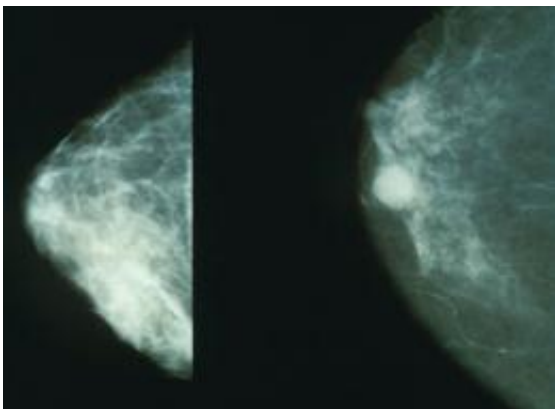


Stop the damaging messages about advanced breast cancer and include us in your discussions

November 5 2015



Mammograms showing a normal breast (left) and a cancerous breast (right).
Credit: Wikipedia.

Organisations that issue "damaging messages" about advanced breast cancer need to be identified and educated to change the way they talk about the disease, a patient told the Advanced Breast Cancer Third International Consensus Conference today (Thursday).

In another presentation, a second leader from the community of USA patients with metastatic [breast cancer](#) told the conference that the voices of patients needed to be included in discussions between policy makers and the medical community about whether the high costs of second and third line treatments for the disease is financially sustainable by society.

"CJ" (Dian) Corneliussen-James, Co-Founder and President of METAvivor (a US organisation that funds research to transition metastatic breast cancer into a survivable condition), who has been living with [advanced breast cancer](#) for nine years, told delegates that people and organisations often unintentionally issue damaging messages and would benefit from coaching about the disease.

"For example, many cancer organisations promote the concept that if you live a healthy life, your odds of being diagnosed with cancer are greatly reduced and you'll almost certainly not develop metastases. This sends the message that metastatic patients are at fault for their metastasis, which only further isolates and stigmatises them. Educating those who are doing this on the damage they are causing is one way forward, and we have begun doing this. But we also need to educate the public on the realities so that they don't believe faulty messaging."

She said that this type of faulty messaging played into the hands of those patients who feared a metastasis. "They convince themselves that the metastatic patients caused their disease and thus they are safe, it won't happen to them and they turn their backs on our community. Some doctors view us as just another patient doomed to death so they expend little effort. Some cancer organisations don't want us at their rallies and conferences because they find us a 'downer' and they want to be positive. What we are doing is taking those in need of the greatest support and isolating and haughtily dismissing them as being at fault for having the disease in the first place. This is prejudice and this is what we are trying to change. Until we do, we are failing a whole community of patients worldwide, on a massive level."

Shirley Mertz, President of the US Metastatic Breast Cancer Network, who has been living with [metastatic breast cancer](#) since 2003, told the conference that more people were living longer with advanced breast cancer (described by her as "long-term responders"), and they had lived

long enough to see approval of new therapies, such as trastuzumab for HER2 positive breast cancer, that could be used for second and third lines of treatment. Second and third line treatments are given when the disease progresses or recurs after initial therapy.

"These new treatments and a new era of precision medicine provide hope to HER2 positive metastatic patients that, upon progression of their disease, there will be other viable treatment options to consider. While these developments are occurring, long-term responders are aware that discussions have begun within the medical community and among policy-makers about whether the high cost of cancer treatments in the second and third line make their future use sustainable by society. However, the voices of long-term responders with all types of [metastatic cancer](#) have been missing thus far in the discussion. This excludes any debate about the relative costs to society when the lives of patients who have responsibilities to others are cut short.

"Some argue that in societies where the costs of cancer treatments can no longer be justified, expensive treatments should only be available to those who can afford them. If such policies are adopted, the number of patients whose long-term survival has been made possible by the dedication, intelligence and talents of scientists, researchers and clinicians, will no doubt decline."

Professor Karen Gelmon, a medical oncologist from the BC Cancer Agency and the University of British Columbia, told delegates that patients living longer with serious disease were "pushing the boundaries of what science explains and clinicians can confidently interpret using available evidence" and that medical professionals should learn from other chronic diseases, such as AIDS and cystic fibrosis, where medical advances have improved survival.

New challenges created by people living longer included lack of

knowledge about the long-term physical effects caused by cancer treatments, many of which would not have been described in the clinical trials conducted over a limited time period, and the best ways of treating these adverse effects; how to help patients adjust psychologically from being "about to die" to "living with the disease in the long term"; how to deal with financial, employment and family problems arising as a result of living long-term but being unable to make long-term commitments; and issues around quality of life and palliative care.

She said: "I think the biggest challenge for [patients](#) and family is the uncertainty of not knowing how long life and, in particular, good quality life, will last. This makes it hard to make plans, including financial and support plans, while still trying to live like a 'normal' person. The second challenge is deciphering what symptoms are caused by cancer and what are other health issues. People need to be treated within the [medical community](#) as not just a 'cancer' patient but as a person living with chronic cancer. The third is continuing as a 'patient', coming for regular appointments, treatments, investigations and not letting either fear or complacency overtake, dealing with the challenges of being a long-term patient and with chronic side effects and chronic treatment.

"The medical caregiver who has delivered the sobering news of recurrent disease and its usual inevitable end must ensure other health needs are looked after appropriately, although what is appropriate for a patient with advanced breast cancer may vary with each individual."

Provided by European School of Oncology

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