

THE BRISTOL CANCER RESEARCH: A Patient's View

by Heather Goodare

Self and Society's editorial (Jan/Feb 1991) stated that the fundamental "error in the design and interpretation of results" made by the research team investigating survival of breast cancer patients attending the Bristol Cancer Help Centre "would have been spotted by any first-year undergraduate on a degree course in the social sciences". Or indeed by any patient in the study itself.

I was one of these patients, and I knew from my own experience that going to Bristol had been life-enhancing; to suggest that it might have made my prognosis worse was intrinsically absurd. It was plausible perhaps to suggest that it might not have lengthened my life, but ridiculous to suppose that it might have shortened it. Anybody who had actually refused orthodox treatment had been screened out of the study; how could relaxation and a vegetarian diet, in addition to orthodox treatment, have worsened my chances of survival so spectacularly? Moreover, how could valid conclusions about survival have been reached after less than two years into a five-year study? At the time of publication I had in fact survived for nearly four years disease-free.

Younger Women

The figures given in the original report: that Bristol patients were twice as likely to die and three times as likely to relapse as the control group receiving only NHS treatment, were clearly implausible, so the intelligent reader looked for differences between the Bristol cases and the control group to account for this. These differences were easy to spot: the main one was that the Bristol patients were on average younger than the controls. Surely, I thought to myself, it was a well-known fact that tumours grow faster in younger women? I checked this out with several health professionals, and they agreed, but could point to no research papers to confirm it. The correspondence in *The Lancet* gathered momentum, and this point was referred to by Drs Jean Monro and Mark Payne ('to ignore the difference in age distribution is not acceptable'), but the researchers did not revise their original statement that 'menopausal status is not a strong prognostic factor for breast cancer'. This puzzled me greatly.

Over Christmas a chance meeting with an old friend put me in touch with a doctor at Mount Vernon Hospital, engaged for many years on breast cancer research. Her findings, just published in *The British Journal of Radiology*, confirmed my hunch that on average 'younger women have more rapidly growing tumours' and 'their

metastases show up sooner'. These findings also confirm those of previous workers. This is not to say, as I understand it, that the long-term prognosis of younger women is worse, simply that if you inspect the data after less than two years, which is what the ICR researchers did, the younger women will appear to be doing worse.

Surely here was the 'ghost in the machine' that Penny Brohn (co-founder of the BCHC) suspected might be at work? At the time of writing, this point has still not been acknowledged by the researchers.

Sadness and Distress

And what of us, the subjects of the research? Are we to be consulted about what happens next? Since the data we supplied in annual questionnaires on compliance with 'Bristol' therapies (including following 'the diet') were not used in the report, the Bristol programme itself has not yet been evaluated as an aid to survival. Instead, guesses were made about the effect of following the diet, and (without asking us) about why we chose to go to Bristol in the first place. Despite the gloomy prognostications in the report, more than a third out of the original 334 are apparently still alive. The issues arising for us now being addressed in the newly founded Bristol Survey Support Group.

My personal feelings are of regret (that a project that might have been enlightening, if the research design had been better, has proved abortive), anger (that publication of incomplete and imperfect interim results should have gone ahead without thought for the consequences), frustration (that the time I spent, in good faith, filling in questionnaires, has been wasted), and incredulity (that scientific research could have been so botched). I am also profoundly sad that the whole sorry enterprise has had such a devastating effect on the Bristol Centre and caused distress to so many cancer patients. Another cause for deep shock and dismay was the suicide of one of the report's co-authors, Professor Tim McElwain. Nobody, it seems, has benefited.

Psychology is Crucial

Readers of *Self and Society* will be particularly interested in the psychological and sociological aspects of the problem. The fact that the Bristol cases were on average younger than the controls indicates that more of them are likely to have had young children and so have been subject to stress, which as Amanda Ramirez and others have shown, is another significant prognostic factor. No psycho-social data were sought from us, which seems a curious omission. For me personally, I believe psychological factors were crucial, both in the onset of my disease and, with the help of Bristol, in my recovery. The considerable body of research now published on the psychosomatic aetiology of cancer and the psychotherapy of cancer patients is neatly summarised in a recent book by Patrice Guex, *Psychologie et Cancer* (which I am at the moment translating).

