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Is There a Need to Follow-up Cancer Patients?

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INTRODUCTION

FOLLOW-UP of cancer patients after treatment remains an expensive and time-consuming cornerstone of clinical activity. A visit to a clinic, which consists of a brief history, examination, a few tests and reassurance seems to fulfil the expectation of the oncologist and the cancer patient alike. The majority of oncologists claim that such follow-up is necessary for the detection of recurrent disease and for patient support. Patients also believe that seeing a sympathetic doctor and having a sprinkling of tests is worthwhile as it will improve their chance of early detection of disease and cure. However, continuing the tradition of follow-up without a more solid basis is no longer tenable.

Potential reasons for follow-up have been extensively documented, particularly following primary treatment of breast cancer [1]. They include early detection and treatment of recurrence, rehabilitation and psychological support. Physicians and governments require monitoring of treatment outcome within and outside clinical trials, and follow-up is a popular component of medical training. These objectives, though worthwhile, may have solutions other than the conventional medical model of follow-up. The primary reason must be benefit for the patient in terms of survival and quality of life. In the patient's mind, the priority for the ritual encounter with an oncologist is also likely to be cure. Does the traditional follow-up improve the chances of cure, and given full information, would the patient still want to come?

FOLLOW-UP AND SURVIVAL

Follow-up after primary treatment of cancer can be viewed as a form of population screening, where the aim of surveillance is early detection and treatment of recurrent disease to improve individual and population survival. There are occasional situations where delayed primary treatment or salvage therapy prolongs survival. These include surveillance following orchidectomy for stage I testicular tumour, or after minimal local treatment of breast cancer. What is the evidence that treatment of recurrent disease detected early by surveillance improves the chances of cure in common cancers which form the bulk of the clinical workload?

There has been considerable interest in the evaluation of routine follow-up practice in the context of breast cancer. While some retrospective studies suggest a survival benefit in patients with early diagnosis of asymptomatic recurrence, this may be

entirely due to lead time and length bias [2]. Two large randomised studies of follow-up after primary treatment of breast cancer examined the value of routine investigations [3, 4]. Patients who had routine radiography, bone scans and a variety of other tests had no better survival than patients followed by history, clinical examination and annual mammograms alone. The GIVIO study [4] also demonstrated that the intensity of follow-up does not affect quality of life (QOL) measured prospectively with a fully validated health-related QOL score. A minimalist surveillance scheme also comes with an enormous cost saving, which in the US was estimated as over \$600 million a year in 1990.

There are a plethora of tests claimed to be of benefit in the early detection of recurrent disease. Biochemical markers such as carcinoembryonic antigen (CEA) in bowel cancer, CA125 in ovarian cancer and prostate-specific antigen (PSA) in prostate cancer are considered useful tools which help the clinician to make treatment decisions. They have variable specificity, sensitivity and predictive value in the detection of recurrent disease and are frequently employed in routine follow-up. While the activity of the disease can be monitored by the pattern of marker level, the value in terms of survival benefit has not been demonstrated. The only randomised trial of biochemical screening for early detection and treatment of recurrent disease was conducted in patients with colorectal cancer [5]. Patients randomised to undergo intensive investigations and second-look surgery as a result of rising CEA had no better survival when compared to patients where CEA information was not acted on. More sensitive markers using DNA technology can detect tumour cells with a sensitivity up to 1×10^6 . There is considerable debate about whether the detection of so few cells represents active disease. While it can be of prognostic significance, there is no convincing evidence that early treatment of such minimal recurrent disease alters prognosis.

