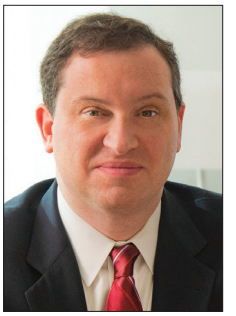
Informed Consent?



This month, I continue my series of letters on thought-provoking clinical scenarios that have arisen during my time on the inpatient lymphoma service.

The subject of this letter is a 70-year-old man with Richter transformation who had recently undergone autologous stem cell transplant. Approximately three months after the transplant, he presented to the emergency department with a fever, malaise, and mild hypoxia, and was found to have COVID-19. He was then admitted to the inpatient lymphoma service and the house staff offered remdesivir and dexamethasone, both of which he refused.

It is helpful to provide some background on this patient. He had been diagnosed with CLL almost 20 years earlier and had first developed Richter transformation in 2013. He underwent allogeneic stem cell transplant and maintained a complete response—although he did lose the graft—until he developed lymphocytosis in 2019. Flow cytometry confirmed a relapse of his CLL with no evidence of high-grade disease. He began treatment with a BTK inhibitor and did well for one year before developing a second Richter transformation. Throughout his 11 years as my patient, he has always come across as someone who is neither excited by his good outcomes nor concerned by his poor outcomes.

When I rounded on him the next morning, I was furious that the house staff had allowed someone who had just undergone autologous stem cell transplant to simply refuse treatment for COVID-19. After all, this was someone who had already undergone an intensive elective procedure and had received treatments far more dangerous than corticosteroids and remdesivir, illustrating that he was not hesitant about receiving medication or medical care in general. Why had I not received a call from a worried house officer, asking for my assistance in pleading with the patient to take the therapy? When I discussed with the patient the rationale and need for the interventions and asked why he had refused them the previous evening, his response was simple and dry: "I did not think they were necessary."

I was struck by his response. This was a patient who had already been through one of the most arduous procedures we put patients through—not only once, but twice. The treatments he had refused could have led to a marked improvement in his symptoms and outcomes and were associated with only minor or no adverse effects. I understand that some patients are tired of being poked and prodded and just want to be free of medical interventions, but if this had applied here, why had the patient bothered to come to the emergency department?

I believe this scenario raises an important issue regarding how we approach informed consent with patients. The bar is highest when we enroll a patient in a clinical trial, which involves reviewing and signing a consent form that can run 10 pages or longer. When we discuss a chemotherapy regimen with a patient, we also provide a thorough discussion of benefits and risks—including death—and document this discussion in our office notes. Many medical facilities require the patient to sign a consent form for treatment as well. Although we recommend chemotherapy when we consider it to be in the patient's best interest, we also understand the logic behind the wishes of some patients to avoid treatments that will negatively affect their quality of life.

Where was the logic behind the current patient's decision? Our recommendations to this patient were made after having been through years of schooling and training, followed by years of additional medical experience. He, on the other hand, had no medical training. Did the patient think remdesivir and corticosteroids were a bad idea? Did he consider himself better equipped than a doctor was to make a medical decision? I was hard pressed to believe that he had undertaken the lengthy process of researching the treatments, weighing the benefits and risks, and making an informed decision. Was I so arrogant that I was unable to understand how someone could disagree with my point of view? Was this a case in which I should practice paternalism and force the treatment on him because it is in his best interest? Or was this really a person trying to demonstrate self-determination?

Finally, after a detailed explanation of why I wanted the patient to receive the treatments, he replied, "okay."

Now I am left with the question of how poorly we must be providing informed consent on a regular basis. The patient clearly had responded to me differently than he had to the house officer. I will never know exactly what the house officer said to the patient and how adequate of an explanation it was, but we need to do a far better job exploring the reasons behind every treatment refusal.

Sincerely,

Richard R. Furman, MD