patients that optimal control of blood glucose and blood pressure, in addition to other interventions such as lipid control and weight loss, are the main ways to prevent CKD and CKD complications in people who do not yet have the disease. RAAS inhibitors can be used for hypertension in patients who do or do not have diabetes and for the management of CKD in patients with diabetes and albuminuria

[12]. SGLT-2 inhibitors were initially used as blood glucose-lowering agents in patients with diabetes but are now recognized to have kidney and cardiovascular protective effects [12]. Finerenone is a newer kidney protective medication that can be used in patients with CKD and diabetes to reduce the risk of CKD progression [12, 13]. Additionally, it is apparent from their experiences that the connection between obesity, diabetes and kidney disease, and between diabetes and kidney disease was not effectively communicated by the healthcare provider (HCP). So, while this might have been interpreted as though the clinician was avoiding the topic, in actuality, these are essential elements in their treatment of CKD that should be included in discussions. It is also important during these discussions with patients that the clinician or HCP does not inadvertently mislead the patient into thinking that if they follow all the prevention advice, it will remove all risk of them developing CKD, because this is not necessarily the case; following the advice should reduce their risk of developing CKD but may not eliminate it. This education clearly needs to be more effectively communicated to patients by the medical team.

Because our understanding about the mechanisms of CKD has broadened, and available therapies have expanded over the past 3 years, we now have an opportunity to speak about risk reduction in a different way with improved, targeted treatment options. Indeed, recent major advances have positively influenced our ability to treat CKD in patients with T2D, and their associated cardiovascular complications. As described previously, evolving evidence regarding the new therapies and their combination will likely continue to impact the standard of care for patients with CKD and T2D.

Shared Decision-Making

In order to improve communication with our patients, it is important to take a more patient-centric approach. Ultimately, this could lead to enhanced quality of care, improved patient experience, and subsequent risk reduction in the development of complications. To increase

Table 1 Examples of focused questions that a clinician can ask to gain their patient's perspectives on their T2D and CKD and cover the treatments options available to them

1. What is your understanding about T2D and CKD?
2. What concerns (if any) do you have about conditions or organs affected by T2D?
3. What concerns (if any) do you have about having T2D?
4. What is your understanding of the relationship between good T2D control and complications?
5. What is your understanding of the long-term problems that can occur due to uncontrolled blood glucose in T2D?
6. What do you want to accomplish in the management and treatment of your T2D?
7. Are you clear on the preventative measures that you can take (independently of drug treatments) to reduce your risk for or slow the progression of your CKD?
8. Do you understand the reason for inviting you for annual screening checks for CKD, even though you may have no CKD symptoms?

The answers to these questions can also be used to gauge the patient's current level of understanding about these aspects and prompt further discussion and learning
CKD chronic kidney disease, *T2D* type 2 diabetes mellitus

the quality of medical consultations to a more shared decision-making process, clinicians may consider asking patient-focused questions related to CKD to ensure their patient's understanding of the interventions and medications that are being used to prevent complications (Table 1). Additionally, clinicians should be prepared to answer questions their patient may ask about their T2D and CKD risks (Table 2) [4, 5, 7, 12–19]; the answers given should consider the patients' level of health literacy and be communicated in a clear and consistent way to ensure understanding and to promote effective dialogue. The responses from the patient coauthors suggest that in some instances there was ineffective communication by their HCPs. It is

difficult to believe that there was intentional neglect on behalf of the HCPs, using a patient-centric approach in conveying information on a specific disease state, as well as a shared decision-making approach to treatment strategies, will hopefully result in more effective and gratifying interactions between the patient and the clinician.

There is also the need to address the fact that the intentions of HCPs are sometimes misinterpreted or, in many cases, discussions around relevant topics are simply forgotten by the patient [20, 21]. Tools such as the Agency for Healthcare Research and Quality toolkit can help in improving health literacy among patients [22], but it is possible that some patients may not be receptive and do not hear or understand what their doctor is saying and may not remember much of what they have been told even within a short time following a consultation. This is particularly true in the early stages of CKD when the condition is "silent" [23] and patients are not as "tuned in" or open to receiving pertinent education. As such, clinicians may want to encourage patients to be more amenable to receiving teachings related to the earlier stages of CKD. For example, the experiences of the patient coauthors are supported by a recent survey by the American Health Information Management Association in which the majority of respondents reported being disappointed by questions and answers exchanged with their physician and confused about their health [24]. Most (80%) stated that they were likely to research medical recommendations online after an appointment with their physician, and 22% of respondents said that they did not feel comfortable asking their physician certain health questions.

