Is tuberculosis taken seriously in the United Kingdom?

Meirion R Evans

Tuberculosis has been the subject of much concern in recent years. Notifications have increased, inadequacies in surveillance revealed, and policies for BCG immunisation and screening of immigrants questioned. Until recently the disease was given low priority in the United Kingdom. There is no overall strategic framework for tackling tuberculosis, and fears have been expressed about the future of local tuberculosis control programmes in the new market economy of the NHS. An action plan for tuberculosis within the context of a national programme is urgently required. Only then will a major impact on the incidence of the disease be seen.

Until the late 1980s, tuberculosis had been in steady decline in the United Kingdom for over 40 years. However, between 1982 and 1993 there were an estimated extra 8000 cases,[1] and around 6000 cases of tuberculosis are now notified annually in England and Wales.[2] The rise has reopened debate about the effectiveness and adequacy of control measures and highlighted the lack of an overall strategy for tackling tuberculosis in the United Kingdom.

Tuberculosis strategy in the United States

In 1989 a strategic plan for the elimination of tuberculosis was published in the United States.[3] This declared a goal of eliminating tuberculosis (defined as an incidence of less than one case per million population) by the year 2010, with an interim target of 3·5 cases per 100 000 population by the year 2000. The plan identified several problems, including deficiencies in identifying and reporting tuberculosis cases and contacts, failures in prevention and in compliance with treatment, and inadequate evaluation of prevention and control programmes in the community. It recommends three priority areas for action:

- Identifying and screening high risk population groups
- Making adequate and appropriate treatment and prophylaxis more widely available
- Developing other approaches to disease prevention and more rapid and effective tests for identifying infective tuberculosis cases.

Since the strategic plan was published a detailed strategy has been set out in a series of reports covering tuberculosis and HIV infection,[4] tuberculosis in correctional institutions,[5] screening for tuberculosis in high risk populations,[6] use of preventive treatment for tuberculosis,[7] tuberculosis in communities in the United States with minority populations at high risk,[8] and initial treatment for tuberculosis.[9] With hindsight it has become clear that the target is unattainable and renewed activity against tuberculosis in the United States has as much to do with resurgence of the disease as with the plan. Nevertheless, the plan serves as a clear statement of the key objectives and strategies for controlling tuberculosis.

Tuberculosis strategy in the United Kingdom

But what of the United Kingdom? Tuberculosis is at a similar stage of decline to that in the United States. In spite of the recent rise, the incidence of tuberculosis remains at just under 10 cases per 100 000 population and the disease is retreating into focal geographic areas and demographically well defined groups. Yet, there is scant mention of tuberculosis in the *Health of the Nation*, pertaining to England, or the *Local Strategies for Health*, pertaining to Wales.[10,11] There are no clear national strategic goals and there is continued confusion about policies to control tuberculosis.

Detailed and succinct guidance on the control and prevention of tuberculosis has been published by the British Thoracic Society, most recently in December 1994.[12] However, this was all issued piecemeal and not as part of an overall strategy. Widespread variations in the United Kingdom in policies for BCG immunisation[13] and screening of immigrants have recently been highlighted.[14] Concerns have also been raised about the threat of increasing poverty on the control of tuberculosis.[15,16]

Tackling tuberculosis depends on effective surveillance, prevention, and control. Well established systems that fulfil each of these functions are already in place in the United Kingdom. However, local services vary considerably in what priority they are given and how well they are funded. The future of such public health services in the new NHS is by no means clear, and concerns have been raised about the impact of changes in NHS management on the funding of local tuberculosis programmes.[17,18]

Surveillance

The statutory notification system is the mainstay of tuberculosis surveillance in the United Kingdom. It is necessary for accurate epidemiological information and to enable contact tracing, but the existing system is both incomplete and limited. As many as 27% of cases of bacteriologically or histologically proved tuberculosis and 14% of cases of tuberculosis with positive sputum smears may not be notified.[19] The data collected are limited to age, sex, district of residence, and site of tuberculosis and do not include information on sputum smears, ethnic group, country of origin, or duration of residence in the United Kingdom. Every five years or so a national survey of tuberculosis notifications is conducted by the British Thoracic Society and others.[20-23] The very existence of these surveys is a reflection of the limited data available from routine notifications. Reasons for the recent rise in the incidence of tuberculosis have remained a mystery because notification data can shed little light on the matter. By contrast, an ambitious, computerised enhanced surveillance system for tuberculosis across all 50 states has been introduced in the United States; the system has considerable shortcomings, not least because of underreporting from the private sector. The NHS in the United Kingdom is probably better placed to develop such a system, but progress is painfully slow and inadequate.[24]

