Let’s talk about sex

NANCY LIN, MD, DISCUSSES THE IMPORTANCE OF SEXUAL HEALTH WITH SHARON BOBER, PHD, DIRECTOR OF THE SEXUAL HEALTH PROGRAM FOR CANCER PATIENTS AND SURVIVORS AT DANA-FARBER.

NL: How did you get into the field of sexual health?

SB: Doctors don’t get much training on this topic. It was only in the context of clinical work that I started to pay more attention to sexual health. I was working with adult survivors of childhood cancer and, as part of the intake process, I would ask if they had any concerns around sexual function. For many, I was the first person to ever ask that; but those patients often did have questions. That was the beginning of a new career path for me.

Sexuality often takes a backseat to other issues that come with advanced disease. But sexual health is one of many pieces central to quality of life. The fact that we systematically ignore it is for many people beyond distressing—it really feels invalidating.

NL: Tell me more about the sexual health program.

SB: We have a dedicated gynecologist who works with a physician assistant. In addition to myself, we have a second psychologist, Dr. Cristina Pozo-Kaderman. We also work closely with pelvic floor physical therapists, as well as other consulting providers such as endocrinologists and urologists. We have built a robust multidisciplinary program.

We really understand sexuality to be at the intersection of biology, psychology, and interpersonal relationship issues, with cultural expectations also in the mix. I think anyone who wants to understand sexual challenges in a comprehensive way needs to take what we call a bio-psychosocial approach and work closely with the patient to identify where there’s a disruption in function or distress.

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I am thrilled to introduce Dr. Sarah Sammons as the new Associate Director of the Metastatic Breast Cancer Program at Dana-Farber. Previously a faculty member at Duke University, Dr. Sammons joined the breast oncology program at Dana-Farber in November 2022, where she divides her time between patient care and research. Her focus is on developing new treatments for patients with metastatic breast cancer, including patients with brain metastases and leptomeningeal disease. Please join me in giving her a very warm welcome!

At the year’s end, I am looking back and grateful to all of the individuals who have chosen to participate in clinical trials. We’ve seen positive results from phase 3 trials for patients with metastatic breast cancer, including Sacituzumab (Trodelvy) for estrogen-receptor-positive breast cancer and trastuzumab deruxtecan (Enhertu) for HER2-low breast cancer. I’m also grateful to the many patients who have donated blood or tissue toward research efforts, including the over 2,800 participants in the EMBRACE metastatic breast cancer research study.

We are in the midst of a large-scale effort to characterize thousands of blood samples from patients with estrogen-receptor-positive metastatic breast cancer to try to understand why treatment resistance occurs. I am hopeful that we will continue to see new advances over the next year.

Despite these advances, cancer treatments can have many effects on the mind and body, including on sexual health. In this issue, Dr. Sharon Bober talks about options available to address intimacy issues in people living with a cancer diagnosis. Finally, we have a patient profile which lays out so poignantly one person’s experience with metastatic breast cancer.

Warm regards,
Nancy Lin, MD
Forum snapshot

THE EMBRACE CLINICAL PROGRAM HAS GROWN TO REACH MORE THAN 4,500 PATIENTS with metastatic breast cancer (MBC). During the 2021 virtual EMBRACE patient forum, we hosted attendees from 30 different countries. This year’s forum kicked off on October 1, 2022, with a welcome session with Drs. Nancy Lin and Sara Tolaney. Research and treatment sessions are ongoing into 2023. Visit https://tinyurl.com/EMBRACE23 for more information.

EMBRACE research gains momentum

Though COVID-19 slowed research activities, as of November 1, 2022, we have consented nearly 3,000 patients to participate in our EMBRACE cohort study where clinical data, archival tissue, and blood are collected to support studies.