It is essential that we start by grasping what patients truly understand before they leave our offices. Individuals can access a wealth of information via the internet and/or social media. In a recent survey of US patients, 39% of respondents reported turning to the internet (using search engines such as Google) when looking for reliable health information [25]. In addition, 9% evaluated new treatment options and 7% obtained information about drug side effects via social media. It would therefore seem

Table 2 Examples of questions patients may ask their clinician/HCP during a clinic visit

Question	Response guidance for the clinician/HCP
1. Is there a connection between T2D and CKD?	Having T2D is a risk factor for developing CKD. <i>(Things that the patient could do to reduce their risk of developing CKD are noted in the answer to question 5 below.)</i>
2. What other conditions related to T2D can cause or worsen CKD?	In addition to T2D, having high blood pressure (hypertension) and heart (cardiovascular) disease and being obese can increase the risk of developing CKD or worsen CKD
3. What are the possible complications of uncontrolled blood glucose in T2D?	Uncontrolled high blood sugar levels can cause complications such as heart (cardiovascular) disease, CKD, and vision loss
4. What are the stages of CKD, and what do they mean?	<p><i>The text in this section assumes that a patient has a very good understanding of CKD already, so if this is not the case for your patient, adjust your language accordingly to ensure understanding.</i> CKD is classified as early CKD (CKD 1 and CKD 2), moderate CKD (CKD 3a and CKD 3b) and advanced CKD (CKD 4 and CKD 5 or kidney failure). Early CKD stages are often asymptomatic, so it is important that the patient asks you or one of their other diabetes care providers about kidney function screening and diagnosis. <i>(As part of the answer to this question, you may want to show the patient Fig. 1ii [4], which gives information on how CKD is staged as well as progression risk.)</i></p> <ul style="list-style-type: none"> • CKD stage is typically determined using two approaches <i>(although clinical features and biopsy examination may also be used)</i>: (1) by taking a blood sample, processing it, and calculating the eGFR (the eGFR value tells us how well the kidneys are functioning; the higher the value, the better); (2) by taking a urine sample and calculating the UACR (albumin in the urine [albuminuria] suggests kidney damage, so the lower the UACR value, the better) • A person with CKD stage 1 has some kidney damage but with normal or high-level kidney function (UACR < 30 mg/g and eGFR ≥ 90 mL/min/1.73 m²) • A person with CKD stage 2 has some kidney damage with some loss of kidney function (eGFR ≥ 60–89 mL/min/1.73 m²). CKD stages 1 and 2 may be asymptomatic • CKD stage 3 has moderate kidney damage and moderate loss in kidney function and the patient may begin to develop symptoms. Patients may be at CKD stage 3a (eGFR 45–59 mL/min/1.73 m²) or the more advanced CKD stage 3b (eGFR 30–44 mL/min/1.73 m²) • CKD stage 4 is advanced CKD where patients often have advanced kidney damage with a severe decrease in kidney function (eGFR 15–29 mL/min/1.73 m²). It is likely that a kidney transplant or dialysis will be needed in the near future • CKD stage 5 is the most advanced stage and is called end-stage kidney disease or kidney failure (eGFR < 15 mL/min/1.73 m²); at this stage the kidneys have lost almost all function, and dialysis or transplant may be required to sustain life
5. What do you recommend that I know from the very beginning of being diagnosed with T2D as far as risk of CKD?	<p><i>(As part of the answer to this question, you may want to show the patient Fig. 1i)</i></p> <p>High blood sugar levels (hyperglycemia) that occur in T2D can cause harm to the kidneys in just a couple years. Therefore, having an A1C of 7%^a (or as recommended by the patient's HCP) will reduce the patient's risk of developing CKD. It is also important that they control blood pressure, lose weight if needed, and control cholesterol levels to help reduce their risk of developing CKD. If they start to develop signs of CKD (and CKD is confirmed), there are medications that could slow progression of the disease</p>

