A Tale of Two Perspectives on Cancer: What I Wish I Knew Before Cancer—Radiologist and Patient Perspectives

Jennifer Kemp, MD, Christine Zars, MS, RD, LDN

Medicine is making a concerted effort to make sure we put the patient at the center of all we do. Radiology is a part of this process, as exemplified by numerous articles, lectures, and campaigns focusing on how radiologists can be more patient centered. Both the ACR and the RSNA are at the forefront of these discussions. The recently formed ACR Commission on Patient- and Family-Centered Care is helping promote constructive relationships among radiologists, their patients, and caregivers. The RSNA’s Radiology Cares campaign and website are designed to help radiology professionals optimize their patients’ experiences throughout their radiologic care with online toolkits, links to educational resources, and customizable PowerPoint presentations. The ACR’s Imaging 3.0® initiative is shaping our environment to embody principles of appropriateness, quality, safety, efficiency, and patient satisfaction. When we put patients at the center, we learn from their experiences and stories. This will in turn make us more empathetic to patients’ needs and feelings while they are in our radiologic care. There are many types of patients in any radiology department, and every patient is equally important. But because 41% of the population will be diagnosed with cancer at some point, and 21% of the population will die of cancer [1], cancer is a common diagnosis, and it makes sense that we learn from patients with cancer. The reality is that it is likely that any one of us reading this article will become, or has already been, a cancer patient or a caregiver to a cancer patient in a radiology department. Every patient in the waiting room has a story and, along with their loved ones, they all share an experience. Although the cancer experience is heterogeneous, the fear and uncertainty are shared by most with this diagnosis. We share our personal experiences here as a personalized frame for this special issue on integrating the patient and caregiver experience in the practice of radiology.

CHRISTINE ZARS (PATIENT PERSPECTIVE)

It’s been 14 years since my diagnosis of a grade IV glioblastoma at age 19. About one month after my brain surgery, I started my radiation treatment and then simultaneous chemotherapy. My treatments were complete after about one year. But my follow-up will never be complete. I am all too familiar with lying in the MRI scanner, meeting with doctors, and waiting for the results of a study. Here are five things I wish I had known when I first became a patient 14 years ago.

Cancer is not an illness you get over and it’s done; it is a permanent part of your life. Life is very different for me now than when I was diagnosed with cancer. I’m married and have four small children while trying to continue to work part-time. Even though I am at a very different place in my life, I’m constantly reminded of the battle I fought. I’m constantly reminded that I will always be a patient who has to undergo routine MRI studies and follow-up with specialists. I also get a sick feeling in my stomach every April 15, the day of my surgery. While most people are thinking about taxes, I’m getting flooded with phone calls from family and friends telling me that they’re thinking of me. My husband and I decided several years ago that we needed to make that anniversary something to celebrate, rather than something to resurrect scary memories. We now make it a point to go out for a very nice dinner every year together while my parents watch our kids for the evening. Little things like this help focus attention on the positive.
Follow-up visits over the years get easier, but they are still hard. An MRI examination, 14 years after diagnosis, is not as scary as it was at diagnosis, but it’s still scary. I know exactly what to expect every time I go in for MRI, but the challenge of lying still in an uncomfortable position with the loud noise of the MRI machine is still not the most pleasant experience. After that, there’s also the anxiety of waiting for confirmation from the doctor that nothing concerning was found. Although these have become more routine and less stressful, I’m not sure they will ever be easy.

Even though the patient is at the center of care, I wish I knew the effect the diagnosis would have on the loved ones in my life. When I was first diagnosed with cancer, I immediately had thoughts of the impact the diagnosis would have on me. However, while coming to terms with my diagnosis, the impact it had on the people around me wasn’t something that was at the forefront of my mind. It was overwhelming to see how my diagnosis caused sadness, anxiety, fear, and confusion among my closest loved ones.

Never underestimate the power of prayer. There is a lot of uncertainty as a cancer patient. Turning to my faith was a big part of how I handled surgery, treatment, and how I continue to handle follow-up visits. My dad started going to Mass daily after I had surgery. He felt he had to do something, and praying and attending Mass seemed to be the best thing to do. Although this may not be suitable for everyone’s background or faith, it was very comforting for my family.

Success stories of others who survived my diagnosis. When the pathology reports came back after I had brain surgery, the discussions I had with the doctors made it clear that the prognosis for my type of cancer was poor. Radiation and chemotherapy treatments were frightening and exhausting. My family, friends, and doctors provided me with constant hope and support. However, having a survivor as part of my support circle would have offered a perspective and comfort that no one else could have provided. No matter how many friends and loved ones you have in your support group, when you’re going through something none of them have experienced, you still feel somewhat alone at times. Having someone you know you can relate to on that level would be very helpful to mitigate this feeling of isolation.

