

# Model Program to Improve Care for a Unique Cancer Population: Young Women With Breast Cancer

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## Abstract

Young women with breast cancer face a variety of problems unique to or accentuated by their age. Attention to these concerns is warranted, yet research has revealed inadequacies in care and that the needs of these patients are not being met. To address these critical issues, we have developed a comprehensive program to provide additional support and education for young women with

breast cancer and their providers. On the basis of the preliminary success of the program, we have developed and pilot tested an exportable version that may serve as a national model for care of this unique population. We believe this work will not only improve care for young women with breast cancer, but also may serve as a paradigm to overcome barriers to delivering optimal care for unique groups of patients in other settings.

## Introduction

When a young woman is diagnosed with breast cancer, she and those close to her encounter not only the usual concerns of breast cancer survivors, but also a variety of problems unique to young women.<sup>1</sup> Although breast cancer is relatively uncommon in young women, it is the leading cause of cancer-related deaths in women 45 years of age and younger, and survival rates for young women with breast cancer are lower than for their older counterparts, despite receipt of generally more aggressive therapy.<sup>2,3</sup> Young women are likely to be diagnosed at a stage in life when they serve multiple roles that may not easily be filled by others (eg, parenting of young children, completing education, developing a career). Moreover, many young women are interested in having children after treatment, and fertility may be impaired by treatment. Data regarding the ability to become pregnant and safety of pregnancy after breast cancer have been limited.<sup>4,5</sup> Younger women are also more likely to be concerned with appearance, attractiveness, and body image than older women.<sup>6</sup> Finally, in comparison to older women, young women often feel isolated and uninformed, and they may worry that their doctors are unsure of how to treat them.<sup>7,8</sup> These varied concerns may contribute to the greater psychosocial distress seen in younger women, both at diagnosis and in follow-up, compared with older women.<sup>6,9-18</sup>

Research has revealed that the needs of young women with breast cancer are often not met. Available evidence suggests that there are important and potentially serious gaps in the care of this population. Inadequate attention to supportive care and survivorship issues, including fertility, menopausal concerns, body image, sexual functioning, genetic risk, and psychosocial health has been documented repeatedly in young women.<sup>19-25</sup> In particular, previous research has demonstrated that the focus on fertility and menopausal risks in this population remains deficient, despite recent guidelines recommending that they be addressed with every young patient.<sup>19,26-30</sup> In a Web-based

study focused on fertility issues in young women with breast cancer (mean age at time of survey, 33 years), 72% of women recalled discussing fertility at diagnosis, but only half responded that it had been addressed adequately.<sup>19</sup> In another survey of women treated in practices in the northeastern United States, Duffy et al<sup>26</sup> interviewed 107 women younger than 45 with early-stage breast cancer and reported that only 34% recalled a discussion of the risk of infertility with adjuvant treatment. It is likely that these data overestimate how often fertility concerns are addressed in routine practice, as we suspect that those who participate in Web-based research and/or see physicians doing research in this area may be more well informed than the general population.

Fertility concerns should be addressed early in the course of a woman's cancer care because risk of infertility may affect treatment decisions and/or the use of interventions for fertility preservation.<sup>30</sup> Some providers may be uncomfortable with the subject, and others may not have the time, resources, or information necessary to assist patients.<sup>28</sup> We believe that attention to fertility concerns may be an important surrogate for awareness of other factors facing young women with breast cancer, including genetic issues, psychosocial concerns, and difficulties with sexual functioning. Discussion of these issues may be associated with better satisfaction with both care and decision making. It is also possible that attention to the unique concerns of young women will lead to improvements in adherence, enhanced follow-up care, decreased distress, and better overall quality of life. In the overall population of patients with breast cancer, access to information and psychosocial support is associated with better quality of life. However, few studies to date have focused specifically on improving the care and support of young women diagnosed with breast cancer.<sup>31-34</sup>

To address the significant challenges facing young women with breast cancer, we have developed the Program for Young Women with Breast Cancer, a comprehensive program at Dana-Farber Cancer Institute and Brigham and Women's Hos-

pital that aims to optimize care, provide additional support, and improve knowledge for these vulnerable patients. In addition, the program provides education to health care professionals and establishes a platform for research focused on young women. This article describes this model program that addresses the unique needs of this patient population.

