Physician Assistant Cares for Colon Cancer Patients — Then She Became One

The colon cancer diagnosis came out of nowhere for 38-year-old Bekah Kooy, who worked at UW Medical Center in Seattle.

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Bekah Kooy was convinced she had food poisoning when she felt nauseated and experienced stomach pain following lunch one day in February 2023. By the next day, the pain had moved to the right side of her abdomen and she wondered if her gall bladder might be the culprit.

Kooy, a general surgery physician assistant at UW Medical Center – Northwest, had a colleague perform an ultrasound, which looked normal, but by the next day, she could barely move. “I was ready to scrub into an operation with a surgeon I work with when one of the anesthesiologists said, ‘You should go to the ER, you look terrible.’”

At the ER at the hospital where she works, Kooy had a CT scan. “My chief of surgery came into the room after I got back from the scan and said I had a mass in my right colon obstructing my intestine,” she said. Kooy was 38.

Kooy was admitted to the hospital and scheduled for a colonoscopy, followed by robotic surgery for tumor removal a day later. When the pathology results came back, Kooy learned she had colon medullary carcinoma, a rare cancer subtype that accounts for less than 1% of patients with colon cancer. The vast majority of colon cancer cases are classified as adenocarcinoma.

Not only was the microscope appearance of Kooy’s cancer uncommon, but she also has ultra-hypermutated colorectal cancer, which means her tumor is rife with DNA mutations. The upside is that this type of cancer appears more likely to respond to immunotherapy, unlike the more common forms of colon cancer.

“She got treated a bit unconventionally, with immunotherapy, which is used in a small subset of colon cancer cases,” said Kooy’s oncologist, Stacey Cohen, MD, who directs Fred Hutch’s Colorectal Cancer Specialty Clinic. “Her case shows it’s important to understand the molecular features of cancer because that helps us individualize treatment, looking for options a standard patient might not have.”

A biomarker obtained after surgery called circulating tumor DNA, or ctDNA, suggested low risk of recurrence. But Cohen wanted to minimize that risk, no matter how small, because Kooy's tumor was locally advanced.

An increasing number of diagnoses in people under 50

Colon cancer rates are on the rise in younger people, even as the overall rate is on the decline. "Over the past three decades, colorectal cancer cases have doubled in people under age 50," said Rachel Issaka, MD, MAS, who directs the Fred Hutch/UW Medicine Population Health Colorectal Cancer Screening Program. Issaka holds the Kathryn Surace-Smith Endowed Chair in Health Equity Research.

Increased emphasis on getting screened and adjusting lifestyle-related risk factors has resulted in incidence rates dropping by 1% each year from 2012 to 2021, according to the American Cancer Society. But within the same time period, rates of diagnosis have increased by 2.4% per year in people younger than 50.

The reasons for this increase in younger people are not entirely clear, but Issaka said in a UW Medicine video that "a Westernized diet appears to be an influential factor."

Further complicating the increase in cases is that many providers don't realize colorectal cancer is on the rise in young people, which may lead them to attribute symptoms to more common causes.

For Kooy, her sharp and worsening pain was impossible to ignore. But others with undiagnosed colon cancer may ignore their symptoms, especially when they're not as obvious.

"We know to go see a medical provider when we have severe abdominal pain like Bekah or blood in the stool, but many colorectal cancer patients have more subtle symptoms," said Cohen.

More than half of patients have symptoms that might be nonspecific, like intolerance to certain foods, more bloating, changes in bowel habits such as more diarrhea or being prone to constipation — not necessarily classic symptoms like blood in the stool. Even when there is blood in the stool, patients are often told the cause is hemorrhoids or inflammatory bowel syndrome (IBS).

"If you have a persistent change in your body, it makes sense to be evaluated," said Cohen, who noted that people experiencing symptoms should rely on a colonoscopy, not a FIT test. "We encourage patients to advocate for themselves to see if colonoscopy is right for them."

As a health care provider, Kooy appreciates how Cohen reached out to other experts and shared her pathology slides to help develop a comprehensive treatment plan. "Everyone agreed I should be treated with a year of immunotherapy," said Kooy, who received nivolumab, a type of checkpoint inhibitor immunotherapy, directly from the manufacturer after Cohen's team helped her apply for authorization because her medical insurance company declined to pay for the drug.

