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Key Findings from Living Beyond Breast Cancer's National Needs Assessment of Young Women Affected by Breast Cancer

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In 2012, Living Beyond Breast Cancer conducted the National Needs Assessment of Young Women Affected by Breast Cancer, which informed the development of more and stronger programs and support services for people diagnosed with breast cancer at or before age 45. Building on our long-term commitment to providing young women with tailored services and support, we developed a new needs assessment in 2020 to analyze young women's changing preferences and information needs. The findings will allow us to refine our programming for future generations.

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. LBBC received institutional review board (IRB) approval after the survey launched online. IRB approval is granted to research that upholds high standards for data analysis and protection of participants in the study.

The 2020 needs assessment focused on demographic differences and several specific topic areas, including sexual health impacts and long-term impacts on physical and emotional health. A total of 717 women diagnosed before age 45 completed the 88-question online survey in August and September 2020. Our hope is that these findings will aid Living Beyond Breast Cancer, healthcare providers, cancer advocates, and cancer organizations in taking intentional steps toward meeting young women where they are. Here, we present six key findings.

1 Breast cancer diagnosis and its treatment causes significant physical, mental, and emotional impacts on young women. These impacts differ based on race and ethnicity, cancer stage, and time since diagnosis.

Our survey participants reported experiencing stress, depression, and problems with their emotions nearly one-third of the time 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 (9.2 vs 4.9). Those who reported the highest average number of days with poor mental health were those within a year of their breast cancer diagnosis or were very young women (age 29 or younger), Hispanic women, and women with stage III and stage IV (metastatic) breast cancer.

Respondents also reported poor physical health, which includes physical illness or injury, nearly one-third of the days over the past month (9.05 days). 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 taking the survey between 1 and 2 years since diagnosis, and women diagnosed with stage IV breast cancer reported the highest average number of days of poor physical health.

Both the 2012 and 2020 needs assessments consistently showed that young women struggle with breast cancer side effects for many years after completing treatment. However, the 2020 study showed differences in the rates of side effects based on race and ethnicity. The 2020 survey asked participants whether certain side effects were a problem never, in the past, now and in the past, or now. Black (32.5 percent) and Hispanic (47.5 percent) women reported a higher rate of fatigue, insomnia, and trouble sleeping now than did Caucasian women (25.7 percent). Hispanic women (37.5 percent) also reported more anxiety, depression, or panic attacks now than did other ethnic groups.

The data showed that certain side effects linger, regardless of the passage of time. Notably, a high percentage of women reported these side effects now or now and in the past: fatigue, insomnia, or trouble sleeping (77 percent); trouble with memory, concentration, and/or organization (72.5 percent); anxiety, depression, or panic attacks (67.9 percent); difficulty adjusting to changes in the way their body looks (65.6 percent); weight loss or gain (67 percent); and hot flashes or other menopausal symptoms (63 percent).

A high percentage of women reported certain side effects were never a problem, regardless of time since diagnosis: bone loss (66.5 percent), lymphedema (64.9 percent), and loss of mobility (41.3 percent). A similar number of women reported experiencing hair loss only in the past as reported it now or now and in the past (39.8 percent vs. 43.5 percent). Over half of all women chose to have breast reconstruction. Of those women, 34.6 percent were satisfied with the results, and 19.8 percent were dissatisfied or very dissatisfied.

Age at diagnosis had little significant impact on the side effects experienced. A notable exception was neuropathy, which participants age 29 and younger overwhelmingly reported as never a problem. Age differences in the chances of developing neuropathy remains an active research question, with some studies suggesting neuropathy impacts older people more frequently than it does younger people.[1-3]

2 Addressing impacts on sexual health is a critical gap in the treatment, management, and survivorship of those diagnosed with breast cancer.

Many women reported that breast cancer and its treatment had a significant impact on their sexual health, yet most (86 percent) reported that their healthcare provider was unable to help address sexual health issues. Over half (62 percent) reported that their healthcare provider did not discuss potential sexual health impacts of treatment. Of those who did speak to a healthcare provider about sexual health impacts, 67.6 percent reported that the healthcare provider initiated the conversation.