This year, we also consented 44 MBC patients to contribute tissue from their clinical biopsies at key points in their disease and treatment. These samples will aid studies like the HR-positive/HER2-negative MBC CDK4/6 inhibitor project supported by the Saverin Breast Cancer Research Fund and a new upcoming study focused on the use of the new antibody drug conjugates like TDx≥, TDµ, Sacituzumab Govitecan, and DatoDx≥’ supported by the Susan Komen Breast Cancer Foundation.

Additionally, we consented 24 MBC patients to a similar U.S. multi-center study called AURORA-US, supported by the Breast Cancer Research Foundation. Primary and metastatic tissue samples from these patients will help researchers identify molecular drivers of metastatic disease.

We thank all who have consented and contributed to these research studies.

Saverin Breast Cancer Research Fund: Tackling treatment resistance

THE SAVERIN EXECUTIVE COMMITTEE and its working groups and researchers continue to make progress studying metastatic hormone receptor (HR)-positive breast cancer. Notably, researchers are analyzing treatment resistance in metastatic estrogen receptor (ER)-positive breast cancer to identify therapeutic strategies and improve outcomes.

A working group led by Dr. Nancy Lin is organizing and integrating clinical, genomic, and biomarker data from cohort studies of patients with MBC. The study comprises a cohort of 295 patients with ER-positive/HER2-negative MBC—one of the largest annotated cohorts of this subtype in the world.

Using genetics. Researchers collected samples from patients either before treatment with a CDK4/6 inhibitor or at the time of disease progression on a CDK4/6 inhibitor. Of note, 32 patients in the cohort consented to provide matched pre- and post-treatment tissue samples, letting investigators compare their genomic profiles before and after therapy. These rare sets of matched samples are invaluable for studying the genetic changes and resistance mechanisms adopted by breast cancer cells during treatment.

Categorizing resistance. The team categorized the samples as having either acquired or intrinsic treatment resistance. This categorization will help researchers identify and study patterns that may inform more specific approaches to addressing resistance. In total, 207 biopsy samples were categorized as possessing acquired resistance.

“Liquid” biopsies. The working group has collected blood samples from consenting patients at various points of treatment. By comparing this data with analysis of the tissue samples, they hope to determine if this less-invasive method can provide the same insight into disease progression as a biopsy.

Next steps. Now that the samples are organized and linked to clinical, treatment, and outcome data, Drs. Nancy Lin, Daniel Abravanel, and Rinath Jeselsohn can use genetic studies to characterize acquired CDK4/6 inhibitor resistance using these samples, as well as the paired blood samples and tissue biopsies.

Next steps include collating all cohort samples and sequencing them. The team hopes this valuable collection of annotated samples and data will be available for study by investigators around the world, accelerating research advances. We have identified close to 2,000 blood samples in 894 patients with ER+/HER2- MBC where in the coming year we will 1) examine the mechanisms of resistance to endocrine therapy alone and with CDK4/6 inhibitors, 2) identify biomarkers of sensitivity and resistance to chemotherapy, and 3) understand genomic alterations that contribute to death from cancer.
I had just finished breast feeding my middle child, and was pregnant with my youngest, when I was diagnosed with stage 3 inflammatory breast cancer.

It was January 2019, two weeks after I first experienced symptoms that initially seemed to be mastitis. But, when antibiotics didn’t help, and I developed orange-like dimpling of the skin, a common sign of inflammatory breast cancer (IBC), my testing and care accelerated. The word going through my head in those first scary days was “hustle.” This is still one of my best strategies for coping with cancer.

Because Dana-Farber has both the IBC Program and the Breast Cancer during Pregnancy Program, I transferred my care here, met with Dr. Erica Mayer just a week after my diagnosis, and started chemotherapy the following day. In that first week, the hustle was about transferring my records, which was a large and complicated task. It was a big relief how quickly I could start my treatment.

