Challenges in Providing and Receiving Quality Breast Cancer Care

Through the Breast Cancer Disparities Learning Community, ASTHO works with the state health departments strengthen their ability to mobilize data resources more effectively to address sociodemographic disparities in breast cancer mortality, with a focus on the elevated mortality rates of black women in the United States. Through this learning community, state-specific data helped to identify geographic spatial analysis needs and establish decision makers' priorities to reduce the health disparities gaps in breast cancer screening, follow up after abnormal screening result, and treatment quality.

Receiving high quality care after a breast cancer diagnosis can be a challenge not only for the patient, but for the physicians treating that patient as well. To gain both perspectives, ASTHO spoke with Dr. Benjamin D. Smith, Associate Professor of Radiation Oncology at The University of Texas MD Anderson Cancer Center in Houston, TX, and Marina Kaplan, a patient of Dr. Smith. Their comments highlight some of the difficulties that physicians face in providing quality care to their breast cancer patients, and the barriers that patients face in receiving the highest quality care available.

Marina, how did you begin to receive treatment at MD Anderson despite living on the east coast?

Marina: I found MD Anderson after a literature search on sternal resection in cancer patients. I had metastatic breast cancer that had spread to the sternal bones and I was considering surgical removal of the sternum after I'd completed chemotherapy. It's an intense and complicated surgery, and very few surgeons have performed it on cancer patients. A group that had performed with great outcomes was based out of MD Anderson, and I reached out to the corresponding author of the article directly. I had the nine-hour surgery and I recovered remarkably fast and surprisingly well. I then began to receive radiation with Dr. Smith, who developed a carefully thought out, completely customized radiation plan for me. That's the great thing about MD Anderson – the doctors really look at each case individually and customize treatment to your unique case.

Would someone without access to the journal literature have taken that same path?

Marina: The more typical path is to seek a second opinion, which I did, but they were all over the place – a surgeon in Pittsburgh was suggesting a heavy reconstruction that would have limited long term mobility, and surgeons in Boston recommended not having surgery at all. That being said, most hospitals do have a patient library that allows patients to do literature search, often with the assistance of a clinical librarian.

From your perspective Dr. Smith, what does it mean to provide and receive high quality breast cancer care?

Dr. Smith: Receiving high quality cancer care is an intricate dance between physician and care team, and the patient. We need the patient to do things to make sure they get adequate care. If either party doesn't do everything the right way, it's a bad outcome for the patient. Quality [breast cancer care] is a complex thing to measure and it's important to ensure that everyone upholds their responsibility. Being a good doctor is more than keeping up with the literature – it involves being thoughtful and self-critical, and making sure you're not missing things.

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As an example, I was caring for a young woman who had pretty bad breast cancer, which I would typically treat with radiation of the internal mammary nodes beneath the sternum. This patient's old physician didn't do that, and so her cancer came back in that internal location, requiring invasive and expensive procedures which might have been avoided.

Is it common for breast cancer patients to receive care from multiple providers?

Dr. Smith: It's not uncommon for my patients to receive care from different providers because people come to MD Anderson from all over the world, and this fragmented care can put a patient at risk for poorer outcomes. My typical form of communication [with other providers] is to put something in writing and have that patient give something to their doctor [if they are leaving my care]. The responsibility is then on the patient to provide this information to the doctor, and for the doctor to take that recommendation into account. It's very ad hoc.

I take a passive approach for patients leaving my care and going into someone else's care because you have to respect that the patient is seeing a new doctor who needs to make treatment decisions. I have no active role in referring patients to a radiation oncologist when they leave MD Anderson because I don't have that expertise.

What prevents patients from receiving high quality care?

Dr. Smith: Patients need to come to their appointments and receive chemotherapy and radiation as recommended, and take their medicine as prescribed. When patients have a tough time doing that – due to lack of transportation access, being the caretaker of their family, or due to anxiety over their treatment and their prognosis – that puts them at risk for poorer outcomes and the need for greater toxicity treatment later on.

Marina: When you first get the news and learn of your diagnosis, it's absolutely shocking and stunning. Your mind goes blank, you're completely overwhelmed, and the information is difficult to process. At the beginning, I could not remember any instructions or information unless I wrote them down immediately. I think the best model is to have the instructions repeated multiple times – for example having a second meeting with a nurse navigator because you don't retain much the first time you meet with your care team.

I had a pre-chemo educational meeting with my nurse navigator at a community-based oncology practice – it was a one-on-one meeting several weeks after the initial diagnosis, just prior to starting chemo. That meeting was very informative on what to expect when going through chemotherapy and what to do. Another thing that was great in that practice was that they had a dedicated phone line directly to a chemo nurse who could answer or triage any questions you may have had during chemo.

What other barriers exist that prevent all patients from receiving the same quality of care?

Marina: When you are diagnosed with metastatic breast cancer things are complicated in terms of treatment guidelines. It seems from reading blogs and talking to other patients that it's very much a trial and error approach. I think there needs to be a central national database that tracks all patients'

treatment protocols and outcomes beyond the typical five-year follow-up – that would provide great data to patients, doctors, policy makers, funders and epidemiologists.

On a personal level, finding and accessing appropriate clinical trials is important to me. There are multiple trials-matching services and multiple resources online where you can get information, it gets overwhelming and you have to know where to look. I feel that your doctor or nurse navigators locally should help you navigate clinical trials based on your cancer sub-type and willingness to travel. Typically, you don't receive any help in accessing clinical trials unless your oncologist or hospital is participating in a particular trial.

Dr. Smith: Cancer treatment is a team effort – you need a great radiologist, a radiation oncologist, a pathologist, a breast surgeon, a medical oncologist, and a plastic surgeon. Payment systems are not always aligned to incentivize patients to receive this type of cooperative care. Many states are without a major cancer center and so this variety of expertise might not be easily available to everyone.

I've been negative in my comments, but there are positive takeaways. Epidemiologic data indicate that breast cancer rates are declining, but there are pockets of poor outcomes and poor care. The extent to which we can help doctors make good treatment decisions, and put patients in a position to receive high quality care, we will continue to see improvements.

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