Treatment wasn't easy for her. In spring 2023, nivolumab caused temporary hyperthyroidism (overactive thyroid), which then turned into permanent hypothyroidism (underactive thyroid). Mara Roth, MD, an endocrine specialist at Fred Hutch, is managing this aspect of Kooy's care.

Kooy also had an allergic reaction to the drug, which required her to be pretreated with large doses of IV steroids and Benadryl before each infusion. That worked for a couple months until March 2024, when Kooy experienced another allergic reaction. "I would start to feel hot and burning all over my chest, and it would spread through my whole body. And then my vision would tunnel, like a dark tunnel," she said. "It was super uncomfortable and honestly felt like I was dying. The nurses were immediately responsive with medications and fluids, and James Drechsler, PA-C, would show up immediately and reassure me and direct the care. I always felt in the best hands. But it was still so uncomfortable and scary."

That experience — paired with Kooy's ctDNA levels remaining negative, meaning no evidence of cancer, after nine months of therapy — led Cohen to recommend that Kooy wrap up her treatment. Kooy is now getting bloodwork every three months and regular imaging to monitor her recovery.

Integrative medicine and survivorship clinics have been key to recovery

One year after wrapping up treatment, Kooy still finds it hard to believe that someone like her — no genetic predisposition, no family history and no underlying diseases predisposing her to cancer — was diagnosed with colon cancer.

"I had just had twins three years prior, and I was otherwise completely healthy," she said. "It came out of the blue — I had no prior pain, no blood in my stool, I wasn't anemic. For years, I had felt exceedingly fatigued, but I was a mom of three young children who worked full-time. I attributed my exhaustion to being a woman."

Before her cancer diagnosis, routine bloodwork that her provider ordered had come back negative. Yet the tumor, once identified via imaging, was so large that it was blocking her colon.

"I feel like when I tell my story, it freaks friends out because it's like how on earth would you know?" she said. "Fatigue is not enough of a symptom to warrant a CT scan. So I can't really blame my [primary care] provider. It's a scary thing because how am I supposed to know if it comes back? The reassurance I'm given is that I'm under surveillance with routine scans and bloodwork for the next five years."

Statistically, it's uncommon for colon cancer to return after five years. "That's reassuring but at the same time, statistically it's pretty uncommon for a 38-year-old who is otherwise healthy to have colon cancer," said Kooy. "But I trust and wholeheartedly believe I had the absolute best medical care. The fact that Dr. Cohen took the time to sit and think about my case and consult with other colleagues to say, 'Hey, what would you do with this very rare cancer?' gave me the belief that she was always going to be thinking about my case."

Kooy also took advantage of Fred Hutch's integrative medicine offerings, including acupuncture and meditation. Susanna Myers, ARNP, an integrative nurse practitioner at Fred Hutch, gave Kooy a book, Anti-Cancer Living, that was "super powerful and profound for me." Written by integrative providers who did research on lifestyle changes people can make in combination with conventional standard of care treatment, the book espouses a holistic approach to cancer care.

"It was get your cancer treatment and pay attention to nutrition, exercise, sleep, relaxation, meditation and being part of community," said Kooy.

To help manage her anxiety, Kooy made an appointment at Fred Hutch's survivorship clinic, where she sees Barbara Regis, PA-C.

"I found I had an insane increase in anxiety when treatment was done, which surprised me," she said. "I thought I'd get done with treatment and start to feel good because I was done with that stage of my life. But I panicked because when I was in treatment, I was fighting but when it was over, I felt like I wasn't doing anything. It has been incredibly helpful to be reminded that even when you're not in treatment, what you are doing — eating a well-balanced diet, lifting weights, meditating, continuing with acupuncture and massage — help keep me physically and mentally well."

Back at work at UW Medical Center – Northwest — where Fred Hutch and UW Medicine work as a team to provide cancer treatment for patients — Kooy assists the surgeons who performed her own surgery and regularly scrubs in to help with colon cancer surgeries. When appropriate, she will discuss her own cancer experience with patients, mostly as a way to help them feel that she truly understands what they're going through.

"I think they appreciate knowing that I have been where they are," she said.

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