To conclude, I should like to outline my own case history, which may shed some anecdotal light on the matter. At diagnosis in December 1986, aged 55, I was Stage 11, node-positive. I had suffered from clinical anxiety and depression (following a sequence of stressful life events) for several years before my cancer became palpable, and had had 18 months' hormone replacement therapy for severe menopausal disorders.

I was treated for depression by my GP and referred to a psychiatrist, to no avail. The turning point came when I was able to talk through my feelings during a week-long visit from my brother, normally resident in Australia. As an amateur he was able to listen empathically, which I now know to be the basis of all good counselling. Nobody else had been able to give me so much time. Within three months I had given up all drug treatment and was functioning and sleeping normally - only to discover my breast tumour.

I asked my GP for his support in going to Bristol, and this was willingly granted. It was obvious in view of my history that any additional therapy that could help my mental attitude and prevent my sinking into depression again would be important to my recovery.

When I tried to tell my oncologist that I thought my cancer was linked with my depression, she dismissed the idea. No counselling was offered (nor, for that matter, any psychotherapy or even advice about exercises: I had to find out about physical rehabilitation from BACUP). I wanted to recover my health, my wholeness, not just have the tumour rooted out. My dis-ease had been my depression: to me the tumour was simply its final physical symptom - the ultimate attention-seeking device.

I found all I was looking for at Bristol, and more. I used visualisation techniques during radiotherapy to very good effect, preventing burning and nausea. My blood count remained normal on the recommended diet, which I found palatable and refreshing. During treatment I drove myself to hospital and back (a round trip of 42 miles) without difficulty.

Good GP

Soon afterwards I resumed my work as a free-lance editor. I felt so well that I took on too much, and became anxious and depressed again, reverting to my former pattern of very early waking and sleeplessness. Fearful of a relapse (into depression, not cancer), I consulted my GP. "Have you been doing your relaxation and meditation?" he asked. I had to admit that I had let it slip. "Well, there's no point in going to Bristol and not following the programme", he said somewhat tartly. He prescribed a week off work and an outing to the sea. I resumed my meditation, and I have never looked back since.

The future, it seems to me, lies with greater co-operation between orthodox and complementary medicine, exemplified by my truly holistic GP. The patient should not be the battle-ground for gladiatorial combat. In the past it has sometimes needed a lot of nerve on the part of patients to defy their consultants and go to Bristol for therapy not available locally on the NHS - in my case, psychological counselling. It would be tragic if recent events were to make things even more difficult for cancer patients seeking emotional support at a time of stress.

In an effort to contribute towards filling this gap I am now training as a counsellor myself, and playing my part as a supporter in cancer self-help groups and national organisations such as the Breast Care and Mastectomy Association. Should we not be looking at ways of preventing breast cancer through prophylactic psychotherapy, particularly at times of crisis such as divorce or bereavement, rather than putting resources into hypothetical chemopreventive agents such as tamoxifen for which the long-term risks are still unknown and the short-term side-effects inadequately monitored? I look forward to the day when every district general hospital offers complementary therapies to people with cancer; only then, possibly will the Bristol Cancer Help Centre be redundant as a place of pilgrimage for patients from all over the world, and be able to fulfil a new role as a training centre for health professionals.

Full references are available. S.a.e. to Self and Society, Gale Centre Publications, Whitakers Way, Loughton, Essex, IG10 1SQ

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Back to the cold war of healing

John Illman on a blow to 'alternative' treatments of cancer

ELEVEN YEARS ago Penny Brohn learned she had breast cancer. Her first feeling was one of helplessness. She claimed that a response to the "There is something about..."

ments were restricted to counselling, relaxation, group therapy, healing and visualisation (a technique described by Betty Upton Jacobs). Professor Sikirica

only expert to the Bristol Cancer Centre and to claim: "If all you listen to is the poor prognosis from the hospital and the head-shaking pity of our friends, then we run a very serious risk of becoming a self-fulfilling prophecy and dying because that's what society expects us to do."

The Bristol philosophy is all about mind and body medicine. Featured in the BB2 series A Gentle Way With Cancer, and visited by Prince Charles. Bris-



Betty Upton Jacobs explains how

Picture story

WHEN I felt anxious before my operation, I imagined a crack in my subconscious, full of fear. I pictured a welder's flame penetrating the crack, burning away the fear and joining the two sides

To begin with it was easy. In the case of patients are encouraged to visualise the two warring armies, at the body's counter-attack