

NCI 2007 PRE-OP THERAPY IN BREAST CANCER
40_SESSION 6, TALK 9 - MARY LOU SMITH

DR. CLIFFORD HUDIS: OK, our final speaker is Mary Lou Smith, who is going to talk about the role of advocacy in preoperative trials. She's a co-founder of the Research Advocacy Network. Welcome and thank you.

DR. MARY LOU SMITH: Well, I'm very aware that you've all sat in those seats for a long time, and I am the last presentation before lunch. Lisa understands the situation. So, I hope... My hope is that you will take something of value from the next ten minutes that you can use in your work. And this will be a little different -- we have no charts, no graphs, and no pointer... And no advancing of the slides. (Laughter) There we go.

The role of the advocate is to provide the patient perspective to the research process. We support the science and translate the science into lay language for patient decision-making. We also try and influence policy. And we do that by trying to help early therapies get payment and coverage, access issues, and increased funding.

I want to explain that advocates and patients are not the same. So I'm going to explain things from the patient perspective and then from the advocate perspective. Patients have a varied knowledge of their disease, while advocates have a much more in-depth knowledge of a specific cancer. The focus of the patient is on their family and themselves, while the advocate focuses on the health care system and understanding the latest findings. The main concern of the patient is for the best treatment, while the main concern of the advocacy is influencing research and health-care delivery. The patient is on an emotional roller coaster, while the advocate really takes their passion and uses it for the larger community.

So, I'd like us to take a few moments now and think about this from the patient perspective. We want to focus on what she needs to understand in order to know preoperative therapy and whether it might be an appropriate treatment for her. What

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happens to a patient when they're diagnosed with cancer? They're told they have something that's growing in their body that could kill them. The natural human reaction is to want it out. When we do our research about cancer, we find out that even small tumors have cancer cells that can migrate through the bloodstream to distant organs. And when we talk to our family and friends, they tell us they've never heard of anybody waiting to have surgery.

Research, thankfully, has produced a lot of options for the patient. However, the patient really wants the best treatment. And while you, as physicians, are really excited about these options, for the patient, it does add to the complexity of her decision-making. And it does create more stress. Explaining the treatment options and helping her determine what is the best treatment for her takes time.

You'll hear that patients say, "I understand". But you, as doctors, need to verify with active listening what it is she actually knows. The words we use to talk about breast cancer treatment don't make it easier for the patient. A great source of information right now for patients is the Internet. Leading cancer sites list treatment options beginning with surgery, not with preoperative therapy. When preoperative therapy is queried on the Internet, it does not appear as a breast cancer treatment.

And I think Deb [Collyar] said this yesterday -- most of all, this is a life decision. We need to help the patient understand, what are the costs in dollars and discomfort? What is the effect on future treatments? And how much time is this going to take away from family and from her work? I think Dr. Miller said something very interesting this morning when she talked about -- HE talked about the fact that -- I just changed his sex, sorry -- talked about the fact that quality-of-life decisions are accepted by patients, that they really do know what is the appropriate decision for them. So, I think it's important

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for us to ask patients what their priorities and values are. Because if we don't, we have no choice but to substitute our own.

It's important for patients to understand something about the new science, about what it means to research and what it could mean, ultimately, to patient care. And we need to separate out what about this new science is going to help this patient, versus what is going to help the research and future patients.

The Research Advocacy Network developed a brochure explaining tissue research for the IU DOD Breast Cancer Center of Excellence. We shared this brochure with Rosemary Padberg at the NCI, and she used the approach with focus groups of patients and nurses in developing the NCI brochure on providing tissue for research.

When the Research Advocacy Network was approached by a large pharmaceutical company to develop educational materials, we presented them with the NCI brochure. They loved it. But they thought they wanted a more expanded explanation of the risks and protections in tissue research. So, we developed an eight-page booklet.

Both these tools -- the NCI brochure and the RAN booklet -- are available at no cost. They can be downloaded from respective Web sites, or printed copies can be ordered. The bottom line is, this was a successful collaboration that provided information for patients with varying levels of information needs.

So, we've said that advocates and patients are not the same. So, what are the advocate questions?:

How many patients have responded or progressed with preoperative therapy? How many patients were over-treated? Does preoperative therapy enhance the rate of breast

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conservation? Does it improve response? Does response correlate with outcome? What does a proven therapy mean to a patient? Is it only available at academic medical centers? Or is it available in the community? And, if so, how is it used?

Are patients at academic medical centers really the same as those in the community? The Eastern Cooperative Oncology Group found that the average age of women in their breast cancer trials is 51. The SEER data shows the average age as 65. We also know that patients at academic medical centers who enter trials are really more likely to be white, better educated, and have a higher socioeconomic status. Given these differences, can we really take the results of clinical trials and apply them to the community? Will the results be the same?

Researchers and advocates have many common interests. And I think this trial, which has already been mentioned, is an example [ACOSOG-Z1031]. Advocates want to be able to compare and contrast A.I.'s. And they want to know which patient population is going to benefit from which A.I. And they'd like to educate patients about how to use A.I.'s in this particular setting. Researchers, in addition, want to do clinical trials using A.I.'s and chemotherapy and want to know which is the right A.I. to use.

So, advocates think that what you're doing here is very important. We think it's important to disseminate the information of what the research has shown, what the questions are that still exist, and what are the gaps in knowledge and clinical practice.

Advocates can help inform the process by telling you what are the questions patients have. We'd like an opportunity to ask questions. And we'll help by providing patient information through our Web sites, through our conferences, support groups, and hotlines. So, this is an opportunity for us to collaborate. And I'd like to thank the organizers for including a patient representative.