

From Invisible Experts to Active Caregivers:

Pathologists
Emerge
from the
Shadows



As with many inspired ideas, it started with a tweet.

It wasn't Dr. Lija Joseph's tweet. By her own admission, she knew nothing about Twitter, nor about social media in general. But, as a scientist, she was curious, and she was ready to learn.

The tweet in question came from a woman recently diagnosed with cancer. Lija Joseph, MD—the medical director of the Department of Pathology and Laboratory Medicine at Lowell General Hospital in Massachusetts—learned about this patient in a weekly meeting in which she and her fellow pathologists discuss the latest published literature in their field. One article suggested by a group member featured a story about a patient newly diagnosed with lung cancer. That patient wanted to view her biopsy, so she reached out via Twitter to a pathologist who has a significant online presence. When the pathologist agreed to meet with the patient, he related his account of her traveling from her home in Lowell for a consultation with him in Newton.

It struck Dr. Joseph as wrong that the patient had to travel to simply see her pathology images. “The fact that she had to go so far to meet with a pathologist wasn't right,” says Dr. Joseph. “I felt that anyone in Lowell who wanted to view their pathology images should not have to travel to do so.” To explore this thought further, Dr. Joseph knew she would have to venture into some unfamiliar territory. She approached social media much as she would a sample in her lab: She observed it closely before coming to any conclusions.



Lija Joseph, MD

A Whole New World

Dr. Joseph began searching various social media outlets, where she discovered a vibrant community of pathologists and patients communicating about their diseases. “There was a lot of this interaction on Facebook and Twitter” says Dr. Joseph. “But I didn't feel very comfortable with it. How would it affect my professional reputation, and what about patient privacy issues?”

For answers, Dr. Joseph invited into her lab radiation oncologist Matt Katz, MD—a big social media proponent. In the beginning of 2017, Dr. Katz gave Dr. Joseph and her colleagues a primer on how to use social media as a medical professional. “He showed us what we were missing,” recalls Dr. Joseph. “My colleagues were still hesitant to take the leap, so I decided to be the brave one, and I opened a Twitter account in January 2017.”

Those first few months, Dr. Joseph stayed in observation mode, listening to and learning about this new arena. In time, she reached out to the pathologist who had met with the patient with lung cancer whom she and her colleagues had read about. He accepted Dr. Joseph’s invitation to meet. Dr. Joseph emerged from that meeting determined to make it possible for interested Lowell General Hospital patients to meet with the pathologists who diagnosed their diseases. Of course, that meant that Dr. Joseph had to be prepared to meet patients herself. “Before this, I had not seen a patient for 18 years—not since my training,” she says.

As a pathologist, Dr. Joseph’s position was not unusual. Although it is estimated that objective laboratory data influence a significant percentage of clinical decisions, patients are often unaware of the role that pathologists play in their diagnosis. “Many patients believe their surgeon or oncologist diagnosed their malignancy,” says Dr. Joseph. “In fact, pathologists are the engines that drive the car, but most of the time patients haven’t looked under the hood.”

Dr. Joseph says that this perception of pathologists as invisible forces operating behind a curtain can extend beyond the patient care arena. “Even in the medical community,” she says, “there is a misconception that pathologists are introverts uninterested in meeting patients.”

Dr. Joseph perceives her efforts to open a dialogue between patients and pathologists as not only a patient service but also a benefit to pathologists. A consultation program, she reasons, has the potential to transform pathologists from invisible experts into active participants in patient care and the multidisciplinary care team.

“There is a perception out there that pathologists only do autopsies, and they don’t like to talk to patients,” Dr. Joseph explains. “I personally think that pathologists are very compassionate and caring physicians. Like most doctors, they chose to go into medicine because they want to help people. But if they are behind the scenes, it takes something away. The patient encounter truly helps maintain a physician’s wellness.”

A Complete Unknown

Determined to help patients better understand how their diseases affect their bodies, Dr. Joseph began exploring how to create a program at Lowell General Hospital in which patients could meet with pathologists to view their biopsy slides. She reached out to other pathologists she found online who had experience consulting with patients about their diagnoses. Knowing that she would need the full backing of her hospital’s leadership, Dr. Joseph met with the hospital’s administration, risk management, and marketing departments, as well as its cancer center and professional liability organization. “Everyone was supportive and eager to

jump-start the initiative,” she recalls, “in part because of our pathology department’s excellent reputation.”

With her hospital’s support, Dr. Joseph established a free oncology consultation program, and she met with her first patient on Mar. 1, 2017. In the early days of the program, Dr. Joseph and the hospital’s leadership kept their expectations low. “It was a complete unknown,” recalls Dr. Joseph. “Would I have one or 20 patients a year? We had no roadmap and no precedent; we were starting from scratch.”

Dr. Joseph and the hospital’s oncology department decided to market their new pathology consultation services to patients with breast cancer. “In general, breast cancer patients tend to be very motivated,” she explains. “They are young and engaged, and they’ve done research on their disease.”

In Dr. Joseph’s first consultation, the patient came prepared, equipped with multiple diagnostic reports and plenty of informed questions. Dr. Joseph shared with the patient slides of her biopsy and invited her to view them through a microscope. She showed the patient a sample of “normal” cells to compare with her cells. “We talked about her diagnosis together,” says Dr. Joseph. “It was exciting for me and for her.” When their consultation was over, Dr. Joseph gave the woman her card and cell phone number, a practice that she continues today. “No patient has ever abused that information,” she says.

Practical Considerations

To date, Dr. Joseph has met with approximately 76 patients, and she continues to see about two to three per month for 30-minute consultations. She sees mostly patients with breast cancer who are referred to her by a breast cancer surgeon who has come to champion Dr. Joseph’s program. “Right now, this is an informal referral service,” says Dr. Joseph. “Patients find out about it from surgeons who offer the service to them if they want to see their labs before surgery.”

