



Understanding Dialysis Patient Perspectives on Advocacy

Related Article, p. 29

I applaud the study by Schober et al¹ in this issue of *AJKD*, which focuses on patients treated with dialysis to assess their attitudes and overall potential to engage in advocacy related to chronic kidney disease (CKD). As the study states, even though more than 25 million Americans live with CKD and more than 400,000 require maintenance dialysis therapy for kidney failure, funding for CKD research is relatively low and public awareness of the impact of the disease is limited. Although the Renal Support Network (RSN)—a national, patient-led, nonmedical support and advocacy group for individuals with CKD—was not mentioned by Schober et al, its members have first-hand knowledge of the advocacy limitations voiced by participants in this study. As founder and President of RSN, I believe that understanding dialysis patient perspectives on advocacy requires consideration of group dynamics, institutional support, and characteristics of the illness.

RSN has focused specifically on nonmedical (eg, personal, relational, and social) patient experiences, needs, and grass-roots group organization. I founded RSN in 1993 with the main objective of providing hope, connection, and education to my peers. RSN affirms the current study's contention that "patients who are more active in their care are more successful in self-management behaviors, such as medication adherence, and have better outcomes, including greater quality of life and fewer hospitalizations, compared with less activated patients."^{1(p30)} Having lived with CKD since 1968, when I was diagnosed at 2 years of age, I have had many opportunities to witness peers advocate for the best care and others not take the initiative to improve their well-being. The latter attitude almost always leads to a worse outcome!

I believe people treated with dialysis are encouraged to take steps toward greater involvement in advocacy when they are appropriately recognized and rewarded for meeting basic obligations, which pose a significant burden. They should feel a sense of accomplishment and appreciation for showing up for dialysis treatments and physicians' appointments, taking medications on schedule, adhering to fluid and diet regimens, scheduling early fistula placements, inserting their own needles, and doing their part to stay out of the hospital or to get on the kidney transplant list. In addition, home dialysis and in-center self-care should always be the favored options for dialysis therapy initiation, rather than the usual default of assisted in-center

hemodialysis.² This type of involvement in care is particularly critical for patients who will become kidney transplant recipients because it helps empower and prepare them for managing their care.³

The study by Schober et al attempted to evaluate patient "engagement" in their care settings. Patient engagement can become annoying to some health care professionals in fast-paced medical settings with limited time allowed per patient, which often is incompatible with adequately explaining a situation. The term "learned helplessness" can be applied to dialysis patients who have tried to effect changes in their own care and have been unsuccessful.⁴ However, RSN has seen that patient experiences of engagement in specific care situations and settings can discourage their involvement in advocacy. When patients ask for special consideration or voice concerns, staff may respond in ways that are unsatisfactory or negatively interpreted. For example, a patient may request cannulation by a certain technician, only to have the dialysis unit staff deny the request, citing potential disruption to scheduling and violation of "standard procedure." Such responses stifle patients who are attempting to speak up.⁵ A preferred response by a health care professional would be more positive (eg, "It's great you're advocating for yourself. We'll ask the tech to assist you, and if he's not available, we'll address your concerns to ensure you feel safe before inserting the needles").

In their study, Schober et al compared the overall participation in advocacy of the dialysis population with that of other groups, such as patients with cancer. However, such a comparison is not straightforward. The attitudes of these groups toward their respective illnesses are different. For example, in some cases, patients with cancer recover fully. Also, for the most part, patients with cancer do not have reason to believe they had a hand in causing their illness. Diabetes and high blood pressure are the 2 main causes of CKD, and progression to CKD is slow. There are a number of high-profile diabetes management and blood pressure management campaigns. To the extent that these succeed, kidney failure is forestalled, but because of the existence of opportunities for prevention, I have heard that it is difficult to advocate for CKD awareness and research when

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patients did not manage their prior health problems. Further study should address the attitudes of patients with CKD regarding their disease, its causes, and the reality that it can only be managed rather than cured.

Of note, Schober et al limited their inquiry to individuals; they did not seek out and interview patients with CKD who were advocacy group leaders, and group dynamics were not addressed by either the study questions or in patient responses. A sizeable percentage of the dialysis population have coexisting depression, which can be amplified in a support group setting, making external outreach difficult. Without equipped leaders, dialysis patient support groups fail and people leave feeling worse than when they arrived.