Table 2 continued

Question	Response guidance for the clinician/HCP
6. What kind of medications are used to prevent worsening of CKD?	<ul style="list-style-type: none"> • ACEis or ARBs are used for patients with diabetes who have high blood pressure. ACEis or ARBs are also used (up to the maximum tolerated dose) for patients with diabetes, high blood pressure, and albuminuria (UACR \geq 300 mg/g and/or eGFR $<$60 mL/min/1.73 m²). Depending on local practice, ACEis or ARBs may also be used for high blood pressure in the absence of albuminuria with or without a T2D diagnosis [6] • SGLT-2 inhibitors are drugs that were initially prescribed to lower blood sugar levels but are now known to have benefits in reducing CKD progression and heart (cardiovascular) events in patients with moderate-to-severely impaired kidney function (eGFR \geq 20 mL/min/1.73 m²) • Finerenone, a nonsteroidal mineralocorticoid receptor antagonist, will also help reduce CKD progression and heart (cardiovascular) events or can be used in patients unable to use an SGLT-2 inhibitor
7. Where can I get reliable and patient-friendly information about CKD outside of my medical visits?	<p><i>You may want to write or print out a copy of the following resources for the patient:</i> The National Kidney Foundation (www.kidney.org) and the American Kidney Fund (www.kidneyfund.org) websites offer user-friendly information targeted at all people affected by kidney disease (including CKD) in the USA. Information includes advice about kidney health, risk factors for kidney disease, symptoms, treatment, and testing. The American Kidney Fund notes that they are a leading kidney nonprofit organization that works on behalf of Americans living with kidney disease as well as those at risk of developing kidney disease to “fight kidney disease on all fronts.” The American Diabetes Association also provides patient-friendly information on T2D and associated conditions via their website (www.diabetes.org/diabetes)</p>

The questions are based on the experiences of the patient coauthors, who noted a lack of effective communication exchange during consultations with their clinician/HCP. The response guidance in the right-hand column of the table is directed to the HCP/clinician and should not be relayed to the patient verbatim, but instead communicated on the basis of the patient’s level of health literacy. Points of note for the clinician/HCP in the example responses are in italics [4, 5, 7, 12–19]

ACEi angiotensin-converting enzyme inhibitor, *ARB* angiotensin receptor blocker, *CKD* chronic kidney disease, *DCCT* Diabetes Control and Complications Trial, *eGFR* estimated glomerular filtration rate, *SGLT-2* sodium-glucose cotransporter 2, *UACR* urine albumin-to-creatinine ratio, *UKPDS* UK Prospective Diabetes Study

³50–76% reduction DCCT with A1C of 7% vs 9%; 25% reduction UKPDS with A1C of 7% vs 7.9%

appropriate for clinicians to ask patients what they already understand about their condition at the outset of the consultation. Physicians should acknowledge and commend individuals when they are correct and provide credible patient-centric resources when they are confused or misinformed. An understanding of the patient’s motivation and commitment to their own care can facilitate their empowerment to adopt a healthier lifestyle early in the course of kidney disease that can lead to beneficial impacts on their clinical outcomes. Indeed,

HCPs should refer patients to reliable and credible sources of health information on the internet.

It is also important to remember that CKD in patients with T2D is associated with multiple comorbidities, and as such present many medical management challenges that may significantly impact the daily lives of those living with this condition. A multidisciplinary team approach in both primary care and specialist settings is beneficial to ensure that the diagnosis and ongoing management of CKD in this

population are prioritized [26]. Such team-based care, akin to the “Quadruple Aim” [26, 27] may slow disease progression, improve outcomes, decrease cost of care, and improve patient and HCP satisfaction. A potential strategy to contend with the multiple comorbidities often observed could be to inform the patient that discussions on a variety of topics are planned over several future consultations and encourage the patient to choose their highest priority and address that topic first. It should be emphasized that all of the conditions (e.g., T2D, cardiovascular disease, CKD) are interrelated and that subsequent individual risk factors will be addressed at future visits.

Resources

In order to facilitate shared decision-making between HCPs and patients and to assist with the selection of healthcare options, it seems clear that more information resources are required. Educational materials should be designed to assist patients to become more involved in their treatment, determine why one option may be better for them than another, and increase awareness and understanding of the potential risks and benefits of different choices and the likely outcomes.

It would be helpful to provide HCPs and patients with a set of simple and practical tools to optimize their care and achieve the best possible outcomes. Checklists for HCPs and patients to navigate jointly may prompt discussion and can be visually appealing. Figure 1 (parts i and ii) shows a clinical pathway for T2D and CKD and includes the classification of CKD, the risk of CKD progression, and cardiovascular risk that a clinician could talk through with their patient during a clinic visit [4, 12, 14]. The recommendations in the figure are based on the 2022 American Diabetes Association (ADA) treatment guidelines [12], the 2022 ADA/Kidney Disease Improving Global Outcomes (KDIGO)–consensus statement [14], and the 2020 KDIGO treatment guidelines [4]. The pathway discussion would provide information on the prevention of CKD as well as screening, monitoring, and staging of CKD. Figure 1i could