Dr. Joseph says she knows that not all patients will seek her out. “This [type of consultation] isn’t for everyone,” she explains. “The people who come to see me are patients who are curious, who truly want to ‘own’ their disease and find out everything they can about it.”

Dr. Joseph says that for the patients who consult with her, actually seeing the disease they are battling can be empowering. “Often with a cancer diagnosis, there is not much patients can control,” she explains, “so to actually see [the cancer] helps them understand it and decrease their panic or anxiety.”

In a recent study published by the *Archives of Pathology and Laboratory Medicine*, researchers surveyed 100 patients with cancer to gauge their interest in consulting with a pathologist and viewing a microscopic slide of their tissue. Eighty-five patients indicated that they were either definitely interested or interested, leading the study’s authors to theorize that “a patient-pathologist consultation program could provide value by improving information exchange (through enhanced understanding), could help patients manage uncertainty (through demystifying the process of diagnosis and enhanced understanding), and could enable patient self-management (through empowering).”²²

Although Dr. Joseph is currently the only pathologist at Lowell General Hospital consulting with patients, she says that several of her colleagues have also expressed an interest in doing so. By seeing patients consult with her, says Dr. Joseph, her colleagues have for the first time been able to put faces to the biopsies they work with each day. But she adds that there are skills to meeting with patients that do not always come naturally to physicians who have become accustomed to working in a lab every day.

“Using layman’s language that patients will understand has been something I’ve had to learn myself,” explains Dr. Joseph. “Most pathologists have only worked with other doctors in their careers, so they are mostly accustomed to communicating in a scientific terminology that they know their colleagues understand.”

Another consideration is the pathologist’s time. Currently, patient pathology consults at Lowell General Hospital are complementary. “You are spending a half hour with a patient, and there is no money involved,” says Dr. Joseph. “You could be signing out 15 biopsies in that 30 minutes. For some, that could be frustrating.”

Patient privacy is also a concern. As the first pathologist in her hospital to consult with patients, Dr. Joseph needed a place to do so that would be both comfortable for the patient and Health Insurance Portability and Accountability Act compliant. For now, that space has been carved out of Dr. Joseph’s lab, although she hopes to have a dedicated space in the future.

Finally, says Dr. Joseph, pathologists who consult with patients need to be comfortable when conversations stray beyond the biopsy, and they need to be able to put parameters on their encounter. Dr. Joseph is firm about not going beyond her field of expertise and discussing patients’ treatment plans. Patience and compassion are crucial in these cases, she says. “You have to be able to explain your role; you can’t just say, ‘No, I don’t want to hear about that.’”

New Horizons


Dr. Joseph hopes that by nudging her field to be more hands-on with patients, more medical students will be drawn to pathology, a specialty that currently attracts less than 2 percent of medical school graduates. She says she hears stories about pathologists actively dissuading students from choosing pathology because it has traditionally excluded patient interaction. Dr. Joseph hopes

that her patient consultations will challenge this attitude.

Dr. Joseph now regularly takes to Twitter with her handle @lijjoseph, #visiblepathologists. There she helps facilitate conversations among pathologists around the world who are also engaging with their patients. Pathologists-in-training are also helping promote patient interactions by offering consultations to them.

At the University of Michigan Medical School, students have produced a YouTube video about a leukemia patient’s experience meeting with pathologists who show her the science behind her disease. One pathologist at the University of Michigan has tweeted the results of an online poll of cancer patients in which 75 percent of respondents said they were “definitely interested” in a patient-pathologist consultation program.

Dr. Joseph says she does not want her consultation program at Lowell General Hospital to be confined to her services alone. She says the feedback she’s received has reinforced this. “With the explosion of social media, patients are actively seeking to learn more about their disease,” says Dr. Joseph. To expand her program, she and her colleagues are exploring the possibility of offering consultations remotely via telemedicine sessions. And to tackle the issue of reimbursement, Dr. Joseph is joining her colleagues at the College of American Pathologists to advocate for reimbursement for pathologists providing patient consults.

To document patient interest in pathology consultations, Dr. Joseph has joined forces with several other institutions that are offering similar services to gauge patient satisfaction via post-consultation surveys. She hopes that this nationwide effort will lend credibility to the usefulness of patient-pathologist interactions. “If the closest patients can get to understanding their own disease is a Google search, that’s not good enough,” says Dr. Joseph. “If they can see their own biopsies, they will feel like they can better manage their journey to wellness.” 

Barbara Gabriel is an associate editor for Oncology Issues.

Reference

1. Lapedis C, Horowitz J, Brown L, et al. The Patient-Pathologist Consultation Program: a mixed-methods study of interest and motivations in cancer patients. *Arch Pathol Lab Med*. 2019. Available online at: <https://www.archivesofpathology.org/doi/10.5858/arpa.2019-0105-OA>.

ACCC Resources

ACCC is partnering with the Association for Molecular Pathology, the American Society for Clinical Pathology, and the College of American Pathologists in a three-phase education program (acc-cancer.org/pathology) to help cancer programs effectively integrate the pathology lab and pathologists into the multidisciplinary cancer care team:

- Phase I—Precision Medicine: Integration of Pathology with the Cancer Care Team, including survey highlights, a landscape analysis, a leadership summit executive summary, and a policy white paper.
- Phase 2—Identification, Demonstration, and Promotion of Effective Practices for Pathology Integration, including a gap assessment tool that cancer programs can use to evaluate the level of pathology integration with the oncology care team. Self-assessments can be used to identify short- and long-term opportunities to improve.
- Phase 3—Ongoing Impact and Measurement (look for new tools and resources coming in 2020).