

PROVISIONAL VERSION

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Towards optimum breast cancer services across Europe

Report¹
Committee on Social Affairs, Health and Sustainable Development
Rapporteur: Ms Stella KYRIAKIDES, Cyprus, EPP/CD

A. Draft resolution²

1. Breast cancer is still the most common cancer in European women and has the highest mortality of any cancer in women, despite significant scientific advances in detection and treatment in the last 20-25 years.
2. Progress in fighting breast cancer – and the stigma still attached to it in some countries – has neither been linear nor universal across Europe, for many reasons. Access to quality screening programmes and modern treatment is not yet understood as a right across all of Europe, leaving many women to be subjected to unnecessary mutilating surgery and/or futile aggressive treatment.
3. Providing breast-cancer services and care of guaranteed quality leads in the medium and long-term to improved survival rates, to savings for the health-care system and to a better quality of life for patients. It is thus not just in the interest of the individual patient that the fight against breast cancer be at the top of member countries' health agendas.
4. The Parliamentary Assembly thus recommends to Council of Europe member states to:
 - 4.1. keep the fight against breast cancer at the top of their health agendas;
 - 4.2. ensure that women have access to quality-controlled, organised national mammography screening programmes set up in accordance with European Guidelines, as well as to accurate, evidence-based information on the potential benefits and risks of participating in them, so that they can make an informed decision on their participation;
 - 4.3. ensure that all breast cancer patients have effective access, wherever their place of residence, to quality-assured diagnosis and treatment in multi-disciplinary breast units, which are linked up with the national screening programmes, are set up in accordance with European Guidelines, and encourage shared decision-making between patients and medical teams;
 - 4.4. establish and maintain national cancer registries providing reliable data on the situation in the member States and task them with, inter alia, informing and raising the awareness in the media and the general public on the proper interpretation of this data;

¹ Reference to Committee: Doc.12995, Reference No. 3898 of 1st October 2012.

² Draft resolution adopted unanimously by the Committee on 12 May 2014.

4.5. outlaw discrimination against breast cancer patients on the basis of their disease status, in particular in the employment and insurance spheres;

4.6. encourage researchers in all Council of Europe member and observer states to work together to further the understanding of the disease and to improve screening, diagnosis and treatment techniques with the goal of improving mortality rates and the quality of life of individual patients as well as reducing overdiagnosis and overtreatment, and, ultimately, to find the cure.

B. Explanatory memorandum by Ms Kyriakides, rapporteur

1. Introduction

1. Breast cancer is a disease that has existed for centuries but for which the perception continues to evolve. Gradually, with the efforts of patient advocates, scientists, media and government, silence around the disease has been broken, and it has changed from being seen as a stigma to a disease that in many countries is setting the pace for bringing about change in approaches to health-care.

2. The life experience of breast cancer is similar for patients (most of them women) across boundaries, race and religion. There are, however, still many parts of the world where women continue to hide their diagnosis, where optimum diagnosis and treatment are not available and where fear of death is at the end of the process, not hope and survival.

3. This is despite the fact that it is recognised today that providing breast-cancer care of guaranteed quality leads in the medium and long-term to improved survival rates, to savings for the health-care system and to a better quality of life for patients. It is necessary to call on all member States to ensure the optimal minimal standards of care for all patients diagnosed with the disease.

4. Over the last decades, the scientific and advocacy community have joined their efforts to increase awareness of the issues that are relevant to breast cancer. Issues that have to do with diagnosis, screening, with optimal care in breast units, with the rights of women in employment and to insurance, as well as the importance of palliative and end-of-life care.

5. The aim of the report is to highlight these issues, to ensure that in the Council of Europe member States, efforts are directed to reducing disparity and inequality in breast-cancer services across Europe. It is crucial that the lives of the hundreds of thousands of men, women and families affected by the disease have the level of care that they are entitled to, as defined by the European Parliament Breast Cancer Resolutions of 2003 and 2006 and the Charter of Patient Rights.

2. Breast cancer facts

6. I am not a breast-cancer scientist myself, but I am a member of the Europa Donna breast-cancer advocacy group – whose Executive Director, Ms Susan Knox, attended an exchange of views with the Committee last October. Allow me to summarise the most important breast cancer facts and figures here³:

Incidence

7.1. Breast cancer is the most common cancer and has the highest mortality of any cancer in women worldwide.

7.2. Breast cancer is the most common cancer in European women with an estimated incidence of 499,560 in 2012. Incidence in the EU-28 in 2012 was estimated to be 367,090.

