In any routine meeting of patients on dialysis with their nephrologist, the topic of discussion is usually dominated by an assessment of how well recent laboratory work falls into the desired ranges. There is good reason for this quantitative approach, but when dealing with patients who live every day with a serious chronic illness, does it lead to missing the forest for the trees?

As a patient on peritoneal dialysis, my experience is that there is a slight disconnect between doctors, caregivers, and the patients themselves. I believe that the fundamental desire of most patients is to live a meaningful, minimally affected life while remaining as healthy as possible. Whereas we the patients are more focused on the meaningful and minimally affected part, medical practitioners and caregivers seem to be focused on the as healthy as possible part. The problem is that these two goals are commonly in conflict.

Life can be chaotic and dynamic, and we all find ourselves in situations outside of our planning. For most of us, there are limited or no consequences for these detours. The true beauty and joy of life can be found in these moments: staying out late with friends, an impromptu dinner with friends, traveling. However, seemingly insignificant choices such as this put patients on dialysis in a bind. Do we risk and at times, sacrifice adherence to prescribed medical interventions to enjoy life? On the basis of the effect on quantitative measurements, such as solute concentrations and clearance, the answer from a doctor’s perspective would tend to lean mostly toward no.

Happiness and fulfillment are so much more than a measurement from a blood test. The outcomes that the medical community desires in patients on peritoneal dialysis do not always match perfectly with the outcomes that patients on peritoneal dialysis want. Strict adherence almost certainly creates a boring and monotonous life that is not conducive to fostering mental health.

With the focus on quantitative outcomes, many qualities that cannot be strictly measured are often overlooked or neglected entirely. There is no way to accurately measure levels of fatigue or fulfillment of the patient on peritoneal dialysis, but these outcomes are clearly of high importance to patients.

In this issue of the Clinical Journal of the American Society of Nephrology, Manera et al. (1) discuss whether the kidney community should re-evaluate the relative importance of outcomes in patients on peritoneal dialysis. We live with this disease hovering overhead like our own personal storm cloud. We are mature enough to understand what outcomes are most important to us and what level of risk each of us is willing to accept. When the outcomes are prioritized with the patient in mind, patient satisfaction skyrocketed. We want to live like everyone else—and it is important to have medical care that aligns with our aspirations and goals both professionally and personally.

It is far too easy for patient concerns to get lost in the sea of medical opinions that surround a topic such as kidney disease. This is one of the reasons that I am personally involved with the American Association of Kidney Patients—patients need to take charge of their destiny, band together, and aspire to bring about the change that they want. Although it is perhaps not the norm, something as simple as a conversation about values of different outcomes between patients and nephrologists can make for a more successful experience.

Disclosures
None.

References

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