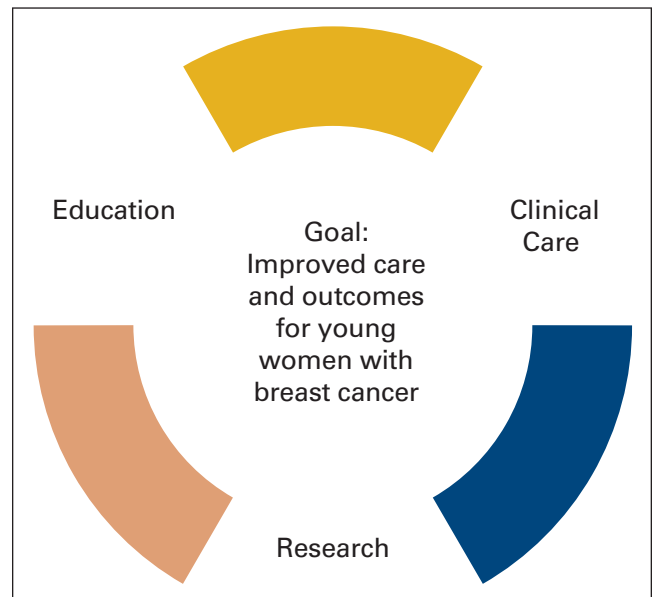
### Program Setting

Dana-Farber Cancer Institute is a National Cancer Institute–designated cancer center in Boston, MA. Brigham and Women’s Hospital is the affiliated teaching hospital where inpatient and surgical as well as other services are provided for patients with cancer. Together, these two institutions make up the Dana-Farber/Brigham and Women’s Cancer Center (DF/BWCC), and they also serve as teaching hospitals of Harvard Medical School. The DF/BWCC adult ambulatory clinics are organized within 12 multidisciplinary treatment centers. Patients with breast cancer are seen in the Breast Oncology Center (BOC) by subspecialists who focus on research and improving the care for patients with breast cancer. Within the BOC, there are more than 2,400 new patients with breast cancer seen each year, of whom approximately 150 are diagnosed at age 42 or younger.