7.3. There are twice as many new breast cancer cases annually than new cases of cancer of any other type.

7.4. One in 10 women in the EU-28 will develop breast cancer before she reaches 80 years of age.

³ All the following facts and figures come from the Europa Donna website (which references them) unless otherwise indicated - <http://www.europadonna.org/breast-cancer-facts/>, downloaded on 26.2.2014.

7.5. An average of 20–30% of breast cancer cases in Europe occur in women when they are younger than 50 years old; 33% occur at age 50–64 and the remaining cases in women above this age. Breast cancer therefore affects many women during their years dedicated to working and raising a family.

Mortality

8.1. Breast cancer claims the lives of more European women than any other cancer.

8.2. In Europe, an estimated 142,889 women died from breast cancer in 2012, 91,495 of whom were in EU-28 member States.

Facts about lifestyle and breast cancer

9. The increasing number of breast cancer cases may be due to changes in lifestyle habits, increase in sedentary lifestyle, weight gain and obesity and sociological changes such as increasing age at first birth and decreasing number of children born to women.

Physical activity and weight

10.1. Excess body weight and physical inactivity account for approximately 25–33% of breast cancer cases.

10.2. There is an inverse relationship between body mass index and breast cancer in pre-menopausal women and a direct relationship in post-menopausal women.

10.3. Physical inactivity is estimated to cause 10-16% of all breast cancer cases.

10.4. The effect of weight loss is independent of physical activity.

Alcohol consumption

11. Consuming three or more alcoholic beverages a day increases the risk of breast cancer by 30-50%, with each drink accounting for about a 7% increased risk.

3. Understanding the statistics

12. As Dr Alberto Costa from the European School of Oncology pointed out at the hearing the Committee held on this report at its meeting in Strasbourg on 9 April 2014⁴, “breast cancer is not one disease, but many”. For hundreds of years, the only standard available treatment for all types of breast cancer was surgery: removing the tumour, or the affected breast. In Doctor Costa’s words: “We always knew that despite the fact that we are trying our best with every single patient, some of them would not manage to survive the disease. Since we could not predict who was going to survive we felt obliged to give the maximum tolerable treatment to everybody: a mastectomy.” However, even a radical mastectomy will not save the life – or even prolong the life – of every breast cancer patient.

13. In the last 20-25 years, significant advances have been made in understanding breast cancer. The discovery of the make-up of tumours has allowed to classify different types of the disease which go beyond classification by size and location type (tubular or lobular), or the involvement or not of the sentinel lymph nodes – it can now be measured how quickly a tumour grows, how quickly it metastasises, whether or not it invades the blood, whether it is hormone receptive, etc. In the future, genetic profiling of tumours may allow even better and clearer classification. At the same time, advances in treatment – in particular for hormone-dependent tumours – have given doctors effective treatment options which go beyond surgery. This means far more individualised treatment is possible now, it is no longer “one size fits all”. However, there is still no 100%-effective “cure” for breast cancer: we are still waiting for the equivalent of antibiotics for tuberculosis to be discovered. According to Doctor Nereo Segnan from the Department of Cancer Screening of the University Hospital of Turin⁵, only one life in five of breast cancer patients (with invasive cancer, not DCIS or LCIS⁶) is saved due to the currently available treatments – but, because it is currently practically impossible

⁴ The minutes of this meeting are available from the Secretariat once they have been declassified by the Committee (AS/Soc (2014) PV3).

⁵ With whom I had the pleasure of discussing this subject over lunch the day of the hearing.

⁶ DCIS and LCIS are non-invasive precancerous lesions confined to certain breast cells, “Ductal Carcinoma in Situ” and “Lobular Carcinoma in Situ”.

to predict which kind of cancer will respond to aggressive chemotherapy, for example, many doctors still feel obliged to “give the maximum tolerable treatment to everybody”.

14. At the same time, technology has evolved to a point where it is possible to detect cancers at an ever earlier stage through mammography screening programmes (see the next chapter). As Dr Segnan pointed out during the hearing mentioned earlier, it is the combination of organised screening programmes and more effective treatment which has at last made a significant impact on mortality rates for breast cancer in Europe in the past 20-25 years.

15. In this context, it is important to understand statistics correctly. There is a lot of confusion even among educated professionals when it comes to the correct interpretation of statistics. Allow me to give you a few illustrative examples. Many women have been shocked at the apparently inexorable rise of incidence rates of breast cancer in the last century. However, this rise was due to many factors, some of them statistical quirks: as less women died from infectious diseases with the advent of better hygiene, the development of vaccinations and the discovery of antibiotics, more women survived to die of other causes – including breast cancer. As the life expectancy of women increased, so did the chance of developing breast cancer within one’s lifetime. This does not mean that certain societal changes had no impact on the rising rates of breast cancer: thus, having children at a younger age, having several and breast-feeding them can protect against breast cancer, while having first menstruation at an early age and menopause at a late age increase the probability of developing breast cancer.