Prevention

BCG immunisation gives 75% protection in the United Kingdom.[25] The Joint Committee on Vaccination and Immunisation recommends BCG immunisation for children aged 10-14 years, newborn babies at high risk, and health care workers.[26]

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Tuberculosis is much more common in homeless people than in the rest of the population

Sutherland *et al* have, however, estimated that there would be only 30 extra cases of tuberculosis per annum if the school programme was discontinued.[27] A decision on the future of the programme awaits analysis of the results of the 1993 national tuberculosis survey. In the meantime, some health authorities have already stopped the school programme and others are considering doing so.[13] The International Union against Tuberculosis and Lung Disease recently published criteria for discontinuing BCG programmes in countries with a low prevalence of tuberculosis.[28] A clear policy decision on the future of the BCG programme in the United Kingdom is urgently required.

Of greater concern is the quality of the selective neonatal BCG immunisation programme, which is the subject of even greater variation in policy and practice.[13] Babies born to parents of Asian (Indian subcontinent) or African origin have an increased incidence of tuberculosis even if they are born in the United Kingdom,[21 22] and neonatal BCG immunisation confers at least 65% protection.[29] Nevertheless, this group seems to be poorly served by existing services. Neonatal BCG immunisation coverage is not monitored, unlike the remainder of the childhood immunisation programme, and at least one study has shown considerable room for improvement.[30]

Control

Effective case finding, treatment, and follow up are also crucial in any strategy to control tuberculosis. Active measures to detect clinical disease are necessary in tuberculosis contacts, immigrants, and other high risk groups such as homeless people and people with HIV infection. Consistent detailed advice issued by the Joint Tuberculosis Committee of the British Thoracic Society has meant that arrangements for the diagnosis, treatment, and follow up of tuberculosis are generally good.[12 31] Failures of notification and inadequate or inappropriate treatment are more likely to occur when patients are not referred for treatment at a chest clinic. As yet, multidrug resistant tuberculosis is not a major problem in the United Kingdom, almost certainly because of well supervised treatment and good compliance with recommended drug regimens.[32]

Those at highest risk of tuberculosis are household contacts of patients with smear positive pulmonary disease; at least 1% of contacts are found to have tuberculosis when screened.[33 34] Detailed guidance on contact tracing has existed since 1985 in the United Kingdom and has just been updated.[12] In practice, operational arrangements for tracing tuberculosis contacts vary considerably. Some health authorities will have a contract for a tuberculosis control programme, but many will not. Contact tracing may be the responsibility of the local chest clinic or the community health services and may be done by a clinical nurse specialist or non-specialist community nurses. This diversity may be inevitable given the wide variation in the incidence of tuberculosis, but it does mean that services are extremely vulnerable.

There is no national policy on screening immigrants to the United Kingdom for tuberculosis. New entrants who are staying for a long time may be referred by immigration officers to the Port Health Control Unit, and details are then forwarded to the health authority within which the destination address lies. This is, however, an immigration system, not a public health system. It was never intended as a tuberculosis screening programme—neither does it function as such. Only a quarter of all new immigrants are referred to the Port Health Control Unit.[14] No national audit of the system has ever been published. In the only published local audit, less than half of all immigrants from high risk areas were referred to the local health authority.[35] In the United States screening of immigrants is a key element in the national tuberculosis strategy, although the efficiency of the system has been questioned.[6 36 37] In the United Kingdom there is no such strategy, no system to identify and target high risk groups, and no means of evaluating outcome.

