Organ Recipients Need Strong Partnerships With Their Doctors

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I am a cystic fibrosis (CF) patient with a complex medical history that either intrigues or intimidates medical providers. At 40, I've dealt with a lifetime of progressive lung disease, gastrointestinal complications and other later onset issues from CF such as osteopenia, diabetes and bowel cancer. I often joke that the recessive CF gene that my identical twin sister and I inherited from our Japanese mother and German father is the "gift that keeps on giving."

Throughout my childhood, I only saw specialists, and was under the impression that primary care pediatricians were only for "normal" kids. Not until adulthood and a change of insurance requiring a primary care gatekeeper did I meet my first "normal" person's doctor- my primary care provider. After two double lung transplants by the age of 35, and progressive CF gut disease, I honestly thought, "What could a primary care physician offer me?"

After years of being followed by many specialists – endocrine, pulmonary, infectious disease, dermatology, GI, oncology, ophthalmology -I've witnessed how easily a fragmented specialty approach can result in a lack of communication between providers. I then realized the incredible value of my primary care physician. They served as the birds-eye view of my health and looked down the lens of the bigger picture, to views that specialists often overlooked. For example, during a 2-year bout with severe gastrointestinal distress supposedly the result of CF, my primary care physician noticed I was extremely anemic. Fifteen years earlier, my mother's colon cancer was detected due to a low hematocrit. This helped raise my suspicions and insist on further investigation and exploratory surgery, which led to a diagnosis of small bowel adenocarcinoma. By offering routine evaluations such as vaccines, pap/pelvic exams, and evaluations for my newest chief complaint- sports injuries as a result of new lungs! – I have gained more respect and gratitude for primary care's role. At my doctor's office, I have a sense of satisfaction and pride that I am at the doctor for something "normal."

Fortunately, my doctor is open to a mutual collaborative learning experience, respects my experiences and knowledge base as a "professional patient," and acknowledges her limitations in being able to treat something as complex as cystic fibrosis, lung transplants and bowel cancer. She partners with me as a patient for care that is truly patient-centered. I appreciate the breadth of knowledge that all physicians must have, and recognize the inability for any health care provider to know everything. I've learned this first hand myself, working as genetic counselor for over 15 years.

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