



Expanding the Knowledge and Experience for Breast Surgical Oncology Fellowships

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Editorial

Traditionally, breast surgical oncology fellowships have provided a well-rounded, comprehensive exposure and experience to virtually all aspects of breast health and breast cancer diagnosis and treatment. Fellows, no matter where their fellowship experience takes place, have had quality time spent in the operating room with breast surgeons, with plastic surgeons, accompanying medical oncology for consultations, witnessing decision making about radiation therapy needs, observing the genetics discussions, and learning about how pathology determines a diagnosis and the prognostic factors of a tumor. There is hopefully also time spent with nurse navigators, palliative care specialists, and administration to provide what would be considered the ideal fellowship training content.

Five years ago, the author made a conscious decision to include a new element to our breast surgical oncology fellowship training program here. The author required that the fellow attend one of our two metastatic breast cancer retreats. This unique program, which launched a decade ago, brings together stage 4 breast cancer patients and their primary family caregiver person, for a 3 day/2 night event. Many of these patients are quite ill. Half come from Johns Hopkins Medicine cancer centers and half come from elsewhere around the country. (I felt it was important to open our doors and enable those getting treatment elsewhere so they too experience this program, and return to their oncology team back home and share their experiences. We want to see these types of programs happening across the country, and not just in Maryland.) We limit the number of patients to twelve, resulting in twenty-four people attending. It draws all ages, all races and ethnicities, all tumor types—from triple negative to occult primary tumors. Most had treatment for their original breast cancer several years prior to their bodies declaring they have metastatic disease, and there are always a few that are more than a decade out from early stage ER+/HER- disease, now dealing with stage 4 breast cancer. They are free to attend, funded by grants and philanthropy.

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Received Date: 22 Feb 2017

Accepted Date: 28 Apr 2017

Published Date: 04 May 2017

Citation:

Shockney LD. Expanding the Knowledge and Experience for Breast Surgical Oncology Fellowships. Clin Surg. 2017; 2: 1461.

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There are two retreats a year: one of for couples so the patient brings their spouse or partner; the other is for women not in a relationship so she brings her primary female caregiver which usually is her mother, sister, daughter or in some cases even a best friend. These people are all anxious to network with others in the same situation they find themselves. Husbands want to talk privately with other spouses, thirsty for information about how to cope, getting confirmation that what they are each experiencing are normal thought processes. Patients want to know about what lies in their future—the good and the bad. What no one knows coming into this retreat, is that by the end of the third day, everyone will be well on their way to creating an end of life plan that will provide them a sense of control while living with great uncertainty.

So why would the author consider it important for a breast surgical oncology fellow to observe this type of retreat? After all, the fellow has had adequate time with medical oncology to observe decision making about the next line of therapy. Due to time constraints in a clinic setting as well as oftentimes the lack of comfort a physician has in discussing end of life, fellows don't get to experience and learn from patients what their real issues are they are dealing with. Here are some of the learning lessons that our fellows have experienced by being observers at these programs:

The author Want to Have Surgery: One patient said that she was diagnosed from the beginning with stage 4 breast cancer. Though she was scheduled for a lumpectomy, her staging work up performed preoperative confirmed that she has metastatic disease in her bones and liver. She had ER+ disease. She initially had chemotherapy to treat the liver lesions and then went on hormonal therapy. She was doing well, still working full time, and asked her medical oncologist, "I would like to have my lumpectomy now." Her oncologist's response was, "It's not part of treatment for stage 4 breast cancer." She didn't discuss it anymore with her treating physician but raised this

desire among those attending the retreat. The author asked her “WHY” she wanted to have a lumpectomy and her response, which her one oncologist had never asked, was important to know. She said that she showered every morning and could feel the tumor in her breast. She knew that having a lumpectomy was not part of her treatment and was not going to necessarily make her live longer but she wanted the surgery done so she could take a shower with pleasure rather than feeling anxious. She knew her blood levels were currently normal, and her lungs were fine. So this request was for the purpose of improving her quality of life. Her doctor was focused on systemic treatment however. The result? She was schooled how to revisit this conversation with her oncologist and get a referral back to the breast surgeon who was supposed to do her lumpectomy originally. The surgery was done without any complications and she was “happier.”

He Want Reconstruction: Another patient said that she had had a modified radical mastectomy, chemotherapy, and 2 years later was diagnosed with stage 4 breast cancers in her bones, lungs and liver. She was 3 years out from her metastatic diagnosis. She had attempted to discuss with her medical oncologist her desire to have implants put in on top of her pectoralis muscle so that when she died she would die “feeling whole.” She said her oncologist told her that this “really didn’t need to be done” and that she “would be fine with breast prosthesis as she currently was wearing.” She didn’t discuss it any further with her doctor. This remained a hope of hers however. The author arranged for her to see a plastic surgeon at Hopkins and have her case also presented at our weekly breast cancer tumor board. Though she was not a Hopkins patient she was local to this geographic area. The result? She did have her reconstructive surgery performed and she was very happy that she would die with her silhouette whole, as she desired.