Similar arguments can be extended to imaging. An example recently examined in a retrospective study is the value of routine imaging with computed tomography (CT) or magnetic resonance imaging (MRI) after treatment of medulloblastoma [6]. This is a seemingly relevant tumour type which retains chemosensitivity in recurrent setting. Starting from the standpoint that medulloblastoma, despite apparent responsiveness to treatment, is not curable, it is not surprising to find that detection of relapse by routine imaging is not associated with better survival compared to recurrent disease diagnosed following clinical suspicion. It is dangerous to generalise on the basis of relatively flimsy evidence. Yet it is possible to advance a hypothesis that early detection of recurrence of any tumour which is known not to be curable at the time of relapse is unlikely to improve survival. It would be

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reasonable and indeed prudent to put such a hypothesis to the test in a variety of common tumours and employing a range of investigations. These should include the latest fashionable tests and sophisticated imaging.

If investigations are superfluous, is a routine visit relying on the rough screening tool of history and examination of any survival value? In the follow-up of breast cancer, routine visits are not a very effective way of detecting recurrence [2, 7] and are probably not very useful as a screening method [8, 9]. In the absence of randomised data, it is reasonable to conclude that an ineffective screening test is unlikely to be of survival benefit. A routine visit may, in fact, result in a higher false-positive diagnosis rate, causing unnecessary and costly investigations as physicians faced by uncertainty seem to resort to diagnostic tests.

PREVENTING COMPLICATIONS

Every clinician carries a list of anecdotes of his or her clinical prowess that was able to prevent a near disaster. Early diagnosis and treatment of metastatic disease at a particularly unfavourable site is considered useful in preventing or delaying serious complications. There is no doubt that early diagnosis of spinal cord compression before the onset of severe disability improves the chances of functional recovery. However, there is no routine screening procedure other than awareness of the early symptoms of impending cord compression [10] which can aid early diagnosis. The timing of the development of spinal cord compression also does not conform to the pattern of routine visits.

One of the oncological pastimes can be described as "preventive palliation". This consists of detection of asymptomatic disease and "preventive" treatment under the assumption that the recurrent tumour is about to cause problems. The strategy for preventing disastrous and unpleasant complications of cancer is considered a clinical skill, but it should be evaluated in the same way as other surveillance policies, with prospective examination of the accuracy of tests and the effectiveness of early intervention.

WHAT DO PATIENTS WANT?

Medicine in general and oncological care in particular is a service provided for the benefit of the patient. The U.K. consultative document for commissioning cancer services [11] appropriately defines the objective of development of cancer services as "patient centred".

Oncologists seem to have clear views of patients' wishes and believe that a visit to see them is useful and provides reassurance—a perception which is not necessarily representative of the patients' views. When asked, most women with breast cancer after treatment express a preference to be seen in a hospital breast clinic [9] and to have frequent diagnostic investigations [4]. This had led to the conclusion that an important function of the follow-up clinic is 'reassurance' [9], although this entity has not been measured. In a randomised trial of follow-up testing [4], the parameters of health-related quality of life, which included emotional well-being, did not differ between the type of care provided, suggesting no extra 'reassurance' from intensive investigations. Perhaps armed with correct information of the lack of value of clinical follow-up, patients may not be too distressed about omitting routine visits altogether.

If oncological services are to deliver truly patient-centred care, it should be patients themselves who are asked what services they want and what they expect from them. It is likely that the main desire is to be cured. Given the full knowledge that a ritual

pilgrimage to the clinic does not provide any better chance of cure, would a patient still want to come? We should find out.

OTHER REASONS FOR FOLLOW-UP

An important component of post-treatment cancer care is physical, social and psychological rehabilitation. A busy conventional clinic staffed only by an oncologist is unlikely to provide this, as it relies on medical diagnosis and treatment solutions alone. However, an increasing number of oncology clinics focusing on a specific disease type include specialised nurses and other professionals skilled in rehabilitation.

Conventional clinical surveillance allows for prospective monitoring of new therapies in the context of clinical trials. Even outside the research setting, it is important to document the outcome of treatment in the form of regular audit, which requires prospective recording of information on patient and disease status. Regular follow-up is undoubtedly an effective method of collecting data, but it is more for medical than for patient convenience. It is clearly important to continue clinical research, but we should examine alternative means of obtaining outcome information. If regular attendance in an oncology clinic is considered essential, this could be identified as part of a research protocol and not assumed to be routine practice.

