What is patient engagement? How does a physician define it, and how does a patient define it? I would think that each has a different perspective of what it is and what it truly entails.

Kevin Fowler: To define patient engagement, we also need to define patient-centered care. In 2001, the Institute of Medicine (IOM) generated a seminal report, “Crossing the Quality Chasm” (1). In the report, the IOM defined patient-centered care as “providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.” Healthcare that is designed and delivered in a patient-centered manner provides an environment for patient engagement to flourish.

For a working definition of patient and family engagement, I use the definition given in Health Affairs (2): “Patient and family engagement as patients, families, their representatives, and health professionals working in active partnership at various levels across the healthcare system—direct care, organizational design and governance, and policy making—to improve health and healthcare. Although we use the term patient engagement for simplicity’s sake, we recognize that those who engage and are engaged include patients, families, caregivers, and other consumers and citizens.”

Dr Lederer: I suspect that there are many different ideas about what defines patient engagement, even among physicians, ranging from the most simple, adherence to a therapeutic regimen, to the most complex, patient-driven healthcare decision-making. Perhaps patients, too, have a similarly wide range of definitions of patient engagement.

Most patients and physicians probably envision some middle ground. I can speak most comfortably about the physician standpoint, because I have fortunately never really had a significant chronic illness. I see a wide range of patient engagement from nearly complete acceptance of decision-making by the physician to presentation of a list of questions and desired therapeutic options to be discussed. Patient engagement to me implies active interest in the disease process, therapies, and outcomes. It means that patients question my testing and recommendations and is willing to have a discussion.

What are the benefits of patient engagement to patients?

Kevin Fowler: There is evidence that patient engagement improves healthcare outcomes. I firmly believe my successful health outcomes are partially attributable to my engagement with my health. By being engaged, I feel that I have some control over my health. I influence the health dimensions within my control: adherence, wellness behaviors, specialty appointments, etc. I achieve a certain peace by controlling what I can control.

Most important, patient engagement shapes my priorities. Health is a priority in my life. I exercise routinely and meditate daily because I have learned how these behaviors enable me to weather and navigate the stormy seas associated with a chronic disease. Although our healthcare system does not reward these behaviors, I have seen their power to strengthen my physical and mental health.

Dr Lederer: The benefits of patient engagement are extraordinary. A patient who asks about medication side effects, looks up his/her disease on the internet, joins a support group, and engages in continuous follow-up provides the elements for an incredibly satisfactory and mutually beneficial relationship. A patient who understands the pros and cons of therapeutic choices and who understands that a therapy may not have the desired result in all cases allows for a safe and nonthreatening relationship.

What are the benefits of patient engagement to the greater nephrology community?

Kevin Fowler: In the short term, patient engagement would help nephrologists lower costs, improve outcomes, and achieve greater professional satisfaction while improving productivity and efficiency.

In the long term, it would raise expectations for patients. As patients advance across their level of being actively involved in their own care, they will learn that the field of nephrology innovation has stalled. Studies looking at improving quality of life for dialysis patients and transplant recipients have been limited, and 5- and 10-year mortality outcomes remain unchanged. Moreover, the treatments for kidney disease have been very limited. For example, although I am at least the 4th generation in my family with polycystic kidney disease (PKD), there are still no approved treatments for the disease. Since my children have a 50% chance of inheriting PKD, I want them to face a brighter future.

What are the potential downsides of patient engagement?

Kevin Fowler: There are some patients for whom their condition limits their ability to be engaged. For example, a patient with a severe stroke may have limits placed on their cognitive functioning or their ability to communicate. In these situations, patient engagement may occur through their caregiver. In other situations, there are patients who have no fixed limits on their engagement, and they choose not to engage. As the saying goes, “You can lead a horse to water, but you cannot make it drink.” I have seen situations like this. Even after a major health event, some patients do not view their health as a priority.

Dr Lederer: The potential downsides of patient engagement, at least in my mind, are nearly nonexistent. Some physicians may become irritated when patients come in with information that they have gleaned from the internet, Dr. Oz, or neighbors. Some patients have very strong feelings about how they view the medical profession. They may wish to use only “natural” remedies. They may not wish heroic, cumbersome, or expensive therapies for a variety of reasons. I view these events as opportunities for education and deepening the relationship, developing trust, and education.

What organizations are leading the way in patient engagement?

