The Jolie effect
Young survivors share their reactions

In May, actress Angelina Jolie shared with the world that she had recently undergone a prophylactic (preventive) double mastectomy after learning that she carried the BRCA1 gene mutation.

In an article published in the opinion pages of the New York Times on May 14, 2013, she states that she shared her story to encourage “every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices.”

Jolie was both praised and criticized for submitting the piece, and many women who were already dealing with a breast cancer diagnosis when it came out have expressed mixed emotions about it.

Survivors speak
Amy, who was diagnosed with breast cancer in March 2012, felt many things. She was sad for Jolie, knowing how hard the decision and the surgery are. She also felt jealous because she is done with the entire thing in just three months. For me, we are going on two years.” Unlike Jolie, who had not developed cancer, Amy had to endure 24 weeks of chemotherapy and six weeks of radiation after her initial surgery, which was a bilateral mastectomy, and she has many more procedures and months ahead of her to complete her reconstruction. “I think it can be a bit misleading to regular people,” Amy says.

Aliza experienced the effect the article had on the public first-hand, saying, “It took 3.5 weeks to get my BRCA results back because of the overwhelming amount of people getting tested, thanks to Angelina!”
Feeling stress when dealing with a breast cancer diagnosis is quite normal. Put simply, stress is “a state of mental tension and worry caused by problems in your life, work, etc., or something that causes strong feelings of worry or anxiety.” Many people report being affected by stress during a cancer diagnosis, including during decision-making, treatment, and into survivorship.

Stress can negatively affect you physically and emotionally. Some common stress responses include: anxious thoughts, poor concentration, irritability, depression, difficulty sleeping, stiff muscles, tension headaches, tiredness, and attempts to isolate oneself. By learning ways to manage this stress, you can ease both physical discomfort and emotional anxiety.

What is stress management?
Stress management involves becoming more aware of situations that cause stress and developing effective coping strategies. One method of stress management is Cognitive-Behavioral Stress Management (CBSM). CBSM techniques increase your awareness of the link between how you think about stressors and your emotional responses to them, and provide more effective ways to respond to those stressors. Some CBSM techniques are discussed below and include developing coping strategies, managing your anger, being assertive, and accessing support from others.

Develop appropriate coping strategies
Coping can mean different things for different people, based on one’s personal experiences. You may think of coping as “getting by” or as “making the most of” an unpleasant situation. When you feel stressed, consider a coping strategy as a way to manage that feeling. There are many strategies to explore, so you can develop an effective strategy for each stressor you are dealing with. Common coping strategies include:

- Seeking information
- Making decisions
- Asking for help
- Reframing your thoughts
- Seeking emotional support
- Exercising
- Relaxation and meditation

To learn more about coping strategies that can work for you, talk to your social worker. If you don’t have a social worker, ask your oncologist for a referral.

Find ways to manage your anger
Anger is a normal emotion to feel after a breast cancer diagnosis. To manage your anger, think about what makes you feel angry and how you express that anger. Some women keep their anger to themselves, suppressing it, while others may express it externally in a verbal, emotional, or physical way. Changing the way you respond to feelings of anger can help decrease your level of stress. If you would like to learn more about managing your anger, your social worker can help.

Be assertive
Communicating assertively can reduce your stress level by allowing you to stand up for yourself and express your feelings and needs without being disrespectful of others. It permits opportunities for disagreement to occur openly and appropriately, and can help you to feel less self-conscious when talking about personal issues. Your social worker can also help you learn specific methods of assertive communication.

Lean on others for support
Support can come from family, friends, coworkers, neighbors, or professionals. It can be provided in emotional ways, such as comfort and encouragement, or in concrete ways, like making dinner, doing the laundry, or communicating with others. When thinking about who to reach out to, remember that an individual may be more helpful at providing a certain kind of support than others. Focus on figuring out what your needs are and identifying who would be the best person to address them.

Helping ourselves, helping others: The Young Women’s Breast Cancer Study update

The Young Women’s Breast Cancer Study has continued to grow tremendously! Over the past seven years, researchers at participating sites have been identifying all women who are diagnosed with a new breast cancer at age 40 or younger. Participating institutions include Dana-Farber/Brigham and Women’s Cancer Center, Faulkner Hospital, Massachusetts General Hospital, Beth Israel Deaconess Medical Center, North Shore Medical Center, Newton-Wellesley Hospital, South Shore Hospital, Cape Cod Hospital, and Lowell General Hospital. We also have two remote participating sites: University of Colorado in Denver and Sunnybrook Health Sciences Centre in Toronto, Canada. To date, more than 1,000 women are participating in this study, and we are still actively recruiting.

By completing surveys, providing blood samples, and granting permission for our study staff to collect a tumor sample, medical records, and gene sequencing data, you have provided a wealth of important information regarding breast cancer in young women, which we hope will help doctors develop more effective, personalized care for young women in the future.

Some of our recent results are summarized below. Please note that these findings may not be applicable to you personally when making decisions about your health or disease management. These are just some of the projects we have been working on over the past few months. We are so grateful for your continued participation, and we look forward to sharing early findings from the research as they become available in future newsletters.

