

Issues at the interface between primary and secondary care in the management of common respiratory disease • 1

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The challenge of improving the delivery of lung cancer care

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Lung cancer has a poor prognosis. It is reasonably common in general practice, needs good palliative care, and requires co-operation between several health care teams to be managed well. This article deals with meeting this challenge within the British NHS, but the issues discussed have implications for other health care systems.

The National Cancer Guidance Group (NCGG) recommends that all patients with lung cancer should be treated by a multidisciplinary team led by a respiratory physician, that both the primary health care team and the palliative care team should be fully involved, and that all decisions regarding the patient's management should be rapidly and effectively communicated between these three teams.¹ The report of the Standing Medical Advisory Committee (SMAC) published in 1994,² among others, clearly recognises the place of primary care in the management of lung cancer and emphasises the need for co-operation between disciplines: "The nature and frequency of the disease means that the work of general practitioners and their colleagues must be integrated with that of secondary, tertiary and palliative care if high quality services are to be provided".

Achieving this level of communication and co-operation is crucial if those treating patients with lung cancer are to deliver high quality care.

How common is lung cancer in general practice?

According to the SMAC report,² "in the United Kingdom a group practice of five general practitioners with 10 000 patients will have around five patients dying each year from lung cancer. At least one patient will require palliative care services at any one time". Averages, however, are misleading. There are very large variations in the incidence of lung cancer both between different regions of countries and between different districts within a region.³ Furthermore, there are demographic changes within the population who experience lung cancer which will modify the way that it will present to general practitioners. The median age at presentation is now rising fairly rapidly from 67 to 70⁴ and it has been estimated that,

by the year 2005, 40% of lung cancer patients will be 75 years old or over at presentation (L Rider, personal communication). At the same time the proportion of women is increasing.

In mature post industrial societies lung cancer is becoming increasingly a disease of the elderly poor, particularly in inner city conurbations.

Prevention

Ninety per cent of lung cancer is preventable, primarily through smoking cessation, although present anti-smoking policies in Western societies are not working. Quit rates reflect social class and there is disturbing evidence that smoking rates amongst teenagers are not falling. There is good evidence that anti-smoking programmes based within general practice can reduce the incidence of smoking, and it has been suggested that the average four or five consultations per year in primary care provides opportunities to reinforce the health education messages of formal stop-smoking programmes.⁵ However, it is clear that opportunistic advice alone is rarely adequate.⁶ The problem is almost certainly one of targeting advice and interventions.

Fiscal and general social policies are needed. In addition, it is naive to think that practice based health promotion activities can be successful without further investment. One might compare the success of increased uptake of cervical cytological testing—which was characterised by a national plan, the involvement of practice nurses, computerised recall, and financial incentives—with the wholly unplanned and largely unsupported efforts at smoking cessation. Evidence based assessments of the likely success rate of such a programme point to a figure of approximately 12%.⁷ The availability on prescription of nicotine substitutes and perhaps other drugs⁸ linked to personal programmes might increase this further. Smoking cessation is currently a bleak area of preventive medicine. Creative interventions developed between specialists, primary care, and others could make a real difference, and such programmes could also be linked with spirometric tests to identify individuals at high risk of future disability from chronic obstructive pulmonary disease (COPD).

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Community screening programmes to detect early lung cancers in high risk populations have been disappointingly ineffective^{9,10} and programmes involving complex techniques are unlikely to be cost effective compared with primary prevention. However, two developments may offer some hope. In Japan mobile spiral CT scanners have identified a larger number of resectable tumours than conventional miniature radiography,^{11,12} and the detection of early genetic changes in sputum cytological samples from high risk individuals is promising.¹³

Presentation

It is often assumed that the “usual” presentation of a lung cancer patient is with typical symptoms to a primary care physician who then refers the patient for a chest radiograph. This is not so. Preliminary evidence from a stratified randomised sample of 400 lung cancer patients in a region of the UK has shown that only about 50% of patients present in this way. The other 50% present either acutely to a casualty department or are referred to a hospital outpatient department with symptoms the general practitioner did not suspect were due to lung cancer.¹⁴ It is difficult to see how the rapidity of diagnosis in this latter 50% could be influenced by better primary care activity.

There are, however, two factors affecting the rapidity of diagnosis in primary care which are worth considering. Firstly, retrospective studies have shown an unexpectedly long interval in many patients between the first appearance of symptoms and their eventual presentation to their general practitioner.¹⁵ This has never been subject to a community study, but patients undergoing radiotherapy reported a median interval of more than two months before seeking help,¹⁶ an observation replicated recently in a non-selected UK population.¹⁷ Clearly, if patients were to present more rapidly to their general practitioner, the prognosis, in biological terms at least, would be more likely to be improved than by an equivalent reduction in any subsequent intra-hospital pathway.

