A Patient’s Perspective on Breast Cancer and the Implications of Genetic Testing

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25 Years ago, when I was diagnosed with breast cancer, screening was unknown in our environment. The media didn’t pay much attention to cancer either. I accidentally felt a gland in my armpit but I didn’t think that something dangerous was going on, certainly nothing in connection with breast cancer.

I was under severe emotional stress at the time because of my father’s illness. He was dying of prostatic cancer and was in great pain. Soon after his death I accidentally noticed, when changing my clothes in front of a mirror, that there was a suspicious looking protuberance on my left breast and I realised immediately what it meant.

Later on, when I was a patient myself I realised that not enough was being done for complete rehabilitation of women. Together with a psycho-oncologist from the Institute of Oncology in Ljubljana we engaged in introducing voluntary work to the hospital and I became a volunteer for Reach to Recovery International — the Breast Cancer Partnership. After 1984 the volunteering spread into many hospitals where breast cancer was treated.

We volunteers act within the Cancer Patients Association of Slovenia, as well as numerous support groups.

I am talking from my personal perspective and as a volunteer meeting hundreds of breast cancer patients up to now, each of whom had her own story; the ways of discovering breast cancer are different and diverse and so is the path to total recovery.

When I got breast cancer my daughters were 8 and 14. At that time my illness didn’t touch them particularly. But, when they grew up the doctors required frequent mammographies with respect to family anamnesis. Every time this caused great psychological stress for my daughters who are now 34 and 40 years old. I think that I taught them about self-examination in time which I considered to be enough. I would not recommend the new genetic screening to my daughters either since a positive result would be too great a burden for them and a negative result would give them a false sense of security from cancer. My daughters don’t care for genetic screening either.

They have no particular fear and are very realistic about all the known facts about cancer.

As in other European countries, breast cancer is a great problem in Slovenia, which has two million inhabitants, since 800 women get breast cancer every year and about 400 die. As a patient I notice great progress in general awareness among women in the last few years. There are many discussions and the media pay a lot of attention to breast cancer. We, the former patients are contributing a lot to changed attitude by public appearances and by talking about personal experience.

We are all aware that when cancer is concerned quick action is necessary, but many
women have difficulties with that. When a woman feels a suspicious lump she usually turns to her general practitioner or her gynecologist.

She should be processed into further diagnostic treatment within the social security healthcare system. Often there is a problem when the general practitioner is not sufficiently acquainted with breast cancer, or when he does not take her suspicions seriously. A number of mammography centers have been opened in our country lately where the women must pay for the examination by themselves. More possibilities for mammographic examination is an important advantage but all these centers are not equipped with up-to-date machines and there is also a lack of qualified specialists. So it can happen that an initial malignant change has been overlooked and the woman is happy with a negative result, so she does not pay enough attention to growing tumor.

When the diagnosis has been confirmed in the majority of cases surgery follows as the first form of treatment. This is a difficult time for the woman because of fear of uncertain future, of treatment, of death... Some women are tortured by guilt that they haven’t discovered the illness in time or that they haven’t insisted on having all possible examinations immediately at the first suspicion of cancer. They also blame themselves for not living in a healthy way. These feelings are often joined by anger with their first physician who hasn’t proceeded professionally enough.

We know that breast cancer is a systemic disease requiring complex treatment, multidisciplinary and multiprofessional specialist approach. Only in this way optimum results of the treatment may be achieved. Unfortunately such treatment is not accessible to all patients. In Slovenia we have one Comprehensive Cancer Center while single treatment phases are carried on in other hospitals as well.

For the best possible quality of life we, the patients, want to do something for ourselves, too. For this reason we organised support working within an international organisation Reach to Recovery International — the Breast Cancer Partnership. The Reach to Recovery volunteer is a woman who has successfully undergone breast cancer treatment, is well rehabilitated and specially trained. In Slovenia this individual support is carried on in all hospitals. The volunteer offers to the patient emotional support and practical information.

Women with breast cancer are well aware that the problem is a complex one and that we too are obliged to do something to conquer this terrible disease. With enthusiasm we have joined individuals and organisations in 21 countries as members of Europa Donna, the European Breast Cancer Coalition.

Europa Donna’s primary aims are:

• the upgrading of breast cancer services throughout Europe for patients and women at risk
• improving public and professional education and
• campaigning for more resources to be dedicated to research.

We accept Europa Donna’s 10 wide-ranging goals and try to realise them in Slovenia too.

**EUROPA DONNA’S TEN GOALS**

1. To promote the dissemination and exchange of factual, up-to-date information on breast cancer throughout Europe
2. To promote breast awareness
3. To emphasise the need for appropriate screening and early detection
4. To campaign for the provision of optimum treatment
5. To ensure provision of quality supportive care throughout and after the treatment
6. To advocate appropriate training for health professionals
7. To acknowledge good practice and promote its development
8. To demand regular quality assessment of medical equipment
9. To ensure that all women understand fully any proposed treatment options, including entry into clinical trials and their right to a second opinion.
10. To promote the advancement of breast cancer research
Genetic screening presents some potentially serious problems to women. For example, there is no legislation to protect women found to have defective genes, from financial or employment discrimination. Furthermore, in many cultures, a woman’s marriage prospects will be seriously impaired, with implications also for other members of her family. As with the HIV/AIDS population, she may be discriminated against, even for taking a genetic test, whether or not it proves to be positive.

We believe that the psychological health of patients and women at risk must be weighed against the hopes and aspirations of those promoting genetic screening.

We see no benefit to women until such time as it becomes possible to manipulate the rogue or defective genes and we need to be assured very much more that any essential research is carried out in the most carefully controlled and protective conditions. At this stage, we remain to be persuaded.