### Basic Principles and Structure of the Program

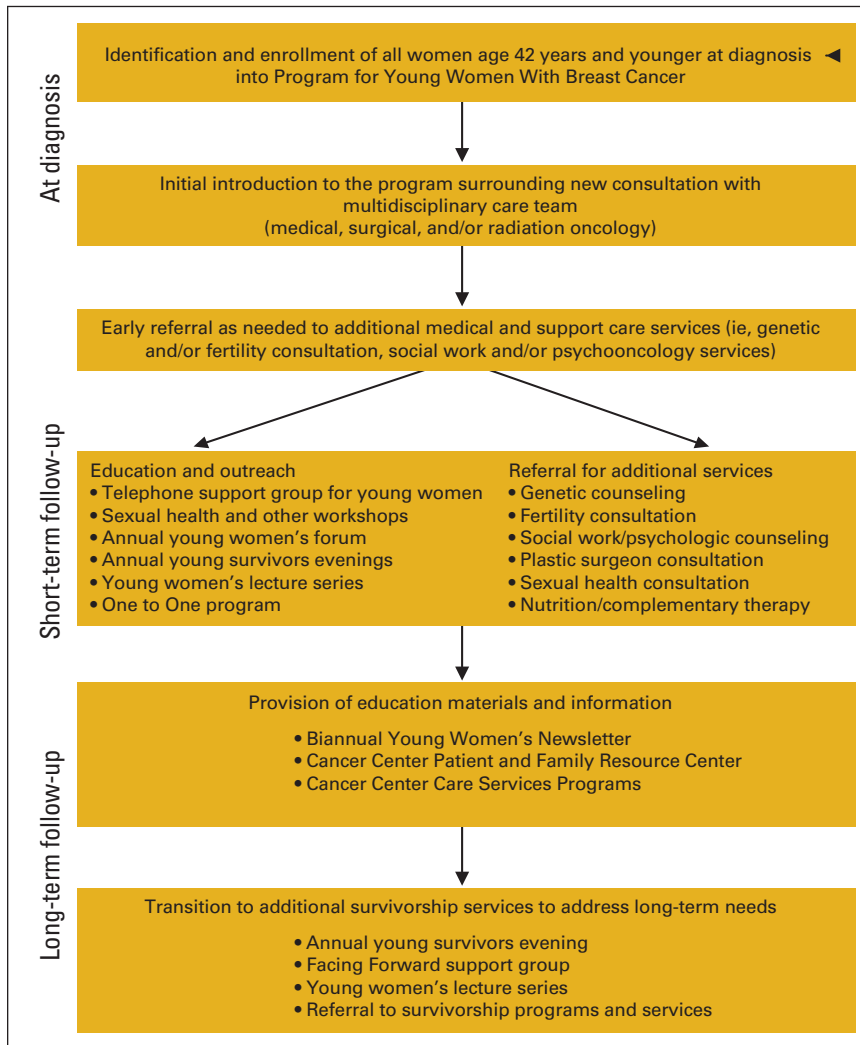
Founded in 2005, the Program for Young Women With Breast Cancer at DF/BWCC helps patients and providers to address issues that are more common among young women with breast cancer, including concerns about fertility and reproductive options, genetics, psychosocial matters, and other treatment and survivorship issues. The program is run by a director (currently author A.H.P.) and a multidisciplinary advisory group composed of patient advocates; providers from medical oncology, breast surgery, radiation oncology, nursing, and social work; and translational, psychosocial, and population-based investigators. A program coordinator and an administrator play a pivotal role in organizing the overall effort. To our knowledge, this is the first such comprehensive program developed to target the multiple and complex issues associated with a breast cancer diagnosis in young women. From its inception, the program has encompassed clinical care, patient and provider education programs, and research initiatives. (Figure 1) The program has been designed and implemented based on perceptions of needs and problems in the population, intervention to meet needs within the scope of the program and as resources allow, regular qualitative evaluation of whether needs are being met, and identification of new or emerging issues to be addressed.

From a clinical perspective, the program serves as an umbrella for all young patients with breast cancer and their providers, helping each woman to access optimal comprehensive care in an environment that provides extra support, enhanced medical services (eg, easily available genetics and fertility preservation consultations), and education. All new patients age 42 and younger are identified through our new patient office and



**Figure 1.** Components of the Program for Young Women With Breast Cancer.

automatically enrolled in the program at their first clinic visit. During this appointment, our program coordinator meets with the patient, introduces the program, briefly discusses the issues that may be important to young women with breast cancer, and gives the patient a brochure that outlines available resources and how to access them (Figure 2). The program coordinator subsequently assists the patient and her breast physicians and nurses in making referrals (eg, to fertility specialists, genetics counseling, plastic surgeons) in a timely fashion, and helps patients to access additional material and emotional supportive services. Because young women, in particular, may have difficulty adjusting to a breast cancer diagnosis, each patient in the program is provided with the name and contact information of the social worker to whom she has been assigned at that first visit. Social workers provide an initial evaluation of each patient and then either monitor them or refer them to other mental health providers, depending on the needs and situation of the individual. Patients who receive chemotherapy are then monitored through treatment by a designated nurse from the program, who assists with symptom management and early survivorship issues. Participants are encouraged to engage in a number of educational and support programs and other services available both during and after treatment. The clinical program functions to (1) promote timely awareness of young women’s unique concerns; (2) streamline and augment services already available at our center (eg, genetic counseling, psychosocial consultation, rapid fertility specialist consultation, survivorship and sexual health clinics) and develop new services; (3) provide educational and psychosocial support directly to patients, with an automatic direct referral to a social worker; (4) provide access to workshops and educational seminars, a dedicated telephone support group, and biannual patient newsletter; and (5) provide assistance to health care professionals with clinical checklists, continuing medical education lectures, and easy access to tumor



