Defining the Unique and Persistent Needs of Young Women Living with Metastatic Breast Cancer through a Multi-Phased Needs Assessment

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Background

In spring 2012, Living Beyond Breast Cancer (LBBC) conducted a needs assessment of women diagnosed with breast cancer at or before age 45. This assessment was a part of LBBC’s Young Women’s Initiative (YWI), a program launched in November 2011 and funded through a 3-year cooperative agreement with U.S. Centers for Disease Control and Prevention. YWI expands and strengthens LBBC’s existing programs for young women and develops new programs and resources for this community.

As part of the analysis, LBBC compared the differences between the respondents diagnosed with metastatic breast cancer (MBC) and those diagnosed with early-stage breast cancer (EBC) to determine how LBBC can better tailor programs to the needs of young women living with MBC.

The comprehensive needs assessment was multi-phased and included key informant interviews, focus groups, an environment scan and gap analysis of 20 organizations, and a national survey of young women.

Focus Group Results

DEMOGRAPHICS OF FOCUS GROUPS

The participants in MBC group …

METHODS

National Survey of Young Women

The 85-question survey asked about breast cancer treatment, social support, insurance through their employer (70%).

Average age was 40 years old (age range: 28 to 52 years old) in the MBC group.

45% were African-American and 75% were white in the MBC group.

Among those who did not join a support group (26%), there were few between-group differences in regard to employment status.

Support Groups

Most respondents had participated in a support group, although it was more common among the MBC group (75% MBC vs. 65% EBC, χ²=17.4, p<.001). Almost half of all respondents used in-person support groups and online message boards. Telephone support groups were used less often.

For reasons using support groups were relatively similar between the groups.

Both groups used support groups for
general cancer information (77% MBC vs. 72% EBC), to have an opportunity to talk about their emotions (69% MBC vs. 66% EBC, ns), and to learn new resources (73% MBC vs. 65% EBC, ns).

Among those who did not join a support group (26%), there were few between-group differences in regard to employment status.

There was a significant difference between the groups in regard to employment status.

Not surprisingly, young women living with MBC were proportionately more likely to be receiving some form of cancer treatment (67% MBC vs. 57% EBC, χ²=39.3, p<.001).

The majority of women had some form of breast surgery although it was significantly more common for women diagnosis with EBC (91% MBC vs. 84% EBC, χ²=32.7, p<.001). Double mastectomies were more common among young women living with MBC (46% MBC vs 25% EBC, χ²=4.1, p<.05).

National Survey of Young Women

METHODS

LBBC launched a national survey of young women affected by breast cancer in April 2012. The online survey was available for five weeks. The survey was open to women diagnosed with all stages of breast cancer at or before age 45 old.

The survey was designed to find out about young women living with MBC and to explore how social media might be used to access health information, connect with other breast cancer survivors, and update friends and family about their treatment and overall health.

SURVEY RESULTS

1,580 women diagnosed with breast cancer at or before age 45 completed the online survey.

40 respondents were diagnosed with MBC.

113 respondents had a distant recurrence after their initial diagnosis of EBC.

In total, 173 women who completed the survey were living with MBC.

4,107 respondents had been diagnosed with EBC and had not had a distant recurrence.

DEMOGRAPHICS OF MBC AND EBC GROUPS

Many key demographics were similar in both groups. The total sample was 81% white, 8% African-American, 4% Latina, with no significant differences between the MBC and EBC groups.

Both groups were highly educated, with 67% attaining a college degree or beyond.

Both groups had the same average age of diagnosis of 37 years old. The MBC group was further out from their initial diagnosis (7.7 years) when compared to the EBC group (5.7 years, p<.05).

Women living with MBC were more likely to have Medicare (13%) than women with EBC (3%). However, 75% of both the MBC and EBC group had health insurance through their employer (70%).

41% of the total sample reported working full-time. Women living with MBC were more likely to be receiving disability payments (24%) when compared to women living with EBC (17%). There were no other significant differences between the groups in regard to employment status.

Accessing Information

Young women with MBC reported accessing breast cancer information weekly or more frequently (67% MBC vs. 44% EBC, χ²=26.4, p<.001). Both groups preferred to access breast cancer information and practical information online, with young women living with MBC sharing more in-person resources than young women diagnosed with EBC.

Limitations

• National survey analyses only included online responses from women who had regular access to the Internet.

• Resulted in self-reported information.

Program and Conclusion Implications

This analysis shows that young women living with MBC have unique and different needs when compared to younger women diagnosed with EBC, and that young women living with MBC are not finding the programs and resources to meet these needs. Young women living with MBC are coping with higher rates of side effects and symptoms. Their finances are also negatively affected by breast cancer at a higher level than women diagnosed with EBC.

More programs and resources should be developed to fill the gap and address the unique needs of young women living with MBC. LBBC is using the needs identified through these assessment results to guide program and resource development for young women living with MBC.

Current Symptoms and Side Effects

Young women living with MBC were proportionately more likely to experience a wide range of physical and psychosocial issues when compared to young women diagnosed diagnosed with EBC.