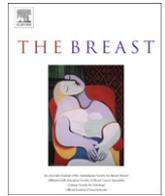




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Editorial

Metastatic breast cancer patients: The forgotten heroes!

Metastatic breast cancer (MBC) patients have long been treated as “forgotten heroes”: forgotten by the research community, by the media, and even by the advocacy world and their fellow breast cancer patients with early disease. Everyone prefers a story with a happy ending, and the fatality burden associated with MBC is often too hard to deal with. It touches the profound human fears of suffering and mortality.

The research community, both pharma-sponsored and academic, are too eager to move any new advances, particularly new drugs, to the larger adjuvant setting, and important management questions specific to the advanced setting are frequently left unanswered. In addition, many new agents are either abandoned or moved to the adjuvant setting without having their full potential and optimal usage explored in the advanced setting. For early breast cancer, cooperative groups and pharma-sponsored networks exist or are rapidly created to run very large prospective trials in a record period of time. The same rarely happens for MBC, for which these collaborative efforts are even more crucial in view of the lower number of available patients (approximately one third of the breast cancer population has advanced disease, whereas two thirds have early disease).

The great majority of advocacy groups have so far chosen to focus their efforts on issues of prevention, early diagnosis and treatment of early breast cancer. This is, of course, totally understandable and even correct since these are the measures that can impact on the lives of much larger numbers of women. However, it should not be at the expenses of much reduced efforts for MBC patients. Even for early breast cancer patients, who have gone through the ordeal of dealing with the diagnosis and harsh path of treatment, MBC patients can be a reminder which is too hard to bear of what might happen in their own future, and one that they do not wish to be confronted with.

Fortunately, two recent initiatives have brightened this dark scenario, and a third one is being prepared. Published in this issue of *The Breast*,¹ the consensus report of the first meeting of the recently created MBC Advocacy Working Group highlights the unmet needs of MBC patients and issues important recommendations in three major areas: a) Improved access to information, resources and support services; b) Heightened attention to the MBC community; and c) Increased understanding of and access to clinical trials.

The second initiative is the first global survey of 950 women living with MBC in nine countries (BRIDGE survey).^{2,3} The BRIDGE survey has identified the major needs of these women in areas of information and support resources, psychosocial support and access to clinical trials.

The fact that these two landmark initiatives have been sponsored by a pharmaceutical company and not by a governmental or academic body constitutes important “food for thought”, but Pfizer’s efforts are worthy of praise. The conclusions from both initiatives are similar and paint a worrying picture of feelings of guilt, abandonment, isolation, and loneliness during the hard journey through MBC. It is particularly poignant that in the BRIDGE survey 44% of respondents reported being afraid to talk openly about their disease and 52% said their friends and family were uneasy talking about the disease.^{2,3} The majority also believe that MBC receives little public attention compared to early breast cancer.

Very importantly, both projects highlight the poor access to clinical trials for the MBC population. In the BRIDGE survey, 78% of women living with MBC had never participated in a clinical trial, and 56% of these women were never invited to consider a clinical trial.^{2,3} The MBC Advocacy Working Group¹ identifies as major contributors for these figures negative misconceptions, lack of access to appropriate information and difficulty in understanding clinical trial materials, as well as the restrictive eligibility criteria of most MBC trials. The truth is that trials accepting patients who have received multiple lines of treatment are extremely rare and specific populations, such as women with MBC from diagnosis, patients with brain metastases and male breast cancer patients, are frequently excluded from clinical trials without a valid reason.

It is clearly a time for a change! And this change must touch all partners involved. MBC has, for too long, been considered a hopelessly incurable disease. This has contributed strongly to the attitude and misconceptions of the public, the media and even the research community, and consequently contributed to the marginalisation of MBC patients. With the rapid advances in areas such as biology, technology and therapeutics, we have the obligation to fight for a cure. It is my firm belief that breast cancer will not be eradicated until MBC becomes a curable disease. No treatment is 100% efficacious in all patients and hence relapses will probably always occur.

While it is understandable to a certain degree that pharma-sponsored research is dictated, at least partially, by commercial constraints, it is far more difficult to accept that academic research is unable to focus on non-commercial but crucial management questions. Cooperative research groups must also start to focus on improving the outcome of MBC. However, this type of research needs large, prospective trials that must be run in a multinational setting and have no commercial appeal. They can only, therefore, be performed if governmental and independent funding bodies start allocating more funds to these initiatives. Unlike the US,

Europe does not have a centralised funding agency with the exception of the European Commission where calls for proposals are few, too complex and often exclude clinical trials. On the other hand, national agencies are extremely reluctant to fund an international project and usually limit their support to the national patients involved. It is, therefore, almost impossible to run multinational trials without the support of the pharmaceutical industry with the constraints that this entails.

By lobbying for funds and attention from governments, regulatory and funding agencies, breast cancer advocates have the power to significantly contribute to changing this situation both nationally and internationally. The advocacy world must also seize the momentum created by the meeting of the MBC Advocacy Working Group and, as suggested in the report, develop support and information resources tailored to the specific needs of MBC patients. In the BRIDGE survey more than 45% of women reported having difficulties locating helpful information and 51% considered that the existing resources do not meet their needs.^{2,3}

A new initiative is being planned by the European School of Oncology (ESO). ESO has proudly made MBC one of its main battles. Several years ago a task force (ESO-MBC Task Force) was created and which aimed to develop international guidelines for the management of MBC.^{4,5} Application of guidelines has been shown to increase survival of early breast cancer patients⁶ but few guidelines exist for MBC and even fewer are being followed in clinical practice. The next ambitious effort of the Task Force is to organise an international Consensus Conference for MBC, along the lines of the famous St Gallen Consensus Conference for early breast cancer.

The united efforts of advocacy, research, regulatory and funding communities have led to formidable advances in the fight against breast cancer. These advances have been far more important in the early setting. It is now time to focus with the same unity and

strength in the advanced setting. We owe it to the courageous fighters and true survivors that MBC patients are.

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