**Shortcuts to a positive outlook**

Because I was first diagnosed with early-stage breast cancer, I understood I faced a tough set of treatments and worry about recurrence. Early on, I was able to hope for a time when cancer was behind me. But, in August 2020, I was diagnosed with metastatic breast cancer (MBC). I now see living with cancer as a marathon. I’ve had to learn to live with varying energy levels, side effects, and uncertainty. I’ve also learned to be present-focused and enjoy life now, versus looking to a cancer-free time in the future.

Because the rabbit-hole of sadness and fear related to MBC can be endless, I’ve adopted useful mental shortcuts for pulling myself out of it. These shortcuts are: accepting that I live with impossible knowledge; resolving not to lose more time to cancer than is needed for its treatment; focusing on what I can control; not catastrophizing; delegating to my future self; distinguishing uncertainty from bad news; compartmentalizing; being present-focused; and recognizing that the results of a test will be what they will be, and it doesn’t matter how I think about them beforehand. Writing things down so they don’t cycle in my mind also helps.

Eileen Joyce, one of the social workers who helped me, introduced me to another important shortcut: Don’t lose any more time to cancer than it’s already taking. I was struggling with situations when sadness would suddenly be overwhelming. What should I do when I’m sitting at the dinner table with my family, and I get sad about not being there in the future? “You don’t want to lose the time you have right now with your kids. You don’t want to lose your time twice to cancer,” she said. That really resonated. It was a reminder that, yes, you need to allow yourself time to feel sad, but you also must be intentional about pulling yourself out of it.

It’s hard to talk about, but, living with MBC, I don’t know how many months or years I have. I want to fill that time with interesting experiences. But, going through this during COVID, there have been few opportunities for exciting activities. In addition, so much of life with children is about following a routine, which would drag me down. I asked my friends how they handle the routine with their kids. One of them explained it this way: “The routine, something repeating, builds memories.” Another friend said, “Every day, you give your kids another layer of who you are, what your values are, and love.” That helped me see routine as a positive thing to dive into. Events that pop up outside the routine, those are vivid experiences for kids. There’s a place for both.

**Knowledge is power**

Three years into it, the hustle and shortcuts are still useful tools. I channel my energy into learning about clinical trials, the trial data, and testing options. I am also a passionate advocate of genetic testing for cancer patients and how important, accessible, and actionable it is.

**Genetic testing.** Before my diagnosis, I was unaware that I have a BRCA1 mutation, which significantly increases one’s risk of breast and ovarian cancer. Even though I have relatives who died from breast cancer in their 50s, no provider offered me genetic testing before my diagnosis. Facing and managing the risk of cancer can help one have a healthier life, so I encourage people to schedule an appointment with a genetic counselor, or do testing via Invitae Genetic Health Screen, which looks at 147 genes related to cancer and other actionable health conditions.

**Clinical trials.** In terms of treatment, I believe it’s important to work with your doctor to approach clinical trials and FDA-approved treatments strategically, and strongly consider trials for early treatment. It might seem like there is solid data for some FDA-approved options now, but with these options, the median survival for metastatic triple-negative breast cancer is about two years, and about five years for metastatic hormone receptor-positive and HER2-positive breast cancers. That’s not good enough. The progress that has been made—and any progress that will be made—is thanks to the trials, and you can be a beneficiary of them, as well as be a trailblazer.

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This article was written a few months before Marina passed away, and it was her wish that it be published and her story shared. She was passionate about educating cancer patients about genetic testing and clinical trials.
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When there is a physical disruption—whether that’s treatment-induced menopause, intensive ovarian suppression treatment, vaginal dryness—there is often a ripple effect. There can be an impact on relationship function—how someone talks or doesn’t talk about this with their partner. There can be body-image issues. We put a lot of attention around how women look, but the idea of feeling comfortable in your body—feeling a sense of body integrity—is not necessarily only about a physical change; it’s also about people’s experience about how they feel, and their experience of how they feel in their body with a partner.

The people I see come from a variety of backgrounds and cultures. They can have very different ideas about what is “normal,” how we are supposed to talk about sexuality, and what kinds of sexual activities are or are not expected or reasonable. If these factors aren’t taken into consideration, I don’t think you can give recommendations that are going to be useful.

