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Cancer in the UK — a question of culture

S.M. Crawford *

Airedale General Hospital, Skipton Road, Steeton, Keighley, West Yorkshire, BD20 6TD, UK

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In the *European Journal of Cancer* in December 1998, a group of European epidemiologists published the findings of their second study comparing the frequency and outcomes of a wide range of cancers between their various countries [1]. This, the EUROCARE II Study includes cancers diagnosed between 1978 and 1989. England and Scotland and, therefore, the UK National Health Service (NHS), come out of this very poorly because the 5-year survival rates for all the common cancers fell well below the European average. That European average was reduced by the inclusion of several East European countries with less well developed health services, so for a service which claims to have provided comprehensive, accessible healthcare to every citizen of a relatively prosperous country this is a major failure.

It has been argued that the disparities are an artefact of different standards of registry data collection. Apart from the care that has been taken to avoid this, other comparisons suggest that the differences are real. For example, in a comparison of lung cancer cases recorded in the Eindhoven (The Netherlands) and Yorkshire (UK) registries, the differences in survival were associated with practice differences which produced different rates of histological diagnosis [2]. The majority of patients cured of lung cancer are those with non-small cell disease treated by surgery and fewer tumours are resected in the UK than elsewhere in Europe [3]. The survival of patients who are not cured is so short that other sources of difference, such as lead time bias, are most unlikely to affect the 5-year survival. The cancer registry processes do not differ between primary sites and The Netherlands data for survival consistently show superiority over the UK, so it is likely that differences in the other sites are equally real.

The sites where the UK performance was worst, in that the 95% confidence interval of the 5-year survival estimate did not overlap with that of the European average, are listed in Table 1. It is essential that we understand how this has come about. In my view, which has been formed from listening to the attitudes expressed by colleagues in the UK and elsewhere over the past three decades, there has been a culture among NHS doctors which has resulted in much of the progress that has been achieved in cancer management passing them by.

England has had specialist centres providing expert treatment for cancer for over 40 years. The late Enoch Powell was the Minister for Health who realised that it would be more cost-efficient to deliver radiotherapy if the equipment was centrally located. A pattern of practice became established in which consultant radiotherapists, who acquired broad expertise in the non-surgical treatment of cancer, were based in these centres and conducted clinics in general hospitals where new patients could be seen and those who had been treated followed-up. This approach, which is the mainstay of contemporary practice, means that every hospital specialist in the country knows which cancer specialist is designated to serve his or her patients. It has not produced a culture of specialist management of cancer.

I was a student in the early 1970s when the Powell model for providing radiotherapy was well established, but when, apart from the interesting results being seen in haematological and childhood cancers, chemotherapy had little to offer. Hormone-sensitive cancers were treated by destruction of the relevant gland or the administration of simple hormone preparations as appropriate. Our teaching reflected this; by and large, cancers that could not be excised or treated with local radiotherapy were beyond further help, so the services of a cancer specialist were not needed. As a consequence, once it had been concluded that advanced cancer was present, or even likely to be present, there was no need to investigate further.

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* Tel.: +44-1535-651189; fax +44-1535-295319.
E-mail address: moncam@cix.co.uk

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Table 1
Cancer sites where the 5-year survival in England is well below the European average[a]

Males	Females	Sex not specified
Stomach	Stomach	Kidney
Colon	Colon	Chronic lymphocytic leukaemia
Lung	Lung	Chronic myelocytic leukaemia
Prostate	Ovary	Multiple myeloma
	Breast	

[a] Adapted from Coebergh and associates [1]. 95% confidence intervals mutually exclusive.

This approach pertained throughout that decade. The consultants and general practitioners (GPs) who were trained then are the senior doctors of today, who teach subsequent generations of GPs. The radiotherapists were rarely seen by doctors practising and training in other fields because their commitment to general hospitals was, and usually is, confined to a weekly visit, much of which was taken up by a very busy outpatient clinic. There was, and is, little or no time to participate in the professional development of other specialists and certainly not that of GPs. Their colleagues therefore continue with the understanding of oncology which they acquired during their training.

The resourcing of services in this period reflected the low demand for cancer treatment facilities, and determines to a large extent what is available today. Sikora has argued that the lack of oncologists practising in the UK is, at least in part, responsible for the EUROCARE II findings [4]. The fact that, although oncology services are ill-supplied, they are not associated with the serious waiting list problems associated with high demand demonstrates attitudes within the NHS.

