

Advocate's Viewpoint on Hereditary Breast/Ovarian Cancer

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The Working Party on hereditary breast ovarian cancer of the Dutch Breast Cancer Patient Organisation

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Abstract

This paper discusses the presentation I held at the symposium on genetics during the 4th European Breast Cancer Conference held in Hamburg in March 2004.

Primarily, the goals and working methods of the advocacy group specialised in Hereditary Breast/Ovarian Cancer of the Dutch Breast Cancer Patient Organisation known as BorstkankerVereniging Nederland (BVN) are explained. Furthermore, some specific individual problems that mutation carriers might encounter before and after BRCA1/2 susceptibility testing are discussed. These include: dilemmas in choosing preventive interventions, dealing with the psychological impact of knowing you are a mutation carrier, dealing with the social implications of being genetically at risk, an example of insurance discrimination. In addition, some controversial social and ethical issues that are currently under debate are highlighted, such as the issue of the European patenting of the breast cancer susceptibility genes BRCA1 and BRCA2. Since this topic could also become relevant for other gene-related diseases, society as a whole has to consider the ethical and social implications related to the patenting of human genes in general. Another ethical area of debate is the controversial issue of prenatal BRCA testing and the choice of pregnancy termination.

Finally, the Working Party pleads for the international co-operation and exchange of data and experience among professionals as well as patients. It appears that professionals in different European countries tend to advise on different risk management strategies and treatments and as such, the Working Party strongly advocates the international standardisation of risk management and treatment of mutation carriers. In this respect, specific attention should be given to a group that has had a non-informative or negative BRCA test result, because this group is still considered to be at high risk to develop the disease.

The Working Party on hereditary breast/ovarian cancer: goals and methods

The Working Party on hereditary breast/ovarian cancer, which I am currently chairing, primarily safeguards the interests of and offers support to

people whose lives are affected by hereditary breast and ovarian cancer. The Working Party consists of 10 non-professional volunteers (mostly mutation carriers and their relatives) and 4 professional advisory members. The Working Party was originally founded by the Rotterdam family cancer clinic of Erasmus Medical Centre, but is now part of the BVN,

a nationwide Patient Organisation exclusively for breast cancer patients, with more than 5,000 members.

Raise awareness and give information

It is one of the main goals of the Working Party to raise awareness on hereditary breast and ovarian cancer among patients and their relatives, doctors, nurses and other professionals, but also among the general population.

Providing information is also one of the main goals and it is of course used as a tool in creating more awareness. The Working Party specifically directs its efforts to find healthy unaffected mutation carriers and make them not only aware of their risks of developing cancer, but also of the advantages of risk management strategies that are offered to prevent them from developing cancer.

Working methods

Some examples of the methods of the Working Party are: to spread information brochures and have a monthly "walk-in consulting hour" in two major clinics in Amsterdam and Rotterdam; to give testimonials at conferences and hearings for patients and professionals such as training courses for nurses; to seek publicity via various media outlets which focuses not only on specialised journals, but also on well-known women's weekly magazines; to co-operate with television programmes and have teaching sessions with students. Furthermore, the Working Party organises informative meetings, workshops and symposia across the country: in 2002 the Working Party organised a conference for mutation carriers and their families which was attended by 250 people. The Working Party advertises itself on the website of the BVN but also has a specialised website on hereditary breast/ovarian cancer with general (accurate) information, contributions from professionals and links to relevant institutions and other websites. We are also represented in and co-operate with national and international organisations with similar interests.

Offering support

The Working Party also acts as a service-support group and is involved in the helpline of the BVN. The members of the Working Party aim, from their personal point of view and using their own experience, to offer emotional support to a wide range of people who face

hereditary breast and/or ovarian cancer. All these individuals have the responsibility to handle the knowledge of being at increased risk and passing this information on to their relatives. They have to deal with the knowledge of their genetic predisposition for the rest of their lives. By being a mutation carrier they face emotional as well as social problems that they must share with their partners and children. Women with positive BRCA test results are confronted with dilemmas about their individual risk management: they have to decide on preventive surgery, such as oophorectomy, mastectomy and on breast reconstruction surgery.

There is an immense psychological impact of these decisions: dilemmas that are often underestimated in the clinical situation when dealing with cancer risks are the main objective.

In genetic centres and family clinics in the Netherlands psychological support is generally offered within a multi-disciplinary team as part of the entire counselling procedure. But the Working Party explicitly stresses the need for more research on the long-term psychological impact of these dilemmas, of intervention surgery and of any kind of problems in the society related to hereditary cancer. The Working Party has suggested establishing a fixed programme of psychological support that will take into consideration the psychological difficulties that mutation carriers could encounter after some time.

Knowledge

In order to offer support and give information it is essential for members of the Working Party to be informed and keep themselves updated on all recent developments. For that purpose, the professional advisory members of the Working Party organise special training courses and provide a direct communication line if questions should be raised. The Working Party also needs to be aware of new developments in society and is actively involved in the debate on various ethical issues related to hereditary aspects.