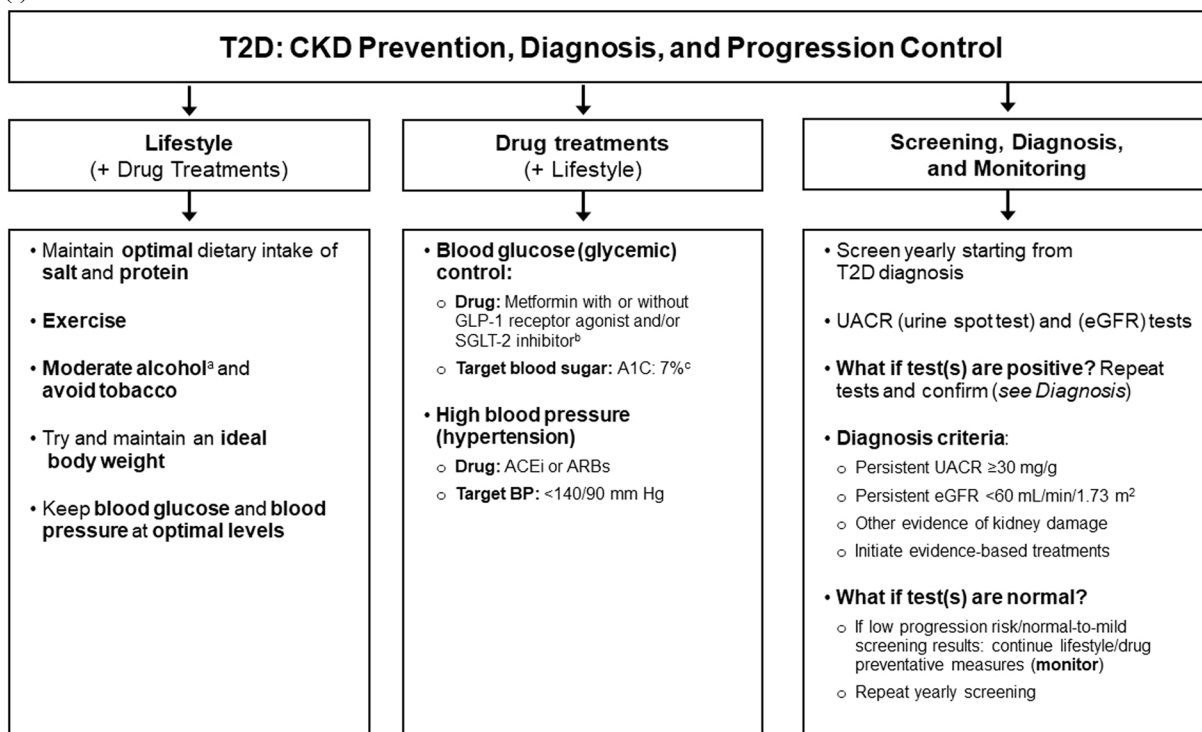
be printed onto a card and aspects of the pathway relevant to the patient discussed during the visit, thereby encouraging dialogue between patient and clinician.

In addition, easy-to-digest infographics have proved to be efficient, easily reproducible, and powerful tools in various therapy areas to facilitate the process of patients understanding the causes or risks related to a disease or condition [28–30]. Such infographics are often used in patient-accessible online disease information sites such as the CardioSmart infographic on T2D (published by the American College of Cardiology) and the “Diabetes: Facts, Statistics, and You” infographic series published by Healthline (www.healthline.com). It is important to use plain, unambiguous language with simple illustrations throughout and ensure patients’ understanding of the key points of the information being provided.

Another observation from the patient responses received is that resources, education, and support may often be reserved until the patient is at end-stage kidney disease, when they have the least chance of making a difference; this seems akin to fishing bodies out of a river rather than stopping people from jumping in. Therefore, it would be beneficial to include diabetes educators and patient partners to increase appropriately timed referrals at diagnosis of T2D and to incorporate CKD awareness, early detection, and prevention strategies in their patient education materials. The evidence suggests that referrals to diabetes education and support are woefully underused [31, 32]. These strategies could help clinicians to intervene early and care for the expanding population of patients with advanced CKD.

The patient coauthors in this article want to have a voice to advocate for themselves and others. We should embrace and enable patients to be advocates for themselves and for others with a similar condition, empowering them to be more proactive through peer-to-peer mentoring and directing other patients to access reliable information. Talking to another patient who has had the same or similar experience may give someone a better understanding of living with their condition and help them make informed decisions.

