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PERSPECTIVES IN ONCOLOGY

PYNK: Breast Cancer Program for Young Women

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ABSTRACT

Consider this scenario: A 35-year-old recently married woman is referred to a surgeon because of a growing breast lump. After a core biopsy shows cancer, she undergoes mastectomy for a 6-cm invasive lobular cancer that has spread to 8 axillary nodes. By the time she sees the medical oncologist, she is told that it is too late for a fertility consultation, and she receives a course of chemotherapy. At clinic appointments, she seems depressed and admits that her husband has been less supportive than she had hoped. After tamoxifen is started, treatment-related sexuality problems and the probability of infertility contribute to increasing strain on the couple's relationship. Their marriage ends two years after the woman's diagnosis.

Six years after her diagnosis, this woman has completed all treatment, is disease-free, and is feeling extremely well physically. However, she is upset about being postmenopausal, and she is having difficulty adopting a child as a single woman with a history of breast cancer. Could this woman and her husband have been offered additional personalized interventions that might have helped them better cope with the breast cancer diagnosis and the effects of treatment?

Compared with their older counterparts, young women with breast cancer often have greater and more complex supportive care needs. The present article describes the goals, achievements, and future plans of a specialized interdisciplinary program—the first of its kind in Canada—for women 40 years of age and younger newly diagnosed with breast cancer. The program was created to optimize the complex clinical care and support needs of this population, to promote research specifically targeting issues unique to young women, and to educate the public and health care professionals about early detection of breast cancer in young women and about the special needs of those women after their diagnosis.

KEY WORDS

Breast cancer, young women, program, survivorship, oncofertility, psychosocial

1. INTRODUCTION

Although fewer than 10% of North American women diagnosed with breast cancer are 40 years of age or younger, those women account for a disproportionate number of life years lost to breast cancer[1]. That loss is not only a result of their younger age, but also a later stage at diagnosis and a higher rate of systemic relapse at any given stage[1,2]. Approximately 85% of young women with breast cancer now survive more than 5 years[3]. However, women fortunate enough to remain disease-free have greater early and long-term morbidity, both physical and psychological. Sources of distress include premature treatment-induced menopause, infertility, alterations in body image, fear of starting a new relationship, marital strain, financial loss, childcare difficulties, feelings of alienation from healthy peers, and the constant threat of recurrence and death (the latter prospect being particularly terrifying for mothers of young children). Younger breast cancer patients are also more likely to test positive for a *BRCA* mutation, a situation that involves additional difficult decisions[1,4,5].

Although treatment of the cancer does not itself differ greatly with age, optimal management of young women with breast cancer often requires complex interdisciplinary supportive care. However, because of the relative rarity of breast cancer in women less than 40 years of age, awareness of the special needs of this population may not be adequately addressed in oncology training programs, and appropriate expertise to provide for those needs may not be readily available. For example, the American Society of Clinical Oncology has recommended that oncologists address the possibility of infertility with all patients about to be treated with systemic adjuvant therapy during their reproductive years, and that oncologists also be prepared to discuss possible fertility preservation options or to refer patients to reproductive specialists as early as possible during treatment planning[6]. Yet studies have shown that those discussions and referrals often don't happen[7,8]. Similarly, few health care providers are equipped to deal with the medical and psychological treatment–related sexual difficulties that many of these women face. Understandably, young women are often unable to relate to the supports available to their older peers.

In 2001, the Canadian Breast Cancer Network and the Ontario Breast Cancer Community Research Initiative undertook a study examining the experiences and unmet needs (if any) of young Canadian women with breast cancer. In 5 cities (Vancouver, Winnipeg, Toronto, Montreal, and Halifax), 65 women 45 years of age or younger at diagnosis were consulted in a series of 10 focus groups. The main theme that emerged was "nothing fit me," which became the title for the study results. The women reported that appropriate information and support either did not exist or did not "fit" or match their age or life stage. The women complained that health care professionals did not provide them with timely assistance to deal with emotional and mental health concerns, and partnered women reported that a breast cancer diagnosis put a strain on their spousal relationships. The women emphasized the need for a "navigator" to assist them through the cancer care system, and the importance of peer support by other women of a similar age. They recommended that health care workers could help by providing information about fertility, early menopause, body image, talking with children about their cancer, and the supports and programs or services available for young women and their families, including workshops about sexuality and breast reconstruction[9].

