Young Women With Breast Cancer: Findings from LBBC Young Women’s Initiative

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Living Beyond Breast Cancer

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Breast Cancer and Young Women

- The impact of breast cancer among young women has increased in public awareness and is gaining significance in public health, research and clinical practice.
- 10% of breast cancers are diagnosed in women ≤45 years. Ethnic minority women are more likely to be diagnosed at younger ages.
- Each year 24,000 women are diagnosed with breast cancer under the age of 45.
- Younger women face specific medical challenges related to breast cancer and its treatments, including endocrine changes that result in early menopause and infertility; and skeletal-muscular changes that can result in bone and heart concerns.
- Unique psychosocial and quality-of-life issues, including greater fear of recurrence, and phase-of-life concerns such as parenting, marital stability, career and identity development issues.

(American Cancer Society Breast Cancer Facts and Figures)
LBBC launched the Young Women’s Initiative (YWI) in November 2011. YWI is funded through a 3-year cooperative agreement with the Centers for Disease Control and Prevention. The purpose is to develop support and educational programs for women who were diagnosed with breast cancer before age 45. Expands and strengthens LBBC’s existing programs for young women while developing new programs and resources for this community. In the first year, we conducted a comprehensive national needs assessment in preparation for program expansion in years 2 and 3 of the grant.
Needs Assessment Goals

- To assess the information and support needs of young women affected by breast cancer
- To further understand the treatment experiences and treatment decisions made by young women
- To assess how women seek breast cancer information
- To evaluate the subgroup differences in regard to ethnicity, stage of breast cancer, time since diagnosis and age at diagnosis
- To determine what types of breast cancer programming are available to women across the country and which are being used
- To identify existing gaps in program areas for young women
In your opinion....

What are the most pressing needs of young women affected by breast cancer?
Needs Assessment Components

1) Key informant interviews with healthcare providers and cancer advocates
2) Focus groups with young women
3) Environmental scan and gap analysis
4) National survey of young women
Key Informant Interviews

- 12 interviews completed with two medical oncologists, a prominent cancer advocate, an oncology social worker, a leader in psycho-oncology, a reproductive endocrinologist, a breast surgeon, a breast cancer coordinator and cancer advocates who work closely with Latina, African-American and Asian young women affected by breast cancer.

- Interviewees were asked to identify:
  - Three most pressing needs of young women
  - Resources and programs they use when working with young women
  - Types of programs they would like to see developed for this population

- Primary needs identified were:
  - Lack of social support
  - Strain on personal relationships
  - Raising young children
  - Financial concerns
  - Body image

- Preliminary findings were integrated into the quantitative survey tool.
Focus Groups

Four focus groups with young women who were:
- Diagnosed less than one year ago with early-stage breast cancer
- Diagnosed 2-5 years ago with early-stage breast cancer
- Diagnosed more than five years ago with early-stage breast cancer
- Living with metastatic breast cancer

Demographic Information of Focus Group Participants
- 33 women participated in four groups
- Average age was 40 years old (age range: 30 to 64 years old)
- 76% of the women were married or living as married
- 60% had a college degree or graduate degree
- 47% were employed full-time
- 25% were African American, 6% were Latina and 62% were white
- Participants from all four regions of the United States
Focus Groups – Recurrent Themes

- Described their needs as unique compared to older women.
- Reported advocating for their needs with healthcare providers who did not understand their unique needs as younger women.
- Desire to connect with other young women like them.
- Found significant benefit from finding peer support.
- Difficult to find quality survivorship programming for young breast cancer survivors.
- Challenges with communication with friends and family.
- Concerns about impact of breast cancer experience on partners and children.
- Sought emotional support from counselors and friends and family, not from organizations.
- Using social media to access health information, connect with other breast cancer survivors and update friends and family about their treatment and overall health.
Focus Groups – Unique Differences

- Many in the newly diagnosed group expressed a need for breast cancer information to be tailored to their life stage.
- Lack of support and information at the end of treatment and the need for more information on long-term side effects and other survivorship concerns were themes of the mid-term and long-term survivor focus groups.
- The women in the long-term survivor group shared how their experience with breast cancer has impacted their ongoing health and how breast cancer has shaped how they view their health and body.
- The metastatic group focused more on their experience as women living with metastatic breast cancer than on their experience as younger women.
- The metastatic group discussed the significant financial impact their treatment has on them and their families.
- Death and dying was also discussed during the metastatic group. The women expressed wanting to talk openly about their mortality but shared that often their friends and family did not want to talk about death.
Environmental Scan and Gap Analysis

Purpose: To identify existing resources for young women affected by breast cancer, areas lacking in coverage and potential partner organizations.

