

Transforming the Culture of Patient Care

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Collaboration and Information: Conquering My Uterus

By [Jen LiMarzi](#) | November 7, 2016

Abstract

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For over 15 years I've been a medical writer, which has afforded me the opportunity to joke among friends and family that "I'm not a doctor, but I play one at work." In my current role in the medical education field, I work with international physicians to help produce education for doctors on a variety of topics including those focused on shared decision making and patient-centered care. While I had an abstract understanding of the value of this education, it wasn't until I actually took on the foreign role of being a patient that I truly understood how important it was to ensure that both the clinician and patient worked as a team to determine and commit to the best course of care.

Until January of this year, my personal engagement with the health care system was limited to annual checkups at a primary care office. That changed when my menstrual cycle morphed from a monthly nuisance to a brute force that made me aware of my internal organs nearly every day of the month. As someone who never gave a second thought to my period, I was now purchasing tampons and bottles of Advil like I was stockpiling supplies in advance of a catastrophic disaster set to decimate all drug stores within a 20-mile radius. When the pain and frustration hit a boiling point, and at the urging of my supportive husband, I made an appointment with my primary care physician to attempt to address my issues.

Armed with far too much internet research and a family history of fibroids, I walked in and explained my symptoms. My doctor listened thoroughly, took time to feel around my abdomen, and drew some blood. At the end of the appointment she said, "We'll see what the blood says, but I think your body may just have gotten used to the birth control pills you're on. I think you just need to try a different kind."

Despite being equipped with information that suggested a more substantial biological change and having an inherent feeling that my body didn't simply get "tired" of a medication I took for years, I nodded in obedient agreement at this figure of authority. She wrote me a prescription and told me to be in touch in a few months if the switch didn't solve the problem.

Months later, my issues had escalated rather than resolved and I called to make a follow up appointment. When I was adamantly told that there were no appointments to see the doctor within the next month, the delay gave me time to think about how all-consuming this health issue had become and served as a catalyst to empower me to take control of my situation. I decided to approach this challenge as I would any other in my life. If the pipes in our home rattled and leaked and a general maintenance person hadn't remedied the situation, I would call a plumber who exclusively dealt with these issues. Not only that, but I would research and find the plumber with the most experience and best reviews.

Through Google searches, Yelp reviews, and even a few YouTube cross checks, I weeded through the numerous gynecologists within my area and set my sights on a highly experienced and respected gynecology practice in downtown Chicago. Thankfully my insurance allowed for self-referral and I was able to secure an appointment for later that same week. From the moment I stepped into the office I immediately felt I had made the right choice. My physician approached my case in a logical manner I could relate to, akin to how, as a medical writer, I might set out to define unmet educational needs. She listened to my symptoms, asked questions about my family history and whether I wanted children, and conducted a physical exam. Without hesitation she said, "You have at least one fibroid. What I would like to do now is run some tests and see what the information tells us. Then we can discuss options."

Two weeks later I returned for an ultrasound and was told that a large fibroid had taken up residence in a poorly positioned location in my uterus that was at the root of my issues. While my daily role as a medical writer makes me capable of discussing the mechanism of action of emerging drugs and complex disease states, I found that when it came to discussing my own body I became an idiot who couldn't come up with a coherent sentence. Thankfully, my doctor could sense this and began reviewing my options in great detail including rudimentary drawings on the back of a piece of paper.

After hearing all of my options, of which many sounded like temporary solutions to a permanent problem, I looked up without a shadow of a doubt and said, "It's gotta come out."

At 39, I decided to have a total laparoscopic hysterectomy and bilateral salpingectomy (removal of the uterus and fallopian tubes, but retaining the ovaries). Without hesitation, judgement, or asking me 5 more times about whether or not I was sure I didn't want children, my doctor responded, "I think you're making a good choice. We'll get that scheduled."

Empowered by that decision, my native New Yorker neuroses apparently felt comfortable to emerge and take over from that point forward. I assumed anything that could go wrong would go wrong from insurance issues, to scheduling problems, to dying from anesthesia due to a reaction with something as mundane as a multivitamin. I became a ball of nerves wondering if a lobotomy might be a better cure to my ailments than a hysterectomy. Thankfully, I had put my trust in a team that ran like a well-oiled machine, expertly answering all of my questions as they came up and providing timely and detailed updates on the status of my procedure and what I needed to do to prepare.

I checked into the University of Chicago's Center for Care and Discovery on the morning of July 6th. The relatively new and smartly designed building was the perfect punctuation to what had emerged as an ideal healthcare experience. The check-in area resembled that of a luxury hotel where my husband and I were given clear instructions about what to expect by all personnel we dealt with. From there I moved to pre-op where my nerves were calmed by kind, caring, and informative nurses, residents, and more doctors than I could remember.

Several hours later I awoke in recovery being attended to by a wonderful recovery nurse who spoke to me in terms that my anesthesia-confused brain could understand. Upon the arrival of my husband, she explained the next steps of the hospital process clearly to him and emphasized how my procedure went extremely well with no complications.

We spent the next 24 hours in a pleasant and well-appointed private hospital room (as are all rooms in the Center for Care and Discovery building) being attended to by courteous and responsive nursing and hospital staff, all who marveled at the fact that I had an enlarged organ removed and only had 3 Band-Aids on my abdomen to show for it. By the following afternoon, I was back home in my own bed, managing pain with oral medications and strolling around the house, albeit slowly, no longer worried that my reproductive organs were out to ruin my life.

While I realize I am extremely lucky in my outcome, what this entire experience has taught me is that in addition to luck, choice plays a substantial role in one's healthcare. I took an active role in choosing the clinician and type of care I wanted and my clinician provided all the information I needed to make informed choices throughout the process. Through collaboration and information, in my case, an optimal outcome was achieved.

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1 Comment

Danny van Leeuwen on November 14, 2016 at 8:25 am

Nice job, Jen. Thanks for this. I will share.

Reply

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