Dr Lederer: There are several organizations that are promoting patient engagement. There are support groups and foundations for many illnesses, including kidney diseases, where patients interact and share more seasoned and knowledgeable individuals mentor newer members in disease process, questions to ask the doctor, side effects of medications, and the like. The Kidney Health Initiative (KHI), a partnership between the American Society of Nephrology and the Food and Drug Administration, has actively engaged patient groups to develop patient-centered projects to guide clinical trials in aspects of kidney diseases that are important to patient quality of life, not simply medically defined outcomes, such as cardiovascular death. Death, of course, is a key outcome, but patients with kidney diseases on the whole have a deeper appreciation of their mortality than we give them credit for, and often, they are asking for relief from day-to-day symptoms, not freedom from death.

Kevin Fowler: I recommend two organizations and one periodical:

• The Institute of Patient and Family Centered Care (IPFCC): The IPFCC was formed in 1992, and its mission is to integrate Patient and Family Centered Care into healthcare organizations. This will help you think about creating a sustainable environment and strategy for patient engagement.

• Kidney Health Initiative: KHI’s Patient Family Partnership Council is integrating the IPFCC principles in order to develop a patient engagement strategy for kidney disease patients.

• Health Affairs February 2013 issue: The entire issue is dedicated to patient engagement.
What do you think is key to successful patient engagement? What are the various ways and means by which successful patient engagement is carried out?

Kevin Fowler: The foundation for patient engagement exists in the trust between the patient and their physician. Trust is developed based upon mutual respect, honest and clear communication, and alignment on the care plan. I have had excellent relationships with my various specialists. I have viewed my physicians as coaches and teachers. Patient engagement occurs when both the patient and the care team are aligned on treatment goals—it’s about teamwork, learning, and activation.

Dr Lederer: Enabling patient engagement takes many forms. The first step is the establishment of an open line of communication in the office, by phone calls, and by electronic medical record-assisted messaging. Making yourself or another member of the healthcare team available for quick consultation is another way to communicate to the patient that “we want you to be part of your medical care.”

What are some of the barriers to patient engagement?

Kevin Fowler: Strategically, the number one barrier is that healthcare has never been designed for patients. While the Patient Protection and Affordable Care Act has made great strides in placing the patient at the center of care, the US has a long way to go. The delivery of kidney care in the US also has a long way to go. Although passage of Medicare ESRD legislation in 1973 assured dialysis access to all patients, the policies have provided reimbursement incentives for ESRD rather than prevention or care coordination. This has not really changed in almost 44 years.

In the short term, the number one priority to increase patient engagement is for patients to understand their GFR. As everyone knows, less than 90% of patients with CKD stage 3 know their kidney function. This has to be improved as soon as possible if we want to truly have meaningful conversations about patient engagement. Granted, there are limitations with the CKD classification system. However, from a public health perspective, it is unacceptable that patients at risk for kidney disease do not know their kidney function.

Dr Lederer: I identify two significant barriers to patient engagement. Time is the first. Office visits are rushed. It is only human to feel harassed if you are running behind in clinic and a patient or family member pulls out a legal pad full of questions. Days can be long. Coming back to the office and seeing a list of patient phone calls to answer can be daunting. The second barrier is the invisible wall that patients and physicians erect to detach themselves from each other. How many times a day in clinic do I hear a patient say, “I didn’t want to bother you with this” or “I know you are really busy but…”? And I can’t help but think to myself: Why are you afraid to ask your questions? Are you worried that I will consider you a “difficult” patient? This barrier takes time to crumble and comes only with trust. Once that trust is established, then even if you forget to answer a patient’s phone call, the response by the patient is not “you are too busy for me”; the response is more likely to be “she just forgot, I will call again.”

How have you benefited from patient engagement?

Kevin Fowler: Tremendously! Although I was given the best treatment option with a preemptive kidney transplant, my kidney function has exceeded the expectations of my transplant nephrologists. I believe that is partially attributable to my lifestyle changes posttransplant. On average, I exercise 30 minutes daily five days a week. I practice daily meditation, and I write in a journal. I developed these habits after struggling with depression posttransplant. Through trial and error, I learned that these habits create strong mental health while maintaining optimal cardiovascular function. I learned through experience that strong mental health is key when dealing with the uncertainty of a chronic disease.

When I was diagnosed with prostate cancer, my physician recommended that I pursue surveillance rather than active treatment. I asked my physician for a second opinion, and asked him to take my case to a Tumor Board. The Tumor Board then recommended treatment. This led to another odyssey because I was receiving conflicting opinions on the best treatment option. Ultimately, I made my treatment selection with the help of a transplant nephrologist outside of my health system. I arrived at this decision by asking lots of questions, and leveraging all of my contacts.

Dr Lederer: Patient engagement has enriched my practice immeasurably. When patients are willing to talk about why they agree or disagree with a decision that you have made, you begin to learn who they are and vice versa. —Dr. Lederer

How have patients benefited from patient engagement? Discuss some examples.