Those findings suggested that a specialized program for young women with breast cancer was needed. Given that Sunnybrook Health Sciences Centre has one of the largest academic breast cancer care teams in Canada, creating such a program at our facility seemed a logical choice. In 2004, 1558 newly diagnosed breast cancer patients were referred to Sunnybrook, among whom 165 were diagnosed at 40 years of age or younger [statistics from OPIS (Oncology Patient Information System: Cancer Care Ontario, Toronto, ON)].

2. PYNK: BREAST CANCER PROGRAM FOR YOUNG WOMEN

In 2008, after 4 years of planning and fundraising, our cancer centre's breast site group launched PYNK: Breast Cancer Program for Young Women, for women 40 years of age or younger newly diagnosed with breast cancer. The name PYNK was chosen because the colour pink has come to symbolize breast cancer, but the letter I was replaced with a Y for "young."

2.1 Goals of PYNK

The goals of PYNK are to

- optimize the complex clinical care and support needs of young breast cancer patients and their families;
- promote research focused on the unique medical and psychosocial needs of these women; and
- educate affected women, the general public, and health care professionals about those unique issues, so as to promote earlier cancer detection and better patient management.

2.2 Development and Governance of PYNK

The PYNK program was created by an interdisciplinary steering committee with representation from medical, radiation, and surgical oncology; nursing, psychology, and social work; and young breast cancer survivors. The steering committee meets monthly to monitor patient accrual and data entry, to strategize about fundraising, to monitor the progress of ongoing projects, and to implement new research and education initiatives. In addition, a large advisory board provides expertise in fertility, gynecology, epidemiology, physiotherapy, nutrition, psychiatry, and medical imaging.

2.3 Eligibility for PYNK

All women 40 years of age or younger who are newly diagnosed with breast cancer and who are referred to a surgical or medical oncologist at our centre are eligible for PYNK. Some patients are referred to our centre specifically because of the program, which receives referrals from across the greater Toronto area (population: 6.3 million)[10] and which has been accommodating all patients referred to the program, with no maximum capacity and no wait time of more than 2 weeks.

Currently, PYNK supports more than 175 young women at various stages of treatment and follow-up. With increasing physician and patient awareness of the program, PYNK currently receives 1–2 new referrals each week. Assuming that 10% of breast cancers are diagnosed in women 40 years of age or younger, and given that approximately 8000 new breast cancer cases are diagnosed each year in Ontario[11] and that close to half of those cases occur in the greater Toronto area (based on population percentage)[12], approximately 400 women in the greater Toronto area would be expected to be eligible for referral to PYNK annually. The mean age of women currently enrolled in the program is 36 years (range: 21–43 years).

Outside its target population, PYNK has been a resource for numerous young women not receiving treatment at our centre and also for some health care providers who contact the program by e-mail or telephone for information, support, and advice. Some patients treated elsewhere have also come for a formal second opinion.

2.4 Role of Health Care Professionals

The lynchpin of PYNK is its nurse navigator. The nurse navigator has a central role in recruiting eligible patients as soon as they are referred to our centre; in standardizing and coordinating their interdisciplinary care; in facilitating decision-making; and in providing education, advice, coping strategies, and personalized support throughout treatment and follow-up. The nurse navigator is the primary contact for any problems or questions that these women may have. She ensures that all appropriate oncology and non-oncology consultations (fertility, genetics, psychology, and plastic surgery, among others) and all necessary tests are obtained in a timely and coordinated manner.

The nurse navigator has extensive knowledge of the resources available at our centre and in the community that specifically target young breast cancer patients. Those resources include formal support programs for patients and families, childcare helpers, and age-appropriate books for children about cancer and its treatment. The nurse navigator's role has become particularly critical for these women in recent months, because our cancer centre has abandoned the primary nursing model of care. The PYNK nurse has now become the only nurse providing ongoing consistent care to these particular women.

