The patient's perspective – patients should be made aware of the options of sedation or no sedation and have a choice in screening colonoscopy

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The other day, I ate lentils for lunch and then went on a bike ride. It was 9.75 miles of pure agony. And then I thought of all of you. Because next to that, my unsedated colonoscopy was a walk in the park.

I believe I'm the only person ever to have my colonoscopy immortalized in the pages of the Wall Street Journal. The story, which appeared on February 13, 2009, was entitled, "Take a Deep Breath. Doctors are pushing sedation-free colonoscopies. Really."

My editors thought I was crazy. But I absolutely loved it. The discomfort was minimal, and the benefits were great. All the patients who had been in the waiting room with me before the procedure were either dead asleep, or wandering around talking nonsense. I jumped off the table, took a bite of the rubbery muffin they gave me, tossed it aside, and went out to a Thai restaurant for lunch. After that I pumped iron in my home gym and then put in a productive afternoon at the office.

After the experience, what struck me, is why is this option a secret? The only reason I found out about it is because, well, I'm a reporter. The hospital had sent me a thick packet of information pre-procedure, but all of it was about the prep and it did not even discuss sedation. So I called the Faulkner Hospital endoscopy unit, where I was scheduled for the next morning, and asked my options for sedation or anesthesia. The nurse said, "You'll get Versed." I said, um, "are there other options?" She said, "Well you can have it with nothing

at all." But the tone of the voice conveyed that would be a really, really stupid idea.

I looked up Versed online and found out that a major side effect, which some consider its major benefit, is to make you forget what happened. According to the package insert for midazolam, its generic now, 71% of patients getting a colonoscopy had no recollection of the tube being inserted, and 82% had no recollection of it being withdrawn. I also read that many patients don't remember the conversation with the doctor after the procedure. Okay, so I'm going to find out information important to my health and I'm not going to remember it? As a control freak, this didn't sit well.

Still, the nurse had sounded so ominous when she talked about the nonsedation option. When I got to the hospital the next morning, I still hadn't made up my mind. When they took me in back to take my blood pressure, put in the IV etc., I asked the nurse if doing it without sedation was very painful. She said, "All the doctors and nurses do it that way." I was shocked. I thought, okay, if it's so nuts, why do all the medical professionals do it? I asked another nurse, and she said she'd had it unsedated and it was fine--a little rocky at the first turn, but after that not too bad. She said if I tried it she would help me breathe. I was sold.

When I got home I did some research on the Web, and I found out that the unsedated option is common in Europe and Asia. Here's a study by researchers at the University of Lausanne, in Switzerland,

published in 2002, which included data from some five thousand patients at 21 centers in eleven European countries. As you can see, nearly 20% of the procedures were done unsedated. I wasn't able to find U.S. numbers, but everyone I spoke with estimated that fewer than 1% of procedures are done unsedated. Most of those people are doctors, nurses and other highly paid professionals.

What is the reason for the gap between Europe and the U.S.? One thing that shocked me about the email listing criticisms of the funding application for this conference was the comment that the conference needed to discuss how to convince patients. You don't need to convince patients. It's the doctors that need convincing.

Joseph G. White, a gastroenterologist at Scott & White Healthcare in Temple, Texas, found that 72% of 158 patients offered the sedation-free option chose it. Most completed the operation successfully and would do it again. He presented his data at the 2000 meeting of the American College of Gastroenterology and at the time, called for unsedated colonoscopy to be the new standard in the U.S.

But he chickened out--and still does sedation with most of his patients. He told me in a conversation for the story, "If you go in stone cold and say 'Hi, I'm Dr. White, let me try this without sedation, that isn't going to come across real well. It's easier to go with the flow, and the standard is sedation.'"

We got some mail on this story. This person wrote, "You are an idiot. Period. End of discussion." But this reaction was not typical of our readers (**Fig. 1**). Of the 34 letters we received, 24 were positive about the idea of unsedated colonoscopy. Five were negative, including one gastroenterologist, three patients who had not tried it but didn't think they'd like it, and the guy who called me an idiot. Five were neutral--they wrote to say they liked the story, or had a question about it, but they didn't express an opinion on sedation-free colonoscopies.

We also got letter from 17 readers who had actually had at least one sedation-free colonoscopy each. Five of them specifically said that they chose this option as a result of the article, and all were delighted.