The psychology of symptom delay is complex and is not confined to respiratory disease. There is similar evidence relating to the cardinal symptoms of other tumours—for example, testicular growths.¹⁸ A number of factors influence this behaviour including generalised fear and the view that, if something serious is present, then nothing can be done. The question of how early attendance can be encouraged for minor but important symptoms deserves more research, especially if it can identify helpful ways of communicating positive messages to the general public.

The second problem is the speed with which general practitioners recognise and react to potentially serious symptoms. Primary care physicians, particularly those working in areas with a high prevalence of smoking, see large numbers of patients with acute respiratory infection and exacerbations of COPD. Expert advice is often of the form “general practitioners should be particularly alert for mild or

moderate symptoms which persist for two weeks or more, or of a chest infection or an episode of bronchitis which does not settle as expected after a course of antibiotics”.² Such patients, however, are very common and some lower respiratory tract symptoms often persist for two weeks or longer.^{19,20} Research is needed into the predictive value, if any, of these episodes.

It is nonetheless a simple and important message. Undergraduate and postgraduate teaching should emphasise, in addition, two other potential traps for the unwary: the over-ready diagnosis of late onset asthma in ever-smokers, and persistent unexplained chest wall pain which is attributed to musculoskeletal problems. The assessment of both problems should include a chest radiograph.

Primary investigation

The appropriate action to be taken in primary care when dealing with a potential lung neoplasm is clear and unambiguous: all patients should be referred rapidly for a chest radiograph and an opinion on future management. Uncertainty at this time is very stressful for patients.²¹

Possible pathways of referral can be summarised as (1) primary care to chest physician for radiograph and automatic clinical referral with a simultaneous report to the general practitioner; (2) primary care to radiologist with automatic referral to chest physician’s clinic with a simultaneous report to the general practitioner; (3) primary care to radiologist with report to general practitioner and then separate referral by the general practitioner to chest physician with the report.

Most areas of the UK have an open access general practitioner radiography service.²² A recent survey of members of the British Thoracic Society showed that the majority of patients (86%) reach their respiratory physician by the third, potentially longer, pathway. In only 9% of cases did the chest physician both read the radiograph and recall a patient immediately to clinic while in only 5% of cases was this done by the radiologist.²³

There are anxieties in primary care about the automatic referral of patients with abnormal radiographs. These are not just about loss of autonomy, but because experience shows that patients and relatives may and do seek advice from their general practitioner in this period of uncertainty. Although a policy of automatic referral with a simultaneous report to the general practitioner is quicker, these other considerations carry some weight. However, systems of reporting radiographs are often determined by local tradition rather than current needs, and the optimum pathway for a particular service may be worthy of assessment in a formal study.

Diagnosis

Wherever the diagnosis of lung cancer is communicated, it should be done in a caring, professional, and well organised manner. The components of this process are listed in the BTS guidelines on the care of patients with

lung cancer.²⁴ Involvement of an appropriately trained nurse specialist is essential because patients and their relatives at this time value consideration of the psychosocial consequences of bad news which a nurse can give, and provide the nurse with an opportunity of setting in place a scheme of parallel support alongside the patient's formal medical care.

Skill in telling the patient is not enough; it is also important to communicate with other medical services. Many patients or their relatives will want to see "their" doctor shortly after receiving the diagnosis. Unless steps are taken to inform the general practitioner rapidly (which, in reality, means on that day), it is unlikely that the general practitioner will have the information given to the patient and family at the hospital, or be able to provide anything other than general information about prognosis and treatments.

There has been little research into the optimum method for the rapid communication of information from a busy outpatient clinic to a primary care physician. Clearly, pressure of time is the main problem. Ways round this might be the routine faxing of stylised forms with basic information or asking a specialist nurse to communicate directly with the general practitioner again using a form. Perhaps, however, there is really no substitute for a telephone call from the physician. Doctors in training should learn by example what is and is not acceptable. In return, individual practices need to have policies about receiving and using this information.

Role of specialist palliative care

The problems for the primary care/palliative care interface are those of communication and organisation. Hospital-based palliative care teams made up of clinical nurse specialists and physicians working in parallel with lung cancer teams have much to offer. The particular issues which such a team can consider include the management of difficult symptoms and the psychosocial complications of a life threatening disease with a poor prognosis. The palliative care team can also provide a useful link between the lung cancer team and primary care.

However, specialist palliative care is still widely perceived to be synonymous with terminal care. Referral is therefore often made too late in the patient's illness, and patients and their families come to associate the work of the community Macmillan nurses and hospices with death and dying, which greatly increases their problems and limits their usefulness. Because about 80% of lung cancer patients die within a year of diagnosis, the majority are, at presentation, already in a phase of their illness where they may benefit from seeing a member of the palliative care team such as a specialist nurse.