JENNIFER KEMP
(CAREGIVER/RADIOLOGIST PERSPECTIVE)
My husband’s diagnosis of stage 3 rectal cancer 13 years ago taught me more than I ever wanted to know about what I didn’t know about cancer as a radiologist. Following are a few things I learned from my experience as a caregiver for my husband that I wish I had known before that experience.

Cancer is an emergency. Before the diagnosis, I put all cancer follow-up CT studies at the bottom of my “stack” to read. I told myself that “cancer is no emergency” and that my reading would not change anything that happens for this patient in the next 24 to 48 hours. What I learned is that cancer is an emergency to the patient behind the scan. The patient behind the scan is waiting for these results; his or her very life may depend on it. The patient’s next move very likely depends on that reading. The patient may feel paralyzed until he or she knows one way or the other. The patient has been waiting for the results of this scan since the previous imaging study, typically 3 or 6 months ago. I no longer put cancer follow-up imaging at the bottom of my stack.

Patients are scared. Before my husband’s diagnosis of cancer, I had no idea the fear the patients sitting in my waiting room were feeling. Fear, as we know, elicits a fight-or-flight response in the best of us. Patients who, before my husband’s cancer diagnosis, I may have thought were “high maintenance” or “grouchy” I now understand were simply scared. Knowing this helps me be more empathetic to patients who may project themselves as being angry if their visits are not completely perfect—for example, if there is a delay or a difficult intravenous placement.

Uncertainty is uncomfortable. Uncertainty is very much a part of radiology and any cancer diagnosis. It is part of our day-to-day lives in a radiology reading room. We are comfortable with the phrases “can’t rule out,” “uncertain significance,” and “recommend follow-up.” These phrases have different meanings to a cancer patient. Patients see imaging results as black and white. They do not expect this uncertainty from us. I am not implying that we can get rid of uncertainty in our imaging reports, but by simply being cognizant of the effect it could have on our patients, we may be able to use these terms a little more sparingly. We may be able to reassure a patient that this is radiology lingo and explain it to them in more detail verbally.

The doctor speaks the word of the all knowing. I noticed this most when my husband was in the hospital and we were waiting for the doctor to visit us on rounds. We never really knew what time the doctor would arrive. And often the attending physician never came around, only a resident and a fellow. The day centered on that visit. Anything the nurses would do or not do the rest of the day was based on that 5-minute doctor visit. Once the
Before my husband’s diagnosis, I really had no idea of the pain and suffering caused by cancer and its treatment. My husband was young and otherwise strong and healthy. If cancer and cancer treatment were this difficult for him, how do elderly and frail patients manage? Knowing this, I now think twice about what I am asking of my patients, such as asking them to not eat or drink before an imaging examination or to drink a large volume of oral contrast. This could be asking a lot of a very sick patient. If it is of no definite benefit to me in interpreting their examinations, I no longer ask patients to do these things on the basis of habit alone.

CONCLUSIONS

In this new era of realizing the importance of patient-centeredness to improve patient outcomes as well as the patient experience, radiologists need to explore new ways to add value to the system. Enhancing the patient experience starts with the radiologist’s acknowledgment of and empathy for the complexity, induced anxiety, and omnipresence of a cancer diagnosis and the subsequent care process. Cancer remains an emergency to cancer patients and their loved ones. Patients and caregivers measure and anticipate our words, and we should communicate accordingly. We need to be cognizant of diverse cultural backgrounds and diverse faiths. These challenging times in patients’ lives may be comforted by their spiritual beliefs and traditions. On the other hand, cancer can have the opposite effect on a patient’s sense of spirituality. Cancer and its treatment are difficult and the cause of a great deal of fear and uncertainty. To the extent possible, radiologists should create an environment that accepts the patient experience.

While charting the new waters of patient-centered radiology, we also need to remember that physician burnout is at an all-time high, and radiologists are the least happy at work compared with other physicians, as reported in a recent Medscape survey [2]. As noted in Gunderman and Moneva’s [3] recent article “Unhappiness and the Radiologist,” a crucial factor in work fulfillment is a sense of making a difference. The more radiologists act as a commodity, churning out the work like a hamster on a wheel, the more burnout we feel. By becoming more patient centered, we will have a symbiotic relationship with our patients. We will improve their experiences and outcomes, while making our careers more fulfilling and in turn decreasing radiologist burnout.

Approximately 40% of all US citizens will be diagnosed with cancer at some time in their lives. Cancer patients make up a large percentage of patients who will be in our radiologic care. It makes sense to listen to the stories of cancer patients, so that we can learn how to improve their experiences, which will in turn improve our own experiences.

ADDITIONAL RESOURCES

Additional resources can be found online at: http://dx.doi.org/10.1016/j.jacr.2016.09.014.

REFERENCES


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