All the surgical, radiation, and medical oncologists in our breast site group treat PYNK patients, but some physicians have a special interest in this age group and see a greater number of these women.

2.5 PYNK Follow-Up Clinic

The transition from active treatment back to everyday life and work is difficult for many cancer patients. Anxiety often mounts as the safety net of support from frequent contact with health care professionals is perceived to no longer be available. For these women, PYNK provides a follow-up clinic after they have completed adjuvant chemotherapy and radiation treatment. Women who are still receiving endocrine or biologic therapy are also followed in this clinic, which is run by the nurse navigator, a dedicated medical oncology resident or fellow, and a medical oncologist with a special interest in young women. Appointment slots are 30 minutes (compared with the usual 20 minutes) to ensure sufficient time for answering questions, managing the long-term effects of treatment, and helping the women deal with recurrence-related anxiety. An additional benefit of the clinic is that several other young women are usually sitting in the waiting room, which helps to "normalize" the breast cancer experience, encourage informal peer support, and often, create new friendships.

Accrual to PYNK has plateaued at the expected rate, which is unlikely to change significantly in the foreseeable future. Given that follow-up has not reached 5 years for any patient, no patients have yet been discharged from the program. However, discharges will likely have to begin soon, because financial resources are insufficient to hire additional nurse navigators, and the current nurse navigator is rapidly reaching maximum capacity. Patients appropriate for discharge would be women who are recurrence-free after 5 years, who are functioning well in the community, who are not planning a future pregnancy, and who have a good relationship with their family physician.

2.6 Formal Support Services

2.6.1 Psychosocial Support

To ensure that additional psychological support is available to those who need it, PYNK patients are asked (after giving informed consent) to complete three self-assessment scales—the Hospital Anxiety and Depression Scale, the Illness Intrusiveness Rating Scale, and the Impact of Events Scale—before, during, and at the end of active treatment. These instruments screen for emotional distress so that appropriate interventions can be implemented. Women who score above a predefined cut-off and who are not already receiving formal psychosocial support are seen promptly by one of the psychologists, but continue to be part of PYNK and to receive additional attention from the nurse navigator.

2.6.2 Support Events

Because of the positive feedback of the "waiting room model" of informal peer support, we recently started a new initiative. One evening per month, the nurse navigator facilitates a 2-hour social networking event that is open to PYNK women at any stage of treatment or follow-up. The meeting takes place at Sunnybrook's Wellspring Westerkirk House in the Alli's Journey Room, which, by coincidence, is dedicated to the memory of a young woman who died of cancer. Feedback to date has been overwhelmingly positive. A partnership has also just begun with the cancer organization Gilda's Club (http://www.gildasclubtoronto.org) to create workshops for young breast cancer patients dealing with treatment-related intimacy and sexuality problems.

2.6.3 Sexual Health and Rehabilitation Clinic

A clinic initially created for women with gynecologic cancers has now been expanded to include women with breast cancer, particularly young women suffering from sexual dysfunction because of premature or artificial menopause. This clinic has proved to be an invaluable resource for PYNK patients.

2.7 PYNK's Research Component

In addition to the clinical trials available to all breast cancer patients at our centre, PYNK offers younger women the opportunity to participate in research studies focused on their unique needs. Some of those studies are initiated at our centre; others involve collaboration with principal investigators (PIS) at other centres. In addition, women in PYNK are asked to give informed consent for collection and storage of blood and tumour specimens and for storage of their clinical information, including cancer risk factors and treatment, in a prospective database.

