Routine follow up of breast cancer in primary care

Follow up by non-specialists should not be encouraged

EDITOR,—While I welcome new initiatives in the management of breast cancer, I believe that the study by Eva Grunfeld and colleagues must be interpreted with caution.¹ The authors report no delay in the diagnosis of recurrent breast cancer or reduction in the quality of life of patients randomised to follow up by their general practitioner, but their conclusions must be questioned. The data on recurrence are based on a short follow up (18 months) and small numbers (10 women followed up by their general practitioner, 16 followed up in hospital), and the comparisons of quality of life are flawed. Women randomised to follow up by their general practitioner knew that they were under special surveillance, which is different from being "discharged" from hospital. A third of women declined to enter the trial even under these circumstances.

Guidelines drawn up by the breast surgeons' group of the British Association of Surgical Oncology recommend that a breast clinic sees a minimum of 50 cancers a year, rising to 100-150 to be cost effective,² and this view is endorsed by the senate of the royal surgical colleges. Grunfeld and colleagues' study seems to lend support to the development of double standards, encouraging follow up by non-specialists, who individually will see less than one recurrence every six years (from their figures). This is surprising, because the detection of recurrence is often difficult, particularly after breast conservation and

when metastases present with more generalised symptoms such as hypercalcaemia, lymphangitis, and retroperitoneal disease. Claims for compensation for delay in the diagnosis of breast cancer are second only to those arising from the birth of neurologically impaired infants in the United States,³ and litigation in this field is increasing in Britain. A policy that endorses double standards would be difficult to defend in court and might place well intended general practitioners in the firing line.

Common sense must prevail at a time when the Department of Health (which funded this study) seems intent on a wholesale shift of health provision towards primary care. Patients deserve more consideration than this, with the need for surveillance being decided by personal prognosis⁴ rather than political expediency.

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Study of open access centre for patients with breast cancer is planned

EDITOR,—Routine follow up of patients with breast cancer is believed to serve two main purposes: to provide early detection of loco-regional recurrence and new primary tumours and psychosocial support for the patient. Since it does not, at present, translate into improved survival, early detection of distant metastatic disease is not a priority.^{1 2}

The clinical trial reported by Eva Grunfeld and colleagues suggests that the two main aims of follow up in breast cancer may be achieved as well by general practitioners as by specialists.³ Perhaps more interesting is the finding that most (69%) recurrences (distant, regional, and local) were discovered by patients themselves. We recently investigated the mode of presentation of locoregional recurrence of breast cancer. We reviewed the charts of all 579 patients with stage I-III breast cancer seen in 1982 at our institution, who were treated by mastectomy (367 cases), lumpectomy alone (53 cases), or lumpectomy plus radiotherapy (159 cases).

Between 1982 and 1996 only 13 patients were lost to follow up. Locoregional recurrence was diagnosed in 184 patients. Recurrent disease was first detected by the patient in 79 cases. Recurrences were also detected at routine mammography (13 cases) and at visits to doctors other than an oncologist (40 cases). In 18 cases the method of detection was unknown. Only 34 locoregional recurrences were detected at routine visits to the oncology clinic. Although patients may see hospital based follow up as "their best defence against recurrence of their cancer,"⁴ the belief that routine follow up at an oncology clinic is an efficient method of

detecting recurrence is illusory. It is also questionable whether a busy ambulatory care clinic is the ideal environment in which to provide the emotional support needed by patients with breast cancer.

Given the limitations of routine follow up, we plan to establish a breast cancer resource centre at our institution. It will be staffed by an advanced practice nurse, and patients will be able to attend it whenever they have concerns relating to breast cancer. We will carry out a study to measure the use that patients make of this facility as well as a controlled, prospective evaluation of the influence it has on survival, time to detection of recurrence, quality of life, and cost effectiveness. Certainly, our observations suggest that, given sufficient education and support, patients with breast cancer are well placed to take greater responsibility for their care than is currently the norm.

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- 1 GIVIO Investigators. Impact of follow-up testing on survival and health related quality of life in breast cancer patients: a multicenter randomized controlled trial. *JAMA* 1994; 271:1587-92.
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More use should be made of specialist nurses

EDITOR,—Eva Grunfeld and colleagues' randomised trial in patients with breast cancer compared community follow up by general practitioners with follow up in a hospital oncology clinic.¹ This is an important contribution to our understanding of selected consequences arising from competing surveillance regimens after treatment for operable breast cancer. The rising incidence of breast cancer imposes increasing costs, borne by individuals, the health sector, and society. The end points of the authors' trial were clinical (the time to diagnosis of recurrence and quality of life related to health). These did not differ between the two arms of the trial. The trial did not, however, include any parallel or integrated economic evaluation, which might have identified the more cost effective mode of follow up.

Having a suitably trained clinical nurse specialist to undertake clinical follow up in conjunction with doctors may provide an alternative model. With the increasing trend for patients with breast cancer to be managed in specialist centres as a result of the Calman proposals,² we expect that the follow up of patients will remain hospital based rather than become community based. There is growing evidence that the involvement of specialist breast care nurses is beneficial during primary treatment.³ Recently, Hammond *et al* described an innovative scheme

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in which a nurse practitioner undertook outpatient clinics for patients with breast cancer interchangeably with a senior house officer.⁴ Randomised trials of follow up in breast cancer are needed in which the clinical and cost effectiveness of specialist nurses and doctors are compared.