**Figure 2.** Flow of patient care and support in the Program for Young Women With Breast Cancer.

board discussions focused on young women. The program has also recently developed a working group focused on developing clinical algorithms to inform the management of women diagnosed with breast cancer during pregnancy. We are developing a prospective registry for this specific patient population.

**Progress to Date**

Over the past 6 years, the Program for Young Women With Breast Cancer has served more than 1,600 women age 42 and younger with newly diagnosed breast cancer in our clinics, and hundreds more through our patient education and support programs. Before developing new programs, we carefully evaluate whether there is a way to use an existing resource. We have found that resources often exist within our system but are not well advertised or easily accessible. We have also created new services when there is no appropriate resource available already to meet a high-priority need. For example, when we discovered that available support groups were logistically difficult for younger patients and that they often had difficulty relating to the concerns of older women in these groups, we created, to our knowledge, the first Young Women’s Telephone Support

Group. More than 100 young women have participated in these formally facilitated groups over the past 4 years, and informal support networks have blossomed from them. In light of the success of the telephone support modality, we also created a telephone support group for young women with metastatic disease; this group focuses on the challenges of parenting school-age children and communicating with children during difficult and uncertain times.

Eight years ago, before the program’s inception, we began hosting an annual Young Women’s Forum. This all-day event includes lectures from medical professions, a survivor panel, and an “ask the expert” session that focuses on topics most relevant to young women. The program hosts an array of workshops for young women that deal directly with sexual health, mindfulness and other techniques for stress management, as well as nutritional counseling. We also annually host a Young Survivors Evening to focus on issues that are pertinent to women who are at least 1 year out from their initial diagnosis. Previous Survivor Evenings have highlighted genetic testing for young women, exercise and nutrition after treatment and through survivorship, and breast reconstruction.

The Program recently started a new lecture series. In May 2011, our first evening focused on breast cancer survivorship, and the second, held in September, highlighted local therapy issues after breast cancer. We continued to host this series throughout the fall and winter of 2011. We are also continually developing patient materials to help educate women about the unique issues they may be confronted with both during and after a breast cancer diagnosis. Through our biannual newsletter, we share ongoing research updates, informational articles, and links to regional and national resources. In addition, the program works closely with the Survivorship Program and Lance Armstrong Foundation Center of Excellence at Dana-Farber Cancer Institute, as well as several other advocacy and professional groups.

### Optimizing the Program

Qualitative surveys and needs assessments from patients enrolled in the program have revealed that many patients are satisfied and comfortable with the approach we have adopted. Feedback from providers has indicated that they appreciate the extra support, services, and information available for their patients. Three years ago, we conducted a formal needs assessment. Ten young women enrolled in the Program for Young Women With Breast Cancer at DF/BWCC were interviewed. A number of common themes emerged, and several unmet needs were identified, including

- The timing of introduction to the program at first visit made it challenging to digest information; more follow-up information at future appointments and during chemotherapy treatments would be appreciated.
- Patients felt they were not made aware of childcare and would have taken advantage of this service had they known about it.
- Yearly online evaluations of the program could improve the services provided.
- There was interest in workshops specifically designed for survivorship, including coping with recently completing treatment and transition to post-treatment life.
- There was a need for more consistent and frequent availability of workshops (on a quarterly basis), as well as new workshops focused on survivorship and couples or partners of young women.
- There was interest in local services available to patients outside of the Boston area.
- There is a need to update the program Web site with the most current information regarding research, calendar of events, and additional resources.