Studies completed to date include a multinational randomized trial of three adjuvant endocrine therapy regimens (SOFT—International PI: Dr. Gini Fleming); a study comparing CYP2D6 genotype and tamoxifen metabolite levels (PI: Dr. Saira Nasim); a study of satisfaction with fertility preservation referral and consultation (PI: Dr. Ellen Warner); a study of *BRCA* testing referral, uptake, and results, and the impact of those results on local treatment choices (PI: Dr. Asma Ali); and a study of the effect of breast cancer in a young woman on the mother–daughter relationship (PI: Dr. Asma Ali). Ongoing studies include a comparison of tumour biology in women of various ethnicities (PI: Dr. Ann Partridge), a study of the effects of chemotherapy on ovarian reserve (PI: Dr. David Hodgson), an online intervention for young couples affected by breast cancer (PI: Dr. Karen Fergus), and a randomized controlled trial of a group intervention for women with long-term difficulties with body image or sexuality (PI: Dr. Mary Jane Esplen).

2.8 PYNK'S Educational Component

Based on the many women seen at our centre whose diagnosis was delayed by many months because they were "too young to have cancer" or had "a blocked milk duct," we perceive a need to raise awareness among primary care physicians, obstetricians, and the general public of the relatively high incidence of breast cancer in women less than 40 years of age, particularly in the postpartum period. We also want to educate oncology health care providers about the unique issues relevant to young breast cancer patients, including the importance of early referral for fertility preservation and genetic testing, and the high prevalence of problems with sexuality. To further those goals, PYNK was formally launched with an evening educational event for primary care physicians and general surgeons. Since then, PYNK steering committee members have frequently delivered presentations at local and national conferences and continuing medical education events; publications have also appeared in peer-reviewed journals.

3. OTHER SERVICES AND PROGRAMS FOR YOUNG WOMEN WITH BREAST CANCER

Since the early 2000s, recognition has been increasing of the complex care needs in young women with breast cancer. A few programs have started in the United States to increase awareness and meet the age-related needs of these women. Directors or nurse navigators in such programs were contacted by e-mail to further clarify the structure and impact of their programs on care.

In 2001, the Siteman Cancer Center and Washington University School of Medicine, St. Louis, Missouri, started its Young Women's Breast Cancer Program (http://www.siteman.wustl.edu/ContentPage.aspx?id=3789) for women 40 years of age or younger at diagnosis. The program offers education and support led by health care professionals, facilitates peer support, and coordinates healthy activities for participants. The research component of the program focuses on identifying novel genetic risk factors for breast cancer in young women. To our knowledge, the program does not have a nurse navigator.

In 2005, the Dana–Farber/Brigham and Women's Cancer Center, Boston, started its Program for Young Women with Breast Cancer (http://www.dana-farber.org/Adult-Care/Treatment-and-Support/Treatment-Centers-and-Clinical-Services/Breast-Cancer-Treatment-Center/Program-for-Young-Women-with-Breast-Cancer.aspx#About), a large comprehensive clinical and psychosocial care program for women in their early 40s and younger with breast cancer. Their program has clinical, research, and educational objectives somewhat similar to those in our program. Although it focuses on facilitating appropriate urgent consultations to meet the unique needs of younger women, the program is not intended to have a major impact on the clinical or supportive care of those patients. The role of "clinical navigator" was initially assigned to a nurse, but was later thought to be more appropriate for an executive administrative assistant. The program's major thrust is the research component, which has been highly successful in obtaining funding. To date, blood and tumour samples and serial epidemiologic and psychosocial questionnaires have been collected from many hundreds of women across the State of Massachusetts. Several centres outside the state, including ours, are collaborating on some of their studies. Formal and informal assessments of their program and needs assessments have been performed[13].

The Diane O'Connor Thompson Breast Center, University of Colorado, started a Young Women's Breast Cancer Translational Program (http://www.uch.edu/conditions/cancer/breast-cancer/ywbctp). In addition to increasing awareness and addressing the unique needs of these women, their program focuses on pregnancy-associated breast cancers. They have a dedicated nurse navigator who serves as a medical advocate from diagnosis through follow-up. Providers work closely with oncologic and non-oncologic support services such as obstetrics and gynecology, fertility specialists, and the hereditary cancer clinic. Besides offering support, the program connects women and their families with appropriate resources.