ALTERNATIVES IN FOLLOW-UP PRACTICE

Alternatives to conventional oncologist follow-up include surveillance by a primary physician/general practitioner, surveillance by a trained nurse specialist or regular contact by phone. Primary care within the community by the primary physician is considered the focus for cancer care [11], but the value and cost effectiveness of this method of follow-up has not been tested. Who benefits from the replacement of specialist by generalist?

Devolving aspects of follow-up and care to nurses is not new. Midwives function effectively in the monitoring of normal pregnancies and in a large proportion of normal deliveries. Nurses have also been delegated medical tasks such as endoscopy [12]. In oncology, specialist nurses have successfully monitored patients on treatment [13] and in palliative care. Their role has so far not been extended to routine follow-up, but with appropriate training the demands would be well within their clinical competence.

Telephone care can also be an effective substitute for routine clinic follow-up. In a randomised trial of routine general medical follow-up, telephone care resulted in fewer clinic visits, reduced use of medication, fewer admissions to hospital and shorter stays with a significant saving in expenditure [14]. A phone clinic staffed by a nurse specialist rather than a clinician has been introduced in the early post-treatment follow-up after radiotherapy [13]. It provided support and effective medical surveillance. The structured contact with a nurse specialist reduced the number of clinic attendances accompanied by cost saving and increased convenience for the patient. It also allowed medical time to be targeted to patients in greatest need.

LIFE WITHOUT FOLLOW-UP

If it is possible to prove that abolishing regular visits is without detriment to survival and quality of life, and at the same time results in financial saving, why not drop the habit? Perhaps in the first instance we need the reassurance of randomised studies to prove these assumptions. It is also likely that both patients and oncologists would contemplate a life without the tradition of hospital visits with apprehension. What would they lose? Regular visits provide easy access to hospital medicine and

convey a sense of being looked after within a caring system. The contact may also serve other than purely medical purposes which are largely undefined. The overall concept can be described as the caring aspect of medicine.

Cancer medicine is not an industry measured in performance terms; it should remain a caring service and this may be possible without perpetuating the hospital and oncologist centred tradition of follow-up. Personal contact can be maintained on the phone, especially if we have the knowledge of patients' wishes and expectations and the likely content of a routine follow-up visit. The phone clinic model [13] staffed by a nurse specialist could provide and maintain a regular link and surveillance based on clinical history. It would also allow for gathering of basic clinical information.

The most important component of traditional follow-up which needs preserving is easy access to the otherwise forbidding system of specialist care for help and advice. This could consist of a phone help line as an entry point to a comprehensive daytime service, a walk-in clinic or a combination of both. It should allow the patient to be seen efficiently, without fuss and bureaucracy, and exist as an addition to the standard emergency service. It may be possible to construct other models; in every case patients and clinicians must be convinced that all the important aspects of oncology care are met without anyone being put at risk.

WHERE NEXT?

There is little evidence that follow-up of asymptomatic cancer patients influences survival or quality of life. It is a costly system, inconvenient for the patient and without a clearly defined purpose. Perhaps now is the time to consider change. This could include both careful scrutiny of the traditional methods, ideally in the form of randomised studies and the development of new alternative approaches. It is unlikely that a single method of follow-up will be appropriate for all cancer patients, but all could include phone care and contact with nurse specialists and other professionals as alternatives to routine visits to an oncologist. Any change will have to be carefully introduced and prospectively evaluated, and should aim to preserve and improve the caring aspects of oncology.

Medical services are faced with the pressure of increasing demands and limited resources, while wishing to improve patient care. In the follow-up of cancer, it seems we could achieve the impossible—a better and cheaper service. Managers looking

over doctors' shoulders probably rub their hands with pleasure in anticipation of the saving made possible by abandoning the traditional system of follow-up. We must ensure that oncology takes the initiative to develop a rational and more effective alternative before the traditional system is simply axed as a cost-saving exercise.

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