

The Emotional Toll of Metastatic Breast Cancer on Young Women

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BACKGROUND AND METHODS

Young women diagnosed with metastatic breast cancer (MBC) face unique 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. The RTT found that research into MBC in young women was rare and determined that a top research priority was “How can we better meet the psychosocial needs of young women with MBC and their families?”

After identifying this priority, 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. The survey was conducted from September 2013 to February 2014.

RESULTS

Four hundred seventy (470) participants met the inclusion criteria, with 360 young women completing the entire survey. Results showed that since their MBC diagnosis, their stress level is worse (31%) or varies (56%), with some days stressful and some not. Emotional well-being worsened in 57% of respondents. Emotional well-being due to MBC was impacted by: anxiety (71%); trouble sleeping (61%); depression (45%); withdrawal from things they once liked to do (31%); and withdrawal from friends (24%). Before their diagnosis, less than one-third had anxiety (28%) or depression (24%).

Eighty-six percent reported that they take time to rest while 14% said “no” with guilt, lack of time, lack of willingness to do so and childcare cited as causes. Asked if they take time to “do nothing,” 25% said “no,” with similar reasons cited. Only 48% of young women sought professional psychosocial help related to their MBC. Typical responses from those who had not sought help were that there was “no need,” or their issues were “not serious enough.” Lack of money, fear and “seeing enough doctors already” were also listed as reasons.

Anticipatory grief was a term used in the survey to describe the feelings and emotions that young women diagnosed with MBC may be experiencing about a loss that has not yet occurred. Respondents said they were grieving: loss of life cut short (86%); leaving spouse or partner (75%); leaving behind kids without a mother (67%); and loss of identity (38%).

Other losses specified in comments included: missing important events in the lives of family members, feeling that there was more they wanted to do with their life, never getting married or finding love, leaving behind family and friends, and dying before their parents. Although anticipatory grief was a topic of great importance to this population, 71% had not sought information about anticipatory grief or how to manage it. When asked with whom on the healthcare team they discussed anticipatory grief, the largest response (42%) was “no one, I don’t discuss it.”

How can these issues be addressed? The survey revealed that connecting with other young women living with MBC to receive support and information is desired and important. Therapy and counseling were also listed as helpful sources of support for emotional issues. Suggestions for what could make finding information and support easier included: easy-to-find online information specifically for young women with MBC, as well as physician referrals to support services such as social workers. Seventy-six percent responded that tools to communicate about their disease and prognosis would be helpful. Top sources of information that would be utilized by young women with MBC to learn more about stress, emotional well-being and anticipatory grief are identified in the graph.

CONCLUSION

Young women living with MBC are an understudied population in need of psychosocial and emotional support and tools. YSC’s survey sought to understand how to address these issues. Using these survey results, YSC has revised its Metastatic Navigator guidebook to include more support and resources, and YSC is updating the MBC portion of its website.

FOR MORE INFORMATION

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DESIRED SOURCES OF INFORMATION ON THESE TOPICS

Anticipatory Grief



Stress & Emotional Well-being