Two other high risk groups deserve special attention —namely, homeless people and people with HIV infection. Homeless people have as much as 100 times the incidence of tuberculosis in the normal population.[38] Vagrancy, alcoholism, and drug misuse can also hamper management of the disease. Recent studies in the United States that used the technique of restriction fragment length polymorphism have shown that the same organism may infect several people living in hostels for homeless people.[39] Screening this group for tuberculosis poses considerable problems, though health services for homeless people have been successfully established in some cities and guidance has been published.[40] Supervision of treatment is also important but requires adequate resources.

Several problems are described in relation to HIV infection and tuberculosis. Guidelines on the management of tuberculosis and HIV infection have been published that give detailed advice on diagnosis, chemoprophylaxis, and control of cross infection.[41 42] Of particular concern is the failure to notify cases of tuberculosis in people with HIV infection. One study suggests that notification rates might be as low as 30%.[43] Concerns about confidentiality are understandable, but failure to notify cases may mean that tuberculosis contacts are not traced, despite the fact that tuberculosis has spread within groups infected with HIV.[44-46]

Action for the future

In the United Kingdom strategic goals for tackling tuberculosis need to be set and an action plan to achieve them drawn up within the context of a national tuberculosis control programme. Existing surveillance systems need to be enhanced to ensure more complete and more comprehensive data collection. BCG policy must be clarified to ensure consistency and uniformity of approach. The excellence of current treatment programmes must be maintained by ensuring that patients are treated by physicians with an interest in tuberculosis, and the programmes need to be monitored by continued tracking of drug resistance.[47] Contact tracing services need to be safeguarded by requiring purchasers and providers to devote adequate resources to local tuberculosis control programmes.

Screening policies for new immigrants and other high risk groups such as homeless people and people with HIV infection need to be urgently reviewed and improved. Only if tuberculosis is tackled seriously and given the priority it deserves can we expect to see any major impact on the incidence of the disease.

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A MEMORABLE NON-PATIENT

Taking everyone in

I'm normally bad at names. I remembered this one only because the letter sat for so long in my in tray. It explained that she was a teacher and had a friend with leukaemia. Could I answer a few questions about the disease? The letter ended with a hint of a donation, if I could also give her the address of a leukaemia charity.

The problem was the questions read like the final paper for the examination of the Royal College of Pathologists. Other letters and documents seemed more urgent and important. Three weeks passed and it was nearing the end of the summer term. I had begun to get twinges of guilt about the letter, especially as I did not want a charity to miss out on a donation. So I settled down and answered it. I sent her copious information.

The following autumn, during a busy clinic, I had a telephone call from a local headmaster. He apologised for ringing me directly, but needed some urgent advice. One of his staff had been taken ill at work. What should he do? As she was a patient of mine and was seriously ill with leukaemia he was sure I could help. I replied that I had no idea who she was, so I suggested he telephoned her general practitioner. He seemed surprised that I could not recall her instantly. He said that I had contacted him about her by telephone several times and had been helpful. At this point I was beginning to doubt my sanity. All haematologists know their patients with leukaemia well. I still could not remember her, but I had an uneasy feeling that I ought to. I promised to ring him back after I had checked through our records. Was he sure he had the right doctor? At this point he confessed to being a little non-plussed, as the consultant haematologist with my name to whom he had spoken before had been a man. I have an unmistakably female voice.

Later that day after I had sent my secretary searching for the lady's notes, it came to me. The letter from the schoolteacher. Of course she could pass herself off as a patient with leukaemia, with all the help I had given her. I must have signed my letter with my initials and surname and she had assumed I was a man. There was no patient known to the hospital with her name and I was now certain that hers was the name on the letter I had received. My defence society confirmed that there would be no breach of confidentiality in disclosing that she had never attended the hospital, so I telephoned the headmaster back.

Apparently she had collapsed at work several times before. The staff and parents all thought she was brave to continue to work when so gravely ill. Her "consultant" had telephoned to suggest that she was not put under too much strain and the headteacher had readily acquiesced. I never found out what became of her after that, but it is a fair bet that her career floundered. Was it Munchausen's syndrome or was her deceit more deliberately contrived? Either way it is a good example of how easy it is to take everybody in.—DEBORAH CLARK *is a haematologist in Sydney, Australia*