



Viewpoints and debate

The European patient advocacy perspective on specialist breast units and accreditation



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ARTICLE INFO

Article history:

Received 26 November 2014
 Received in revised form
 5 January 2015
 Accepted 28 January 2015
 Available online 18 February 2015

Keywords:

Breast cancer advocacy
 Specialist breast units
 Quality assurance
 Accreditation
 Best practice
 Multidisciplinary team

ABSTRACT

Europa Donna-The European Breast Cancer Coalition has been advocating for all women to have access to care in specialist breast units since 2003. Two European Parliament Resolutions, (2003 and 2006) as well as the Written Declaration against breast cancer in the EU of 2010 called on member states to ensure that all women in the European Union have access to treatment in such units set up in accordance with the “European Guidelines for quality assurance in breast cancer screening and diagnosis,” by 2016. Once mammography screening implementation according to EU Guidelines commenced, it became evident that it would be essential to have high-quality units where women would receive specialised treatment upon diagnosis. Europa Donna was a member of the revision committee for Chapter 9 of the 4th edition of these Guidelines (2006) which provided a detailed description of these services as previously defined by EUSOMA. Moreover, the 2010 Written Declaration on the fight against breast cancer in the EU called on the Commission “to develop a certification protocol for specialist breast units in accordance with EU Guidelines by 2011”. The most important thing for a woman diagnosed with breast cancer to know is where to go to get the best treatment, i.e. she needs to know that the clinic or unit is accredited as having implemented appropriate quality standards that meet EU Guidelines thus ensuring provision of high level breast services, and that her national health system will pay for it. Progress on accomplishing this has not moved quickly, nor has it been accepted by all stakeholders involved.

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While much has been done to implement specialist breast units across Europe, it is important to emphasise once again why this is of such importance to women and why Europa Donna, Europe's breast cancer advocacy organisation, continues to fight for these services to be available to women. This needs to be reiterated because there are still many medical professionals who question the need for these units, the need for specialist practitioners in this field, and who would like to convince their health ministries that breast cancer can be treated effectively in the general hospital setting, with general surgeons performing the surgery. This is indeed frightening in 2014 when we consider the many very complex and sophisticated procedures that have been added to the arsenal of treatments that should be made available to women and that require a specialist unit with a multidisciplinary team (MDT) e.g. sentinel node biopsy, genetic counselling, ultra sound and MRI when indicated, intra operative radiotherapy, gene array testing, immediate breast reconstruction, advanced breast cancer clinics,

not to mention access to the newest drugs and targeted treatments that have been proven effective. The most effective, up to date treatments and procedures are available in specialist breast units and not in general hospitals. Specialist breast units have tracking and monitoring to measure outcomes, to provide data on procedures so that they can be analysed and services improved over time; for instance, they ensure that women who are eligible are offered lumpectomies instead of mastectomies, and that services are provided and followed up in a timely manner.

Why care in breast units is important

There are 500,000 newly diagnosed cases of breast cancer and 143,000 deaths in Europe every year [1]. Studies have shown that women who are treated in a specialist breast unit will have a 18% better chance of survival [2] and they will also enjoy a better quality of life knowing they have received the best possible treatment for their diagnosis. Breast cancer is a complex disease; there are many types of breast cancer and each must be diagnosed correctly through optimum pathology and radiology, and analysed by a

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multidisciplinary team (MDT) to determine the correct therapy for that individual woman. There is no longer just one type of breast cancer; the treatment plan, followed from the outset based on the MDT decisions, is critical for the success of the treatment, and the life of each woman. Also joint decision making is often vital in deciding treatment, in that there may be more than one choice and the woman's preference, her own vision of herself, must play a role in making the right choice for that woman. All the options must be explained, and examined, so that the woman can arrive at the best decision in her particular case. One size does not fit all.

