


An Insider View of the Cancer Radiation Experience Through the Eyes of a Cancer Patient

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Sylvie Leotin¹

Abstract

While oncology providers see and treat thousands of cancer patients every year, few have had cancer themselves, or know what's it like to be in the shoes of a cancer patient days in and days out. This article written by a cancer survivor, writer, and experience design consultant lifts the lid on the cancer patient experience, for the benefit of noncancer patients. Through visual imageries, the author helps oncology providers and caregivers visualize and realize the vulnerability of the cancer experience and discover the treatment experience through new eyes. The article reveals emotional, mental, and somatic stressors, which add stress and/or trauma to the treatment experience and have been largely overlooked by health-care providers.

Keywords

cancer, empathy, patient/relationship centered skills, patient perspectives/narratives, service excellence, patient experience, clinician–patient relationship, patient satisfaction

A few months ago, I underwent a monthlong daily radiation therapy for breast cancer. It was hard for my frail rail thin body. The treatment left me physically, emotionally, and mentally depleted—like nothing I had experienced before.

Several months after completion, I still suffer the side effects. (I know survivors who remain affected many years down the road.) I feel lucky to be alive. A large part of me is filled with deep gratitude for the advances in cancer medicine – and for my oncology team. Another part of me, the human-centered strategy consultant, is bewildered by the gap in understanding of human needs in the radiation therapy process.

From the very first day I stepped into the radiation waiting room, and treatment room, I witnessed the void. Efficiency versus humanity. It chilled my spine. Lots of efforts had been placed into maximizing output. Less so on ensuring a conducive experience for cancer patients. Why does it have to be so dualistic? Efficiency married with humanity would produce better outcomes for both cancer patients and radiation oncology employees. (The strain was visible on both sides.) On the first day of treatment, a stressed radiation therapist greeted me with: “Next time I won’t come get you. Go straight to the dressing room, put on a gown, and wait in the waiting area I’ll show you.” That’s all he said. Then left me to figure out the rest. I was stunned by the coldness of this first reception. I felt a pang rise in my chest. The waiting area was dismal. The temperature freezing. The lighting chilling.

Haggard cancer patients, exposed and vulnerable, were waiting motionless in oversized gowns. Fatigued fishes in a decrepit aquarium completed the decor.

Although radiation therapy saves lives on a massive scale, the treatment process has much room for improvement. By process, I mean the way radiation therapy is administered from first to final treatment. Existing processes place excessive stressors on already stressed cancer patients. Many of which could be preempted with a greater awareness of psychological human needs. These stressors are largely overlooked yet fundamental to understand because they represent primal barriers to human well-being and healing. They can also have repercussions on medical performance. As an example, a patient who is stressed by the process will take longer to position on the radiation machine than one who is at ease. This in turn can increase stress on medical staff and lower productivity.

In all truthfulness, there are growing efforts to improve the patient experience in health-care organizations. Some hospitals (like the one I received treatment at) have a whole

¹ Founder and Principal, Tech Atelier

Corresponding Author:

Sylvie Leotin, Tech Atelier, 655 Oak Grove Ave #754, Menlo Park, CA 94026, CA 94025, USA.
 Email: sleotin@gmail.com



department dedicated to the patient experience. While a positive endeavor, in my experience, these efforts only scratch the surface of human needs. They address the low hanging fruits and fail to go deep enough to understand the root causes of patient distress.

During my monthlong radiation treatment, I experienced these stressors firsthand. It took concentrated efforts to acclimate to the process and be able to somatically experience treatment as treatment—and not torture or threat. It didn't help that the radiation suite looked like a torture museum I had visited long ago. The neat rows of radiation molds and masks (openly displayed for faster access) also added a sense of dread. Intellectually my mind was aware that I was receiving treatment, but at a primal level my somatic bodily response didn't reflect my intellectual knowing. As a mindfulness practitioner I stayed attuned to my body during treatment. My body felt hijacked. The alignment process (the procedure used to position patients for the radiation beams) and breathing instructions made my body tense up. Thoughts of feeling dehumanized popped in my mind on many occasions. I had to make special requests to make the process more conducive. The technicians graciously responded, and it reduced the strain for all of us.

