

The Patient Voice in Health Care Decision Making

The Perspective of People Living with Diabetes and CKD

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Learning you have diabetes is one of those moments you never forget. In an instant, your life has changed, and you have no idea what direction it has taken. Most patients who are diagnosed with diabetes know little about it, or about the CKD many will face as a result of diabetes. Unsure what questions to ask, patients travel a path filled with challenges, doing the best they can with directions from their physicians and health care teams. And often, they do not participate in decisions about their health care. At this stage, key decisions are being made, such as the level of self-care required by the patient, setting reasonable hemoglobin A1c goals, potential changes in lifestyle, and especially those related to diet and exercise. It is also important at this time to establish a strong partnership between the patient and physician.

But we strongly believe that all patients should have a say in decisions that affect their well-being. Because we both have a history of diabetes and CKD, we were asked to participate in a work group to develop clinical practice guidelines for managing patients with diabetes and CKD. The group was established by the Kidney Disease: Improving Global Outcomes (KDIGO) organization, and it included an international group of physicians who treat the broad array of effects diabetes and CKD can have (1).

The work group produced the KDIGO 2020 Clinical Practice Guideline for Diabetes Management in Chronic Kidney Disease. Being part of that group gave us a unique opportunity to explain how the patient's voice can help improve health care decisions. Sharing our views with physicians—and having them listen and carefully consider what we said—was extremely gratifying. The benefit of patient involvement in creating the guidelines was most evident when discussing topics that involved patients being asked to change or alter aspects of their lives. As patients, we were able to state that what may seem reasonable to a physician may not necessarily be reasonable for a patient. One example is setting appropriate hemoglobin A1c goals for patients with type 2 diabetes and CKD. Tight control can often lead to hypoglycemia, and we questioned whether the risk of numerous episodes of hypoglycemia was worth setting a hemoglobin A1c goal at a level that may compromise the health of the patient. Each patient is different, and although a goal of 6.5% may work for some, 7.5% may be more realistic

for others because of lifestyle, age, and multiple health issues. This article explains why we think it is important for patients to take part in managing their diabetes and CKD, and highlights some of the recommendations of the management guidelines.

What Are the Benefits of Physicians and Patients Working Together?

Physicians have the medical training to treat the many health problems diabetes and CKD create. But patients know their bodies, and when something goes wrong, patients are often the best source of information for physicians considering treatment plans. Patients and physicians working together can make much better decisions about how to manage both type 1 and 2 diabetes, and CKD.

The KDIGO management guidelines note that every patient is different, with an individual lifestyle, so what works for one patient may not work for another. For example, it is critical for people with diabetes and CKD to monitor their own eating habits to maintain a well-balanced and moderate diet. But that diet may not be the same for everyone because patients may be more active, or less active, and differ in other ways. When patients and physicians both take part in decisions about diet and agree on a program that meets the needs of a given patient, both patients and physicians benefit.

Another crucial part of good health for patients with diabetes and CKD is maintaining a healthy hemoglobin A1c level. The KDIGO management guidelines recognize that the best hemoglobin A1c level can vary somewhat among individual patients. So, a key recommendation of the guidelines is that physicians establish specific hemoglobin A1c targets for individual patients, within a given range. Physicians who work closely with their patients are better able to determine such targets; and patients who work with their physicians to learn about diet are also better able to deal with the struggles of achieving their hemoglobin A1c targets.

How Can Patients and Physicians Listen to Each Other?

Patients do not always know they can take an active role in their health care, because that was not common

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in the past. One of the questions they often ask, in conversations about the importance of being part of their own health care team, is “How do I do that?” It is an excellent question, and one that not only the patient, but also the physician and health care team, should address.

At times, patients may feel like they are not on the same page as their physicians. In that case, it is critical for patients to speak up, ask questions, and make their voices heard before physicians make final health care decisions. Physicians should not assume they know what patients want and need. They, too, must ask questions and get to know their patients so that they can develop a treatment plan that is not only in the best interest of the patient medically, but also fits the patient’s lifestyle.

Many patients are living not only with diabetes and CKD but other health problems, such as hypertension and high cholesterol. Patients may become frustrated with so many issues to deal with, but it can be equally frustrating for physicians when patients are uninformed and unable—or unwilling—to take part in their own care. Patients should try to understand everything they can about diabetes and CKD. Besides asking questions, they should do research and talk with other patients who face similar issues.

Physicians must listen to their patients’ voices. They should communicate often and clearly and take the time to explain things, because it is the sharing of information that allows patients to learn and help with their own care. Physicians should encourage patients to be proponents of their own health care, and offer patients examples of how they can work with others to make that happen. For patients, adhering to a specific treatment plan can depend as much on a good working relationship with their physician as on the physician’s medical training.

How Can Patients Be More Active?

Besides asking questions and learning about their health problems, patients have another tool that can significantly help them contribute to health care decisions: technology. Today, patients can learn about new tests their physicians have ordered, look up results of their laboratory tests, and use text messages to quickly let physicians know about changing symptoms. Patients who take the time to review test results and try to have at least a basic understanding of what they mean can be a valuable resource as physicians consider treatment plans.

Diet is another area where patients can be active in managing their own health. Patients may not be able to eat all the foods that they want, including those that interact with specific medications, but working with dietitians and their health care teams can reveal many new options. Patients who are willing to educate themselves about diet and nutrition, and are motivated to adopt a sound diet plan, are more likely to improve their own health.

Can Physicians Make More Time to Hear Patients?

We want to recognize that even when physicians are willing to listen to their patients’ voices, they may face a very real constraint: the cost of spending more time with patients. Often, physicians are encouraged to see as many

patients as possible every day, not allowing them enough time to really talk with and educate patients, let alone develop comprehensive treatment plans. And even if patients want to participate in their own care, limited time with physicians can oftentimes make that difficult. Physicians who can delegate part of their patients’ care to other members of the health care team, such as a dietician or an ophthalmologist, are able to focus more on working together with patients to make important health care decisions.

What Can We Conclude?

There are many ways patients can become partners with their physicians in managing their diabetes and CKD. They should ask thoughtful questions about decisions that will affect their health. They should educate themselves about diet and other factors that are critical to their well-being. Patients should use current technology to help them understand the results of medical tests and communicate quickly with their physicians. They should work with and learn from dietitians and others on their health care teams.

Physicians also have a responsibility to listen to their patients and learn about them: the best health care decisions are based not only on a physician’s experience and knowledge, but also a patient’s lifestyle and preferences. With close cooperation between patients and physicians, the work of the health care team will be enhanced, and the lives of patients will be better.

In conclusion, we say to our fellow patients: speak up and let your voice be heard—your life may depend on it.

Disclosures

T. Sadusky reports serving as a scientific advisor or member of Transplant House, Board of Directors, University of Washington, Kidney Research Institute, Patient Advisory Council, University of Washington: Transplant Advisory Council, Kidney Education and Support Group, and Team Transplant Strategic Planning Committee, and speakers bureau for AstraZeneca, Kidney Disease: Improving Global Outcomes, and NovoNordisk. The remaining author has nothing to disclose.

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