A Patient Perspective on Brain Metastases in Breast Cancer

Musa Mayer

A decade of work as a patient advocate with women who have metastatic breast cancer has sensitized me to their fears and hopes as well as their feelings about available treatments. Although novel systemic therapies have extended survival and improved quality of life for many such patients during these past 10 years, there has been little comfort or hope in research news about brain metastases.

Were you to search the tens of thousands of e-mail messages archived over the past 6 years at http://bcmets.org, a web site with a mailing list serving those affected by advanced breast cancer, you would soon learn that, for many women with metastatic disease, brain metastases represent the greatest conceivable threat.

"Your brain controls your independence, your quality of life, your entire existence," one woman wrote. "Brain mets can bring on a loss of hope and a fear of loss of self. It's not just a body part that's at risk, it's our life as who we are."

For these resourceful, self-sufficient women, most in their vital middle years and still working and caring for their families, the prospect of being diagnosed with brain metastases is terrifying, even for those who fully grasp the gravity of their ultimate prognosis. As another woman put it, "our fear is perhaps greater about living an extremely compromised life, wheelchair bound or unable to remember things or see clearly, or live independently, than it is about dying."

They feel at risk not only from the cancer in their brain but also from the crude and inadequate available treatments, especially from fatigue-inducing, memory-scrambling whole brain radiation and personality-altering steroid treatments. They often learn—the hard way—that by the time brain metastases are symptomatic, they have become too numerous or too large and are beyond the reach of stereotactic radio-surgery. It is unclear to them why brain scans are not routinely recommended to find these metastases at an earlier stage.

In women with HER2+ metastatic disease, who are more likely to develop brain metastases, this fear can be particularly acute: "I went into a deep depression, waiting with overwhelming anticipatory dread of getting the brain mets diagnosis."

Those diagnosed with brain metastases may find the experience devastating. "My first thought was not my brain!" said one woman. "To me, that meant I would lose me. The threat of dying was not uppermost in my fears but losing my identity and becoming totally dependent on someone else for personal needs."

After treatment ends, the fear may actually intensify. "I was diagnosed with 'many' small brain mets in October 2005. I've counted about 15 to 18 on the MRI. I had whole brain radiation and the subsequent follow-ups eventually said 'some decrease'," one woman confided. "They are now 'unchanged'. Do I just do nothing? My oncologist says yes. You don't treat while they are just inactive. I feel like a waiting time bomb. I am so scared."

"Once you have mets to your brain," another woman said, "you feel very vulnerable and have a hard time not thinking about it constantly. You are monitoring your speech, your memory, and you worry every time you get a headache."

These eloquent voices are cries in the darkness. They starkly express the critical importance of research in this neglected area. As more systemic therapies have emerged to control advanced disease, the question becomes ever more urgent: where are the safe and effective treatments for brain metastases?

Patients and advocates are seeing some hopeful signs that the flow of meaningful research will soon increase and begin to match progress in other areas. We are seeing funding that works to bring together an eminent group of scientists, clinicians, and advocates to address collaboratively the problem of brain metastasis in breast cancer.

Today, as patients increasingly undergo treatments that control their liver and lung metastases but fail to protect them from the onset of brain metastases, advocates realize that more effective systemic therapies will only serve to magnify this problem, unless the underlying mechanisms are addressed.

Clearly, site-specific research can make a difference to patients. High-potency bisphosphonates have made significant inroads in the management of bone metastases, offering patients improvement in quality of life through lessening their pain, risk of fracture, incidence of hypercalcemia, and slowing the progression of the disease in bone.

Innovations in blood-brain barrier disruption that permit effective therapies to safely reach the brain are likely to have implications for patients far beyond the treatment of brain metastases—expanding the scope to therapies for brain cancers and other diseases affecting the central nervous system. Research in this area deserves broad support across medical disciplines.

Without effective drugs that are able to cross the blood-brain barrier, radiation has become the workhorse of brain metastasis treatment. Yet, whole brain radiation can leave patients with persistent fatigue, permanent hair loss, profound memory problems, and other serious cognitive deficits—side effects that may worsen with time, raising serious quality of life issues as patients are able to live longer. Often tumors resume their growth, or new brain metastases develop. Less damaging approaches that deliver radiation more precisely may not be feasible and are frequently not offered as a first option. "We are human, we are scared," one woman told me. "In the rush to
battle brain mets, I think patients can be railroaded into therapies they're not comfortable with.”

The women living with brain metastases with whom I spoke were eager to share their experiences with researchers and physicians and excited at the emerging research efforts now focusing on their plight. They had a great deal to say, particularly about the effect of treatments on the time remaining to them. “Spend some time researching what quality of life means to patients in the context of brain mets and treatment,” one woman advised, “so you can put appropriate measures in your studies. Try to quantify the trade-offs between quality of life and extended survival time.”

Another woman put it more simply, “Please make the cure better than the disease.”
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