During the early 1980s, we saw the establishment of new hormonal treatments and chemotherapy was beginning to be recognised as being of value in some of the common cancers of adults. Radiotherapists by this time were called ‘radiotherapists and oncologists’ to reflect the wider use of other treatments. This was the era that the EUROCARE II project studied [1]. The UK results in that study for gynaecological cancers epitomise what was happening. Cancer of the body of the uterus is readily diagnosed because its main symptom, postmenopausal bleeding, is well recognised as needing urgent investigation. A straightforward hysterectomy cures most patients. The UK survival figures are as good as those elsewhere in Europe. Screening for cancer of the cervix has been established practice in the UK for many years so a high proportion of tumours are identified early and treated by surgery or radiotherapy. This is a tumour in which the UK’s performance compares very favourably with the rest of Europe. Cancer of the ovary is not easy to diagnose early and the advanced disease requires, in addition to skilled gynaecological surgery, the input of the oncologist because, as was recognised at this time, chemotherapy using the drugs based on platinum is needed to maximise the survival prospects of the individual patient. The only drug in this group that was widely available throughout the 1980s was cisplatin, which requires considerable expertise for its safe administration. The cost of cisplatin at that time was very high and many doctors expressed the opinion that it was prohibitive. Not infrequently, this was given as a reason for not referring patients to oncologists, so treatment was denied. UK results in ovarian cancer were very poor.

The question of timely diagnosis is important here. Most NHS patients consult their GPs about their ailments; when these are obvious symptoms of cancer, early referral is usual. When the symptom is a common complaint that is sometimes due to cancer, the problem the GP faces is much trickier [5]. For example, an early symptom of colorectal cancer is the presence of blood in the faeces. Most patients with rectal bleeding do not have bowel cancer, so when a GP advises a patient about the simple measures required to treat piles, he or she will have the satisfaction of being proved right most of the time. Thoughts of referring these patients with rectal bleeding for formal exclusion of the possibility of a cancer are inhibited by the waiting times for specialist assessment and a perceived need to protect the hospital service from excessive demand. When patients are referred, the assiduity and accuracy of the GP’s assessment is low [6]. These are the processes which resulted in the colonic cancer of the television presenter Lynn Faulds Wood being missed for many months. She has established a charitable trust to promote early diagnosis of bowel cancer and to train personnel in colonoscopy. In the EUROCARE study of the outcome for rectal cancer, where the bleeding is more likely to be overt and other symptoms present, the UK performance is slightly better than that for colonic cancer, where symptoms are more vague and rarely due to cancer [7].

The commonest cause of cancer death in the UK is lung cancer. The classical way in which such patients are managed is that the GP arranges a chest radiograph for someone presenting with a persistent chest problem and, on receiving a report that indicates the possibility of a cancer, refers the patient to a chest physician. A recent study of this disease revealed that less than half the patients who are diagnosed with lung cancer follow this pathway [8]. When I have asked GPs their views on requesting radiographs for middle-aged smokers with persistent chest infections, they have argued that radiology departments could only cope with examining a selected few of such patients.

Consider the position of GPs. Most of the patients they see do not have cancer. Chest infections and bleeding piles are common problems. They have to pick out from these the patients with serious illnesses. The pressures from a system whose policy is to minimise costs do not help; they encourage GPs to do as much as possible in primary care and to minimise the use of hospital services. The fact that in the UK we are not very good at treating those cancers where the presenting symptoms do not clearly indicate the diagnosis follows on from this.

There has been some major improvement in services to cancer patients over the past 30 years. We have kept up with the treatment of testicular cancer. The outstanding example is the development of palliative medicine. The pioneering work of Dame Cicely Saunders and others has brought great benefits to the way symptoms of advancing cancer are controlled and to the environment in which patients are nursed. However, the comparatively rapid spread of this approach in the 1970s and early 1980s itself illustrates the problem facing other aspects of the service. Palliative medicine takes patients off the hands of physicians and surgeons who are at a loss as to how to handle those that they feel they can no longer help. It uses cheap drugs and its services do not burden the NHS too much because charities are willing to provide much of the finance. Over this time, palliative care physicians have developed into essential members of the multidisciplinary team that modern practice demands. Palliative interventions which are not intended to affect the biology of the disease do not affect survival; indeed their use is mandated as part of ‘best supportive care’ in the control arm of randomised studies designed to identify an effect of a new anticancer treatment on survival.

Despite very poor results in EUROCARE II, another success story in the UK is breast cancer. During the period of the study, the mortality from this disease plateaued after a period of a steep rise, but it has fallen since the early 1990s [9]. Why might this be? The timing of the start of this trend precludes screening or the development of management guidelines as a cause. Chemotherapy in early breast cancer may have made a minor contribution, but in the early 1990s it was an accepted policy in only a limited group of women, approximately half of whom actually received it [10]. By far the most likely reason is the use of adjuvant tamoxifen.