16. Another example is the focus on “survival rates”. Of course, this is one of the first questions that many women will ask their doctor when diagnosed with breast cancer – “how long do I have?” However, the answer is not easy even now, due to the many sub-categories of this disease. Some tumours are so aggressive, they will kill a patient quickly at whatever stage the cancer is detected, and whatever treatment is administered. Some cancers are not invasive (eg. DCIS and LCIS, which should arguably not be called “cancers” at all), or grow and metastasise so slowly, that the patient would have survived (and died of other causes) at whatever stage the cancer is detected, and whatever treatment is administered (including no treatment at all). When making the leap from the individual to the statistical level, this creates no end of misunderstandings. For example, say a woman has an aggressive tumour which will kill her at age 45. If the woman presents herself to doctors at the age of 43 with symptoms, she is counted as having survived 2 years after diagnosis. Had the same woman’s tumour been discovered via a mammography screening at the age of 40, she would have been counted as having survived 5 years after diagnosis. The same facts, the same outcome, but statistically-speaking, the woman has just gained three years of life, and the survival rate has gone up “due to early screening”. Or take a woman with DCIS discovered via mammography screening at age 40. She is aggressively treated, and dies of other causes (not linked to breast cancer) at the age of 80. Has her life been saved by the screening and the aggressive treatment as it will be interpreted by some, positively affecting the breast cancer survival rate? In fact, no: DCIS is by definition not invasive (the IS stands for “in situ”), and thus does not kill. This is why it is so important to teach the general public and patients themselves to interpret statistics correctly and not to jump to conclusions.

4. “To Screen or Not to Screen”: evidence and guidelines in a context of continuing debate

17. Mammography screening is the source of an ongoing debate. There have been reports by a large number of experts, in both the United States and Europe, evaluating the effectiveness of mammography screening, assessing all the evidence (provided by the European Breast Cancer Screening Network, the International Agency for Cancer Research and WHO). Europa Donna, the European breast cancer advocacy organisation representing groups in 46 European countries, which continuously reviews all the evidence, supports population-based mammography screening programmes when carried out in accordance with the European guidelines for quality assurance in breast cancer screening and diagnosis – meaning a mammography every 2 years after a certain age, usually set at 50.

18. It is unfortunate that there is often confusion caused by the way media report the evidence related to breast cancer mammography screening programmes. Doctor Segnan explained the evidence very well at the Committee hearing: Large-scale, organised breast-screening programmes which conform to European guidelines do save lives when combined with modern treatment. This is because it is not screening or treatment as such which are having an impact on mortality rates, but rather the combination of the two. The different large-scale studies came to different conclusions regarding the extent of the benefit which can be attributed to screening programmes⁷, but the evidence points to significant benefits. Doctor Segnan thus recommended that guidelines-compliant screening programmes should continue – while warning against individual, ad hoc, non-organised screening which can do more harm than good.

⁷ For details please see Doctor Segnan's presentation, available on Extranet and from the Secretariat.

19. Dr Segnan also pointed out the drawbacks of screening, which – while outweighed by the benefits – also need to be clearly communicated to women so that they can make an informed choice about their participation in breast-cancer screening programmes: “false positives”, overdiagnosis and overtreatment. The studies he cited showed that 20% of women had been recalled after mammography screening for further check-ups (sometimes including invasive procedures) in the last 20 years, most of which had been “false positives”, ie. the lesions detected had not been cancerous. While the anxiety, stress and (in cases of invasive procedures to exclude cancer) discomfort to women in this situation should not be underestimated, the harm done is small compared to cases of overdiagnosis leading to overtreatment.

20. Dr Segnan defined “overdiagnosis” as cases of cancer or precancerous lesions such as DCIS or LCIS which would not have been detected without mammography screening, ie. were not palpable or causing symptoms. Diagnostic variability is high – thus, DCIS makes up between 4% and 23% of all screen-detected “cancers”⁸. It is now known that DCIS and LCIS only rarely lead to invasive cancer, and that “treatment” for these precancerous lesions should thus be limited to keeping an eye on them via standard-interval mammography screening. Sadly, not all doctors are aware of these recommendations, and many women have suffered unnecessary mutilating surgery for these conditions – which would, in most cases, never have turned cancerous. This type of overtreatment is best avoided by following guidelines to the letter and developing an alliance between organised screening and breast cancer units (see next chapter).

