

Breast Cancer in Young Women: Quality of Life and Survivorship

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Breast Cancer in Young Women is Different

- Disease differences
- Host differences
 - Issues unique to or accentuated by young age at diagnosis

**Young women are at
increased risk of
psychosocial distress at
diagnosis and follow-up**

Psychosocial Distress in Young Survivors

- Higher risk disease and receipt of more aggressive therapy
- Greater effects of disease and/or treatment on:
 - Menopausal symptoms
 - Fertility and family planning
 - Genetic risk
 - Role functioning at home and/or work
 - Beauty and attractiveness
 - Sexual functioning

Psychosocial Distress in Young Women

- Distress among young women with breast cancer may be further compounded by:
 - Lack of information about the risks for many of these issues
 - Lack of provider awareness, information, and resources to address young women's issues with patients
 - Lack of peer group support



Breast Cancer in Younger Women: Reproductive and Late Health Effects of Treatment

- 577 women ages 25-51 at diagnosis (N=42 age 25-34; N=93 age 35-40)
- Surveyed ~ 6 years later
- Majority of women pre- or peri-menopausal at diagnosis
- Majority received adjuvant therapy



Reproductive and Late Health Effects of Treatment (2)

- Overall, high levels of physical functioning
- However, social and emotional functioning, and vitality were lowest in the youngest women
- More depression symptoms, more negative affect in youngest women



Reproductive and Late Health Effects of Treatment (3)

- Experience of menopausal transition with treatment was associated with lower mental health among youngest women



Functional Impact of Breast Cancer by Age at Diagnosis

- 122,969 women from Nurses' Health Study 1 and 2, ages 29-71 years responding to pre- and post- functional status evals
- 1,082 diagnosed with breast cancer between 1992-1997
- Age categories ≤ 40 , 41- 64, 65+ years



Functional Impact of Breast Cancer by Age at Diagnosis (2)

- Women with breast cancer age ≤ 40 years experienced significant functional declines compared with young women without breast cancer
- Young women with breast cancer had the largest relative declines in HRQOL (SF-36) compared to older women with breast cancer



Functional Impact of Breast Cancer by Age at Diagnosis (3)

- Declines greatest for younger women in physical roles, bodily pain, social functioning, and mental health
- Much of the decline in HRQOL for older women attributable to aging
- Youngest women also reported worse sexual functioning compared with older women

(Kroenke et al., JCO, 2004)



Web-Based Survey of Fertility Issues in Young Women with Breast Cancer

- 657 women median age 33 at diagnosis of breast cancer
- 57% of women recalled substantial concern at diagnosis about fertility after treatment
- 29% reported that fertility concerns influenced treatment decisions

(Partridge et al., J Clin Oncol, 2004)



Chemotherapy-Induced Amenorrhea/Menopause/Infertility

- Due to effects of chemotherapy on rapidly dividing cells that surround eggs in the ovaries
- When these estrogen producing cells are destroyed, eggs are also destroyed
- If no eggs remain at all, there will be no menstrual periods, and the lack of estrogen often causes menopausal symptoms
- Chemotherapy-related amenorrhea (and symptoms) may be temporary

