



## BACKGROUND

Nearly 9% of new breast cancer diagnoses in the United States are in women under age 45. In 2012, Living Beyond Breast Cancer (LBBC), a national nonprofit organization, conducted a needs assessment of young women diagnosed with breast cancer at or before age 45. In 2020, LBBC conducted another assessment to better understand young women's service preferences and information needs. The 2020 assessment focused on demographic differences, sexual health, and long-term impacts on physical and emotional health.

Both the 2012 and 2020 needs assessments were part of LBBC's *Young Women's Initiative*, a program funded through a cooperative agreement with the U.S. Centers for Disease Control and Prevention.

## METHODS

An 88-item online questionnaire was administered via REDCap between August and September 2020. Inclusion criteria were women diagnosed with breast cancer at or before age 45 and who live in the United States.

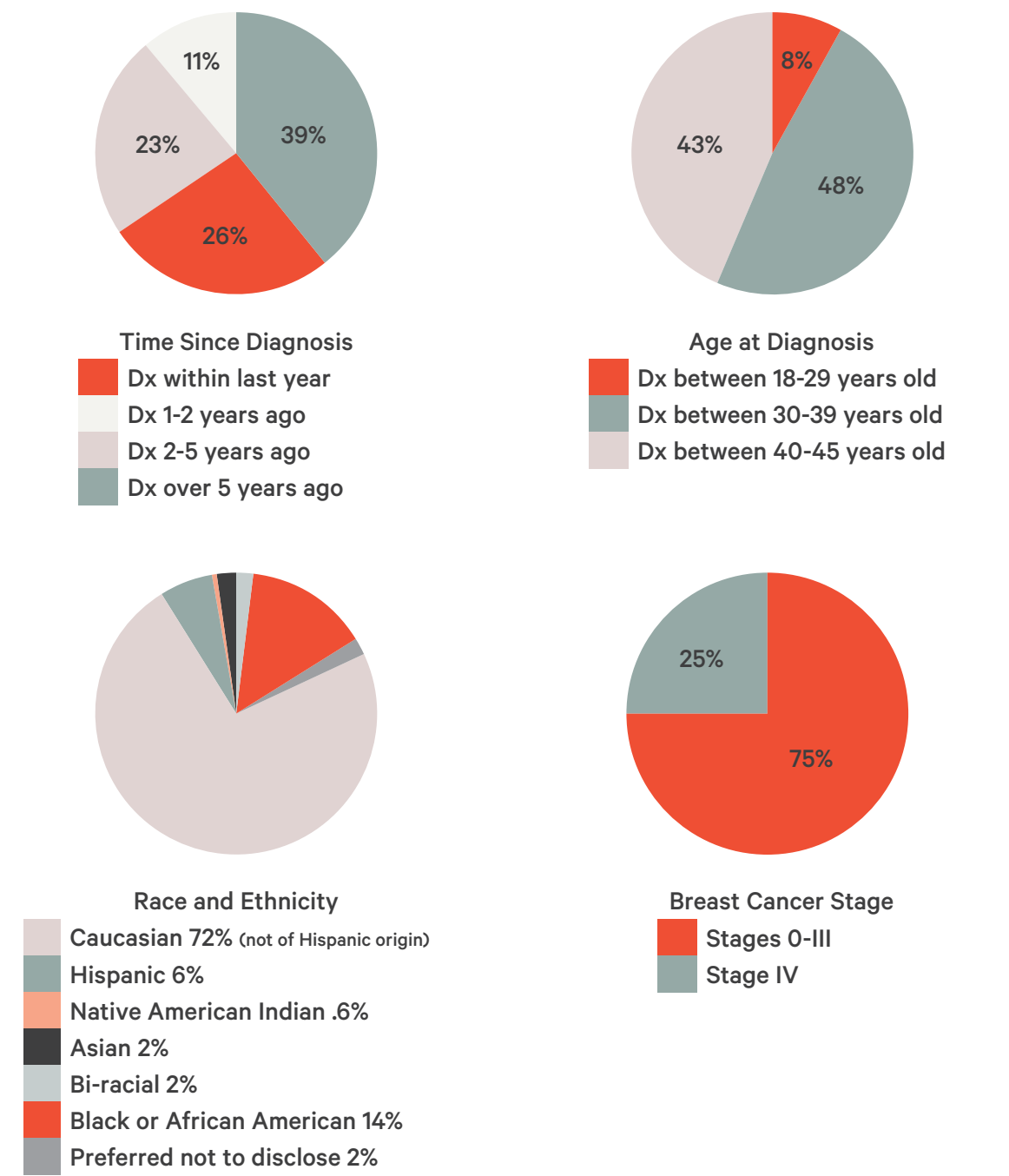
The survey included questions about respondents' experiences with treatment side effects, communication with healthcare providers, and methods of seeking emotional support services and breast cancer information. Questions centered on sexual, physical, and emotional health needs of respondents throughout their treatment journey. Demographic and cancer diagnosis data was collected. The survey results were analyzed by examining the responses by race/ethnicity, cancer stage, age at diagnosis, and time elapsed since diagnosis.

SPSS Version 26 (IBM, 2019) was used for all analyses, including descriptive statistics and Chi-square tests.

LBBC received institutional review board approval.

## DEMOGRAPHICS OF RESPONDENTS

The survey was completed by 717 women diagnosed with breast cancer before age 45. The survey respondents were mostly Caucasian, and diagnosed with breast cancer in their 30s, over five years ago with early stage breast cancer.



## RESULTS: KEY FINDINGS

### Physical and Emotional Impacts

Breast cancer diagnosis and treatment caused significant physical and emotional impacts. A woman's race/ethnicity, cancer stage, and time elapsed since diagnosis resulted in differences in experience.

