Women diagnosed with breast cancer before age 45 want health information and emotional support tailored to their age but report difficulty accessing this information and support. This notable finding was determined by Living Beyond Breast Cancer’s national needs assessment of young women affected by breast cancer, which engaged more than 1,500 people. This document contains a summary of the needs assessment process and the primary findings. The conclusions will aid healthcare providers, cancer advocates and cancer organizations that work with young women, helping them better serve this unique community.

LBBC completed this needs assessment for its Young Women’s Initiative, a new program funded through the U.S. Centers for Disease Control and Prevention. The needs assessment sought to assess the information and support needs of young women, to evaluate subgroup differences by ethnicity and medical and age characteristics, and to identify existing program gaps for young women. LBBC will use the needs assessment findings to strengthen and expand its existing programs for young women, as well as to create new programs.
LBBC’s needs assessment utilized four data collection methods. First, 12 key informant interviews were conducted with healthcare providers and cancer advocates who work closely with young women. Second, four focus groups were conducted with 33 young women. Third, an environmental scan and gap analysis was completed, which identified existing resources for young women affected by breast cancer, areas lacking in coverage and potential partner organizations. The environmental scan reviewed 29 national organizations that provide educational and support resources relevant to young women affected by breast cancer. Fourth, a national survey of young women was developed using the information collected through the three previous activities. A total of 1,473 women diagnosed with breast cancer at or before age 45 completed the survey online, and 25 women completed the survey on paper. Only the online survey responses were analyzed for this report. Together, the four needs assessment activities were analyzed. These common themes arose across all four methods:

1. Young women want breast cancer information and emotional support tailored to their age group but many have difficulty finding this information and support.

LBBC’s survey found that 70% of respondents reported it was very important to have health information about breast cancer tailored to them as younger women. However, only 21% of women reported that it was easy or very easy to find this tailored health information. African-American women and women diagnosed before age 30 were more likely than other ethnic groups and age groups to report that it was very important to access health information tailored to their needs as young women. In addition, women diagnosed under age 30 had a harder time finding health information tailored to their needs compared to women diagnosed over age 30. A similar pattern was found with emotional support: 60% of survey respondents indicated that it was very important to have emotional support services tailored to their needs as young survivors. However, 40% of women reported that it was not at all easy to find emotional support services tailored to their needs. More than one-third of respondents reported seeking information on breast cancer from any source on a weekly basis. African-American women reported that it is very important for them to connect to young women who share their ethnic background. Other ethnic groups did not rate this as highly important.

2. Women diagnosed with breast cancer before age 30, African-Americans, Latinas and women living with metastatic breast cancer report different concerns and interests compared to other groups of young women.

The needs assessment data were analyzed by comparing group differences in time since diagnosis, age of diagnosis, ethnicity and stage of breast cancer. This subgroup analysis revealed that some groups of young women have distinctly different responses and experiences. African-Americans and Latinas reported different breast cancer treatment results when compared to white respondents. African-Americans and Latinas were more like to be diagnosed before age 30 than other ethnic groups. African-American women were less likely than white respondents to get breast reconstruction, and Latinas were more likely than white respondents to get breast reconstruction. African-American women were less likely to receive genetic testing than other ethnic groups. Both African-American and Latina women were less likely to see a genetic counselor compared to white women. Women diagnosed before age 30 were also more interested than women in older age groups in learning more about sex and intimacy concerns. African-American women and women living with metastatic breast cancer reported significantly more current side effects than other groups of women. When asked if they were experiencing current side effects related to breast cancer, African-American women were more likely than white women to report current side effects of menopause symptoms, fatigue, weight loss or gain, trouble sleeping, arm stiffness, pain, neuropathy, difficulty communicating with family, and lymphedema. Young women living with metastatic breast cancer were more likely to report current side effects at a higher rate in almost all side effect categories compared to women diagnosed with early-stage breast cancer. The assessment found that women diagnosed before age 30 were more likely to want to access health information and receive emotional support online than women diagnosed over 30. They were also more likely to be involved in breast cancer online message boards and chatrooms than women diagnosed at an older age.

3. There are limited national educational programs for young women affected by breast cancer. There are even fewer resources for traditionally underserved subgroups of young women, such as women of color, women living with metastatic breast cancer and lesbian, gay, bisexual, transgender and queer (LGBTQ) women.
LBBC’s environmental scan and gap analysis reviewed 29 national organizations that provide education or support to young women affected by breast cancer. This review concluded that a small number of national educational programs target young women affected by breast cancer, and they are often physically concentrated in major metropolitan areas. There are limited resources on long-term side effects of breast cancer in young women and other key survivorship concerns. Even fewer programs exist for potentially vulnerable populations of young women affected by breast cancer. These subgroups expressed the need for tailored information for their experiences as women of color, women living with metastatic breast cancer or LGBTQ women.

