Enraged about radiotherapy

Karol Sikora

The use of radiotherapy in treating breast cancer has meant that many women are able to avoid mastectomy, which is both physically and psychologically damaging. The side effects of radiotherapy, however, are given little attention. Many women have developed brachial plexus injury after radiotherapy for breast cancer, often resulting in severe pain and loss of use of the arm. There is no effective treatment for this injury and little help can be offered. In addition, many of the women did not require radiotherapy of nodal areas. A pressure group has been formed to support these women, to establish the right to compensation, and to ensure that radiotherapy regimens given to future patients will not damage the brachial plexus.

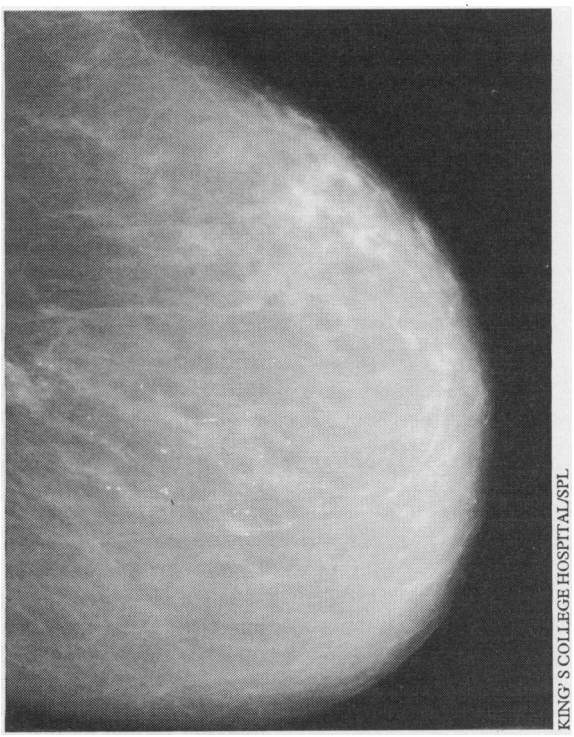
Radiotherapy is an essential treatment for many women with breast cancer. Irradiation of the breast and surrounding draining lymph nodes after surgical removal of the primary tumour means that many women do not need the more mutilating procedure of mastectomy, which has an increased risk of local recurrence.[1] Unfortunately, radiotherapy can produce long term side effects, including damage to normal structures in the volume of tissue irradiated.[2]

Before 1960 some form of mastectomy was the most commonly used treatment for breast cancer, and few women received radiation as part of primary treatment. During the 1960s conservative approaches, which avoided mastectomy, were developed. These often used orthovoltage radiotherapy. The dose was limited by the tolerance of the skin which became red and inflamed. Higher energies of radiation became more common as the skin was no longer the critical tissue because the higher energy photons deposit their energy beyond the rapidly regenerating layer of cells just under the skin. This led to the use of higher total doses and, in some centres, larger individual fractions of radiotherapy.[3] Such hypofractionation was logistically attractive as more patients could be treated at any one time within a centre. Although many studies have been made on normal skin reactions, the effects of radiotherapy on nerve tissue are less well documented.[4] Such neurological damage develops more slowly and is usually permanent.

Since the key paper in 1966[5] over 100 papers have been published that document the development of irreversible brachial plexus injury in women who have had radiotherapy for breast cancer. Most studies put the incidence at 1-4%. Once the damage has occurred little can be done to help. Physiotherapy, compression bandages, slings, prolonged rest, steroids, and surgical decompression have little effect on the progressive functional decline of the affected arm. To make matters worse, radiotherapy to the nodal areas was probably unnecessary in many of the women.[6]

The fight for support

Radiotherapy Action Group Exposure (RAGE) is a pressure group formed to highlight the plight of these women. It offers support and help as well as having a defined mission. Many of its members are angry at being dismissed as cranks by their doctors and at being told that because their cancer is cured they are fortunate and should not complain. I have much sympathy with these women—their permanent injuries are in many cases extremely serious, disrupting their lives completely. Most have lost the use of a hand or arm and many suffer intractable pain. It has cost some of them their careers and others their marriage. Several have had amputations because of persistent pain in a useless limb.



KING'S COLLEGE HOSPITAL/SPL

Radiotherapy has reduced the number of women requiring mastectomy for breast tumours

There are three issues that RAGE wishes to address —firstly, how to stop women getting this problem in the future; secondly, how best to help those affected now; and, thirdly, to tackle the legal issues which have remained open since the Lady Ironside case. In 1991 Lady Ironside went to court to sue the Royal Marsden Hospital for a brachial plexus injury after radiotherapy. The trial was stopped after three days with no verdict and both parties agreed to share the costs incurred.

