Searching for Evidence-Based Reassurance Where None Could Be Found

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"I do not recommend any further scans, unless you develop concerning symptoms, now that you are in complete remission."

I am a young woman with two preschool-age children, a wonderful family, and a rewarding career. Three months ago, I completed a 6-month course of chemotherapy for advanced Hodgkin lymphoma (HL). I am also a physician and health services researcher, and I deeply believe in the theory and practice of high-value cost-conscious care. In fact, my research focuses on improvement of the patient-centeredness and value of diabetes care and on reduction of overtesting and over-treatment that may lead not only to wasted resources but also to real patient harm.^{1,2} Throughout my career, I have been involved in state³ and institutional efforts to identify and reduce low-value services, consistent with the American Board of Internal Medicine Choosing Wisely initiative to promote and enable a conversation between patients and clinicians to ultimately avoid unnecessary medical tests, treatments, and procedures.⁴ I also advocated for patients and clinicians to both play a role in fostering high-value cost-conscious care through the use of shared decision making to marry autonomy and paternalism and thus ensure patient-centeredness without the undue burden of unsupported choice. That is why my visceral reaction to my oncologist's recommendation not to perform routine surveillance scans after HL was so unexpected. I was surprised, confused, fearful, and even defiant. Could I really forego these tests?

The American Society of Hematology Choosing Wisely recommendation advises providers to "limit surveillance computed tomography (CT) scans in asymptomatic patients following curative-intent treatment for aggressive [non-HL] lymphoma."⁵ In HL, the National Comprehensive Cancer Network guidelines were not definitive in their recommendation for post-treatment surveillance of HL,⁶ but my oncologist felt strongly about foregoing CT and other routine imaging unless warranted by symptoms or signs of illness. She argued that routine imaging generates false-positive

findings, anxiety, and high costs without definitive or meaningful survival benefit.⁷⁻¹⁴ Wearing my professional hat, I agreed. But, as the patient, I found myself anxious, afraid, and wanting more. Not because I was confident that doing more would help, but because doing something—anything—gave me the illusion that I had some semblance of control over what would happen to me. I was scared.

During the past 9 months, I had been engaged, composed, and realistically optimistic as I underwent diagnosis and treatment (6 months of ABVD [doxorubicin, bleomycin, vinblastine, and dacarbazine] chemotherapy) for HL. However, when I emerged on the other side of treatment, instead of finding peace, I was more anxious than ever before. I longed for the comfort of a defined, structured, and standardized treatment program, with its unwavering cycle of biweekly blood work, clinical evaluation, chemotherapy, and post-chemotherapy symptoms, no matter how incredibly unpleasant these were. I was, of course, thrilled to be done with treatment and elated to return to parts of my life that had been put on hold. However, I also could not shake the fear that this reprieve was an illusion, that my lymphoma would come back, and that I would be blindsided by its unrelenting return. As I sat in my oncologist's office, I understood something I should have realized a long time ago: it's hard to practice what I preach. Although common sense and simple in the abstract, the application of value principles to individual circumstances was much harder. I was torn between following my oncologist's advice to do less (thereby pursuing high-value and cost-conscious care) and acquiescing to my yearning to do more. Imaging seemed essential to early detection of recurrence, even if not consistently supported by the evidence. I was afraid that we would miss something, that my disease would progress, and that I would die. My oncologist taught me that such fear of recurrence is common,^{15,16} and I am grateful for her insights as she patiently guided me through the confusion and fear and allowed me to find some comfort in our decision in my own time and in my own way.

We have deliberately replayed our discussion about clinical versus routine radiographic surveillance

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at every subsequent appointment as I near the end of my first year with the diagnosis. It is a conversation that echoes in my mind every time I have a cold, feel tired, or ache from a long day with two young kids. I wonder if my symptoms are normal or if they herald the recurrence of lymphoma. Because the National Comprehensive Cancer Network guidelines are not prescriptive and surveillance imaging is said to be “reasonable,”⁶ I invariably find myself wondering, “what’s the harm of just one more CT?”

I know the harms. I saw my medical bills and know the costs that repeated imaging could add. I understand the anxiety of waiting for routine imaging—in essence, living from scan to scan. I had also experienced the downstream effects of false-positive findings. Just 2 months earlier, a post-chemotherapy positron emission tomography–CT revealed a minimally concerning, but nonetheless positive, new lymph node that had to be worked up and biopsied. In retrospect, this scan may have been low value, but my oncologist had relented to my request to get it done. The biopsy came back benign, but I cannot forget the build-up of anxiety that led to the scan and the biopsy as I waited for the results that I hoped would provide a temporary reprieve from my disease. I did not want to experience this again, yet I yearned for the affirmation of being cancer free.

Living through these experiences led me to question and appreciate the basic tenets of shared decision making. Shared decision making is predicated on the idea that clinical decisions should be reached through conversation and consensus between clinician and patient. In this dynamic conversation, clinicians contribute clinical expertise about the disease and treatment options, and patients provide expertise about their body, circumstances, goals for life, and expectations from care.¹⁷ Yet, after my diagnosis, unlike a patient with chronic disease, I did not feel like an expert. I had not had the chance to learn my new post-cancer preferences or my capacity, and I did not know how they aligned with my treatment and surveillance options. My goals were to live every day the best I could, have no regrets, survive, and put these months behind me. I did not know how surveillance imaging or the many other day-to-day decisions I have had to make throughout this journey map to these personal goals.

Through open conversation about my fears and concerns, my oncologist and I have agreed on clinical follow-up visits and laboratory check-ups for now, with the use of imaging if new or concerning symptoms develop. Through exploration of the reasons for wanting to do more, I was able to accept doing less. I still long for the additional reassurance that imaging offers, but I realize that no test can provide complete reassurance. I hope that, with time, I will grow to be more comfortable with uncertainty and less afraid of what may be hiding underneath my skin. As a physician in clinical practice, I no longer have the same naïve confidence in my ability to counsel patients about the waste of low-value tests, procedures, and treatments. Instead, I can empathize in a new and real way with their worries, hopes, and internal conflicts about treatment decisions. I hope that I can do

for them what my oncologist continues to do for me: practice evidence-based medicine, instill trust through compassion, and empower all patients to freely express their fears, uncertainties, and expectations along with their goals, preferences, and values.

AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at jco.org.

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