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Point of View

The Voice of the Breast Cancer Patient—a Lonely Cry in the Wilderness

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I WAS invited to give a patient's perception of breast cancer to open the symposium on the psychological aspects of breast cancer in the 7th EORTC Breast Cancer Working Conference, Bordeaux, France, September 10–14, 1996. This article summarises my experience of breast cancer.

I was given the "breast cancer label" 5 years ago, on 11 September 1991. In the same consultation, I was invited to join the U.K. Randomised Trial for the Management of Screen-detected Ductal Carcinoma *In Situ* (DCIS) of the Breast. It was an invitation, given to me at that traumatic moment of being given the diagnosis of breast cancer, that precipitated an urgent fact-finding exercise in order that I should be able to give a reasoned response to this request [1].

I remember how it felt to be disadvantaged by my ignorance, not only of breast cancer in all its manifestations, but of research concepts and the need for research. I remember my surprise at realising that my experienced and eminent consultant did not know how to treat my condition, and was asking for my help in determining the best way forward. I had expected to be told which adjuvant treatment was necessary: he, after all, was the expert and I, the passive recipient of his accumulated wisdom and expertise!

Five years later, this patient's perception of breast cancer and research is very different. I hope it might be constructive to try to explain what has brought about this "sea-change" [2] from passive patient to involved participant [3] and to ask whether there is benefit in this change of attitude. I am convinced that there is benefit, not only for those patients who do become involved, but also for those other breast cancer patients who wish to "leave it to the doctor". There is benefit also for the profession in this partnership [4, 5]. We all have the same objective: to reduce the morbidity and mortality of women with breast cancer. Is it not right that we should share the responsibility?

How did this change of attitude come about, and what have been the influences which have resulted in my energy being directed to the promotion of these notions and to bringing about involvement of the patient at the design stage of trials?

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A major change in my perception of breast cancer occurred after 2 years when I was fortunate to be invited to participate in a round table discussion at King's College, London, about ethical issues in Breast Cancer Screening. To direct this discussion, participants were provided beforehand with thought-provoking questions covering many aspects of population screening: the likely benefits and possible drawbacks. The background reading was a revelation to me.

I belatedly realised that I had been given the "breast cancer label" because I had accepted the invitation for screening. Re-reading the screening invitation leaflets made me realise that my trust in the medical profession had caused me to accept their idea that screening was "a good thing", that I had not given balanced consideration to the proposition, partly because I had not been given balanced information. I became aware that both my acceptance of the screening invitation and my refusal of the trial invitation depended on education, adequate information, understanding and attitudes. It had required the trauma of the cancer diagnosis and the trial invitation to jolt my complacency, triggering my evaluation of the enormous activity presumably directed at improving morbidity and mortality of women with breast cancer, utilising enormous resources in the process.

It eventually seemed to me necessary to ask, not whether the screening programme would achieve its target of reducing mortality by 25% by the year 2000, but whether we had become unbalanced both in our use of resources—in the fullest sense of that word—and in overlooking the creation of morbidity by concentrating on a dubious and expensive intervention initiated solely by health professionals and inflicted on healthy people? I, now labelled "a breast cancer patient", am more interested in ensuring that available resources are applied with justice and good sense where they are most needed, both for treatment and research into breast cancer. Currently, at least in the U.K., I do not believe this to be the case.

The strength of the evidence available in 1986 when the Forrest Report [6] was published, based on controversial views, is contestable. Nevertheless, in response to the recommendations contained within it, the Screening

Programme was introduced in the U.K. on the ping of a division bell in the House of Commons, where, as Edwina Currie, the then Health Minister, describes in her book [7], "In medical terms it was worth doing. In political terms, with the election only a few months away, it was also attractive". Yet this report was prepared solely by health professionals, without public consultation, with no lay representation on the working party. Even expert witnesses called were bound to secrecy. As P. Skrabanek afterwards commented [8], "Those invited to give evidence to the working party were bound to secrecy about the matters discussed, and, as a result, dissent was, at least in the short term, effectively silenced". The short term was very short indeed, seeing that Norman Fowler announced that the Government was going to implement the recommendations of the Forrest Report the day it was published. Skrabanek adds "The Forrest Report is a consensus document that does not mention the arguments of the dissenting minority" [8].