Last year, the U.S. Centers for Disease Control and Prevention funded seven organizations to support breast cancer patients less than 45 years of age at diagnosis and their families. The funding will support the development of tools and resources to increase patient and provider knowledge, to reduce the risk of disease recurrence, and to improve the general wellbeing of these patients[14].

Our program is the first of its kind in Canada to provide special supports to young women with breast cancer, with a pivotal role for the program's nurse navigator. Eastern Health recently appointed seven nurse navigators across Newfoundland and Labrador to help young adults with cancer (http://www.youngadultcancer.ca). Those nurse navigators provide patients and their families with education, advice, support, and links to community resources. However, to the best of our knowledge, none of those nurses deals specifically with women with breast cancer.

Compared with those other initiatives, PYNK is the only program that combines "upgraded" clinical and support services provided by a nurse navigator together with comprehensive research and education components.

4. CAN PYNK MAKE A DIFFERENCE?

The PYNK program has been extremely well received, consistently receiving positive feedback from referring physicians, patients, and their families. Much of the program's popularity is undoubtedly a result of the extra attention the patients receive from the health care team, particularly the nurse navigator. However, we believe that the program also has more tangible benefits. Although many young women have enough inner fortitude, support from family and friends, and luck to get through breast cancer treatment with little permanent physical or psychological impact on their quality of life, others are not as fortunate. Consider, for example, the scenario mentioned in this article's abstract: a 35-year-old recently married woman whose husband had difficulty coping with her breast cancer diagnosis. Treatment-related sexuality problems and infertility increased the strain on her marriage, which ended in divorce. Had this woman been referred to PYNK immediately after her cancer was diagnosed on core biopsy, the PYNK health care team would have had the chance to assist the couple in dealing not only with their immediate concerns but also with any problems that developed over time. The PYNK program encourages referral at the time of diagnosis so that immediate fertility consultation can be arranged, with the opportunity to preserve eggs or embryos without significantly delaying adjuvant systemic therapy. Based on the screening questionnaire or clinical observation, women felt to be at risk of greater-than-average psychological distress can be seen urgently by an experienced psychologist, and couples can enroll in the online intervention study mentioned earlier. Young women who are identified on follow-up as having sexuality or body image difficulties can be seen in Sunnybrook's Sexual Health and Rehabilitation Clinic and can be offered participation in the centre's study of an imaging intervention to improve body image and sexuality. These women can also participate in one of the sexuality workshops we will soon be offering.

One of our PYNK patients recently wrote to us: "I am thankful that you are so dedicated to helping young women with cancer, I know that [not having PYNK] would have made what is already a tough journey tougher; you knew what my needs were as a young woman with cancer before I knew what they were."

5. SUMMARY

The novel interdisciplinary program for women 40 years of age and younger newly diagnosed with breast cancer, PYNK: Breast Cancer Program for Young Women, was developed by a team of health care professionals and young breast cancer survivors with the aim of optimizing the complex clinical and psychosocial care needs of such women, promoting targeted research that addresses issues unique to young women, and increasing awareness about early detection of breast cancer in young women and about the special needs of such women after their diagnosis. More than 175 women are currently participating in the program, which is now enrolling 1–2 new patients per week. We are excited about our new monthly support meetings, and we are looking forward to working with Gilda's Club to develop sexuality workshops that can then be adapted for women with other malignancies. A formal evaluation of how well PYNK is fulfilling the clinical and support needs of our patients, and how well it is functioning from the perspective of the health care providers in our breast site group, is planned for the near future.

In September 2012, the Canadian Institutes for Health Research and the Canadian Breast Cancer Foundation hosted a meeting in Montreal to develop a research strategy for young women with breast cancer. The organizing committee included the director of PYNK, Dr. Ellen Warner, and was chaired by Dr. Karen Fergus, the psychologist on the PYNK steering committee. Drs. Warner and Fergus and the PYNK nurse navigator, Christel Helwig, were among the 60 researchers, allied health care providers, and survivors from across Canada who participated in breakout sessions and group discussions to determine how best to utilize the $6 million earmarked by the Canadian Institutes for Health Research and the Canadian Breast Cancer Foundation for research focused specifically on young women with breast cancer. With a large population of young breast cancer patients, a prospective clinical and epidemiologic database, and stored blood samples, the PYNK program will be in a unique position to take a leadership role in that research. The formal request for grant applications should be announced in the near future.