I want to know how many more treatment options the author have: This is a common statement made by patients attending these retreats. When they get brave enough to ask their doctor, commonly the response is, “there isn’t a need to discuss that yet. We will talk about that at another time.” However the patient wants to talk about it and deserves the opportunity to have some concrete answers. This is the only way a patient and her family can plan for the future. Is she receiving currently treatment option number 5 out of 15 options or treatment option number 5 out of 7 options? Again, time is spent educating patients how to remain assertive for themselves and how to word their questions and statements so that their questions get answered rather than tabled.

I am worried the author won’t be able to afford the treatment the author need: As drug costs get much higher and copayments and deductibles increase too, patients are very worried about the out of pocket expenses they will incur to be able to continue their treatments. Family members are quick to tell the patient to “not worry about it” but the patient does worry and frankly the family should worry too. Leaving tens of thousands of debt for the family to pay after the patient has died can result in sibling rivalry, bankruptcy, anger, and confusion. A family member may have thought that this next treatment was the magic bullet because they doctor said he “was hopeful the tumor will respond to their new treatment.” People confuse the word “respond” with “cure.” And though it is sad that healthcare economics needs to be a big part of the treatment planning discussion, it is nonetheless a reality that it must be discussed so no one has false hope as well as no one is blindsided by the balance of the bill they receive that can be hundreds of thousands of dollars.

One of the most profound sessions we hold at the retreat

which occurs on day 2 is to divide the patient from their loved one, sending them into two different rooms with the following question to be discussed: Of everything that lies ahead, what is your greatest fear? Nearly all patients are frightened of the possibility of being in intractable pain and no way to get relief from it. Anxiety about losing their dignity due to dependence on others for basic needs. For those with children, they are very upset that they won’t “be here” to raise their children, instill their values in their kids, provide motherly love and advice, be present for their children’s milestone moments—birthdays, driver’s license, graduation, getting married, even when their child gives birth to their own child twenty years from now. Spouses in the other room are also talking about children and that they don’t feel they can adequately raise their children themselves. Some will even say that they told their wife that she can’t die and leave him with this burden (as if she has control over her future.) Female caregivers talk about fearing that they are not getting all the information they need from their loved one to prepare for her end of life. They believe that the patient isn’t being open and honest about how she feels as well as what her latest scans showed, and what we learn when we come back together in a group again is the these concerns are all valid. There are solutions for them however, and that is what we focus on as a group. We discuss hospice for pain management and preservation of quality of life as well as dying with dignity. We talk about the importance of maintaining honesty with their loved ones so that those who are caregivers will be better prepared to support the patient through to the end of her life. Then we talk about children... We provide at the retreat boxes and boxes of cards for patients to select for their children that cover every milestone that will lie ahead. The patients take these cards home to write in them what they want their children to know on that specific milestone day. The children continue to receive their mother’s advice, her undying love, and can still instill her values in her children long after she is gone. (It is heartfelt for me to be contacted by children who now are grown and hear their stories about opening a card from their mother on their wedding day, seeing her handwriting, and reading her love and hopes for their daughter’s marriage. In some ways, these women, long deceased, may be doing a better job of rearing their children from the grave than many parents do who are here on this earth.)

Another key element of these discussions is having everyone understand what the elements are that comprise a good death experience. They include:

- Knowing your purpose for living and it was valued by at least one other person
- Being pain free
- Dying with dignity and in the environment of your own choosing
- Knowing she will be spoken of fondly after she is gone
- Giving forgiveness and receiving forgiveness
- Leaving no financial debt associated her cancer care or treatment
- Leaving a legacy (which is not related to leaving money)
- Feeling a spiritual connection to a higher power
- Having all legal and financial affairs in order

The breast surgical oncology fellow comes away with a new understanding and appreciation for the issues that patients forced to deal with stage 4 breast cancers are wrestling with. The fellow

also now sees her role and responsibility in supporting a patient who desires surgery and may never have the opportunity to discuss it with a doctor. There also is new found knowledge is observing how to give bad news, how to preserve life goals that exist in the future (like “being there” for their daughter’s wedding two decades from now). The fellow learns about the healthcare economics that directly impacts the patient and her family, and the need to factor in drug costs with the decision making about what treatments to try. Last but not least, the realization that breast cancer impacts everyone who loves and cares about the patient.

Below is a link to a short video from one of these retreats.

<https://www.youtube.com/watch?v=Bg02G2a7uHo>

(If not able to click on the link go to www.youtube.com and type in “metastatic breast cancer retreat” and click on the person wearing the pink shirt).

Though we are each members of a multidisciplinary team, after physician training is done and we are working with a breast surgical oncology group, it can be difficult to see beyond the phase of treatment (surgery) that we are responsible for managing. Once a patient has been diagnosed with metastatic breast cancer she no longer sees a surgeon. Period having fellows observe a metastatic breast cancer patient retreat opens their eyes to the importance of always remembering the patient will need patient centered care until the day she dies. And toward the end of her life she may still psychologically benefit from the expertise of a breast surgeon.