Now in 1996, ten years after publication of the Forrest Report which led to the introduction of the screening programme, I believe it is again necessary to assess the strength of evidence both as it was then and as it is now, to judge the ethics for this massive health promotion scheme which the policymakers in their uncertainty had to consider. It is difficult, with hindsight, to imagine the ethics of inaction in 1986. Nevertheless, we can consider the strength of evidence in the light of the 1968 WHO general principals [6] of screening both then and now: they present strong cautionary indications to guide decision making.

Much has happened in the field of breast cancer since 1986 which will require skillful appraisal if we are to draw conclusions about the value of the breast screening programme, which cannot be done in isolation from reduction in mortality brought about by better treatments: the epidemiologists face a very difficult task!

My concern now as a patient is not to focus solely on the screening target of reducing the death rate for breast cancer in the population invited for screening by at least 25% by the year 2000, but rather to determine what the cost has been both psychologically and economically, using six of the 1968 WHO principles—these should have been seriously considered before the introduction of screening:

- The natural history of the condition should be well understood;
- There should be a recognisable latent or early stage;
- Treatment of the disease at an early stage should be of more benefit than treatment at a later stage;
- For disease of insidious onset, screening should be repeated at intervals determined by the natural history of the disease;
- The chance of physical or psychological harm should be less than the chance of benefit;
- The cost of case-finding (including diagnosis and subsequent treatment) should be economically balanced against the benefit it provides.

A patient's perception of this problem will cover many aspects when considering how the best interests of women may be served in society's attempts to cope with the scourge of breast cancer. The crux of the ethical issue could well be the conflict of individual ethics versus collective ethics. How can we even consider what some today label 'the right' a woman has to make her own health decisions against her responsibility to society? What are the ethics of screening centres encouraging or coercing women with scanty, unbalanced information to come for screening because "It's well worth it!" [9] simply to achieve recruitment targets? What are the ethics of not asking for consent, knowing it would probably limit recruitment? Where should the responsibility lie for deciding health priorities—with the politicians, the profession or the public? Has proper consideration been given to fairness and equity in terms of the cost, both psychological and financial, of one life saved through screening? Is it right for the profession to initiate an interaction with healthy people which requires a target 70% uptake to make the system work?

A breast cancer patient really only becomes one, so mysterious is carcinogenesis, so insidious is the onset, at the moment of diagnosis. However, breast cancer is not one disease, but many. How then to 'find the disease early' in a healthy population age-band by screening, when 'small', if rapid, may be 'late'; and 'large', if slow, may be both early and not a danger to life?

Fisher's scientific speculation [10] and chilling, inconclusive list of questions in 1992 concerning 'early' are food for thought. So is his view of women's potential for receipt of the 'breast cancer' label in his defined spectrum, where the lowest category are "women who may have no phenotypically expressed lesions and no biological changes in the breast" who, he tells us, "are at risk even though they may have no definable risk factors". His keenness to explore the next Kuhnian paradigm may be scientifically fascinating, but is abhorrent to those assessing the psychological repercussions of such imposition on those unsuspecting women who prefer to live their daily lives with hope and optimism, taking no thought of the morrow, rather than have imposed on them (without adequate balanced information) predictive probabilities, prevention and precautions.

If speed of tumour growth is widely variable, and the natural history not well understood, how are we to determine the screening interval which (as the WHO principles advise) "should be repeated at intervals determined by the natural history of the disease"? The findings in the U.K. concerning the level of interval cancers [11] in the third year which equal those in the general population caused a clamour for two-year, two-view screening [12]. Even if this was affordable and resourced, it would surely call into question the last WHO principle that "the cost of case-finding (including diagnosis and subsequent treatment) should be economically balanced against the benefit it provides" we now have evidence about these neglected aspects. The composite question we should be asking is: what is the optimum interval, the most efficient method, the financial cost and the use of resources, and how does this balance with the benefit/harm ratio economically and psychologically? Is it sufficiently sensitive and specific to detect enough treatable cancers to delay death, and can this be fairly and equitably balanced against those for whom there is no benefit, i.e. those for whom the time of death is not delayed; those who are psychologically harmed (through false positives, false negatives, cancerphobia, delay of recall, false reassurance, etc.); those who receive the 'cancer label' who will never die of the disease, and the majority who will never have the disease?