Race and ethnicity impacted how women experienced sexual health issues. Hispanic women reported the highest percentage of pain during sex as the primary sexual health issue. With the exception of Black women, women of all ethnic groups similarly reported problems with little or no interest in sex as the primary sexual health problem. Black women reported this issue at a significantly lower rate. A higher percentage of Black women (52 percent) reported that they were satisfied with their sexual health than other ethnic groups (other groups ranged from 16.7 to 38.5 percent).

> “[Breast cancer treatment has] seriously affected my relationship with my husband and the doctors don’t seem to care.”

Women diagnosed with different stages of disease also reported differences in sexual health impacts. While between 40 and 62 percent of people in all cancer stage groups reported little or no interest in sex as the sexual health problem that was most bothersome, those diagnosed with stage III and stage IV breast cancer reported significantly higher percentages of problems with little or no interest in sex than women diagnosed at other stages. Women diagnosed with ductal carcinoma in situ, also known as DCIS, were significantly more satisfied with their sexual health than other cancer stage groups. People living with stage IV disease had the highest percentage of women reporting pain during sex as the sexual health problem that was most bothersome.

Women taking the survey within 1 year of diagnosis were less likely to report that cancer treatment extremely impacted their sexual health than other groups stratified by time since diagnosis.

3 More young women with breast cancer are accessing appropriate and treatment-recommended genetic counseling and testing services, but key disparities exist for some racial and ethnic groups.

At the time of the 2012 needs assessment 75 percent 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. Today, 90.2 percent of survey participants report receiving genetic testing, with 72.2 percent of them reporting that they saw a genetic counselor or geneticist. Despite the overall improvement in use of counseling and testing services, 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 (around 82 percent vs. 92 percent). Hispanic participants were less likely to see a genetic counselor.

4 Although 8 years have passed since our last needs assessment, healthcare providers are no more likely today to discuss the potential impacts of breast cancer treatment on fertility with young women than they were in 2012.

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 percent and 29 percent respectively; in 2020, these numbers are 48.6 percent and 28.2 percent respectively.

Close to 2 percent of participants reported having fertility preservation. Of those who did not have preservation, about half reported not wanting future pregnancies as the reason not to pursue preservation.

> “I think it is very important to address those of us who are diagnosed prior to having children.... No one told me that breast cancer impacts fertility. Most breast cancer [programs] are tailored for women over 40 and/or women with kids. It’s hard to read stories about women complaining about not having a third kid when you didn’t even get a chance to have one.”

Women who were very young (under age 29) at diagnosis more often reported that their healthcare provider started the conversation about fertility than did women in other age groups, but this difference was slight. These same women were also more likely to report that understanding treatment impact on having biological children was very important than other age groups, and they were the most likely to report understanding fertility options at the time of diagnosis as most important.

Over half of all participants reported that understanding fertility options was not important at the time of breast cancer diagnosis; of these, Caucasian women and women age 40 to 45 at diagnosis reported the highest percentage of feeling it was not important.

Women diagnosed 5 or more years ago were more likely to report not discussing fertility concerns compared to other groups. Among those more recently diagnosed, women diagnosed within the last year were most likely to report discussing fertility with their healthcare provider, though the percentages were similar to women diagnosed 1 to 2 and 2 to 5 years ago.

Stage of cancer also had an impact on fertility discussions. Women with stage IV breast cancer were slightly more likely to initiate the conversation about fertility with their healthcare provider than women with other stages of cancer. Women with DCIS and stage I breast cancer were more likely to discuss fertility concerns before surgery, while those with any other cancer stage were more likely to discuss before the start of chemotherapy or biological therapy.

5 More young women are finding information and support, but there are differences in the ways people want information based on ethnic background. LBBC and other organizations should consider these differences in developing new programs and services.

Unlike 2012, when most young women reported difficulty finding breast cancer information and support tailored to their needs, most young women in 2020 reported participating in some type of breast cancer support service. Many (70 percent) reported knowing where to find these services. Women with stage IV breast cancer used these services most often (87.5 percent vs. 72 to 78 percent). Ethnic background impacted whether they reported it easy to find tailored breast cancer information and how participants preferred to receive health information. Young women reported differences in means of finding sexual health information by ethnicity and age at diagnosis.