The Nolvadex Adjuvant Tamoxifen Organisation (NATO) trial was published in 1983 in a widely available journal, *The Lancet* [11]. It showed that a well-defined group of women given this drug after the diagnosis of breast cancer was made had fewer relapses and fewer deaths from breast cancer than did a control group. The results of this study formed the centrepiece of an advertising campaign by the manufacturers, at the time ICI Pharmaceuticals Division. They were well known to the doctors actually seeing the patients, the surgeons in the breast clinic. The prescription pad was the only facility needed to initiate treatment, so the specialist oncology service was not burdened by it. The two years (now five years) standard period of treatment was handled by the GP, so the (not inconsiderable) cost was easily absorbed in that doctor’s drug expenditure and funding was never an issue. This was, therefore, a treatment that was not affected by the obstacles that usually stand in the way of a new treatment for cancer attaining a high market penetration.

The deficiencies in the UK cancer services that the EUROCARE study has exposed were most likely to be due to problems around the diagnosis and surgical treatment of these cancers; chemotherapy was mostly an issue in the survival of patients with ovarian cancer, early breast cancer and some of the less common conditions. In the next few years, chemotherapy will be much more important in the outcome of common cancers, raising the problems that surround the use of new, more expensive drugs. The treatment of ovarian cancer has been enhanced over the past 5 years by the introduction of paclitaxel. In Europe and the USA, this, in combination with a platinum-based drug is the standard treatment [12]. In the UK, its introduction, like that of cisplatin in the 1970s and carboplatin in the 1980s has been inhibited on the grounds of cost. NHS funding authorities, guided by public health doctors trained in the approach to cancer that pertained in previous decades, have felt that a drug that significantly improved its treatment was a legitimate item for rationing.

Paclitaxel and the related docetaxel are very promising drugs in breast cancer, but the funding issue will be of greater significance because there are many more patients. It has not yet been addressed. Irinotecan and oxaliplatin have the potential to make a large difference in the treatment of patients with bowel cancer. They are already becoming standard treatment in Europe. They are likely to result in an even greater financial impact. The manufacturer of topotecan has simply abandoned promoting it in the UK. We have not begun to think about the use of the monoclonal antibody trastuzumab.

The EUROCARE II study teaches us that we must improve the outcome for British people with cancer. This does not mean that we have to go to the American extreme where anything that can be sold to the healthcare consumer, provided he can afford it, is actively marketed with a consequent burgeoning of expenditure. However, to approach a realistic ideal service for cancer patients we need to invest in every step in the sequence of events. GPs need to be encouraged to take a positive approach to opportunities to diagnose cancer that come their way and to use more diagnostic resources to identify these patients in a timely manner. The staff of the general hospitals who investigate these problems need to have sufficient resources and skills to meet an increased workload. The NHS needs many more cancer specialists of all disciplines to treat the patients after the diagnosis is made. They need to have the freedom to practise contemporary cancer medicine without bureaucratic restriction. Cancer specialists also need to interact much more with their colleagues in other branches of medicine. Recent political pronouncements have shown that the Government acknowledges the problem, but so far the amount of new money available to address it is not great and the immediate response to a policy which requires patients suspected of having cancer to be seen in the outpatient clinic within 2 weeks has been to establish means of defending the service against large numbers of referrals.

In my view, it also shows us how a publicly funded system like the NHS is very vulnerable to the parsimonious approach of the authorities. This received considerable publicity in the UK following the publication of an interview with Lord Winston, an academic gynaecologist and supporter of the Government in the House of Lords, the upper House of Parliament [13]. This parsimony damages the NHS both by the direct effect of the restriction of resources and the indirect effect of doctors responding to restrictions by making clinically inappropriate rationing decisions. As Winston said in his interview, "If we don't want (a continually deteriorating Health Service), then we pay more tax or have an insurance system." We also need to change the culture that discriminates against people who have cancer. This has the effect that they are the among the first to be denied treatment in the rationing process, and their needs have been, until very recently, among the last to be drawn to the attention of the funding authorities.

Note added in proof

The increased funding which the UK government has promised since this article was written is most welcome. What remains to be seen is whether or not the way in which it is used will enable NHS staff to adopt a more positive culture and a proactive approach to the management of cancer at all levels of the Service.

Conclusion

Compared with the European average for 5-year survival, the results of cancer treatment in the UK, as measured in the EUROCARE II study, were especially poor for common tumours where the presenting symptoms are ambiguous. This was likely to be due to cultural attitudes. During the study period this will have been the attitudes to the process of obtaining a diagnosis, but in the past decade, attitudes to applying contemporary treatment will have been more prominent. These results are also associated with the low level of healthcare funding in the UK and to consequent perceptions that expenditure should be avoided.

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