Background

Ten percent of breast cancer cases occur in women under age 45, resulting in an estimated 24,000 new diagnoses a year. Younger women are less likely than older women to be diagnosed with breast cancer, but their cancers are more likely to be found at higher stages and have cancers are more likely to be with breast cancer, but their older women to be diagnosed a year. Younger cases occur in women Ten percent of breast cancer

National Needs Assessment

In 2012, LBBC conducted a national needs assessment of young women and used the findings to set program priorities and direct program expansion. The goal of the needs assessment was to explore the information and support needs of young women affected by breast cancer, examine subgroup differences and identify key programs and services.

Needs Assessment Components:
- Key informant interviews with healthcare providers and cancer advocates (N=22)
- Four focus groups with young women (N=13)
- Environmental scan and gap analysis of organizations (N=23)
- National survey of young women (N=1,473)

Primary Needs Assessment Findings:
- Young women want breast cancer information and emotional support tailored to their age group but many have difficulty finding this information and support.
- Women diagnosed with breast cancer before age 30, African-American, Asian, and women living with metastatic breast cancer report different concerns and interests compared to other groups of young women.
- There are limited national educational programs for young women affected by breast cancer. There are even fewer resources for historically underserved subgroups of young women.
- More healthcare providers should discuss the potential impacts of treatment on fertility with premenopausal women prior to cancer treatment.
- All young women should receive genetic counseling when they receive genetic testing.
- Many women diagnosed before age 45 report side effects many years after completing treatment.

Program Expansion

ONLINE CONTENT: LBBC.ORG/YOUNGWOMEN

Fifty percent of the survey respondents reported preferring to receive health information in an online format. Based on this finding, LBBC expanded online resources tailored to young women.

- Developed over 500 website articles specific to young women. They include easy-to-read summaries of breast cancer research studies and profiles.
- Posted 16 Web content pieces relevant to young women for the “Learn About Breast Cancer and Young Women” section. Topics included advocacy, using social media to find information and support, bone health, sex and intimacy, fertility, early menopause, and communication with health care providers.
- National survey of young women (N=1,473)

Breast Cancer Helpline: (888) 753-LBBC (5222)

- Trained 15 young women as Helpline volunteers since 2011.
- Increased percentage of Helpline volunteers who were diagnosed before age 45 by 44%
- Received 1,200 calls per year, with an estimated that 15–20% from young women.
- Conducted national marketing campaigns for Helpline.

Publications

Psychosocial topics and side effect management were ranked of high interest by survey respondents. LBBC focused efforts on developing print publications on topics of high interest to young women. They included:
- Guide to Understanding Intimacy and Sexuality
- Guide to Understanding Therapeutic Recovery
- Guide to Understanding Genetic and Family Risk
- EReader version of Guide for the Newly Diagnosed Cancer Patient
- Guide for the Newly Diagnosed Cancer Patient

New Programs

Let’s Talk About It Video Series

The needs assessment found that young women prefer to learn from other young women and want interactive online resources. The Let’s Talk About It Video Series brings together in short online videos the perspectives of young women and healthcare providers on relevant health topics.

- Videos in Series:
  - Let’s Talk About Sex (and Breast Cancer)
  - Let’s Talk About: Hope: For the Newly Diagnosed
  - Let’s Talk About: Cancer Treatment
  - Let’s Talk About: Cancer and Fertility
  - Let’s Talk About: Living with Breast Cancer

- Over 3,200 combined views
- Three additional videos in development: the financial impact of breast cancer, body image, and communicating with your support system as a young woman living with metastatic breast cancer.

Young Advocate Program

The Young Advocate Program helps young women harness their personal experience to make a difference in their communities.

- Targets women with incomes at or below 200% of the federal poverty guideline who are within three years of diagnosis or living with metastatic breast cancer
- Eight hour in-person training covers topics on the spectrum of advocacy, breast cancer health disparities, and effectively sharing one’s personal story of breast cancer
- Participants reported an increase in their knowledge of breast cancer and young women, national advocacy resources, and LBBC as a result of this training
- Program participants are required to complete two advocacy activities and share LBBC’s publications with at least one healthcare provider within six months of training
- Trained 29 young women through the program

Challenges

LBBC faced multiple challenges when expanding programs to better meet the needs of young women affected by breast cancer. Some challenges include:
- Measuring impact and outcomes of online content
- Tracking marketing efforts
- Engaging diverse populations
- Reaching young women upon diagnosis
- Find a balance between creating inclusive general programming that meets the needs of young women and creating tailored programs just for young women

Conclusion

LBBC’s national needs assessment of young women affected by breast cancer found that young women have significant information and support needs that are not currently being met. LBBC used the needs assessment findings to expand and develop new programming through its Young Women’s Initiative that better meet these needs.

This process demonstrates the benefits of using needs assessments to drive program development. This model can be used for other cancer survivor populations, where knowledge of their needs and program offerings are lacking.