Dr Lederer: Patient engagement has enriched my practice immeasurably. When patients are willing to talk about why they agree or disagree with a decision that you have made, you begin to learn who they are and vice versa. In my experience, patients who take a greater part in their decision-making are more invested in their care. I see that commonly with dialysis decisions, I like to start discussing renal replacement therapies early and repeatedly, emphasizing that I want the decision to be theirs, not mine. When the time comes for fistula formation, peritoneal dialysis catheter placement, or evaluation for kidney transplantation, the patient with whom I have discussed these options on several occasions seems much more accepting of the next steps. I have had many patients come to me with side effects of medications that they were experiencing and had researched on the internet or the medication information insert. We were able to change the medication to something that they tolerated better instead of having the patient simply stop the medication.

Why did you become engaged in your health?

Kevin Fowler: Growing up, I saw my mother suffer on dialysis. While my mother suffered greatly, she approached it with a wonderful spirit.

When my primary care physician diagnosed me with PKD and informed me that I would eventually experience renal failure, I thought I would have to start dialysis first. That prospect scared me deeply.

When I had my first appointment with my nephrologist, he suggested that I have a preemptive kidney transplant, and thus avoid dialysis completely. When he thought I would be a good candidate for preemptive dialysis, I thought I had won the lottery. I learned that less than 3% of kidney transplants are preemptive. Combined with the fact that our children were 4 and 6 at the time of my transplant, I was very motivated to live a healthy lifestyle, and to see my children grow up.

Over time, I learned that there is still a lot that is unknown about transplantation. Armed with that knowledge, I have learned to trust my instincts. For example, on several occasions, I have not felt well due to oncoming fever. Rather than waiting for the fever to develop, in consultation with my transplant team, I have been admitted to the hospital for the treatment of infections. In this way, the infections were resolved early without severe consequences.

Why did you become engaged in your patients’ health?

Dr Lederer: I became engaged in my patients’ health when I began to realize what having a chronic illness meant to patients and family. When I began to understand what the day-to-day coping with a chronic illness really meant. When I learned what going to the emergency room really meant for the patient and family members: hours waiting in a queue on hard plastic chairs and uncomfortable stretchers.

I have had patients tell me that, after they take their diuretic, they don’t leave the house for 2 hours. They don’t take their diuretic before a clinic visit, because they would have to stop by the side of the road several times.

I have had diabetics tell me that they don’t go out to eat with their friends anymore, because they get dizzy when they stand up, they perspire heavily whenever they eat, and more often than not, a meal is followed by sudden vomiting or diarrhea.

Many of my dialysis patients tell me that they have one good day a week, the only day of the week that is not a dialysis day or the day after a dialysis day.

What is your advice to patients?

Kevin Fowler: Preserving my health is one of the top priorities in my life, and my behaviors support this priority. If you have some form of kidney disease, my question to each patient is where does your health stand as a priority? Unfortunately, we take our health for granted until we have a major event.

If you have kidney disease, I suggest making your health one of your top priorities. If you do not become your own advocate for your health, no one will. During my journey I have felt overwhelmed at several junctures, I have been able to stay the course because my health is not just about me but also about my wife Kathy and our children.
Patient Engagement

I encourage patients to view their nephrologists and care teams as their coaches. I still prepare for my medical appointments with questions for the doctor. When physicians understand that you are engaged with your health, you build respect with your care team and establish the expectation about how you want to be treated. Physicians respect this investment in time because it enables them to help you even more.

What is your advice to physicians?

Kevin Fowler: Recognize that we are in a period of major change in healthcare. Technology is enabling healthcare to be transformed from a paternalistic system to one in which the patient will be the driver of the healthcare system. Granted, we are many years away from this vision being achieved. Nonetheless, we are in the early stages of this healthcare evolution.

I will give the same counsel that I gave to the FDA at the Patient Focused Drug Development Meeting for transplant recipients. Patients are not a monolithic group but differ in their emotional needs, level of patient activation, unmet medical needs, etc. Many healthcare professionals are under the false impression that an app is the solution to patient engagement. With the exception of one app, I have found virtually no value in apps for my patient engagement.

For any nephrologist seriously interested in patient engagement, the first priority should be understanding their patient population. The patient insights will prove to be invaluable in developing effective patient communication strategies. I have seen too often to count priorities placed on patient engagement solutions first without a deep understanding of the patient community. Patient insights will inform a patient engagement strategy.

As a physician, what is your advice to physicians? To patients?

Dr Lederer: I am an unapologetic champion for patient engagement. It enriches the relationship between patient and physician, gives the patients more autonomy and control over their lives, and likely leads to better outcomes.

References

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