How Angiosarcoma and Facebook Changed My Life

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A restaurant in Seattle. A hotel lobby in Boston. My living room in Little Rock. Disney World. Two years ago, I would never have imagined that I would be met and warmly embraced by angiosarcoma patients and their family members in these unusual locations. I would have thought it unlikely that I would ever meet or interact with even a single patient with this rare aggressive blood vessel cancer, even though I am a sarcoma pathologist who has diagnosed this tumor many times. Most pathologists rarely meet their patients face to face, and many cancer patients mistakenly think it is their oncologist or surgeon who diagnoses their cancer, rather than their pathologist.

Two years ago, I joined an angiosarcoma patient support group on Facebook. I introduced myself as a pathologist who had an interest in sarcomas. I couldn't provide medical advice, but I was happy to answer general questions and explain the unique roles and language of pathologists. Their warm reception was overwhelming. It turns out that patients want to talk to pathologists, to hear what we do and why. Rather than seeking medical advice, I was surprised that most patients sought mostly to understand their disease. Their savvy queries even raised new questions in my own mind about a tumor that I had thought I understood so well. I wanted to educate patients, but they have taught me so much more than I have taught them. Long-term survivors, young adults and even children afflicted, patients with significant responses to chemotherapy... I met all of these "exceptions to the rule" in this group.

It turns out that angiosarcoma is more complex and nuanced than I had appreciated. Beyond medical knowledge, these patients also taught me about courage, persistence, and hope. A man my age with a wife and 2 young children has metastatic angiosarcoma, and yet, his optimism and hope far surpass my own. Lauren Skop Ryan, founder of this Facebook group and cureasc.org, told me shortly before her death that she knew it was too late for her, yet she still fought to bring hope and knowledge to newly diagnosed angiosarcoma patients. Her final effort in this life was to pour out the last of her strength to ease the suffering of others. I still stand in awe of that level of compassionate devotion.

Finally, this group taught me that pathologists still possess the art of healing. Yes, we know that the diagnoses we make are crucial to patient care, but we often feel that since we do not treat patients, we cannot heal patients. We forget that healing does not always equal treatment or cure. A year ago, I asked group members if they would share pictures of their own angiosarcoma (it often arises in the skin) for a lecture I was giving to educate my medical colleagues. Of the numerous pictures that flooded my inbox, one stood alone and always will in my mind: Cindy, just prior to her death, her once lovely face now graphically disfigured by angiosarcoma. My audience sat in stunned silence at her visage. She is the face of angiosarcoma that they will never forget. I know I will never forget. With trepidation, I emailed Dave to share the profound impact his late wife had on a room full of doctors. His response: "Thank you, Thank You, THANK YOU! It took me several minutes to read your email because I started sobbing bitterly as I read it, and I couldn't see through my tears... raw emotion; anguish as I recalled what she went through, mixed with joy that her suffering would not have been wasted." And Cindy's eldest daughter, Britt wrote, "I read through that email three times and cried harder each time. I don't really have the words right now to express how incredible it is. I wish that my mom hadn't had to be the one to tell this story. But since she is, I hope that it changes the course of medical history, and that it helps to save lives... After so many years of seemingly uninterested medical professionals, it's absolutely amazing to have someone express so much caring. Truly, I can hardly describe what a relief it is."

In the end, it was not my expertise or knowledge that mattered. It was my willingness to raise awareness that brought "joy" and "relief." This IS healing, and any pathologist with humility and compassion can do this. These patients go to great lengths to meet me in person in Seattle, Boston, Little Rock, or even Disney World, all because I advocate for the rare disease that shattered their lives. I truly hope and believe that patients working together with pathologists will change medical history. I know for certain they have already changed my life forever.

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