4 More healthcare providers should discuss the potential impacts of treatment on fertility with premenopausal women prior to cancer treatment.

Only half of women who completed the national survey reported discussing fertility issues with their healthcare providers, although the majority of survey respondents received chemotherapy. Of the women who had those discussions, 30% initiated the conversation. All premenopausal women diagnosed with breast cancer need to understand how treatment may affect fertility and their options for preserving fertility, regardless of income, health insurance coverage or whether they have biological children prior to diagnosis. The National Comprehensive Cancer Network guidelines recommend all premenopausal women diagnosed with breast cancer be informed about the potential impacts of chemotherapy and asked if they would like to have future pregnancies (NCCN, 2012). LBBC’s needs assessment suggests that this important guideline is not being followed.

5 All young women should receive genetic counseling when they receive genetic testing.

Although 75% of respondents reported receiving genetic testing, only half reported seeing a genetic counselor or geneticist. It is important that young women receive the information and support they need to understand genetic testing results and the treatment implications. The Commission on Cancer recommends that genetic counseling be provided to patients by a qualified genetic professional (Commission on Cancer, 2012). Although LBBC’s needs assessment did not analyze the quality of the genetic counseling women received or how they interpreted their genetic testing results, the discrepancy between the percentage of women who received genetic counseling and the number who underwent genetic testing suggests that young women do not receive appropriate genetic counseling and support.

6 Many women diagnosed with breast cancer before age 45 report side effects many years after completing treatment.

Lingering side effects can greatly affect quality of life for many young women affected by breast cancer. More than 50% of respondents reported that they currently experience side effects of trouble with memory, menopause symptoms, decreased interest in sex, fatigue, weight gain or loss, and trouble sleeping. In addition, these current side effects were reported by at least half of long-term survivors, women who were at least five years from their diagnosis of breast cancer. Young women should be educated about effective strategies for managing these long-term side effects, and healthcare providers in all medical settings should be aware of these concerns and potential treatment options.

7 Young women affected by breast cancer are interested in a wide range of breast cancer information topics.

National survey respondents were asked which breast cancer topics are of interest to them. The top five topics selected were long-term health impacts of treatment, new treatment and research, managing fear of recurrence, nutrition and diet, and prevention of other illnesses. Breast cancer and the environment was of high interest but respondents reported having difficulties finding information on that topic. Breast cancer advocacy was of higher interest to women of color (33-40%) than to white respondents. Sexuality and intimacy was of higher interest to women diagnosed under age 30 and long-term survivors (>5 years post diagnosis) than to women over age 30 or short-term survivors. Clinical research and future health planning were of higher interest to women living with metastatic breast cancer than to women with early-stage disease.

8 Most young women prefer to receive breast cancer information via the Internet, and many use social media to access breast cancer information and connect with other survivors.

Half the national survey respondents said they wanted health and medical information in an online format, whereas 20% preferred in person. Of the sample, 86% reported using Facebook. In addition, 60% said they share their personal experience with breast cancer through
social media platforms, and half said they access breast cancer information and connect with other young women with breast cancer through social media platforms.

**Limitations**

LBBC’s national needs assessment of young women affected by breast cancer included more than 1,500 participants from every state. The organization used a mixed method approach, but there are several notable limitations to the generalizability of its findings. The sample had limited ethnic, sexual orientation and income diversity. Due to a lower response rate than desired from minority women other than African-Americans, generalizability of findings to other ethnic minority young women with breast cancer was not possible. In addition, all the information collected was through self-report, which may lead to incorrect responses.

**Conclusion**

Young women affected by breast cancer have unique needs requiring tailored programs that target their concerns and provide them with emotional support. LBBC’s Young Women’s Initiative is dedicated to strengthening LBBC’s programs, as well as to developing new resources, to better serve young women. LBBC will utilize these needs assessment findings to direct program expansion. In addition, the needs assessment findings will be shared with healthcare providers and cancer advocates to help strengthen their care and programs for young women.

**References**


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For more information on the Young Women’s Initiative or to get involved, VISIT www.lbbc.org/youngwomen or contact ywi@lbbc.org. Sign up for the Young Women’s Initiative email list and receive periodic updates on the project.