- Respondents reported experiencing stress, depression, and problems with their emotions 9.2 days in the past month. They reported twice as many days of poor mental health in the past month as the national average among U.S. women (4.9). Those who reported the highest average number of poor mental health days were those within a year of diagnosis or age 29 or younger, Hispanic women, and women with stage III and stage IV breast cancer.

- Respondents reported poor physical health, which includes physical illness or injury, 9 days over the past month. This is much higher than the national average of 3.87 poor physical health days per month. Hispanic women, women diagnosed between age 30 and 39, women diagnosed between 1 and 2 years ago, and women diagnosed with stage IV breast cancer reported the highest average number of days of poor physical health.

Reported Side Effects at Time of Survey Response	
Fatigue, insomnia, or trouble sleeping	77%
Trouble with memory, concentration, and/or organization	73%
Anxiety, depression, or panic attacks	68%
Difficulty adjusting to changes in the way their body looks	66%
Weight loss or gain	67%
Hot flashes or other menopausal symptoms	63%

### Impacts on Sexual Health

- 64% of participants reported significant impacts to sexual health, yet 86% of healthcare providers (HCPs) were unable to address those needs.
- 62% reported their HCP did not discuss the impact of treatment on sexual health; of those who did, most (68%) said their HCPs initiated the conversation.
- 66% respondents were not satisfied with their sexual health.

The problem with your sexual health is:	
Lack of interest in sex	56%
Vaginal dryness	43%
Pain during sex	32%
Problem reaching orgasm	21%

- Compared to women diagnosed at other stages (32-56%), those with stage III (64%) and stage IV (64%) breast cancer reported higher percentages of problems with little or no interest in sex.
- Those with stage IV disease had the highest percentage (43%) of reporting pain during sex as problem that was most bothersome.
- 52% of Black women reported that they were satisfied with their sexual health, which was higher than other ethnic groups (17-39%).

### Discussing Fertility Impacts of Treatment

The percentage of women who reported discussing fertility issues with their healthcare providers, as well as the percentage who reported initiating the conversation themselves, remains relatively unchanged since the 2012 needs assessment. In 2012, these numbers were 46% and 29% respectively; in 2020, these numbers are 49% percent and 28% respectively.

### Genetic Testing and Counseling

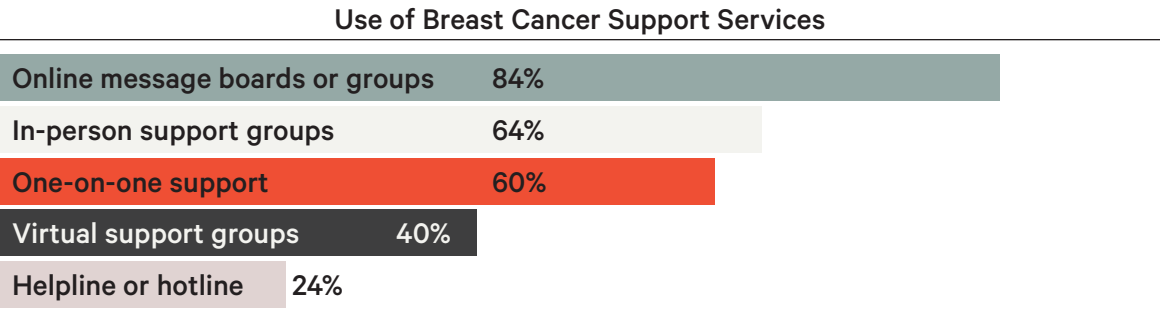
At the time of the 2012 needs assessment 75% of respondents reported receiving genetic testing, and half of those women reported seeing a genetic counselor, suggesting that young women were not receiving appropriate genetic counseling and support. The 2020 survey had 90% reporting receiving genetic testing, with 72% reporting that they saw a genetic counselor or geneticist. Despite the overall improvement, the 2020 needs assessment revealed key disparities for some racial and ethnic groups.

- Black participants were less likely to have genetic testing than other ethnic groups overall (82% vs. 92%).
- Hispanic participants were less likely to see a genetic counselor (35% vs. 25%).

### Finding information and support services

LBBC's 2012 Assessment found that most young women reported difficulty finding breast cancer information and support tailored to their needs. In 2020 many (70%) reported knowing where to find these services.

- Women with stage IV breast cancer used these services most often (88% vs. 72-78%).
- 63% of participants felt that there are adequate breast cancer support services available for young women with breast cancer.



- 52% of respondents reported wanting emotional support services in-person.
- 14% wanted emotional support through social media.
- Those with stage IV rated all types of emotional support services highly, with a lower preference for in-person support.
- Black women were less likely to use social networking sites to seek breast cancer information and support than other ethnic groups.
- More Black women than other races reported that it was very important to connect with other young women with breast cancer who shared their racial and/or ethnic background.

## LIMITATIONS

The survey sample had limited ethnic diversity outside of Black respondents (N=102), so generalizability of findings to other ethnic groups with breast cancer was not possible. The survey was conducted in August 2020, so the COVID-19 pandemic may have influenced preferences about access to emotional and breast cancer support services. The pandemic may also have impacted the number of reported poor physical and mental health days.

## CONCLUSION

Women diagnosed with breast cancer before age 45 reported several significant differences in service preferences and information needs based on race/ethnicity and cancer stage. While some aspects of the breast cancer experience have improved, there remain several gaps in care and survivorship needs, including sexual health. Informational materials and supportive programming may address these gaps by accounting for differences among the diversity of people diagnosed in this age group.