- 29 national organizations that provide educational and support resources relevant to young women affected by breast cancer were analyzed.

Program Areas
- Under-resourced program areas were managing short-term and long-term side effects of treatment (fatigue management, premature menopause, cognitive changes, etc) and aftercare compliance.

Content Delivery
- Content delivery methods that appeared less frequently were live conferences, online message board communities, thematic workshops and teleconferences.

Tailored Programming
- Few programs targeting young women of color affected by breast cancer and young lesbian, bisexual, transgendered or gay women.
National Survey of Young Women

- To increase the diversity of perspectives included in the needs assessment, LBBC launched a national survey of young women affected by breast cancer in April 2012.
- Survey was available online and in a paper format.
- The online survey was open for 5 weeks.

Survey domains include:
- Demographic factors
- Breast cancer treatment
- Social support
- Common side effects
- Use of and interest in breast cancer education programs
- Fertility preservation, breast reconstruction and genetic testing decision making

Distribution methods included:
- Outreach network of more than 30 organizations
- Social media outreach
- Purchasing Facebook ads
- Survey link sent to young women in LBBC’s database
National Survey of Young Women

- 1,473 women from all 50 states completed the survey.
- Half the respondents were not familiar with LBBC prior to taking the survey.
## National Survey of Young Women

### Participant Demographics

<table>
<thead>
<tr>
<th></th>
<th>Total Sample (n=1473)</th>
<th>European-American (n=923)</th>
<th>African-American (n=114)</th>
<th>Latina-American (n=59)</th>
<th>Asian-American (n=38)</th>
<th>Native-American (n=8)</th>
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<tbody>
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*Note: Numbers in the group categories do not add to the total number of participants because of missing data.*
## National Survey of Young Women

### Medical Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Total Sample (n=1473)</th>
<th>European American (n=923)</th>
<th>African-American (n=114)</th>
<th>Latina-American (n=59)</th>
<th>Asian-American (n=38)</th>
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<td>1-2</td>
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<td>3 (38)</td>
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<tr>
<td>3-5</td>
<td>174 (15)</td>
<td>141 (16)</td>
<td>13 (12)</td>
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<td>230 (25)</td>
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<td>14 (12)</td>
<td>11 (19)</td>
<td>9 (24)</td>
<td>2 (25)</td>
</tr>
</tbody>
</table>

*Note: Numbers in the group categories do not add to the total number of participants because of missing data.*

*Participants checked all that applied.*
How do young women want to receive information and support?

- 40% of women reported that it was not at all easy to find emotional support services tailored to their needs.
- 60% of young women indicated that it was very important to have emotional support services tailored to their needs as young survivors.
- 61% of African-American and 66% of Latinas indicated that it was very important to have emotional support services tailored to their needs as young women of color.
- 50% wanted health and medical information in an online format and 20% preferred in person.
- 60% wanted emotional support to be delivered in person and 20% preferred online emotional support.
- 50% wanted practical information and resources to be delivered online and 15% wanted it in person.
Current Symptoms and Side Effects

- 53% of women reported experiencing fatigue. African-Americans (62%) and Latinas (66%) and women with metastatic breast cancer (72%) were more likely to report fatigue.

- 52% of women reported problems sleeping. African-Americans and Latinas (66%) and women with metastatic breast cancer (86%) were more likely to report sleep problems.

- 40% of respondents reported currently experiencing pain. African-Americans, Latinas and women diagnosed within the last year were somewhat more likely to report pain.

- 36% reported anxiety; however, 52% of women with metastatic cancer reported anxiety.