(i)



(ii)

Prognosis of CKD by GFR and albuminuria categories: KDIGO 2012				Persistent albuminuria categories		
				Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30-300 mg/g 3-30 mg/mmol	>300 mg/g >30 mg/mmol
GFR categories (mL/min/1.73 m ²) Description and range	G1	Normal or high	≥ 90			
	G2	Mildly decreased	60-89			
	G3a	Mildly to moderately decreased	45-59			
	G3b	Moderately to severely decreased	20-44			
	G4	Severely decreased	15-29			
	G5	Kidney failure	<15			

CONCLUSIONS

While understanding of CKD in patients with T2D continues to improve and new treatments

to prevent progression are emerging, patients and clinicians still face several challenges, as the experiences of the patient coauthors demonstrate. Practical approaches with effective

Fig. 1 Proposed clinical care pathway for patients with T2D that could be discussed during a clinic visit. (i) Prevention, screening, and CKD progression control [12, 14]. ^aNo more than one alcoholic drink per day for adult women and no more than two drinks per day for adult men [12]. ^bGLP-1 receptor agonists and/or SGLT-2 inhibitors with or without metformin depending on glycemic control needs, with or at high risk of CVD and/or CKD. ^c50–76% reduction DCCT with A1C of 7.0% vs 9.0%; 25% reduction UKPDS with A1C of 7% vs 7.9%. The 2022 ADA guidelines and 2020 KDIGO guidelines recommend an A1C goal of < 7% and a range of < 6.5% to < 8.0%, respectively [5, 12]. (ii) Staging of CKD using the KDIGO staging heat map [4]. (*Reprinted from Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease, Vol.3 [Issue 1], Kidney Disease Improving Global Outcomes [KDIGO], p. 34, Copyright 2013, with permission from Elsevier on behalf of International Society of Nephrology. Published by Elsevier Inc*). The eGFR and albuminuria grid notes the risk of progression, morbidity, and mortality by color, from best to worst (green, yellow, orange, red, dark red). Green can reflect CKD with normal eGFR and UACR in the presence of other markers of kidney damage (e.g., imaging showing polycystic kidney disease or kidney biopsy abnormalities), with yearly follow-ups; yellow requires caution and measurements at least once per year; orange requires measurements twice per year; red requires measurements three times per year; and dark red requires measurements four times per year. However, the approach should be patient-centered on the basis of underlying comorbid conditions and disease state. Patients may be referred (nephrology; depending on local arrangements) if there is significant albuminuria (UACR \geq 300 mg/g) and/or a severely decreased eGFR (\leq 29 mL/min/1.73 m²) [12]. *ACEi* angiotensin-converting enzyme inhibitor, *ARB* angiotensin receptor blocker, *CKD* chronic kidney disease, *CVD* cardiovascular disease, *DCCT* Diabetes Control and Complications Trial, *eGFR* estimated glomerular filtration rate, *GLP-1* glucagon-like peptide 1, *KDIGO* Kidney Disease Improving Global Outcomes, *SGLT-2* sodium-glucose cotransporter 2, *T2D* type 2 diabetes mellitus, *UACR* urine albumin-to-creatinine ratio, *UKPDS* United Kingdom Prospective Diabetes Study

resources are urgently required to improve activities/communications that can help address care gaps and improve quality of care for all patients with CKD and T2D throughout their journey.

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Disease Collaborative-Task Force. Kidney Health Initiative (KHI) APOL-1 Steering Committee. Patient Family Centered-Care Partners (PFPC partners) Diversity, Equity, and Inclusion Workgroup. University of Washington's CDI Human Factors Working Group. National Kidney Foundation Health Equity Advisory Committee. Organ Procurement Transplant Network Kidney Transplant Committee Advisory Board. National Kidney Foundation Spring Clinical Meeting Planning Committee. American Kidney Fund (AKF) Ambassador & Certified Kidney Health Coach. National Kidney Foundation (NKF) Kidney Advisory Committee (KAC) member and Your Kidney and Me Certified Instructor. United Network of Organ Sharing (UNOS) Ambassador. Patient-Centered Outcomes Research Institute (PCORI) Ambassador. American Association of Kidney Patients (AAKP) Ambassador. Donate to Life DC and VA Ambassador. National Coordinating Center (NCC) Patient Family Engagement-Learning Action Network (PFE-LAN) SME and Legacy member. CareDX Ambassador and Speaker's Bureau. Consultancy: Project Tech. Evidation Health, CareDX, VCU Health, and Virginia Union University. **Terry Peeler:** has no disclosures to make in relation to this article/work.

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