21. From a public health point of view, the more women participate in organised screening in the 50-69 year age-group, the better the public health outcome is (the evidence for the 40-49 year age-group is less clear: while the benefits are the same as concerns the numbers of cancers detected, the harms for this age-group are higher with more “false positives” and overdiagnosis due to the denser breasts of women in this age group). Communication materials given to women do not always give an accurate representation of the benefits and the risks of participating in screening programmes: this should change. Women should be treated as adults and be allowed to make an informed decision on whether or not they want to participate in screening programmes, and this decision should be respected and not held against them at a later stage. From the day mammography screening was introduced, women have participated in screening programmes in high numbers. Let’s trust them to make the right decision – the decision that is right for them.

22. To summarise: screening carried out according to the European guidelines provides a significant benefit to women in improving mortality rates from this disease when combined with modern treatment. It is thus important for women to have access to screening programmes that meet guidelines and to correct evidence-based information. As evidence stands at the moment, mammography screening is the best form of early detection of breast cancer available today and it does improve mortality rates.⁹

5. Specialist breast units: increasing women’s quality of life and chances of survival

23. Evidence has shown that treatment of breast cancer in a multi-disciplinary breast unit has been proven to raise the chances of survival and improve the quality of life. The European Parliament, in its Resolutions of 2003 and 2006 has called on European Union member States to ensure nationwide provision of such units in accordance with European guidelines by 2016.

24. All women across the Council of Europe member States and the world should have access to fully equipped, quality-assured dedicated Breast Units that provide competent comprehensive care. Breast care needs to be multi-disciplinary. EUSOMA (the European Society of Mastology) set out the requirements of a specialist Breast Unit (these guidelines were updated in 2013). The guidelines were built on evidence from a multi-disciplinary team of European experts.

25. The guidelines require an integrated breast unit dealing with a sufficient number of cases to allow effective working and continuing expertise,¹⁰ and dedicated specialists working with a multi-disciplinary

⁸ Dr Segnan pleads for removing the word “cancer” in the description of DCIS and LCIS, as cancer is by definition invasive and not localised within cells.

⁹ The European Parliament Resolutions of 2003 and 2006 state that mammography screening can reduce deaths from breast cancer by up to 35% in women from 50 – 69 years, but that screening can also decrease mortality in women between 40 – 49 years. The European Parliament Declaration of 2009 on the fight against breast cancer in the EU calls on European member States to introduce nationwide screening in accordance with EU guidelines.

¹⁰ It is important that a breast unit must be of sufficient size to have more than 150 newly diagnosed cases of primary breast care coming under its care every year. The reason that a minimum number is recommended is so that a minimum case-load is needed to maintain expertise.

approach.¹¹ The guidelines emphasise the need for breast units to provide continuity of care for patients with metastatic disease and a high-quality palliative service. A breast unit also deals with benign disease.

26. As Doctor Costa and Dr Segnan emphasized at the hearing, two more aspects are important which go beyond the guidelines in their current form: First of all, there needs to be an alliance between organised breast-cancer screening programmes and breast units, in order to reduce overdiagnosis and overtreatment. Second, it is important to have dedicated “breast nurses” in breast units, who can accompany patients throughout diagnosis and treatment. This does not mean that doctors should dedicate less time to their patients – on the contrary, high-quality communication between the doctor and the patient is crucial for shared decision-making. However, the presence of a breast nurse during important discussions (when the diagnosis is given, or when a choice needs to be made as regards treatment options) can be of significant help to the patient.

27. Lastly, a footnote on gender. Breast cancer is a predominantly female disease, and it affects a part of the female body which is important to women's self-esteem (and which is regarded as important for “sex appeal” and even “femininity” in society). It is not the same for a woman to suffer from breast cancer or from colon cancer, for example. At the same time, the breast is not a “vital organ” in the classical definition. This has led, historically, to the reinforcement of a certain type of paternalistic attitude in doctors which has further imbalanced the power relationship between doctors and their patients. Women who feel that they have been included in decision-making on their treatment have demonstrably better health outcomes – suffering less from anxiety, depression and fatigue linked to the disease and its treatment. It can be hoped that breast units, with their emphasis on shared decision-making, can be part of the way to reverse the historical trend.

6. Pink is not a colour – it is an attitude: the power of the advocacy movement

28. Advocating for a cause has been part of peoples' behaviour for centuries. This is what is entailed in moving away from the personal experience onto advocating for a cause that is far broader. The importance lies in using a personal experience in a political way to effect change. Advocacy can also lead to the changing of attitudes and beliefs of society, as well as of standards.

29. Advocates need to be well informed and well-educated. Advocacy is in itself an art, an art of changing public opinions. Cancer advocacy can break taboos and stigmas. Breast cancer has been one of the most dynamic fields where patient advocacy has resulted in changing the face of the disease.