My diagnosis was DCIS, although I was not informed about this possibility prior to screening. Twenty per cent of screened women aged 50–64 years are diagnosed with DCIS, yet only one in four will ever progress to an invasive cancer, although they bear the cancer label with the penalties that that confers, at the same time absorbing valuable resources.

The public is prone to believe that histopathological findings are black or white: shades of grey are unpopular, difficult to comprehend. They would be shocked to learn the findings of a quality control experiment [13] for the NHS Breast Screening Programme in the U.K. to assess the concordance of opinion amongst a group of some of the best pathologists. This showed that, when it comes to *in situ* carcinoma, whilst nearly 80% will agree that a particular set of slides is *in stiu* carcinoma, 10% will label it atypical hyperplasia and 5% will label it invasive. And this is without subset designation!

It is salutory to remember that the patient is dependent not only on the pathologist's skill, but also on his choice from a range of terminologies to define his observations which will direct the therapeutic decisions of the physicians, the future well-being of the patient and the judgement of insurance companies. Silverstein and colleagues [14] have made suggestions for a new prognostic classification of DCIS; Foucar [15] has suggested that it might be preferable to find terminologies which rather expressed the risk associated with sharply defined categories of histopathological abnormalities, not on fanciful separations of benign from malignant. Baum [16] has suggested that the balance needs to be redressed by tightening up the diagnostic criteria, trying to define the natural history of the pathological subtypes of DCIS and by questioning the nomenclature of the disease, particularly if a subgroup can be defined where there is 100% cure following local excision alone. Yet patients are not aware of DCIS: the NHS BSP leaflets and the latest NHS BSP 1996 report [17] make no mention of it, although its vastly increased incidence since screening have enormous implications for the psychological well-being of patients, and for statistics. Education of the public, enabling them to participate in this debate, would also certainly affect their attitude and beliefs!

My study of DCIS led me to conclude that the patient information leaflet for the U.K. DCIS trial was inadequate. For example: how is it possible for a patient to assess the treatment options if she is unaware of subsets, their potential aggressiveness and consequent potential for both undertreatment and overtreatment? Protracted dialogue with the trial working party and then the UKCCCR (United Kingdom Co-ordinating Committee for Cancer Research) confirmed my hunch that there would be great benefit to trial activity if there was patient involvement at the design stage of trials.

Such involvement would highlight the issues that were relevant to patients, which, in combination with the scientific expertise, would produce better quality studies. It would ensure that the outcomes being addressed were relevant to patients. It would be of benefit by helping to present the trial hypothesis so that: (1) it would appeal to people, who would then want to participate; (2) it is presented in a clear, understandable way; (3) it provides sufficient information to enable them to make a decision; (4) it clearly indicates that there is a need to resolve the uncertainty being addressed and that this must be done within a trial discipline. This partnership in design and presentation would also have the benefit of increasing accrual rates.

The formation of the Consumers' Advisory Group for Clinical Trials in September 1994, demonstrates the value of this working partnership in the design of clinical trials. It is now a Registered Charity, was welcomed by the Health Select Committee in the 1995 Breast Cancer Report [18], and its activity is progressed by the United Kingdom Co-ordinating Committee for Cancer Research (UKCCCR), with funding granted for a project by the NHS Research and Development Executive. Such a working partnership which has the stated aim of "fostering a new attitude to research by working with the medical profession to provide quality research protocols of scientific merit, but relevant to patients, which have been devised in a spirit of collaboration, with shared responsibility and public involvement" has caught the imagination not only of the U.K. but other countries as well.

There is no doubt that the implementation of findings exemplifying this new attitude will be an enormous challenge. It is already apparent that much illuminating material will be generated by this process; it will exercise the minds of those whose responses may be diametrically opposed. However, at the same time, they may see this method as the best way forward to achieve progress, quality and economy in research activity by the convergence of objective and subjective responses, quantitative and qualitative material, scientific and lay perspectives and professional and patient desires for outcomes. It is as well that we recognise that this marriage of opposites will not be easy. It is also perfectly clear that we have no alternative but to attempt to engage in this quest for a partnership: to have identified a moral responsibility and then fail to accept it is not to be countenanced.

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