Patient-reported outcome measures (PROMs) have become a hot topic over the last decade. The health care community has realized the importance of patients’ perspectives of their care. Putting measures in place to assess patients’ experience of well-being is a step forward. Making sure patients’ perceptions are understood in context, and then acted upon, is necessary to improve care and motivate patients’ participation in surveys, such as the Patient-Reported Outcome Measurement Information System (PROMIS) Preference Scoring System.

The authors of “Evaluation of PROMIS Preference Scoring System (PROP) in Patients Undergoing Hemodialysis or Kidney Transplant,” in this issue of CJASN, evaluated the domains of cognitive functioning, depression, fatigue, pain interference, physical function, sleep disturbance, and ability to participate in social roles and activities (1).

It is not surprising that people who have a kidney transplant perform better on the PROMIS scoring system. After receiving my kidney transplant, I could not believe how good food tasted. I could participate in social activities and not worry about my dialysis schedule or what food/drink may be served, to name just a few improvements.

The study’s PROMIS profile instruments did not include the cognitive function domain (1), but the reason for this is not clear to me. Is cognitive function considered a metasubjective element the authors believe should be measured indirectly rather than relying on study subjects’ responses? If so, this should be acknowledged, and several other “external” variables should be considered in determining patients’ evaluation of outcomes.

For example, at what point in the patients’ interaction with a care regimen (i.e., at what time) was the survey administered? Was the survey given before, during, or after dialysis? It is often reported by patients that their cognitive ability can diminish temporarily during fluid and electrolyte shift during dialysis. I myself have experienced this.

Also, patients’ perceptions of their own care can be influenced by what happens at the dialysis facility. If a peer had a bad reaction during dialysis, I often thought, “Is that going to be me?” The realities of these situations can shift us into the Kubler–Ross emotional stages of an illness. I felt different, and my mood was influenced on the days I had dialysis and by what I observed at the dialysis facility. I preferred home dialysis because I could be more in control of my environment. Kidney transplant recipients also experience critical milestones and points of stress.

Finally, the motivation to report issues in the studied domains is a big factor left unaddressed. One of my biggest complaints about PROM surveys is that nothing is ever done to address what is reported. The domains of depression, fatigue, pain interference, physical function, sleep disturbance, and ability to participate in social roles and activities can strike patients responding to questions in the same way.

What protocols are in place to convey that results of the survey will be used to help patients improve their scores? Without such protocol, study subjects might be disillusioned. Pain and sleep disturbance are two areas that used to be treated by medication, and now, due to the clamp down on prescriptions, this is not always an option. Pain related to kidney disease can be due to bone and mineral disorders, severe itching, or dialysis access issues. Physical function can be related to anemia, and sleep disturbance can be related to not enough dialysis, or napping during the day. Physical function can be due to anemia and low iron, but per the US Food and Drug Administration guidelines, patients on dialysis are kept at lower hemoglobin levels. In my opinion, depression can also drive many of the above symptoms.

I challenge the community to think about Kidney Disease Quality of Life measures the kidney doctor or clinic can improve, on the basis of patients’ responses. For example, a patient may score low in his or her ability to participate in social roles and activities. Was this the case before the patient’s kidneys failed? It is often said you find out who your friends are when you have an illness, and it is up to the person with the illness to make new connections. Mental health, physical therapy, and employment services available to people who have an illness would be greatly beneficial. Depression rates run high for people dealing with a severe chronic illness. Maslow’s Hierarchy of Needs (2) is complex, and the only two areas the health care team can truly affect is the feeling of safety and getting the dialysis treatment and prescriptions right, so...
patients have the energy to work on having their psychologic and financial needs met.

Measuring patient-reported outcomes at dialysis or after kidney transplant should be focused on what can be affected by the person who is caring for them. There are several related questions that could be considered for PROM measures to motivate responses.

For People Who Have a Transplant
- Are you comfortable taking all of the prescribed medications? Do you feel any side effects?
- Do you have any pain in the surgery area or discomfort urinating?
- Has your appetite increased or decreased since the transplant?
- Are you able to meet the diet changes of drinking more fluids?
- Are you experiencing gastrointestinal issues?

For People Who Need Dialysis
- How was your dialysis treatment? Tolerable or not tolerable? Why (e.g., vascular access problems, anxiety, cold, dizziness, fatigue, crashing and cramping, etc.)?
- Are you comfortable taking all of the prescribed medications as indicated? Can you swallow the pills? Do you have any side effects that are uncomfortable?
- How is your appetite?
- Are you experiencing itching?
- Is the dialysis schedule conducive to your lifestyle?

All of these issues can be addressed, and solutions provided, by the health care team in charge of care.

Patients’ experiences of treatment should be incorporated into analyses of their outcome perceptions. How patients feel during and after treatment is clearly related to their perception of health care outcomes and quality of life, and affects compliance issues. What patients would want to continue if they are in misery during treatment? What if they are completely fatigued after treatment, only recovering sufficiently in time to go to the next? And again, how do these experiences affect their PROMIS Preference Scoring System survey responses? Asking these questions may convince patients they need a different treatment option or longer treatment times.

These are the questions that need to be addressed in any future proposed measures to help shore up quality of care, protect patients’ safety, and provide confidence that survey responses will improve care experiences and outcomes.

I believe that if you get the treatment and medication regimen right, the patient has a chance of scoring higher on the PROM domains listed above. The goal of these measures should be to help people who have kidney disease live full and productive lives, so a granular-level approach is needed. I hope measure developers ask these questions when creating future PROM measures, or giving a patient a survey to fill out, to make sure perceptions of care are understood in context and acted upon to improve outcomes.

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