- 35% reported depressive symptoms. Latinas (44%) and women with metastatic breast cancer (54%) were more likely to report depressive symptoms.
Current Symptoms and Side Effects

- 65% reported memory loss.
- 56% reported decreased sexual desire with little significant group differences. White women were more likely to report decreased sexual desire (61%).
- 55% of all women and 60% of African-Americans and Latinas reported weight loss or gain.
- 50% had difficulty adjusting to the way their body looks.
- 47% of women reported sexual health concerns, including vaginal dryness and pain.
- 33% reported neuropathy. Women with metastatic breast cancer (44%) were more likely to report neuropathy.
Interest in Breast Cancer Information

<table>
<thead>
<tr>
<th>Top 10 Educational Topics of Interest</th>
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</thead>
<tbody>
<tr>
<td>1. Long-term health impacts</td>
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<tr>
<td>2. New treatment and research</td>
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<tr>
<td>3. Prevention of other illnesses</td>
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<tr>
<td>4. Breast cancer and the environment</td>
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<tr>
<td>5. Nutrition and diet</td>
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<tr>
<td>6. Treatment side effects</td>
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<tr>
<td>7. Emotional and social support</td>
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<tr>
<td>8. Communicating with healthcare team</td>
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<tr>
<td>9. Cognitive issues</td>
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<tr>
<td>10. Fear of recurrence</td>
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</table>

Resources relevant to breast cancer and the environment was an topic of high interest but low availability by all respondent categories (75%).

Subgroup Differences:
- Breast cancer advocacy was important for women of color (33-40%)
- Sexuality and intimacy for the very young survivors (<30) and long term survivors (>5 years post diagnosis)
- Clinical research and future health planning for women with metastatic breast cancer
Frequency of Information Seeking

- 35% of women report that they seek information on breast cancer from any source on a weekly basis (35%).
- 25% of women who were diagnosed under one year ago report seeking information daily and 47% of this group report seeking it weekly.
- 54% of women living with metastatic breast cancer sought information on a weekly basis.
Social Media Usage

- Almost all women (98%) had regular access to the Internet.
- 66% of all women report regularly accessing the Internet through their cell phones.
- Facebook was the social media service that was the most used by respondents (86%).
- 58% of women who used social networking services reported sharing their personal experiences with breast cancer through social media.
- Women diagnosed less than 1 year ago (67%) and women living with metastatic breast cancer (80%) were more likely to share experiences through networking services.
- Women were less likely to use networking social networking services to keep their networks updated on their treatments with the exception of women who were diagnosed less than 1 year ago.
Genetic Testing and Fertility Concerns

- 50% received genetic counseling.
- 75% received genetic testing; African-Americans were less likely to receive genetic testing (61%).
- 95% did not receive fertility preservation.
- 50% reported that fertility preservation was not discussed by their healthcare provider.
Overall Findings from Needs Assessment

- Young women wanted information tailored to their unique needs, and many report having a hard time finding tailored information and support services.
- There are limited national educational programs for young women and even fewer resources tailored for subgroups.
- Healthcare providers and some women in the focus groups reported that fertility options were very important to young women. However, most of the women who completed the survey reported understanding their fertility options was a low priority for them.
- A larger percentage of young women report experiencing long-term side effects years after completing treatment.
- Younger women need to receive genetic counseling with genetic testing.
- Young women are using the Internet to find information and utilize social media for support and education.
Needs Assessment Limitations

- Limited generalizability of information
- National survey analysis only included online responses and women who had regular access to the Internet
- Limited ethnic, sexual orientation and income diversity in sample
- Relied on self-reported information, which could lead to incorrect responses
Looking Forward

Program Implementation in Year 2

- Share needs assessment findings with women affected by breast cancer, other organizations and healthcare providers
- Continue to expand online content for young women
- Enhance the capacity of the Survivors’ Helpline by training 10 additional young Helpline volunteers
- Increase the geographic diversity and participation rates of low-income women at C4YW
- Develop a new pilot program for underserved young women
- New videos for young women on lbbc.org/youngwomen
How do we compare?

Look at the list we created at the beginning of the workshop.

Is there overlap between what we brainstormed and LBBC’s needs assessment findings?

Any surprises?
Questions?

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