Ovarian function in breast cancer survivors

Cancer treatment can interfere with fertility in many ways, as the chemotherapy agents that are used to kill cancer cells also affect other cells, organs, and hormones in the body. Ovarian function after treatment of early breast cancer may also affect menopausal symptoms, endocrine therapy decision-making, and subsequent health and psychosocial concerns among young survivors. Researchers for The Young Women’s Breast Cancer Study have been comparing anti-mullerian hormone (AMH), estradiol (E2), and follicle-stimulating hormone (FSH) levels in survivors with and without amenorrhea (the absence of menstrual period) to determine if there are any biological indicators in ovarian functioning after treatment. Researchers found that median AMH and E2 were lower and FSH was higher in women with amenorrhea—meaning that AMH, E2, and FSH all are promising biomarkers for amenorrhea and residual ovarian function in young breast cancer survivors. Future research will evaluate whether AMH, E2, and FSH at baseline and early in the survivorship period predict ovarian function later.

Perceptions, knowledge, and satisfaction with contralateral prophylactic mastectomy

Young women with unilateral breast cancer often overestimate the odds that cancer will occur in their other, healthy breast, and decide to have the healthy breast surgically removed—a procedure known as a contralateral prophylactic mastectomy (CPM). In 2010, a sample of Young Women’s Breast Cancer Study participants was surveyed about their decision to have CPM. The survey included questions on decision-making, knowledge, and satisfaction with the procedure. Women who were not carriers of a genetic mutation estimated that 10 of 100 (10% of) women treated with CPM would develop contralateral breast cancer in the five years after treatment, yet the actual risk is estimated to be between 2–4% over the five years. While more than 70% of women knew that undergoing CPM would not mean they would live longer following a breast cancer diagnosis, most women cited improved survival as an important reason for why they chose CPM. These findings tell us there is a need to ensure effective communication of both the risks and benefits of the procedure, as well as a need to better support women when they are making treatment decisions.


The Jolie effect

—continued from page 1

Still others are glad that Jolie has brought attention to an important issue, but have also voiced frustration that Jolie only discussed breast cancer in terms of those with a family history. Maggie, a young breast cancer survivor, explains, “I was very appreciative of Angelina speaking out about such a personal and intimate procedure. That aside, my issue with this piece is that there is only one line briefly mentioning women without the BCRA mutation and as we know, most breast cancers are actually not due to this mutation. My fear is that young women might misconstrue Angelina’s message and assume they are not at risk for breast cancer if they have no family history of this disease.”


If you want to join the conversation, contact Julie at 617-632-3916 or JLonardo@partners.org and ask about our online community for young women with breast cancer.
Sexual Health Workshops
Sharon Bober, PhD
Monday, November 18, 2013, 5:30–7pm
Monday, May 5, 2014, 5:30–7pm
Join Dr. Bober as she discusses common challenges after treatment, including decreased
sexual desire, body image concerns, menopausal symptoms, and communication difficulties
with your partner. To register, contact Julie at 617-632-3916 or JLonardo@partners.org.

Weight Changes and Treatment: What You Can Do
Nancy Campbell, MS, and Heidi Sulman, LICSW
Monday, January 13, 2014, 7–9pm
Join Nancy Campbell, exercise physiologist, and Heidi Sulman, clinical social worker, as they
share ways to cope emotionally and physically with weight gain during and after treatment.
For more information, contact Julie at 617-632-3916 or JLonardo@partners.org.

Young Women’s Evening: Breast Cancer Survivorship 101
Karen Fasciano, PsyD, and Ann Partridge, MD, MPH
Wednesday, March 12, 2014, 7–9pm
Dr. Fasciano and Dr. Partridge will discuss the transition from treatment into survivorship
from a medical and emotional standpoint. For more information, contact Julie at
617-632-3916 or JLonardo@partners.org.

Support and education

Young Women’s Telephone Support Group
Irene Goss-Werner, MSW, LICSW
For young women looking to connect with others who understand the impact of living with
and beyond breast cancer. The next session will begin in early 2014. For more information,
contact Julie at 617-632-3916 or JLonardo@partners.org.

Facing Forward
Julie Salinger, LICSW
For patients who will complete treatment for breast cancer in 4–6 weeks or those who have
completed treatment within the last 3–4 months. Sessions offered year-round. For more
information, call Julie S. at 617-582-8081.

Inflammatory Breast Cancer Support Group
Julie Salinger, LICSW
Third Monday of the month, 2–3:30pm
This group provides a safe, supportive environment to share experiences and build
relationships with others with inflammatory breast cancer. For more information, call Julie S.
at 617-582-8081.

Metastatic Breast Cancer Support Group
Liz Farrell, LICSW
For women of all ages with metastatic breast cancer. The next session will begin in early 2014.
For more information, contact Julie at 617-632-3916 or JLonardo@partners.org.

Survivorship Education Monthly Series
Sarah Singer, MSW, LICSW
November 6, 2013: What to Do When You’re Not Feeling Festive: Preparing for the Holidays
December 4, 2013: Optimal Nutrition for Cancer Survivorship
This monthly program focuses on techniques and tools to help you adjust to post-treatment life.
For more information, contact Sarah Singer at 617-632-3751 or Sarah_Singer@dfci.harvard.edu.