Cost of Immunosuppressive Drugs and the Patient with a Kidney Transplant

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I am responding to your published article "Secular Trends in the Cost of Immunosuppressants after Solid Organ Transplant in the United States" (1). I am a kidney transplant recipient and I will be celebrating my 20th kidney transplant anniversary in March 2019. I am also a registered dental hygienist. I greatly appreciate the opportunity to offer a few comments.

My opinions are on the basis of my education and professional experience as an allied health care provider, and my 21 years of living with CKD. I love science for what is has done for my dental patients and myself. My kidney disease was attributed to ANCA-positive vasculitis and I chose peritoneal dialysis as my bridge to solid organ transplantation. In 1999, I received a living related donor kidney transplant. There have been a few hiccups along the way; however, I am grateful for the independence and quality of life my transplant has given me.

In my experience, in 1999, generic medications were rarely prescribed. Even with group insurance prescription coverage, the out-of-pocket costs for some of my medications were very expensive. Taking the expense of medications into consideration, I selected to enter a double-blind immunosuppressive study for two reasons: (*1*) the study program provided cyclosporin free of charge, and the use of cyclosporin was mandatory; and (2) the study protocol goal was trying to offer patients a medication that would require a lower than normal dosage of cyclosporin to reduce the incidence of nephrotoxicity.

Being a patient with CKD is filled with challenges and decisions that we rarely know much about. I was fortunate to have excelled in classes such as anatomy, physiology, pharmacology, *etc*. I also had a network of medical colleagues that were willing to help me fill in the blanks on topics I knew nothing about. In my personal research, before my transplant, I had read about the risk of nephrotoxicity and I considered the risk versus the benefit and thought this might benefit me many years down the road. If it did not, it could provide much needed information for other patients (or myself) in the future.

After my transplant, it was in the first month that the cost of being a kidney transplant recipient was realized. My copay on just one medication was $500 and this was not an immunosuppressive medication. A hefty sum for someone who had to cut back on working to recover from surgery. Today, 20 years later, all of my medications are generic.

Although I agree with the conclusion reached by Helmuth *et al.*—"The decline in payments by Medicare Part D and by transplant recipients for tacrolimus, and mycophenolate between 2008 and 2013 suggests that the introduction of generic Immunosuppressants during this period has resulted in substantial cost savings to Medicare and to patients, largely reflecting the transition from brand to generic products,"—it left me with more questions.

Yes, switching patients to generic immunosuppressive agents would reduce expenses; however, I am perplexed that the qualification for graft function is only 30 days. I would like to know how many, or if any, of the patients went into rejection? If a patient ends up back on dialysis, I do not believe that would demonstrate cost savings, for it is stated, "…subsequent return to dialysis and/or retransplantation are estimated to be between $70,000 and $106,000 compared with approximately $16,000 for patients with a functioning graft."

Also, "in all three cohorts, candidates were predominately male, white, and aged 50–64 years." This population does not accurately reflect the racial diversity of organ transplant candidates. What would the financial estimate be with a racially diverse population?

Furthermore, the Affordable Care Act was implemented in 2011, which is about halfway through the study. Can we attribute all savings to generic medications or could it be associated with access to care?

Pharmacologic agents are required to be bioequivalent; however, they can have inert differences that may leave patients with allergic reactions or unfavorable side effects. The option/choice of receiving a generic medication (although it may provide a substantial savings to the patient in the immediate future) are now decided by insurance companies, not our health care providers. Today, I am quite frequently switched from one generic to another. I know to confirm the switch with the pharmacist to assure it is indeed my prescription; however, I fear many patients do not realize there has been a change.

My last point addresses patient participation in research. As I stated, my decision to participate in the

clinical trial was influenced by financial concerns. Will patients choose to participate in clinical trials in the future? And if so, what will be their reward. . .their motivation? Will it become difficult to have patients agree to participate in research?

As I am someone who has put my faith in my health care providers for years, I am also inclined to do my own research and ask questions. I am very thankful for saving money on my immunosuppressive medications.

Acknowledgments

C.T., is a real transplant recipient and a registered dental hygienist. In addition to being a patient advocate with the Renal Support Network, C.T. has authored several articles in dental and dental hygiene publications regarding the dental management of patients with CKD, ESKD, and renal transplantation. She will be celebrating her 20th renal transplant anniversary in March 2019.

Disclosures

None.

References

1. Helmuth ME, Liu Q, Turenne MN, Park JM, Oguntimein M, Dutcher SK, Balkrishnan R, Sharma P, Zee J, Leichtman AB, Smith AR: Secular trends in the cost of immunosuppressants after solid organ transplantation in the United States. *Clin J Am Soc Nephrol* 14: 421–430, 2019

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See related editorial, "Are Generic Immunosuppressive Drugs the Solution for Providing Lifelong Medication Coverage to Transplant Recipients?," and article "Secular Trends in the Cost of Immunosuppressants after Solid Organ Transplantation in the United States," on pages 327–329 and 421–430, respectively.