

Working Paper: So Much Pink, Yet No One Counts Canadians Living with Metastatic Breast Cancer

By Heather Douglas, Metastatic Breast Cancer Advocacy Canada, November 2016

Metastatic breast cancer is the deadly form of breast cancer. It is estimated that every two hours a Canadian dies of metastatic breast cancer.¹ Yet the number of Canadians living with metastatic breast cancer is unknown. Metastatic recurrences are not counted and even the number of Stage IV cases appears poorly tracked. Lack of quality data may be resulting in poor resource allocation by health care authorities, government granting agencies and charities. United States and United Kingdom-based metastatic breast cancer charities and advocacy groups have been calling attention to the lack of good data and statistics regarding the number of people living with metastatic breast cancer.^{2,3,4,5,6} Canadians have yet to begin. This paper summarizes available data to draw attention to the issue and begins to explore possible solutions.

Staging – Stage IV versus Metastatic Breast Cancer

While the terms ‘Stage IV’ and ‘metastatic breast cancer’ are often used interchangeably by patients and their oncologists, for cancer registries they are different.

A breast cancer (or any cancer) is classified as Stage IV when at first diagnosis the patient presents with metastasis or spread to distant parts beyond the location of the primary cancer. Sometimes this is also referred to as Stage IV de novo. ‘Early’ breast cancers (Stages I-III) are differentiated by characteristics of the tumours (for instance, size, grade, number of lymph nodes).⁷

Clinicians are required to report this initial diagnosis of cancer and stage to the provincial or territorial registries. This data in turn is collected into the Canadian Cancer Registry maintained by Statistics Canada.⁸

If an early stage patient recurs with metastasis, then this patient is now described as ‘Stage “X” (where X is their original stage) with metastasis’. **The cancer’s stage has not changed.**⁹ This progression to liver, lungs, brain or bones, or other distant sites may have occurred months to many years after the patient’s original diagnosis. The progression is recorded in the clinician’s notes, and treatment begins. Sometimes, for clarity and simplicity given the seriousness of the terminal diagnosis, the metastatic breast cancer patient will be told they are Stage IV. **But no additional reporting is undertaken. The staging has not changed in the registry.**

Number of Stage IV and Metastatic Breast Cancer Cases and Deaths

In their annual publication of cancer statistics, the Canadian Cancer Society and Statistics Canada do not release statistics by stage,¹⁰ and a Canada-wide Stage IV breast cancer total is not reported.¹¹ Staging information has only been collected in Canada in a consistent manner since 2012.¹²

Some provinces provide Stage IV data, which are summarized in Table 1. Applying the range measured by the provinces (5.0-6.7%) to the last actual figure of breast cancer cases reported in Canada (23,100 in 2010)¹³, approximately 1,150 to 1,550 patients were diagnosed Stage IV breast cancer.

Table 1 – Stage IV Breast Cancer Cases Only (excludes early stage patients whose cancer later metastasizes)

| Province | Time Period | Stage IV Cases | % Stage IV of Known Stage Cases | Source |
|--------------|-------------|----------------|---------------------------------|---|
| B.C. | 2013-2014 | 376 | 6.0% | Data request |
| Alberta | 2009-2012 | 394 | 5.2% | 2012 Report on Cancer Statistics in Alberta Breast Cancer, Table 3-4 |
| Saskatchewan | 2007-2009 | N/A | 5.0% | Saskatchewan Cancer Control Report, 2011 |
| Manitoba | 2011-2013 | 176 | 6.7% | Annual Statistical Reports |
| Ontario | | | | Data request pending |

As noted above, the cases of metastatic recurrences among previously diagnosed early stage breast cancer patients are not recorded by the registries. It is estimated that 20-30%^{14,15} of all early stage breast cancer patients develop metastases, but the number of new metastatic recurrences in any given year is not tracked.

If, sadly, the early stage patient dies from the metastasis (lungs, liver, brains are key for life), the registries will record the cause of death as breast cancer. About 5000 people die of breast cancer each year in Canada¹⁶ Most of these people originally received an early stage breast cancer diagnosis, not a Stage IV diagnosis.

How Many Canadians are Living with Metastatic Breast Cancer?

Without tracking the number of metastatic recurrences, the number of people living in with metastatic breast cancer remains unknown. Table 2 highlights this lack of data.

A 2012 paper by Australian biostatisticians suggested the prevalence of metastatic breast cancer as 3 to 4 times the number of annual deaths.¹⁷ Based on 5,000 annual breast cancer deaths in Canada, this approximation would suggest that 15,000 to 20,000 Canadians are living with metastatic breast cancer.