Figure 1. Wall Street Journal (WSJ) readers say getting scoped sedation-free was not painful.

Fifteen of the 17 readers who tried the unsedated option said the pain was minimal--in the words of one, "totally bearable." Two said they had intense pain, but even those two would do it again. One had already had seven or eight unsedated colonoscopies, and only the last one was excruciating. The other one said the pain was only in the last few moments, so he'd happily put up with it again.

Here's what some of them said. "I've had worse experiences in the dentist's chair." "The discomfort of the procedure is mild compared to the colon prep." "Despite the intense pain at the end only, I would do it again." "I was proud of myself, and played golf all afternoon."

WSJ readers are, for sure, an elite segment of the population. We have a circulation of about 2 million. The average age of our subscribers is 55. Eighty-one percent are male. The average household income is \$253,000 and the average household net worth is \$2.5 million.

But our reader experience, like mine, demonstrates that doctors are not adequately informing patients that the option to skip sedation exists. One reader said, "The hospital staff was quizzical, but cooperative." Another wrote, "The doctor looked flabbergasted. After an argument, he seemed annoyed. I told him the nurse could hook up the IV. If I started screaming, she could insert the drugs." And I really like this one, "Doctors were wary of my ability to withstand the so-called pain." That person went on to have his colonoscopy unsedated, and had four polyps removed, all with no problems.

Here's somebody who didn't read the article in time: "I wish I knew about this

before last Friday. Being sedated not only caused me to miss a day of work but also to be in a quasi fog-like state until 5 p.m." Her colonoscopy was at 9 a.m., so that's a whole day lost, and she wasn't happy about it.

Several readers wrote to say they wanted to find a doctor who would do it. This one, from Portland, Maine, is so eager she'd happily travel--thought maybe not this far.

While preparing this talk, I called Benjamin Smith, the doctor who did my colonoscopy. Dr. Smith is director of the Gastrointestinal Endoscopy Center at the Faulkner Hospital in Boston. As a measure of his skill, I can tell you that many doctors and nurses ask for him to do their colonoscopies.

I asked him what he did to make it less painful for me, and whether it took longer. Starting with the last question, yes, it took longer--but not much. Dr. Smith is already slow by the standards of many endoscopists; he schedules one procedure an hour. He says eliminating the sedation adds about five minutes to his usual time of 20-30 minutes. On the other hand, doing the sedation takes about three or four minutes, so it's almost a wash. If it's the patients' first time unsedated, a conversation may be needed--which could add some time.

Technique-wise, Dr. Smith told me that he always uses a pediatric scope for sedation-free colonoscopies. He also goes more slowly on the way in, and carefully manages the amount of air he puts into the colon. He uses some water to help compensate for the reduced air, but I don't think as much water as was demonstrated

here this morning. There's also a few technical tricks, which I imagine all of you know, such as pulling the endoscope back so the colon folds over it like a curtain, which reduces stretching of the colon, and having the nurse press the abdomen to help it travel smoothly.

During my colonoscopy, I didn't know any of this. From my perspective as a patient, here are the things that made it a good experience for me. It really helped me to know that Dr. Smith had done it before, was confident in his skill and did not seem shocked that I wanted to do it. Also, the backup plan was incredibly comforting. He told me if I found the pain unbearable I could choose Fentanyl, an analgesic, or Versed, or both. I'd feel the effect in two to three minutes, he said.

The single most important factor in making this a good experience for me was the nurse guiding me in deep breathing. It helped relax my body, and by dissipating the tension, the pain reduced.

And the video entertainment was awesome. I have some 600 channels on my Comcast cable TV and nothing comes close to seeing my own colon, in real time, when I'm awake enough to really appreciate it.

In conclusion, I hope all of you will not chicken out. If you are here today, you probably have a strong interest in unsedated colonoscopy. But you may feel that you are bucking the trend that it is easier to go with the flow. But I would like to help give you faith that this is an option that is good for patients. Offering

unsedated colonoscopies is not something that needs to be pushed on patients. It is an option that at least a substantial minority of patients will jump at, with delight. Let's end the secrecy, and start telling patients that they have the choice.

Thank you.

Acknowledgement

Laura Johannes is a Boston-based freelance writer, author of the Feb. 13, 2009 Wall Street Journal Story, "Take a Deep Breath. Doctors are pushing Sedation-Free Colonoscopies. Really."