Risk of Treatment-Induced Amenorrhea

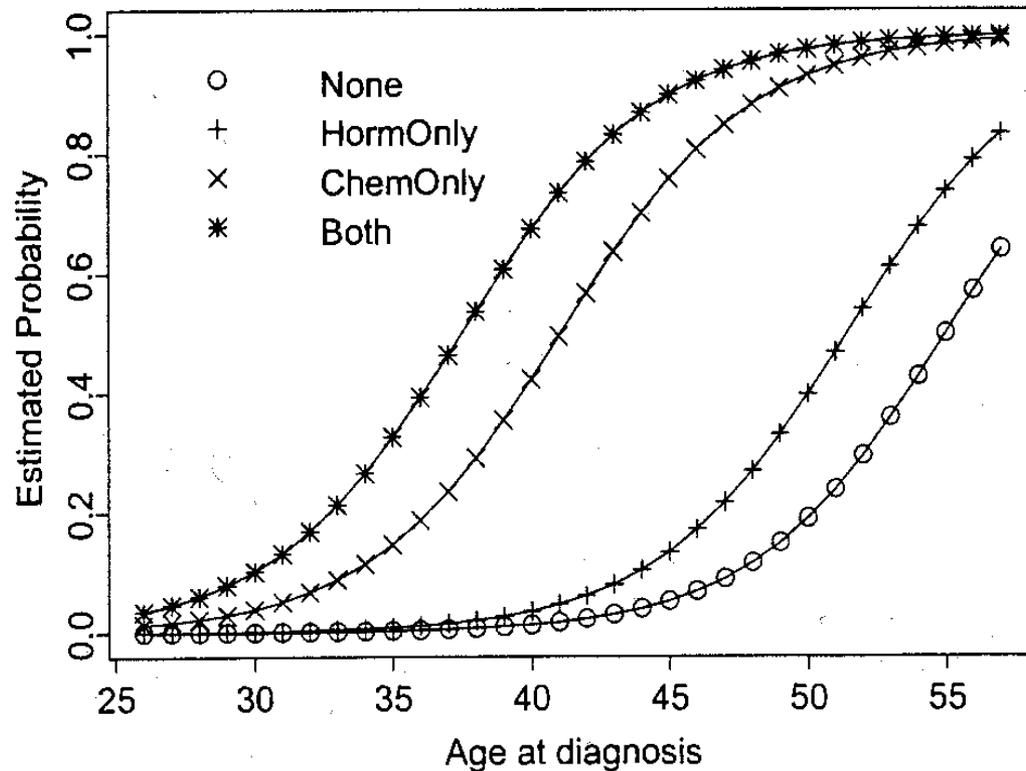


Fig 1. Probability of menopause during the first year after diagnosis (from model shown in Table 3).

(Goodwin et al., JCO, 1999)



Is Pregnancy After Breast Cancer Safe?

- Concerns
 - Stimulation of breast cancer growth from high estrogen state of pregnancy
 - Increased disease recurrence, decreased survival
- Methods of analysis of available studies
 - Case-control studies
 - Retrospective cohort studies
- Evidence suggests SAFE, but studies limited by “healthy mother bias”

Fertility After Breast Cancer

- Very difficult issue for many young women when facing a breast cancer diagnosis and treatment
- Much is known and much still unknown
- Patient preferences critical factor

Psychosocial Effects

More Aggressive therapy,
Unique Side Effects

Diagnosis



The burden of
breast cancer
young women!



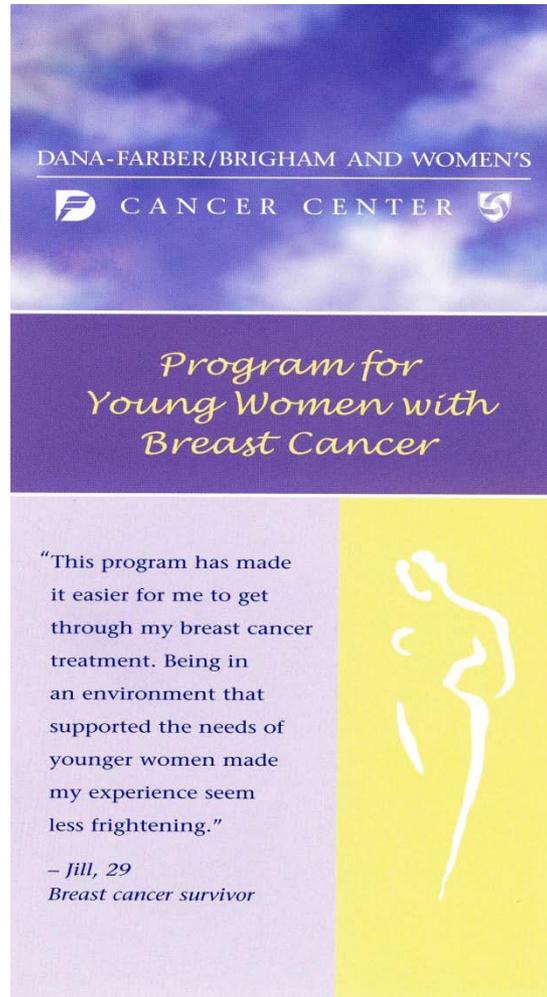
Young Women with Breast Cancer

- Young women with breast cancer face a variety of unique treatment and psychosocial issues at diagnosis and follow-up
- Increasing attention to their unique issues may improve care and outcomes for this vulnerable population

And Yet...

