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Roadmap for treating small renal masses in Michigan: A patient advocate's story

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Background

A 3.5 cm mass was discovered on my right kidney following an October 2021 CT scan to investigate recurring pain in my lower abdomen. I was shocked by the results given that the pain was determined to be unrelated to the mass, and my blood tests were normal. I'm sharing my story to encourage use of the Michigan Urological Surgery Improvement Collaborative (MUSIC) materials to assist with transparent and direct physician-patient conversations regarding kidney masses and to encourage patients to assume more active roles in treatment decision making and improvement of their own health.

Approach

I was referred to a urologist for follow-up treatment and he explained that the mass may, or may not, be cancerous. He also shared draft materials recently developed by the MUSIC team to illustrate treatment options ranging from active surveillance to immediate surgery. After discussing, we mutually agreed that active surveillance was a viable option considering my mass size, overall good health, and lack of any adverse symptoms. The MUSIC roadmap was extremely helpful for me to understand my situation. The document, which was designed with the input of 26 Michigan urologists to assist physicians with patient consultations, was not intended for patient release and lacked patient input. My urologist requested I provide feedback from a patient perspective. This was the beginning of my involvement with MUSIC.

Maintenance

During my 1- year active surveillance period, the mass grew from 3.5 cm to 4.1 cm. To preclude metastasis, my urologist recommended proceeding with surgery. My partial nephrectomy was performed without complications in October 2022.

I utilized the surveillance period to:

1. Enhance my knowledge of kidney cancer and treatment options outlined in the MUSIC roadmap and provide patient input into development of a version specifically for patients;
2. Enroll in "Silver Sneakers" and establish a regular exercise program;
3. Consult with a nutritionist to improve my eating habits and lose weight; and
4. Schedule surgery during April 2022 to replace an arthritic knee joint.

Quality of Life

Guidance provided by my urologist and the MUSIC materials allowed me to make an informed treatment decision regarding my kidney mass and confidently select active surveillance. I am grateful for the continuing opportunity to participate in MUSIC collaborative meetings and provide commentary on patient educational materials. I sincerely believe other patients will benefit if this document is shared (<https://bit.ly/3Yzlc1i>). Ultimately, I attribute my improved health and successful surgical outcome to these collaborative efforts.