Issues at stake

Insurance discrimination

After DNA testing mutation carriers might encounter genetic discrimination by insurance companies. If mutation carriers in the Netherlands, both symptomatic and asymptomatic, want more than very basic health insurance, they could expect a rise in premiums if their genetic predisposition to cancer is known. In the application for life insurance – for instance for a mortgage or disability insurance, the insurance

company is – according to specific criteria – allowed to ask questions about hereditary diseases in the family. The insurance company might then rise the premium or could even refuse insurance.

These kinds of problems related to insurance discrimination will have to be acknowledged and anticipated and at the very least mentioned before genetic testing. It is an alarming development if this proved to be a strong deterrent for many people to have a DNA test and it seems contradictory to all efforts to detect healthy mutation carriers to reduce the incidence of breast and ovarian cancer through preventive health care.

The Working Party keeps in touch with an independent Help-Desk on insurance (“Het Breed Platform Verzekeren”). They offer personal assistance with insurance problems and keep records of all those cases and incoming complaints. In this matter we also intend to co-operate with other patient organisations and alliances for hereditary diseases.

Patenting of human genes

Recently the European Patent Office in Munich revoked one of the patents on the BRCA genes¹. Four patents were granted in the past few years to an American company. European legislation (the Directive on Biotechnological Inventions of 1998) made it possible to patent isolated human genes and “body parts” after they have been removed from their natural surroundings.

The opposition against the patents was widespread in Europe. The BorstkankerVereniging Nederland also supported this legal opposition raised by genetic centres, laboratories and clinics from several European countries, because it is feared that the interests of potential mutation carriers could be harmed by the patenting of the BRCA genes.

Furthermore these patents cover the sequencing of the BRCA genes, and somatic mutations to be found in these genes associated with breast and other cancers. This could prevent any further development of research on these genes and might also have a negative effect on the testing methods (and availability and costs) of all European genetic laboratories that perform the BRCA test.

The revoking of the patent highlighted this controversial situation and fortunately the international debate on this subject has lately become even more widespread². Conferences and workshops are organised to show many different viewpoints on this controversial subject. The Working Party actively participates in this debate.

Prenatal BRCA testing

The breast and ovarian cancer susceptibility genes are – at least in the Netherlands – often used as an example in public debate on genetics and ethics in general. One (controversial) example is the discussion that with the knowledge of being a mutation carrier some parents may consider the possibility of pregnancy termination when a BRCA mutation is identified in the foetus. The discussion whether genetic centres should provide prenatal testing revolves around the ethics of such a decision in relation to the risk, severity and curability of the disease. The BRCA genes are again given as an example, but in the future the discussion could also become relevant in relation to other genetically predisposed diseases.

Standardisation

The Hamburg conference was an excellent opportunity not only to illustrate the work of the advocates for hereditary breast and ovarian cancer in the Netherlands, but also show the international relevance of the issues at stake. The Working Party aims at more standardisation on surveillance and risk management strategies for women at high risk, for instance on preventive mastectomy. For example, mastectomy followed by breast reconstruction surgery is at the moment strongly advised to mutation carriers by oncologists in all family clinics and university medical centres in the Netherlands and Belgium, while in France it is rarely done.

The new Eusoma guidelines on the management of familial breast cancer risk will be an important step forward towards consensus in Europe. With these European guidelines it might become more evident what is generally considered as the best and safest method of treatment and prevention for women at high risk. Constant exchange and use of various data are essential in these situations and we strongly advise the participation from as many centres as possible that are involved in hereditary breast/ovarian cancer syndromes.

The preliminary outlines of the guidelines as presented in Hamburg revealed that women carriers with a non-informative BRCA test result – the majority of all women tested for BRCA1 and 2 – are excluded from preventive mastectomy. Maybe clinics and oncologists will consider offering some kind of mechanism to make preventive mastectomy possible for these women, if mastectomy should be their explicit choice of preventive strategy. Remembering that even with a negative DNA test result on the breast/ovarian cancer genes they are still at moderate to high risk to

develop cancer, according to their family history, the original reason to be tested.

The Working Party believes that we should all benefit from the exchange of data and the co-operation between institutions and clinics, professionally as well as by patients and their families. We could evaluate the outcome of risk management strategies related to the quality of life, but also to the incidence and mortality rates of breast and ovarian cancer in general.

DNA united forward: a European network of genetic advocates!

United co-operation among various disciplines was the final slogan in my Hamburg patients' point of view on hereditary breast and ovarian cancer. It was also a direct call to launch a European genetic advocacy network of BRCA gene mutation carriers, patients and their families, starting with the Europa Donna network of breast cancer advocates who were present at the fourth European Breast Cancer Conference in Hamburg³.

Note 1

¹18 May 2004: the patent in suit EP 699 754 granted in 2001.

²ESHG conference Munich: 14 June 2004; Copenhagen: 28 September 2004: www.estikraad.dk/sw3246.asp

³European Breast Cancer Coalition: Europa Donna:

<http://www.cancereurope.org/europadonna>;

"BorstkankerVereniging Nederland":

<http://www.kankerpatient.nl/bvn>, Churchillaan 11, 2 hoog, 3527 GV, Utrecht or Postbus 8065, 3503 RB, Utrecht, The Netherlands. 0031-302917222.

Note 2

Ethics of patenting DNA, Nuffield Council on Bioethics, 2002: <http://www.nuffieldbioethics.org>; and Patenting human Genes and Stem cells, The Danish Council of ethics, 2004.