- Available evidence and suggests women are not well-informed historically about these issues and risks
- Providers may not be addressing them thus, patients may miss opportunities for intervention
 - Risk of infertility- fertility preservation
 - Genetic risk- choice of local therapy
 - Risk of or experience of distress- psychosocial intervention
- Leading to gaps in care

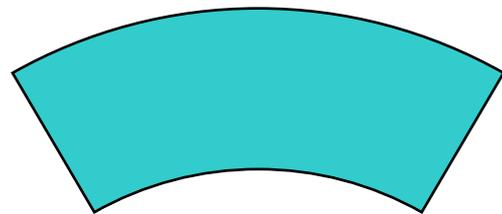
The Program for Young Women with Breast Cancer



- Established in 2005
- Served over 1500 young patients to date

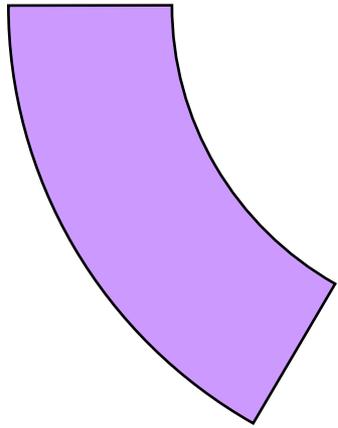


A Comprehensive and Integrated Program Focused on Young Women

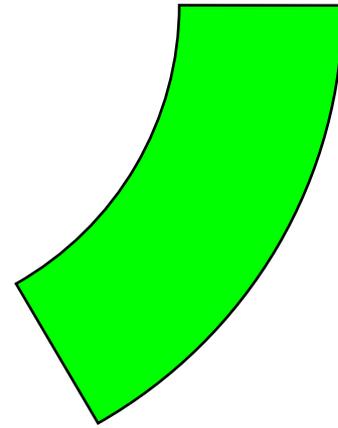


Education

Clinical Care



Research



Goals of the Program

- To support and care for young women through breast cancer
- To educate patients and health care providers about the unique issues for young women with breast cancer
- To provide a model of comprehensive care that can be adapted both within and outside of Dana-Farber/Brigham and Women's Hospital Cancer Center
- To provide a unique setting for research to understand more fully and improve the experience and outcomes of young women

Dr. Carolyn Kaelin Promotes a Healthy and Active Lifestyle



Dr. Carolyn Kaelin, author of *The Breast Cancer Survivors' Fitness Plan*

At the Young Survivors' Evening in May, Carolyn Kaelin, MD, MPH, FACS, Dana-Farber/Brigham and Women's Cancer Center breast surgeon, author, and breast cancer survivor herself encouraged attendees to start or keep moving after breast cancer. As the founding director of the Comprehensive Breast Health Center at BWH, Dr. Kaelin emphasized the importance for breast cancer survivors of maintaining a healthy diet and staying active. She offered various tips on how to maintain a healthy lifestyle (see box below), and noted that, "eating well gives your body the energy and nutrients needed for healing, a process that continues after treatment ends."

Tips to boost physical activity, improve nutrition and manage your weight during and after breast cancer treatment:

- * ***Get moving***- Start slowly, aim to exercise on most days for at least 30 minutes (walking briskly suffices!)
- * ***Make healthy foods available*** – Try to keep healthy food options on hand. For instance, quick, easy foods such as sliced vegetables are great alternatives to less nutritious snacks
- * ***Read labels carefully and make trade-offs that net fewer calories and healthier fats***
- * ***Eat mindfully*** – Make an effort to *taste* your food and enjoy its texture, scent, and visual pleasures rather than hurrying through a meal or nibbling while reading or watching TV.
- * ***Don't confuse thirst for hunger*** – Signals for both thirst and hunger originate in the same area of the brain, the hypothalamus. Often times, it is hydration that our bodies crave, rather than hunger. Dr. Kaelin suggests keeping a glass of water, low-calorie flavored water or juice, or tea easily accessible.
- * ***Tune in to emotional cravings that can trip off overeating and have a plan in place for moments when emotional hunger strikes***

The Program for Young Women with Breast Cancer

The program provides comprehensive care and support to young women confronting the challenges of living with and beyond breast cancer. Our mission is to enhance care and education for patients and their families, as well as to advance understanding of the biology of breast cancer and the experience of the disease for younger women through ongoing research focused on young women.