For a woman diagnosed with breast cancer, the knowledge that she is being treated in a specialist centre or unit for this disease where all the proper protocols will be followed and all options discussed by the MDT and with the patient, is essential. The moment of diagnosis is a time when a woman is concerned with many issues making her more fragile and in many cases rendering her less adept at making the right decisions for her particular case. Regardless of how much research can be done today on the internet and the fact that initiating treatment is not usually urgent, women at this juncture are faced with many challenges. They are often caring for children and families, have career responsibilities and now must make decisions that potentially will require months of treatment, and that may result in side effects lasting for years. Breast cancer is not just a hospital stay. It is a long and often arduous journey.

Key elements of a specialist breast unit [3–5]

The required specifications of specialist breast units ensure that appropriate care is undertaken for the entire journey of the patient from diagnosis through treatment and follow up. The treatment must be carried out by specialists trained and with significant experience in treating this disease: specialist breast surgeons, specialist breast radiologists etc. There must be a multidisciplinary team and each case discussed in team meetings. Quality assurance mechanisms, performance and auditing, alongside defined quality objectives and outcome measures, must be included. There must be data monitoring and constant review of cases. A specialist breast care nurse or professional with equivalent training is part of the core team; she explains the pathway to the patient, and ensures that the patient understands not only what will take place in the unit at the outset, but also what will take place after she has left the unit, as the journey continues. Every aspect of care needed during the journey must be provided by the breast unit including appropriately trained breast specialists, necessary up to date equipment, treatment plans, survivorship plans, clinics for MBC patients, psychosocial support and palliative care.

These elements are all described in the EU guidelines, and in lay language in the Europa Donna Short Guide to the Guidelines [6], as well as in the EUSOMA guidelines. Following guidelines is essential as they describe best practice, and standards that can be measured over time. Nonetheless many women in Europe are still not aware of these, nor do they have access to services set up in accordance with them. Since 2001 Europa Donna has been carrying out an annual training course for women from all of its 46 member countries; to date over 750 women have taken this course; experts and professionals in the field give their time each year to educate these women, many of whom are survivors, on the science of breast cancer and the most up-to-date procedures, treatments and research. A key motivation behind advocacy training is that we have seen first-hand that women treated for breast cancer in many countries, and who want to become advocates, do not know what best practice is, because they have not experienced it themselves. Each year we query the group to see how many have been treated in a specialist breast unit and the response remains quite low, even in

2014, at about 20% of the survivors present. A training course of this type is essential in order to ensure that advocates have the correct messages to take back to their countries.

Why accreditation of breast units is important

Breast units still do not exist in many countries or in many regions of countries. Of those that do exist, many have not been accredited by any governing body.

The Breast Centres Network set up by ESO [7], has gone a long way to both raising awareness of the importance of breast units and to encouraging their establishment. EUSOMA has developed an accreditation system with quality indicators [8] indicating key standards that must exist and be monitored regularly. Breast units may request certification through an independent body, European Cancer Care Certification. Nonetheless, there are still many countries where no breast units exist that in any way conform to the guidelines and there is a risk that there are now entities calling themselves breast units without meeting many of the standards outlined in the guidelines.

This is why an EU accreditation protocol is essential: the women of Europe deserve to know which institutions meet EU standards so they can be sure they are being treated with the most up to date treatments carried out by established experts in this field. They must be assured that all breast units meet the same set of standards across all countries.

The European Parliament Resolutions called for women to be entitled to treatment in certified multidisciplinary breast centres and confirmed that these units should be established across the EU by 2016 [9,10]. The EU Written Declaration called on the Commission to develop an accreditation protocol for breast units by 2011 [11] and in 2012 the European Commission committed to carrying out this project and seeing it through to completion [12].

Conclusion

Time is passing and we are behind schedule. Some progress has been made but not enough. Breast cancer incidence is increasing, so the need for accredited services is even more compelling.

Women who are treated in specialist breast units have better outcomes: a better chance of leading a longer life and a better quality of life compared to those who are not. We all need to work harder – advocates, health professionals, politicians, health ministries, industry leaders, and the European Commission, to ensure that all the women of Europe have access to be treated in a specialist breast unit by 2016 and that these units meet one set of EU standards.

Conflict of interest statement

None declared.

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