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Editorial

Who Truly Represents the Needs of the Consumer Diagnosed with Breast Cancer? Who are these Patients' Advocates? How are they Informed? What, if any, are their Secret Agendas?

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NOT MANY years ago these questions would have appeared irrelevant because it was widely assumed that the paternalistic medical profession would look after all the needs of their patients without the necessity of pressure groups to steer them in the right direction. That is no longer the case, as the medical profession appears to have lost the trust of the lay public and patients with breast cancers and their advocates are becoming impatient with the slow rate of progress in conquering the disease. My own personal experience of some of the patients' advocates whether as individuals or groups would suggest that not all of their agenda are necessarily benevolent. I have witnessed the shrill voice of the feminists who resent the perceived power of the male-dominated profession controlling women's bodies. One such spokesperson has twice publicly declaimed "if men suffered from breast cancer we would have had the cure by now!" On another occasion when speaking at a big public meeting the U.S.A. and reporting on the results of our studies on the psycho-social consequences of breast cancer surgery, I was severely criticised from the floor by a woman who thought it impertinent that a male surgeon should even be studying these issues. There are other groups whose motives seem to stem from a fundamental hostility to the scientific process, they see themselves as advocates of a natural cure and natural ways towards prevention motivating such groups to believe in alternative or so-called holistic medicine. At its most extreme, I suffered the indignity of having half my audience walk out on my lecture in a very rowdy manner when attending a public meeting of the American Cancer Society in Florida, having been asked to talk about my somewhat sceptical views on the value of population mammographic screening. I wonder how many of these women in their righteous indignation recognise that to some extent they were puppets of the medical technological revolution that came up with simplistic solutions to complex problems.

More recently I lived through breast cancer awareness month in England where every underground station had a large poster with a pink ribbon proclaiming that 1 in 12 women develop breast cancer and that we should all be aware of this. Myself and many of my colleagues felt that what was needed was a breast cancer unawareness month to take the pressure off ourselves as clinicians and well women who are being provoked into a state of inappropriate anxiety. I sent away for the information pack that accompanied this campaign and was dismayed to read all the futile recommendations concerning the prevention and early detection of breast cancer. Once again women are being urged to practice monthly breast self-examinations, lead a "healthy lifestyle", eat a diet low in fat, exercise regularly, stop smoking and see their doctor for an annual check-up. None of these activities are evidence based as far as preventing breast cancer or as far as reducing mortality from the disease. I wonder if those well-motivated individuals behind the campaign realise that by perpetuating these myths and pretending that there is a simple quick fix to prevent breast cancer and reduce breast cancer mortality, they are merely distracting from the real issues and putting back their cause by years.

What is needed is a well-informed federation of all the stake-holders in the game. First and foremost are the patients themselves; second, their sisters and daughters who might develop the disease in the future; third, the profession either at the bench or in the clinic who are devoting their lives to try to improve length and quality of life for women with the disease; and last, but not least, those who control the purse strings for the research budgets and the clinical services.

In this issue of the *European Journal of Cancer*, we at last hear a voice of sanity from one of these "consumers" begging us to set the new agenda (pages 825–828). According to Hazel Thornton, it is time that the patients and the profession shared responsibilities and shared their experiences from both sides of the consultant's desk. Furthermore, someone from the consumer's side has at last uncovered the subtle deception and the parsimony of informed consent perpetuated by the advocates of mammographic screening. Someone at last has drawn attention from the consumer's

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side of the desk to the peculiar reversal of the conventional ethic of doctor–patient relationships. General practitioners are asked to be agents of the state rather than agents for the care of the individual woman. How many women summoned for screening recognise that only two or three out of 1000 might benefit from a decade of screening against the many individuals who will be harmed in the ways described in Mrs Thornton's paper. One of the problems that I recognise in this area is the difficulty the lay public have and for that matter many doctors in translating the relative risk reductions for screening into absolute benefits for the individual. For example, the breast cancer awareness month publicised the popular belief that 1 in 12 women will get breast cancer. What is never made clear is that this 1 in 12 applies to women who should be lucky enough to live to the grand old age of 85 and that the women in the age group who are invited for screening have a risk of developing the disease at a rate of 2 per 1000 per year. As a result of all this publicity, women grossly overestimate their risk of developing breast cancer and as a result grossly overestimate the benefits of screening. Black and his colleagues published a paper last year in the *Journal of the National Cancer Institute* that describes how even well-educated women overestimated their real risk of getting breast cancer 20- to 30-fold and their benefits from screening 100 or more fold [1].

As Hazel Thornton points out, the dissenting voices have always been muzzled or marginalised and perhaps the time has at last arrived when there should be a public debate involving all the stake-holders listed above to decide on the allocation of scarce resources, both for research and the treatment of breast cancer. Surely it would make better sense in the short term to implement the recommendations of the Select Committee of the House of Commons, U.K. on breast cancer services so that all women suffering from the disease have equal access to specialist clinics [2]. As no new money has been provided by the U.K. Government to implement these recommendations, why not at least abort the clinical trial for screening of the under fifties and use those millions to improve the chances of those women who already have symptoms of the disease.

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1. Black WC, Nearse RF, Tosteson ANA. Perception of breast cancer risk and screening effectiveness in women younger than 50 years of age. *J Natl Cancer Inst* 1995, 87, 720–731.
2. Breast Cancer Services. Health Committee, House of Commons Session 1994–1995. London, HMSO, July 6, 1995.