For further information about the Program, please call Jamie Kennedy at: (617)632-3916 or visit our website at: <http://www.dana-farber.org/pat/adult/breast-cancer/program-for-young-women-with-breast-cancer/>



Preliminary Evidence for Success of the Model:

- Qualitative research and feedback from patients
- Data from Young Women's Cohort (re: historical controls)

Improving the Care of Young Women with Breast Cancer

- American Society of Clinical Oncology (ASCO) Improving Cancer Care Grant (funded by Susan G. Komen for the Cure)
 - Focus on developing solutions to current problems
 - Increase access to and delivery of (quality) care
 - Develop new models of care

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Welcome to Young and Strong, a program for young women with breast cancer

We have created this website (and the print materials from your doctor) to focus on YOU, a young woman with newly diagnosed breast cancer. This website contains expanded information and resources, helpful [videos](#), and materials to help you with your doctor visits. These materials include a checklist of [questions to ask your doctor when you're just getting started](#) and another with [follow-up questions for optimal survivorship care](#).

If you have study-related questions, please use the contact information below to reach us.

[Why did this happen? >](#)

"Knowing that other women have walked this path and survived to live a full life makes me feel very good."

—Liz F., Age 36



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Fertility

Many young women with breast cancer wonder how cancer and its treatment will affect their *fertility* (ability to become pregnant). Some will get pregnant easily, others will not. It may be harder for a woman to get pregnant after breast cancer treatment than it otherwise would have been. So, deciding to get pregnant after a breast cancer diagnosis can be very difficult for a young woman and her loved ones.

If you think you might want to get pregnant after your treatment is done, you should learn more and talk with your doctor.

[Having children after breast cancer >](#)



*"Making plans to have children in the future helped me get through the tough days and gave me hope."
—Kristin G., Age 28*



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Exploring options

Reproductive medicine offers a variety of procedures that can help you protect your fertility before, during, and after breast cancer treatment. Some of them may fit your needs better than others. It's important to speak with your doctor and a fertility specialist to develop a plan that makes sense for you and your family. You may also consider non-medical options like adoption or foster care.

Cryopreservation

Reproductive procedures that involve freezing are called *cryopreservation* (cry-oh-prez-er-vay-shun). This can be done in a variety of ways:

Freezing a fertilized egg (also called embryo freezing): A fertility doctor gives you hormones to make your ovaries produce lots of eggs. The unfertilized eggs are removed from your body and fertilized with a man's sperm (from a partner or a donor). Fertilized eggs are frozen and stored for later use.

Freezing an unfertilized egg: A fertility doctor gives you hormones to make your ovaries produce lots of eggs. The unfertilized eggs are removed from your body, frozen, and stored for later use. After your breast cancer treatment is over, the eggs can be thawed and fertilized with sperm. This method is less successful than embryo freezing. However, if you don't have a male partner now and don't want to use a sperm donor, this may be the right option for you.

Freezing ovarian tissue: Before your cancer treatment begins, a piece of your ovary is removed and frozen. This helps protect the tissue from damage during chemotherapy. Once your treatment is done and you are ready to try to get pregnant, the tissue is put back in your body. *Note:* This method is highly experimental and has only resulted in a few successful pregnancies to date.



*"Making plans to have children in the future helped me get through the tough days and gave me hope."
—Kristin G., Age 28*

Potential Impact and Implications

- Intervention to provide a cost-effective, easy-to-disseminate strategy to improve the quality of care for young women beyond large cancer centers
- Key to potential success is that intervention coming from the oncology providers
- Future directions include virtual survivorship program, link in directly with advocacy organizations, etc..

Thank you!