

Information Needs of Young Women with Metastatic Breast Cancer to Manage their Treatment, Side Effects and Clinical Trials

AUTHORS: Medha Sutliff, Desiree Walker, Michelle Esser, Jean Rowe, Stacy Lewis, Megan McCann

BACKGROUND

Young women diagnosed with metastatic breast cancer (MBC) face unique issues and concerns. Young Survival Coalition (YSC) is the premier organization dedicated to the critical issues particular to young women and breast cancer. In 2012, YSC began a two-year process called the Research Think Tank (RTT) to determine the most pressing research questions in need of answers.

YSC assembled teams of doctors, researchers and advocates to focus on six areas of importance to its young constituents, including metastasis. One of the top research priorities chosen by the metastasis workgroup was “How can we better meet the psychosocial needs of young women with MBC and their families?” YSC decided this priority warranted immediate action via a comprehensive survey of this population to understand their needs, and to identify and create impactful interventions to meet them.

METHODS

From September 2013 to February 2014, YSC conducted an online survey of women diagnosed with any stage of breast cancer before age 41 who either had MBC at initial diagnosis or developed it thereafter.

RESULTS

Four hundred seventy (470) participants met the inclusion criteria, with 360 completing the survey in full by the end of February 2014. The survey results provided in-depth information about the needs, concerns and struggles of this patient population, as well as interventions they believed would be helpful.

The survey revealed that an overwhelming majority of young women with MBC searched for information on treatment and prognosis (95%), clinical trials (69%) and management of side effects (88%). For each category, 22-33% said there was information they searched for, but could not find. This included prognosis statistics, treatment and side effect information, updates on new treatment and medical advances, information on different types and locations of metastases, clinical trial information, resources on rare side effects, and alternative therapies to manage side effects. Seventy-six percent of respondents looked for information on how long young women are living with MBC, and 80% said this information would be helpful.

There were frequent comments about outdated information and there being “no hope” and “scary statistics.” Respondents complained that there is not enough data that is accurate, easy to understand and scientifically supported. Information found is too general rather than being specific to the young woman’s situation. Young women with MBC had to judge the accuracy of the information found, especially from news reports.

According to survey respondents, a need exists for a centralized location to find information relevant to MBC with easier terminology, a bank of current research and more information overall that is easy to find. A greater focus on young women is also needed.

For clinical trials, respondents identified as helpful tools: better search engines, materials that are easier to read and understand, someone to speak with on the phone to help them navigate through trial information and filter out inapplicable trials, more current information, one clear resource instead of multiple sources and listings for MBC-specific clinical trials. Survey respondents indicated Breastcancertrials.org as a source of information for clinical trials. Some women found clinicaltrials.gov helpful, but others complained about it being outdated or too much information to sift through. Other comments indicated feelings of frustration, because after spending time searching for clinical trials, there were none for which they would qualify.

Despite acknowledging the importance of clinical trials, 74% had never participated in one. Their reasons included: being unaware of any in which they could participate (33%); “healthcare provider didn’t tell me about any” (22%); healthcare provider advised against participation (7%); “I did not want to” (6%); and “I tried to participate but was declined” (7%).

The sources of information preferred by young women with MBC on the topic areas of MBC treatment and prognosis, clinical trials and management of treatment and side effects are shown in the bar graphs to the right.

CONCLUSION

Young women living with MBC have important information needs that are currently unmet. YSC is working to meet these needs by updating its online content specific to young women with MBC. YSC has also partnered on a “Metastatic Trial Search” tool with Breastcancertrials.org, which will help women with MBC find clinical trials specific to their diagnosis.

FOR MORE INFORMATION

Young Survival Coalition
80 Broad Street, Suite 1700
New York, NY 10004
646.257.3000 youngsurvival.org



PREFERRED SOURCES OF INFORMATION ON THESE TOPICS

MANAGE TREATMENT & SIDE EFFECTS



CLINICAL TRIALS



TREATMENT OPTIONS & PROGNOSIS