Although secure funding from either a dedicated donor or institutional commitment for our nurse navigator and other PYNK expenses would be extraordinarily helpful, we will continue to raise money from individuals and corporations and to apply for research grants. Our ultimate vision is that programs such as PYNK will be available to young breast cancer patients at all major cancer centres.

6. CONFLICT OF INTEREST DISCLOSURES

No financial conflicts of interest exist.

7. REFERENCES

1. Anders CK, Johnson R, Litton J, Phillips M, Bleyer A. Breast cancer before age 40 years. *Semin Oncol* 2009;36:237–49.
2. Gelmon K, Partridge AH, Morrow M, Davidson NE. Breast cancer in young women: epidemiology, treatment, and survivorship issues. In: American Society of Clinical Oncology. *2005 Educational Book*. 2005;:61–7. [Available online at: http://www.asco.org/ASCOv2/Education+%26+Training/Educational+Book?&vmview=edbk_detail_view&confID=34&abstractID=61; cited November 29, 2012]
3. Canadian Cancer Society's Steering Committee on Cancer Statistics. *Canadian Cancer Statistics 2011.* Toronto, ON: Canadian Cancer Society; 2011.
4. Avis NE, Crawford S, Manuel J. Quality of life among younger women with breast cancer. *J Clin Oncol* 2005;23:3322–30.
5. Warner E. Impact of MRI surveillance and breast cancer detection in young women with *BRCA* mutations. *Ann Oncol* 2011;22(suppl 1):i44–9.
6. Lee SJ, Schover LR, Partridge AH, *et al.* on behalf of the American Society of Clinical Oncology. American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol* 2006;24:2917–31.
7. Quinn GP, Vadaparampil ST, Lee JH, *et al*. Physician referral for fertility preservation in oncology patients: a national study of practice behaviors. *J Clin Oncol* 2009;27:5952–7.
8. Goldfarb SB, Dickler MN, McCabe MS, *et al.* Oncology physicians' knowledge, attitudes, and practices regarding fertility preservation [abstract e19525]. *J Clin Oncol* 2010;28:. [Available online at: http://www.asco.org/ASCOv2/Meetings/Abstracts?&vmview=abst_detail_view&confID=74&abstractID=47557; cited November 22, 2012]
9. Gould J, Grassau P, Manthorne J, Gray RE, Fitch MI. "Nothing fit me": nationwide consultations with young women with breast cancer. *Health Expect* 2006;9:158–73.
10. Ontario, Ministry of Finance. Ontario Population Projections Update [Web page]. Oshawa, ON: Ministry of Finance; 2012. [Available at: http://www.fin.gov.on.ca/en/economy/demographics/projections; cited August 4, 2012]
11. Cancer Care Ontario (CCO). Cancer Statistics [Web page]. Toronto, ON: CCO; 2012. [Available at: https://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=8630; cited August 4, 2012]
12. Cancer Care Ontario (CCO). *GTA 2014 Cancer Report*. Toronto, ON: CCO; 2004. [Available online at: http://www.ontla.on.ca/library/repository/mon/8000/244989.pdf; cited August 4, 2012]
13. Partridge AH, Ruddy KJ, Kennedy J, Winer EP. Model program to improve care for a unique cancer population: young women with breast cancer. *J Oncol Pract* 2012;:[ePub before print]. [Available online at: http://jop.ascopubs.org/content/early/2012/05/22/JOP.2011.000501.short; cited May 22, 2012]
14. United States, Centers for Disease Control and Prevention (CDC). Cooperative Agreement to Support Young Women Diagnosed with Breast Cancer [Web page]. Atlanta, GA: CDC; 2011. [Available at: http://www.cdc.gov/cancer/breast/what_cdc_is_doing/grant.htm; cited August 4, 2012]

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