Specialist palliative care is developing rapidly and many units can provide a range of services. The discipline's relative youth and the facilities and responsibilities which individual units have inherited is reflected in the considerable variation in provision, expertise, and manpower

throughout the country. Specialist palliative care should be available to the residents of each health district, although not all elements may be located in that district. Geographical problems will not be solved quickly or easily.

The arrangements in general practice are more settled but individual general practitioners have a varying interest in the details of palliative care. Furthermore, the advent of larger practices, extended primary care teams, and out of hours co-operatives mean that the problems of communication within primary care are not inconsiderable. There are formidable potential problems for patients and relatives seeking an experienced and familiar doctor out of hours.

Who should lead?

During the process of diagnosis and staging the lead should be taken by the respiratory physician, but at different stages of the patient's illness other clinicians may be better placed to assume this role. Identifying the lead clinician clearly helps those who become involved incidentally or intermittently to support appropriate follow up.

In seeking to reflect the contributions which the different specialties can make, it is important not to define areas of responsibility so sharply as to create hurdles to effective care. Flexibility within cancer units will remain necessary to cope with local provisions and problems. Although many of the individual elements of lung cancer management can be undertaken by doctors and nurses from several teams, consistency and communication are the key features.

Within the hospital, a care plan for a patient who is not curable and who requires symptom relief only should be organised shortly after the diagnosis as a result of consultation between the chest physician, the oncologist, and a member of the palliative care team (usually a specialist nurse). Simple audit shows that recordings of such care plans within records is still imperfect and that the general practitioner can have difficulty in identifying who holds primary responsibility for a patient within the hospital at a particular time. It is not reasonable that patients should suffer from the difficulties doctors have in communicating with one another. This is clearly a fertile area for research.

Who should follow up?

As in other diseases, brief "routine" visits are unwanted; they benefit neither patient nor doctor and have little to recommend them.²⁵ However, experience suggests that regular follow up is likely to be better than relying on the patient to present when new problems emerge. The question of who should provide that follow up merits further study.

One of the reasons for continued hospital or hospice based follow up is that there is now a much wider variety of techniques which may produce substantial symptom relief late in the disease. These include endobronchial treatments such as stenting, brachytherapy, cryotherapy, early and competently undertaken

pleurodesis and, of particular importance, the need to provide expert pain control in cases where cancer pain is not easily relieved by standard analgesics.

If follow up is left within primary care (as patients may request), general practitioners need to be informed about these treatment opportunities and be able to arrange further referrals easily and expeditiously.

Trials

In many societies there is a natural antipathy towards the concept that patients with life threatening diseases should be subjected to randomisation to different treatment strategies. However, as in other branches of medicine there is little possibility of substantial progress without such research. Although the rationale of a research project may be clear to research workers and, at least transiently, to patients, this information is often not transmitted to the primary care team.

The prognosis of many patients may be substantially altered by the use of chemotherapy. It is particularly important that the reasons for offering what may appear to be quite toxic therapy to patients with a relatively poor prognosis be explained effectively to general practitioners. Often, little effort is made to provide good quality leaflets to a group of doctors who may be very influential in the patient's decision to join or continue important studies.

The patient's point of view

There have been few studies of the attitudes of patients towards their lung cancer care. The Macmillan organisation recently reported disturbingly high levels of dissatisfaction within both primary and secondary care.¹⁵ Redressing these concerns will not be easy. In secondary care there may be a system which is at least reasonably uniform and organised, even if imperfect. Primary care, by its nature, is more fragmented and there are opportunities for general practitioners to discuss these issues. Such problems, although clearly not unique to lung cancer, need to be considered as part of the organisational reforms now being undertaken as part of the Calman initiative.²⁶ We suspect that similar difficulties exist at the primary care/secondary care interface in other countries.

The way forward

Translating the aspirations of those who formulate guidelines into better bedside care which is available to patients will not be easy. Meetings between local colleagues is a traditional and not wholly effective strategy. More creative initiatives are needed, based upon data derived from research targeted at the issues raised in this paper. Grant awarding bodies have a responsibility to support, not only studies into basic mechanisms and therapies, but also research into the best ways of delivering high quality care to patients irrespective of where they are treated.

The following questions therefore could be considered:

- Can we identify symptom patterns which would alert patients to present earlier to their general practitioners and their general practitioners to refer earlier for a radiograph?
- Could a palliative care education programme for community nurses improve the quality of life for patients with lung cancer?
- Can we develop and evaluate a mutually acceptable method of same day telephone communication between hospital and primary care?

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