Table 2 – Breast Cancer Statistics - Lots of Unknowns

| | Available Data | Source: |
|--|-----------------------|--|
| Number of Canadians diagnosed Stage I-IV (2010 - actual) | 23,100 | Canadian Cancer Statistics 2016, Table A1 |
| Total number of breast cancer deaths (2012) | 5,019 | Canadian Cancer Statistics 2016, Table A2 |
| Number of Stage IV cases in Canada (per year) | ? | Estimate 1,150-1,550 based on 5-6.7% of all cases |
| Total number of Canadians with early stage breast cancer who have metastatic recurrence (per year) | ? | 20-30% of early stage breast cancer patients. (endnote 14) |
| Number of people living with metastatic breast cancer | ? | Estimate 15,000-20,000 based on 3-4x deaths (endnote 17) |

What can be done?

The number of Canadians living with metastatic breast cancer would seem to be an important figure to track, to ensure that the resources dedicated to treating metastasis and research to new more effective treatments is appropriate. Trends in Stage IV cases and recurrences would also seem to be important to measure the effectiveness of screening programs.

How can we obtain a reliable figure of the number of people living with metastatic breast cancer? Options could be:

- **A change in policy by the provincial cancer registries** to begin collecting information on metastasis among breast cancer patients (or all cancer patients). This is the approach being taken in the UK with the help of advocacy from Breast Cancer Care, a UK charity.¹⁸

- **A new registry of metastatic breast cancer patients.** The MBC project (www.mbcproject.org) in the US (with Canadians participating) has demonstrated the willingness and interest among patients to be involved in research.
- **Data mining of hospital records.** The B.C. Cancer Agency has used its Breast Cancer Outcomes Unit Database to support research.
- **Surveys/questionnaires for oncologists.** The Alberta breast cancer tumour board is considering this approach.

Getting Canadians living with metastatic breast cancer counted so that their needs can be properly assessed and supported is one of the priorities of our organization, Metastatic Breast Cancer Advocacy Canada (www.mbcac.ca). The prevalence estimate based on the Australian analysis suggested that there are 15,000-20,000 Canadians who are in desperate need of new life extending treatments or, better yet, a cure. These Canadians deserve to be counted.

Author's note: This working paper is based on the information I have been able to glean from various sources, but it is just a preliminary analysis given the paucity of information available. I appreciate any constructive suggestions to improve the analysis and get MBC patients counted.

Endnotes

¹ Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2016, Table A2.

² "Start Counting ALL People Living with Metastatic Breast Cancer!". <https://www.change.org/p/seer-start-counting-all-people-living-with-metastatic-breast-cancer>, accessed October 28, 2016

³ Mayer, Musa, 'Chapter 5: Epidemiology of MBC – Challenges with Population-Based Statistics', MBC Alliance, Changing the Landscape for People Living with Metastatic Breast Cancer, 2014

⁴ Hulbert, Marc, "Where is the Data? The Epidemiology of Metastatic Breast Cancer", http://www.huffingtonpost.com/marc-hurlbert-phd/where-is-the-data-the-epi_b_12311030.html?, accessed October 28, 2016

⁵ Schattner, Elaine, "Why People With Metastatic Breast Cancer Want To Get Counted", <http://www.forbes.com/sites/elaineschattner/2015/10/26/how-many-people-are-living-with-metastatic-breast-cancer/#6e3695ae5b12>, accessed October 28, 2016

⁶ Breast Cancer Care, "Secondary breast cancer Part two: Who's counting? September 2016" <https://www.breastcancercare.org.uk/sites/default/files/secondary-breast-cancer-report-2.pdf>, accessed November 11, 2016

⁷ American Cancer Society, <http://www.cancer.org/treatment/understandingyourdiagnosis/staging>, accessed October 6, 2016

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- ⁸ Statistics Canada, Canadian Cancer Registry, <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3207&lang=en&db=imdb&adm=8&dis=2>, accessed October 28, 2016
- ⁹ See Endnote 7
- ¹⁰ Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2016.
- ¹¹ Statistics Canada, reply to personal email, November 1, 2016.
- ¹² Canadian Partnership Against Cancer, "Canadians to Benefit as Better Cancer Data Translates Into Better Cancer Control", October 10, 2010
- ¹³ Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2016. Table A1
- ¹⁴ See Endnote 3
- ¹⁵ Metastatic Breast Cancer Network, <http://www.mbcn.org/most-common-statistics-cited-for-abc/>, accessed November 22, 2016
- ¹⁶ See Endnote 1
- ¹⁷ Clements, M.S., et al., Abstract: Estimating prevalence of distant metastatic breast cancer: a means of filling a data gap. *Cancer Causes Control*, 2012. 23(10): p. 1625-34.
- ¹⁸ See Endnote 6