This needs assessment facilitated improvement of the program. For example, we had previously identified and harnessed a program that was already in operation at Brigham and Women's Hospital to provide on-site childcare for patients in our program, but the assessment indicated that we needed to communicate better with patients about the availability of this resource. We now highlight it for patients at the time they are first enrolled in the program. We also now offer workshops on a more

consistent and frequent basis and routinely solicit input through regular patient evaluations of our programs.

### Research Within the Program

As part of the research component of the Program for Young Women With Breast Cancer, in late 2006, we began a multi-institutional prospective cohort study (principal investigator, A.H.P.) of women diagnosed with breast cancer at age 40 years or younger. This cohort study is designed to elucidate the unique biologic, medical, and psychosocial issues that young women face at diagnosis and over time. Participants are identified by the Rapid Case Identification Core of the Dana-Farber/Harvard Cancer Center through a review of pathology records at participating institutions. These identified patients receive a mailed invitation to consent to medical record review, complete questionnaires every 6 months, and provide blood samples and tumor specimens for central review. As of September 2011, there were more than 680 women enrolled in the study, with a plan to enroll 1,000 total. Preliminary data have already been presented on presentation of disease in young women, delays in diagnosis, coping after diagnosis, molecular phenotype of breast cancer diagnosed in young women, and fertility concerns.<sup>35-38</sup>

There are also a number of clinical trials for which the program has helped to enhance accrual, including clinical studies to understand the optimal endocrine therapy for young women with early breast cancer, decision-making studies, and an expressive writing intervention for young women.

### Future Directions

There are many resources available to support patients with cancer. However, delivering relevant information and support services at the right time and to the patients who are in the greatest need is often difficult. Our unique program addresses the multiple needs of young women with breast cancer. Through new and expanding partnerships, we are now working to improve the care of women beyond our clinics. We have recently designed and are currently pilot testing Young and Strong, an exportable model of our program that will serve young women with breast cancer who are receiving care outside of the comprehensive cancer center setting, particularly in places where resources are limited. Through this intervention, we provide Web- and print-based materials to patients and the oncologists who care for them. Soon after diagnosis, patients receive a booklet focused on unique issues facing young women and access to a comprehensive Web site that includes more detailed information, videos, questions to ask their doctors, and an extensive list of resources that support young women. Clinicians are provided baseline and follow-up care checklists and disease management algorithms; written clinical care descriptions; and video presentations on fertility, early menopause, pregnancy after breast cancer, psychosocial concerns (eg, coping with anxiety, dating, and dealing with young children), genetic factors, body image, and sexual functioning. Our intervention materials incorporate information about these issues and how to help patients manage them, as well as how improved

doctor-patient communication may promote better quality of care. A dedicated e-mail address is included so that oncologists who focus on the care of young women with breast cancer at our center can respond on a daily basis to case queries, requests for additional support, and questions about the latest data regarding the care of this population. By targeting both the patient and provider, we hope to optimize the care of young women with breast cancer. This effort to improve both the quality of care and the psychosocial well-being of young patients has been supported by an Improving Cancer Care Grant from ASCO, funded by Susan G. Komen for the Cure. At the time of this writing, we are pilot testing the Young and Strong intervention and are planning a randomized controlled trial of the intervention at community and academic oncology sites that see relatively high volumes of young women with breast cancer throughout North America.

## Summary

We started our Program for Young Women With Breast Cancer in 2005 to improve the quality of care received by young women at our institution. We believe our efforts have led to tangible improvements in the present standard of care at our institution. We hope that through our ongoing and planned research we will extend our program to sites throughout the United States and that this work can serve as a novel model to improve care and overcome barriers to delivering optimal comprehensive care for unique groups of patients in other settings.

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