In general, most participants (63 percent) felt that there are adequate breast cancer support services available for young women with breast cancer. Most (84.4 percent) reported using online message boards or groups (such as Facebook groups) to access support services. Over half (64 percent) reported participating in in-person support groups, though only 28.1 percent of participants reported that in-person support groups were their preferred type of support. Over half (59.9 percent) also reported participating in one-on-one support. Just over 40 percent reported using virtual support groups, and only a quarter (24 percent) reported using a helpline or hotline.

> “My diagnosis was 23 years ago. At that time I could not find support from other young women. I am happy to see that things have changed for the better.”

Over half of respondents reported university and cancer organization websites among their top three choices for finding information about breast cancer. Black women were less likely to use social networking sites to seek breast cancer information and support than other ethnic groups.

When asked about finding sexual health information, responses differed based on a woman’s age at diagnosis and ethnicity. Women diagnosed under age 29 reported more often than other age groups that they found the best information on sexual health from cancer organizations. This very young age group (under age 29) were also much less likely to report finding the best information on sexual health from peers diagnosed with breast cancer than women in older age groups (between 42.5 percent and 45.9 percent of the remaining age groups). Hispanic and Caucasian women reported finding the best information on sexual health through peers diagnosed with breast cancer. Black women reported finding the best information through cancer organizations.

Ethnicity also impacted whether participants found it important to have health information tailored to their needs as younger women, and also whether they found it difficult to find tailored breast cancer health information. Caucasian women were less likely to report it was very important to have health information tailored to their needs as a young woman compared to all other ethnic groups, while Black participants were much more likely to report this as very important than other ethnic groups. Black participants were also more likely to report finding tailored health information was somewhat easy to very easy compared to other ethnic groups.

6 **Many young women with breast cancer want emotional support services tailored to their needs, but most find it difficult to find these services. There are differences in how young women want to receive emotional support services and to connect with other women with breast cancer based on cancer stage and ethnicity.**

Most young women (52.4 percent) reported wanting emotional support services in-person. Only 13.9 percent wanted emotional support through social media. Podcast and print materials were the least popular means of obtaining emotional support services.

Women with DCIS were most likely to prefer social media for emotional support and connection than women with other stages of disease. Young women with stage IV breast cancer rated all types of emotional support services highly, with a lower preference for in-person support.

More Black women reported that it was very important to connect with other young women with breast cancer who shared their racial and/or ethnic background. Caucasian women reported this as not important. More Black and Hispanic women reported it was very important to connect with other young women with breast cancer who shared their diagnosis than other ethnic groups.

Limitations

The 2020 LBBC Young Women's Needs Assessment included 717 people diagnosed with breast cancer at or before the age of 45. The 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 and September 2020, during the COVID-19 pandemic, which may have influenced preferences about access to emotional and breast cancer support services, the breast cancer experience, and participation in the survey. The pandemic may also have impacted the number of reported poor physical and mental health days due to restrictions on access to many physical and mental health resources like fitness centers, in-person talk and physical therapy, social interactions, and public spaces.

Conclusion

The 2012 and 2020 LBBC Needs Assessments of Young Women with Breast Cancer show that young women diagnosed with breast cancer before age 45 have unique programmatic and support needs. The LBBC Young Women's Initiative remains dedicated to improving breast cancer support services for young women and to educating healthcare providers about the unmet needs of their young patients. Living Beyond Breast Cancer recognizes several significant differences in preferences and information needs for young women based on race and ethnicity and cancer stage, and we are committed to providing programs and services that fill these gaps, as well as collaborating with colleagues to improve support across the board.

Thank you to all the women who completed the needs assessment survey, since this project would not have been possible without their participation.

REFERENCES

1. National Cancer Institute. *Long Term Nerve Damage Possible After Chemotherapy for Breast Cancer.* National Cancer Institute. Accessed March 28, 2021.

2. National Center for Biotechnology Information. *Age and the Risk of Paclitaxel Induced Neuropathy in Women with Early Stage Breast Cancer (Alliance A151411): Results from 1,881 Patients from Cancer and Leukemia Group B (CALGB) 40101.* The Oncologist. Accessed March 28, 2021.

3. BMC Cancer. *Risk Factors for Paclitaxel-Induced Peripheral Neuropathy in Patients With Breast Cancer*. BMC Cancer. Accessed March 28, 2021.

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visit LBBC.ORG/YOUNGWOMEN or contact ywi@lbbc.org