NL: Can you describe some examples of why patients come to you?

SB: Because many breast cancer treatments disrupt or block estrogen, common challenges have to do with pain with sexual activity, vaginal dryness, and what we consider genitourinary symptoms of menopause. Women hear advice like “use a lubricant” or “have a glass of wine and relax,” but this doesn’t even come close to addressing what’s happening when there’s so much vaginal dryness or pain that sexual activity isn’t possible. It’s not just physical; it’s often psychologically distressing and potentially problematic in a relationship because partners don’t want to hurt each other, so they try to protect each other by keeping some distance. When partners become progressively less connected physically, emotionally, distance can result as well.

Thinking more broadly about vaginal health—this is relevant whether you are sexually active or not, partnered or not, and of any age—genital tissue that has been impacted by treatment often loses moisture and similarly, elasticity, stretch, and blood flow to that tissue. There may well be pain and discomfort not just with sexual activity but with wiping after you go the bathroom, exercise, or even sitting on a bicycle. Women need to be educated about effective ways to moisturize genital tissue regularly beyond using topical lubricant, which isn’t particularly helpful by itself. The number-one problem is a woman tries a lubricant, it isn’t particularly helpful by itself. The number-one problem is a woman tries a lubricant, it doesn’t work, and they give up.

The other piece women rarely hear about is the health of the pelvic floor, beyond kegel exercises. All that clenching you’re taught to do after you have a baby is actually the last thing you should be doing after breast cancer treatment. If you have any kind of sexual activity that’s uncomfortable or painful, the sling of muscles that gird the pelvic floor become hypertonic (very tight). Women lose the capacity to relax those pelvic muscles. Learning how to tone and relax those pelvic muscles as you need to, getting the right combinations of lubricant and moisturizer, understanding the differences between the two—these steps are a good start because, if you have discomfort, most likely you’re going to have a loss of desire.

That’s the other question that comes up all the time. People often struggle when there is a mismatch of desire in their relationship. This is an area where women are targeted by a lot of marketing of products to increase desire. But the truth is these products aren’t going to be helpful if there is pain or discomfort. The images that women see of desire in the media are always of situations that are idealized and perfect. When do we ever hear or see what normal female desire over the course of a lifetime is supposed to be? Our expectations are often really problematic.

We live in a funny culture that is saturated with sex, but doesn’t foster conversations about real sexuality of real people. When we move into midlife, or menopause, or through breast cancer treatment, desire might become something that needs to be cultivated. We need to think about just starting an experience based on something that allows someone to feel relaxed or connected, as opposed to expecting desire to work like a light switch.

NL: What can patients expect when they make an appointment?

SB: People typically make an appointment for an initial evaluation with myself, Dr. Cristina Pozo-Kaderman, or Dr. Sandy Falk, our gynecologist. From there, we make a gameplan, which might include an additional referral such as for pelvic floor physical therapy (PT). People often see me or Dr. Pozo-Kaderman for three to six visits, more if necessary. Sometimes we do couples counseling, which can be useful as a way to give each partner support in communicating about this and create some skills for sexual recovery.

NL: Are program services covered by insurance in general?

SB: Absolutely. It can be paid for through insurance just like gynecology is. If your insurance covers PT, pelvic-floor PT is paid for similarly. Uro-gynecology and other subspecialties can also be paid for by insurance.

NL: Final thoughts?

SB: Living with advanced disease is not a reason to feel like sexual health and desire aren’t topics worthy of attention. If there is anything distressing about it, there are resources available.

My other parting thought is that sexual issues in general do not self-resolve. Whether it’s vaginal dryness, low desire, change in orgasm, pain with or without sexual activity, these kinds of things typically do not get better by themselves. This means that it’s important to get help if you need it. Often, the kind of support folks need may not be intensive; they may only need a little bit of information/education to help put the pieces together.