30. There is still much that needs to be done and advocating for change is crucial. Great disparities continue to exist in the diagnosis, screening and treatment of breast cancer across and within countries. The need to advocate for change does not, however, only relate to screening and treatments, but also to the need to protect women's rights in employment and insurance, and the right to have access to clinical trials. Recent studies show that one fifth of breast-cancer patients do not return to work even though they are deemed fit to do so. Furthermore, women who do return to work are often faced with various forms of discrimination.

31. Breast cancer advocacy sites and support forums brim with stories of discrimination against breast-cancer patients in all types of arenas, but hard evidence is more difficult to come by. Many breast-cancer patients are discriminated against at work – they may be (unlawfully) fired, or harassed until they leave of their own accord. They may be demoted, offered “easier” (and less well-paid) jobs, passed over for promotions, offered only fixed-term contracts or part-time work – the list is practically endless. Similarly, when they want to buy health or life insurance, they may be refused, or even (often unlawfully) excluded from existing insurance policies, or asked to pay higher risk premiums – even if they have been cancer-free for 10 years or longer. While breast-cancer patients have the right not to be discriminated against, such discrimination it is often difficult to prove, as so often with all kinds of discrimination cases – so that many victims of this kind of discrimination do not even try to take their case to court. Much work still needs to be done by the advocacy movement to raise awareness of this discrimination in order to name and shame, and hopefully end it.

32. The issues that face breast cancer patients are complex – funds need to be used for research in prevention, in genetic and environmental factors, in building up country cancer registries, as well as for research into a possible cure. Special attention needs to be given to young women with breast cancer who

¹¹ A breast unit team is comprised of breast surgeons, breast oncologists, breast radiographers and data managers. The associated services of a breast unit are psychological support, reconstruction, palliative care, prosthesis and lymphoedema services and a breast nurse.

face a different set of issues and need services and information geared to their needs, as well as to women living with metastatic disease¹².

33. Pink is not just a colour – the pink campaigns may seem to be almost overoptimistic at times, and the attempts at their “capture” by commercial enterprises have come in for some criticism. Knowing the disparities that exist, they may even seem frivolous as breast cancer is a serious disease, but pink is about an attitude that we can create to build the momentum for change. The pink ribbons need to be interpreted as far removed from the infantilising commercial pink marketed to young girls: as a forceful, enabling, adult pink.

7. Conclusions and recommendations

34. We have come a long way from the days when women diagnosed with breast cancer were systematically subjected to mutilating surgery and aggressive therapies with no regard for how this would affect them and their quality of life. Thanks to the patient advocacy movement, the stigma surrounding breast cancer has also been removed.

35. However, despite all the advances of the last 20-25 years in detecting and treating breast cancer, mortality rates are only coming down slowly. Most cases of invasive breast cancer are, unfortunately, still incurable, though patients may survive much longer and enjoy a better quality of life than in the previous century. Breast cancer is still the most common cancer and has the highest mortality of any cancer in women worldwide – and thus continues to strike fear into the heart of women.

36. Both the incidence rates and the mortality rates vary from country to country in the Council of Europe. Some of the variations are due to differences in lifestyles, genetic susceptibility and age-related demographic make-up, but many of them reflect the lack of optimum breast-cancer services both with regard to guidelines-compliant organised screening programmes and to modern treatment in specialised, multi-disciplinary breast units. With a strong emphasis currently being laid on lifestyle-oriented prevention, and thus moved into the sphere of individual responsibility, breast cancer has also slipped from the top of many countries' health agendas¹³.

37. Fighting breast cancer must return to the top of countries' health agendas. All women (and genetically predisposed men) in Council of Europe member states should have the right to access quality screening programmes, a proper diagnosis and quality-assured modern treatment in specialised, multi-disciplinary breast units. And this right should not only exist on paper, but be implemented in reality. Every member State should have a national cancer registry which can provide reliable data on the situation.

38. Finally, researchers in all Council of Europe member and observer states should work together to further the understanding of the disease and improve screening, diagnosis and treatment techniques with the goal of reducing overdiagnosis and overtreatment, as well as improving mortality rates and the quality of life of individual patients. And, of course, to finally discover the cure.

¹² In this (last) phase of breast cancer, the treatment goal is to extend life as long as possible with the best quality of life possible by relieving symptoms and trying to put cancer into remission with the fewest side effects.

¹³ The fact that the vast majority of breast cancer patients are women, most of them close to pensionable age, may have contributed to this slide in priorities in a subtle manner due to persisting gender inequalities.