"That Was Me" A Patient's Perspective on Flat Lesion in Inflammatory Bowel Disease

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KEYWORDS

• Inflammatory bowel disease • Colonoscopy • Chromoendoscopy • Flat lesion

KEY POINTS

- Flat lesions are often missed on standard colonoscopy.
- Chromoendoscopy is a better detector of flat lesions.

Mr. Z was an active man in his fifties who had worked as an attorney, an investor, and a business advisor. In his free time, he participated in various philanthropies related to health care and housing for the disadvantaged. He exercised, ate a balanced diet, and spent ample time with his wife, 2 daughters, and dogs. On August 31, 2012, he was diagnosed with colon cancer. Four months later, he died. Mr. Z was my father.

Diagnosed with ulcerative colitis at age 19, my dad spent his adult life managing his disease, and following all of his doctors' recommendations. He was closely monitored at expert Inflammatory Bowel Disease centers. He followed the advised gold standard for cancer surveillance, annual colonoscopies.

My dad's ulcerative colitis was considered mild and was limited to a short segment of his left colon. With the help of his doctor and new medications, he rarely had flare ups. Because he considered his disease management a success story, he was happy to give advice to other patients. Over the years, he became the local go-to person for newly diagnosed IBD patients, answering frequent phone calls and questions. He was always upbeat and believed that with proper management his disease would not have to control his life; he had a career and a family, and he still had his colon! His advice to newly diagnosed patients was to find a doctor who was easily accessible and to follow that doctor's recommendations for frequent colonoscopies and vigilance. In order to be a better resource to others, my dad became active in our local Crohn's and Colitis Foundation of America (CCFA) chapter, and he also served on its national board.

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Gastrointest Endoscopy Clin N Am 24 (2014) 349–351
http://dx.doi.org/10.1016/j.giec.2014.03.007 **giendo.theclinics.com**
1052-5157/14/$ – see front matter © 2014 Elsevier Inc. All rights reserved.

Because my dad felt that his disease was cooperating with his treatment, he did not do much independent research on new treatments or colon surveillance protocols followed in other countries. In his mind, there was no need for that; he felt well, and that was all that mattered. His apparent good health was deceiving; unbeknownst to him, his IBD was becoming something malignant.

Until a biopsy from his annual colonoscopy in 2012 showed mild dysplasia, my dad had never heard of a chromoendoscopy, and although he read *The New York Times* daily, he somehow missed the front-page article about chromoendoscopy in March 2008. Had he been having the enhanced surveillance of a chromoendoscopy, as opposed to a colonoscopy, his flat lesion probably would have been detected before it became cancerous, and certainly before it had spread to his lymph nodes and nerves.

According to the current US guidelines and protocol, my father was doing everything right. But the protocol itself is wrong. Traditional white light colonoscopies only detect a fraction of the lesions detectable by chromoendoscopies. The lesion that killed my dad was a flat lesion, one that could have only been detected with a quality chromoendoscopy. In patients with IBD, research shows that chromoendoscopies are better suited to detect flat and depressed lesions. But if patients, especially those suffering from IBD, do not know that this procedure exists, how can they request it of their doctors?

What we have learned from my dad's illness, treatment, and outcome is that patients should enter every doctor's appointment with a critical eye and armed with questions. Before scheduling a colonoscopy and choosing an endoscopist, patients should do their homework. Just as one might research the latest model of a car or washing machine before making an investment, patients should research a potential endoscopist's training and patient outcomes. A few helpful questions[1] might be:

1. In what percentage of patients can you get the endoscope to reach the cecum? (Patients should want endoscopists who reach the cecum in 95% to 98% of patients).
2. What is your adenoma detection rate? (The national benchmark is 25% for men is 25% and 15% for women).
3. How long does the procedure take? (A more thorough test [both in and out] will detect more polyps).
4. Will I get a written report that clearly documents the findings? A good doctor should (1) provide photos of all parts of the colon, (2) comment on bowel preparation, (3) record times (how long the insertion took and the total procedure time), and (4) indicate if he or she examined behind the folds.

Knowing the right questions to ask, my older sister (who also suffers from ulcerative colitis) now has a better handle on her condition. When she first received her diagnosis, our dad assured her that she would be able to manage and live with her disease, just as he had. Because he did not know the questions to ask and did not have annual chromoendoscopies, our dad's illness eventually overtook him. He thought that he was managing his ulcerative colitis when in fact it was silently killing him.

One night in the months leading to his death, our father was awake, looking online at research about his condition. He came across Dr. Roy Soetikno and colleagues'[2] study on chromoendoscopy. Although their findings are very promising for cases such as my sister's, my dad knew that he had come across this research too late. By the time his flat lesion was discovered, it had become invasive cancer. He e-mailed us the link to the article with a short message: "That was me." Armed with the knowledge that a chromoendoscopy could have led to earlier detection of his flat lesion, we

now know that the outcome could have been very different. As a family, we are speaking out to doctors and patients alike. Our approach is two-fold. First, we are urging a change in the current US surveillance protocol from colonoscopy with random biopsies to chromoendoscopy with targeted biopsies as the gold standard. Second, we are encouraging patients to research their endoscopist, ask smarter questions, and when appropriate, demand chromoendoscopies over traditional colonoscopies. My dad died, but other IBD patients, my sister included, need not suffer the same fate. The science is there, but it is now up to us to implement it.

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