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Open door and listening ear are best support for patients

EDITOR,—The data presented by Eva Grunfeld and colleagues confirm clinical experience that most recurrences of breast cancer are diagnosed by the patients themselves, who present to their general practitioner between routine hospital visits.¹ The question therefore raised is not whether routine follow up can equally well be done in general practice but whether it should be done at all.

The only justification for routine follow up is when—as, for instance, in bladder cancer—the early detection of asymptomatic recurrence offers the patient appreciable benefit. Before devolving the discredited “no sign of recurrence” clinic to general practice we must address the fundamental question of what it is we are trying to achieve. I suggest that if we want to help and support our patients with breast cancer then an open door and a listening ear are better than the traditional follow up ritual.

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Most recurrences after breast conservation are detected by regular hospital visits

EDITOR,—Eva Grunfeld and colleagues state that most recurrences of breast cancer (18 out of 25) were detected by the women themselves between routine visits.¹ One must be clear why patients with breast cancer have regular follow up. It is not to detect metastatic disease, as there is clear evidence that early detection and treatment of such disease do not produce benefits.² The aim is to detect local recurrence so that treatment can be introduced at a stage that optimises the probability of maintaining long term locoregional control.

We have recently reviewed recurrences occurring in the breast after treatment by wide local excision and radiotherapy. In a series of 55

patients 10 such recurrences were detected by patients themselves, 23 by regular clinical examination in our follow up clinic, and 22 by annual mammography. Recurrences detected by patients were larger than those in the two other groups. Of the 23 detected by regular clinical examination, eight were not visible on mammography. All but one patient with an asymptomatic recurrence were free of metastatic disease and were suitable for a further excision or a mastectomy, compared with six of the 10 with symptoms.

Our data show that regular clinical follow up does detect local recurrence after breast conservation. After surgery and radiotherapy breasts are difficult to assess, and detecting local recurrences requires specific training. In the Edinburgh Breast Unit trained breast physicians undertake long term follow up of these patients. Each patient is assigned to a specific doctor, and this gets round the biggest complaint of patients attending long term follow up clinics, which is that they see a different doctor each time they visit. It is also a cost effective use of resources, with each doctor seeing 20-24 patients per session.

As Grunfeld and colleagues point out, their study “provides only limited information about local recurrence.” Our data suggest that, in contrast to metastases, over 80% of recurrences that develop after breast conservation are detected by regular hospital visits. Before regular hospital follow up is abandoned for patients with breast cancer a further study looking specifically at the problem of local recurrence is clearly required.

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Audit Commission's report was based on large samples and up to date data

EDITOR,—Kenneth Scott criticises the Audit Commission's recent report, *What the Doctor Ordered*, for relying on small sample sizes and out of date information.^{1 2} His comments are factually incorrect. The main information about the benefits for patients associated with fundholding derives from the largest survey of general practice fundholders yet carried out, with 1256 replies. The survey was carried out between November 1995 and January 1996 (not 1994-5 as Scott suggests). This makes the survey both more recent and much larger than the survey by the National Association of Fundholding Practices to which Scott refers. Given that the Audit Commission's report was published in May 1996, the four month gap between the end of the survey and publication of the data in a nationally available report may well be some kind of record for timeliness.

Other sources of information included 1308 replies to a survey of fundholding managers in 1994-5 and data on savings and overspending for 1156 fundholding practices in England and Wales, drawn by the Audit Commission's appointed auditors from end of year accounts. These data are unique in both their timeliness

and their ability to show individual variation in performance between general practice fundholders across England and Wales, since the only other sources of data—standard financial returns to the NHS Executive—aggregate fundholders' savings and overspending at health authority level and are published at a much later date.

Other information includes the first nationally published survey of multifunds (in which fundholders pool together a proportion of their management allowance to run a central secretariat), carried out in mid-1995; and information about the growth of fundholding supplied by a survey of health authorities, last updated in late 1995. The least timely data, referred to only briefly in the report, are from 1993-4 (information about the training status and the performance in terms of general medical services of every practice in England, drawn from the NHS Executive's general medical services database; and prescribing data for a sample of practices supplied by the Prescription Pricing Authority and the Welsh Office).

Scott is correct in stating that the information from the large scale survey was supported by visits to 56 practices, during which we discussed fundholding with doctors and managers; to my knowledge, this is the largest number of practices visited by any single study. Finally, the study team visited 27 health authorities (not 15) and 15 NHS trusts (not 12).

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Child protection

Referrals to social services may be damaging

EDITOR,—The ethical debate highlighting the problems of the child protection system discusses a particularly difficult case.¹ The child protection system is the social services' equivalent to the consequences of defensive medicine. Social services research shows large variations in practice^{2 3}—for example, in 1992, registrations for abuse in 110 local authorities varied from 0.8/1000 children to 18/1000, with a mean of 3.5/1000. Gloucestershire, with the lowest rate, includes a considerable industrial area. What is so special about its practice? The research calls for social services to develop their services to be more “family friendly.”

Why do parents complain of being intimidated and not helped? One reason is the case conference. Here parents face a proliferation of professionals: representatives from social services for every field of contact with families, each with a supervisor; legal representation for the social services (never mentioned in any government guidelines); and police officers, even when the police have not been involved in the case. Professionals involved in a case often change between meetings, so that continuity is lacking.

Professionals promote their own practice. A particular concern is the degree to which solicitors push conference plans to a legal solution. Humanity, time, and money (from uncapped budgets) are lost in the law courts. These practices are long overdue an inspection by the Audit Commission.

With more serious issues the role of social workers becomes clearer: they are acting as the