The first step is clearly to get to the bottom of the problem. There are several possible causes, including an individual having increased sensitivity to radiation; too high a dose of radiotherapy being given; the use of too large a fraction size; too short a total treatment time; a large axillary boost resulting in a high brachial plexus dose; an overlap of tangential breast and supraclavicular nodal fields; or an error in calculating the dose.

With the help of legal advisers, RAGE has put together the results of a questionnaire based on over 1000 women whose lives have been severely affected by brachial plexus injury. Although full analysis would require access to each woman's treatment plan, some alarming features are beginning to emerge. There seems to be considerable clustering of affected patients to certain hospitals and year of treatment, suggesting that technique rather than individual radiation sensitivity is the problem. Furthermore, there is an asso-

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ciation with the use of high treatment doses and large fraction sizes. I believe that the culprit is overlap between fields. This could potentially more than double the biologically effective dose received by the brachial plexus and the problem would be magnified in those centres using higher doses or larger fraction sizes.

Need for a fair hearing

The women belonging to RAGE have tried all reasonable avenues to achieve their goals and have reached an impasse. They have been to their consultants but were not always greeted sympathetically. After appealing to the Department of Health they received a "so sorry but don't worry" letter from Baroness Hooper enclosing the Macmillan Fund leaflet *Help is There*, which lists some cancer information telephone numbers. They have had a tea party with the President of the Royal College of Radiologists and have written to all the cancer research charities. They are becoming a bit more aggressive and I believe they deserve a fair hearing. The alternative is to leave it to the law—an expensive and often time consuming way to provide a solution. Here the test will be whether a reasonable body of medical opinion would, using the knowledge available at the time, have sanctioned the treatment received.

One way out of the current impasse would be an independent inquiry to consider all the evidence. The inquiry could determine whether compensation is indicated, thus saving expensive lawsuits later. It could also consider the need for special clinics for these women, where counselling and specialist physical help would be available. The clinics could work in collaboration with the treatment centres, which would also allow a proper register of these patients to be compiled. There are precedents for this type of process—for example, the inquiry into the use of factor VIII contaminated with HIV in haemophilia. The inquiry's findings would benefit not only affected patients but all women who are treated for breast cancer now and in the future. Action needs to be taken quickly as the media could make mincemeat of the professional complacency some have shown so far.

British radiotherapy services are overstretched. Staffing and equipment shortages are well documented.[7] There is also good evidence of wide variation in the doses and technique used to treat many patients.[8] Such variation does not make sense. Why should one hospital use 15 fractions and another 30 to treat exactly the same disease? Either one is using suboptimal treatment or the other is wasting resources. This variation, the RAGE women, and the large scale dosimetric errors seen in Exeter and Stoke together with several so far unpublished problems elsewhere highlight the need for an urgent and comprehensive review of Britain's cancer services.

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All Africa conference on tobacco control

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Although the health hazards of smoking are now generally accepted in most Western countries, the arguments have not had much impact on poorer nations. A conference on tobacco control held in Harare, Zimbabwe, in November last year was the largest to tackle this problem. The conference heard how threats of epidemics of tobacco related disease in the distant future held little weight with governments of countries that often already had massive public health problems. More immediate effects needed to be emphasised. Speakers gave three cogent arguments; firstly, the loss of capacity for foreign trade in essential goods, since most African countries are net importers of tobacco; secondly, the extensive deforestation which is occurring to fuel the flue curing of tobacco; thirdly, evidence from Papua New Guinea that raising taxation on tobacco provides governments with increased income for many years before a decrease begins.

The largest and most important pan-African conference on tobacco control to date took place in Harare, Zimbabwe, on 14-17 November. One hundred and ten delegates from 16 African nations and seven other countries attended, along with a huddle of representatives of tobacco growers. Well before the opening session the organisers knew the conference was being taken very seriously by the tobacco industry. Zimbabwe is the second largest exporter of tobacco leaf in the world and derives more than a quarter of its export earnings from the crop so the political sensitivities surrounding Zimbabwe's hosting of the meeting were acute. Proof of industry concern was contained in a local magazine that commented that "the world's tobacco manufacturers are extremely alarmed [since] the conference will attract a wide cross section of the anti-smoking industry's groupies who are known to be particularly virulent, if not necessarily well-informed."[1]

Symbolically, the opening session was momentarily disrupted by a brass band playing *Nkosi sikeleli Afrika* (Zimbabwe and the African National Congress's national anthem) at a function in an adjoining room. The uplifting strains seemed to portend a coming of age from a decade of rather tentative participation by African health and development workers in workshops and meetings. Much of this participation had been focused around the preoccupations of the World Health Organisation and the International Union Against Cancer that the health consequences of tobacco use will add to the continent's current burden of death and disability caused by communicable, parasitic, and vector borne diseases including AIDS, and by poverty, hunger, and violence.

Strength of the disease prevention argument

The appropriateness and immediate political appeal of using disease prevention as the basis of campaigns for tobacco control in Africa was often questioned at