

Study estimates number of US women living with metastatic breast cancer

May 18 2017



Micrograph showing a lymph node invaded by ductal breast carcinoma, with extension of the tumour beyond the lymph node. Credit: Nephron/Wikipedia

A new study shows that the number of women in the United States living with distant metastatic breast cancer (MBC), the most severe form of the disease, is growing. This is likely due to the aging of the U.S. population and improvements in treatment. Researchers came to this finding by estimating the number of U.S. women living with MBC, or breast cancer that has spread to distant sites in the body, including women who were initially diagnosed with metastatic disease, and those who developed MBC after an initial diagnosis at an earlier stage.

The [researchers](#) also found that median and five-year relative survival for women initially diagnosed with MBC is improving, especially among younger women.

The study was led by Angela Mariotto, Ph.D., chief of the Data Analytics Branch of the Division of Cancer Control and Population Sciences at the National Cancer Institute (NCI), with coauthors from NCI, the Metastatic Breast Cancer Alliance, and the Fred Hutchinson Cancer Research Center. The findings appeared online on May 18, 2017, in *Cancer Epidemiology, Biomarkers & Prevention*. NCI is part of the National Institutes of Health.

In documenting the prevalence of MBC, the findings point to the need for more research into how to address the health care needs of women who live with this condition. "Even though this group of patients with MBC is increasing in size, our findings are favorable," said Dr. Mariotto. "This is because, over time, these women are living longer with MBC. Longer survival with MBC means increased needs for services and research. Our study helps to document this need."

Although researchers have been able to estimate the [number](#) of women initially diagnosed with MBC, data on the number of women whose cancers spread to a distant organ site, either as a progression or a recurrence after being first diagnosed with an earlier stage of [breast](#)

[cancer](#), has been lacking because U.S. registries do not routinely collect or report data on recurrence. To develop a more accurate estimate of the total number of women living with MBC, researchers used data from NCI's Surveillance, Epidemiology, and End Results (SEER) Program to include women who developed MBC after diagnosis. The researchers estimated that, as of Jan. 1, 2017, more than 150,000 women in this country were living with MBC, and that 3 in 4 of them had initially been diagnosed with an earlier stage of breast [cancer](#).

The study also shows that despite the poor prognosis of MBC, survival of women initially diagnosed with MBC has been increasing, especially among women diagnosed at younger ages. The researchers estimated that between 1992-1994 and 2005-2012, five-year relative survival among women initially diagnosed with MBC at ages 15-49 years doubled from 18 percent to 36 percent. Median relative survival time between 1992-1994 and 2005-2012 increased from 22.3 months to 38.7 months for women diagnosed between ages 15-49, and from 19.1 months to 29.7 months for women diagnosed between ages 50-64. The researchers also reported that a small but meaningful number of women live many years after an initial diagnosis of MBC. More than 11 percent of women diagnosed between 2000-2004 under the age of 64 survived 10 years or more.

Based on their calculations, the researchers estimated that the number of women living with MBC increased by 4 percent from 1990 to 2000 and by 17 percent from 2000 to 2010, and they project that the number will increase by 31 percent from 2010 to 2020. Although the largest group of women with MBC consists of women who have been living with metastatic disease for two years or less (40 percent), one-third (34 percent) of women with MBC have lived for five years or more with the disease.

To estimate the number of U.S. women living with MBC, the

researchers applied a back-calculation method to breast cancer mortality and survival data from the SEER Program. SEER collects clinical, demographic, and vital status information on all cancer cases diagnosed in defined geographic areas. The method they used assumes that a breast cancer death is preceded by MBC that was either found at diagnosis or after a recurrence with [metastatic disease](#).

Collecting recurrence data has been challenging for cancer registries because recurrence can be diagnosed through diverse methods and in a variety of locations. To help implement the comprehensive and accurate collection of these data, NCI is funding pilot studies aimed at identifying ways to leverage existing data and informatics methods to efficiently capture information on recurrent disease.

By including women with recurrence, this study provides a more accurate number of women in the U.S. currently living with MBC. This estimation can help with health care planning and the ultimate goal of better serving these [women](#).

"These findings make clear that the majority of MBC patients, those who are diagnosed with non-metastatic cancer but progress to distant disease, have never been properly documented," said Dr. Mariotto. "This study emphasizes the importance of collecting data on recurrence at the individual level in order to foster more research into the prevention of recurrence and the specific needs of this growing population."

Provided by National Cancer Institute

Citation: Study estimates number of US women living with metastatic breast cancer (2017, May 18) retrieved 8 May 2024 from <https://medicalxpress.com/news/2017-05-women-metastatic-breast-cancer.html>

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