A useful way to evaluate the readiness of people with CKD to participate in personal and group advocacy is to consider Maslow's hierarchy of needs. Abraham Maslow, an American psychologist, theorized that only when physiologic needs are met can individuals strive to meet needs related to safety, belongingness and love, esteem, self-actualization, and self-transcendence, in that order.^{6,7} Notably, Schober et al did not address primary issues, such as depression, facing patients with CKD who may advocate for themselves and their peers but find their efforts unsuccessful.⁸ Figure 1 provides this and other examples of issues that challenge patients with CKD as they seek to progress through the levels of Maslow's hierarchy. Ways to raise patients with CKD and patient groups to higher levels of the hierarchy of needs and to support and sustain groups in their efforts to improve their care and advocate for others are worthy of further study.

RSN has implemented a number of national programs that engage patients and assist patient groups. It has created and implemented a patient leadership program that helps patients develop speaking skills, conduct local meetings for their peers, educate fellow patients through peer support networks, and set up meetings with elected officials. These programs have been very successful because patients who participated were educated, empowered, and held accountable by their "teammates." The programs had adequate budgets and allowed sufficient time, resources, and travel accommodations so advocates could feel comfortable with the training requirements and the task at hand. An added bonus was that the patients in these programs became lifelong friends, working toward a common goal and feeling accountable to each other.

In addition, RSN holds an annual essay contest encouraging patients to share their stories; it also has created a jewelry line that volunteers can make, sell, and work together to promote. The National Kidney Foundation (NKF) Kidney Walk program is another example of a clearly outlined activity that serves a dual purpose: it engages patients while also raising funds. However, because no financial compensation is involved in activities like the RSN essay contest and NKF Kidney Walk, the emotional rewards for participants must be significant and defined. Also, engaging people in a common goal requires considerable time, preparation, and follow-up. RSN frequently receives requests from patients who want to volunteer, but unless their ideas and skill set fit within current programs, we have difficulty assisting them due to stretched resources. Further studies in this area should focus on developing tools to evaluate the

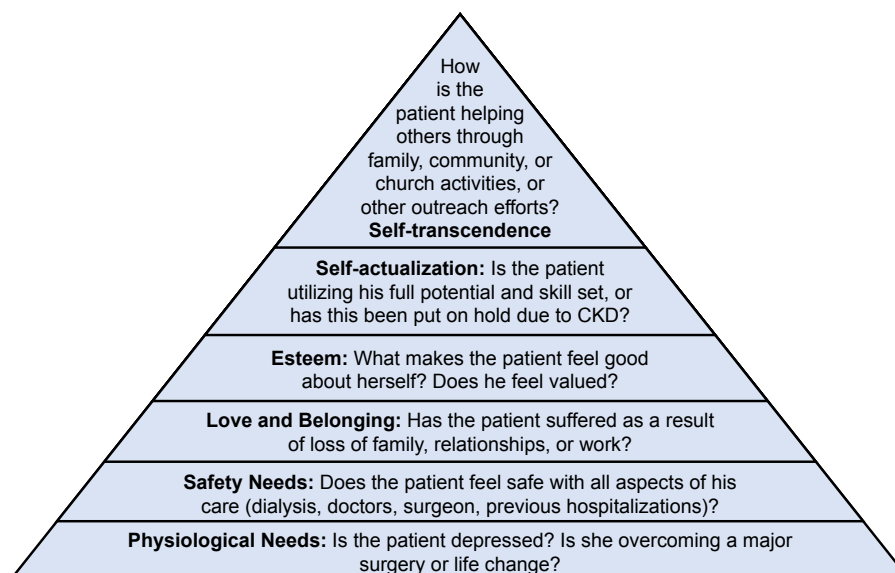


Figure 1. Maslow's hierarchy of needs applied to patients with chronic kidney disease (CKD). Headings in pyramid based on framework defined in Maslow.⁶

advocacy abilities of patients with CKD, as well as organizational strategies to make the most of innovative programs and talented leaders as they emerge.

The dialysis patient focus of the study and analysis by Schober et al is valuable, but I hope that future research directly addresses the challenges of CKD patient advocacy group dynamics and group leadership support. Such investigations will advance continuing efforts to develop best practices for engaging patients and equipping advocates and advocacy group leaders in their efforts at the personal, local, and national levels to improve public awareness of CKD and research funding in this field.

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