I wish hospitals would place more efforts into understanding the holistic human experience of cancer patients. Advanced technology and first-rate oncologists are terrific. But pairing them with processes that don't acknowledge the full humanity of patients adds stress on already stressed cancer patients.

Recommendations to Improve the Patient Experience

Let's take a closer look at some of these stressors and explore ways in which they could be addressed. I've used the term "stressor" to refer to the conditions that impair the physiological or psychological well-being of patients.

The main stressors I experienced in the waiting room were the cold temperature, the dreariness of the room and the lack of empathy of the technician. The coldness of the room could be addressed by adjusting the room temperature, providing robes, warm blankets, cozy socks, slippers, or making hot tea available. The dreariness of the waiting room could be remediated by making the room more hospitable. Oncology providers could take inspiration from spas. Why not turn the radiation oncology waiting room into a spa-like waiting room, with soothing lighting, a relaxing decor, comfortable furniture, and soft background music? This would reduce patient stress prior to receiving treatment and make the radiation treatment application easier for everybody.

Offering empathy training to the radiation staff would also be helpful. The curt greeting of the technician was distressing. I felt treated like a case number instead of a human being. Cancer is hard, and I was especially apprehensive on

Table 1. Examples of Stressors and Stress Reduction Solutions.

Stressors	Possible Stress Reduction Solutions
Coldness of the waiting room	Providing robes, warm blankets, socks, slippers, hot tea. Adjusting room temperature
Dreariness of the waiting room	Creating a spa-like waiting room with soothing lights, comfortable furniture, a relaxing decor, soft music
Lack of empathy	Providing empathy training for staff. Offering stress-reduction services to the radiation staff
Uncertain wait times	Making use of notice boards to keep patients abreast of treatment delays
Dauntingness of equipment	Offering tours of the radiation suite before treatment and explaining what the different machines do
Displayed masks and molds	Hiding masks and molds in the treatment room. Not keeping them openly displayed

my first day. Acknowledging my humanity and greeting me with empathy would have helped.

There were more stressors inside the radiation suite. As an example, I had never seen a radiation therapy machine and felt intimidated on my first day. The machine felt domineering and threatening. Offering guided tours of the treatment room, prior to radiation, would help patients get acclimated with the equipment and lower first-week anxiety. The openly displayed masks and molds of patients were also chilling and disconcerting. Keeping them out of sight would make the room less dreadful.

My recommendations for radiation oncology providers are to start looking at ways to address the psychological stressors impairing the cancer treatment experience. They add avoidable and unnecessary stress on already stressed cancer patients. I shared examples of such stressors in Table 1, along with suggestions to counteract them. There are more stressors in the treatment process, and more ways to address them. But these may be a good start.

In addition, I would suggest offering stress reduction services to radiation technicians. They have a stressful job, and stressed employees cannot effectively take care of stressed patients.

Beyond these recommendations, I believe the best long-term strategy to reduce patient stress would be to empower oncology providers to discover and solve the stressors themselves. Witnessing the void in my cancer journey, I developed a special workshop to address this need. Most providers haven't been in the gown of a cancer patient, and it's hard for them to imagine what it's like to be a stressed cancer patient subject to stress-aggravating medical processes. Through creative awareness-building exercises I help participants gain a felt sense of the patient experience from the inside out. I find it a valuable step to uncover the stress factors affecting patient well-being along the treatment journey. It also helps develop patient empathy.

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Author Biography

Sylvie Leotin is an entrepreneur, speaker, writer, and consultant, with a broad multidisciplinary background in science, marketing, social sciences, the arts, and the humanities. Passionate about the human experience and fostering human well-being, she consults and teaches workshops to help organizations address unrecognized human needs, and increase patient and customer well-being.