

## **The human dimension of tuberculosis control**

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The goal of tuberculosis control is the reduction of the annual incidence of the disease world-wide to less than 1 case per million of the population.<sup>1</sup> The principal strategy advocated at the present time for achieving this goal is the detection of persons with overt tuberculosis and their cure by means of short-course chemotherapy.

There are, of course, major barriers to the conquest of tuberculosis by this approach. Diagnosis is not easy, especially of sputum smear negative disease, and case-finding requires much more for its success than an efficient microscopy service. Modern short-course chemotherapy achieves excellent results under certain programme conditions while under most others the difficulties experienced in case-holding and supervision, and the provision of a regular supply of drugs free at the point of delivery, render the results far from optimal. In recent years, the advent of the HIV pandemic and the increasing incidence of multidrug resistance have thrown additional serious obstacles in the path towards a tuberculosis-free world.

As a result, tuberculosis is on the increase in many countries and, unless more powerful preventive and therapeutic tools are developed and adopted,<sup>2</sup> there is little hope of reversing this trend unless serious attention is paid to the human element, with consideration of psychological attitudes to the disease at all levels of society. This includes perception of the disease and its therapy by patients and their relatives as well as perceptions, priorities and motivating factors at governmental and international levels. The spiritual dimension must also be considered as, in many societies, attitudes to suffering are profoundly affected by religious beliefs and patients may put more trust in traditional healers than in 'orthodox' Western therapies.<sup>3,4</sup>

The importance of the human element in tuberculosis is highlighted, directly or indirectly, in no fewer than 5 articles appearing in this edition of *Tubercle and Lung*

### **COMPLIANCE AND THE QUALITY OF MEDICAL SERVICES**

The World Health Organisation recognises that much of our failure to come to grips with tuberculosis globally results from our inadequate utilisation of tools already available for control of the disease.<sup>1</sup> Problems may arise in case-finding, the supply of drugs and the organisation and administration of chemotherapy but many workers have remarked that poor patient compliance has been, and remains, the principal cause of treatment failure in both developing and developed nations.<sup>3-7,10-16</sup>

Fox noted that non-compliance is no new problem and cited Hippocrates' advice that the physician 'should keep aware of the fact that patients often lie when they state that they have taken certain medicines'.<sup>10</sup> Fox discussed the various technical strategies developed to overcome poor compliance - supervised therapy, combination tablets, blister packs, pill checks, urine tests and hospitalization - but emphasised that the fault often lies as much, or more, with the medical attendants as with the patients. Physicians, particularly those outside tuberculosis services, may fail to prescribe adequate therapeutic regimens. A survey of prescribing habits in Bombay revealed that 100 private practitioners prescribed 80 different regimens, most of which were inadequate and unnecessarily expensive.<sup>17</sup> The need to establish effective communication between national tuberculosis services and private practitioners was stressed.

Even when appropriate therapy is prescribed, physicians may contribute to non-compliance by their attitudes and behaviour. Establishment of a good and trusting doctor-patient relationship is crucially important to the success of prolonged therapy. Sbarbaro<sup>16</sup> has written that 'I am deeply convinced that only through a relationship with a health professional truly concerned with the patient's entire health... can we hope to influ-

more frequently in members of aboriginal and immigrant ethnic minority groups.<sup>6,7</sup> A lack of understanding of cultural differences in attitudes to disease, its diagnosis and therapy can be the cause of an unintentional breakdown of trust between physician and patient, thereby leading to non-compliance. Even a simple gesture, remark or touch meant as a token of encouragement may cause deep offence to persons of certain cultural or religious backgrounds. These problems, and the need for their avoidance, have given rise to the discipline of 'transcultural medicine' pioneered in the United Kingdom by Qureshi.<sup>18</sup> The need for such considerations in tuberculosis control is succinctly summed up by van der Werf: 'Every country, every ethnic group and every society have their own culture and peculiarities which one should know before an effective control programme can be designed'.<sup>3</sup>

The first lesson any doctor learns at medical school is to listen to the patient,<sup>19</sup> and this lesson applies of course to all those who work with patients. It is self evident that talking and listening to the patient costs nothing but time, yet it pays high dividends in the achievement of empathy, mutual understanding and trust. If these are achieved, the physician's duty – a prime duty – of educating the patient with regard to his or her disease and its treatment is made so much easier and the chance of full compliance is much improved. Communication between health care providers and patients requires a common language but in multi-racial, multi-lingual communities this requirement may not be met, with serious consequences to the standard of health care.

Such problems had to be faced at the London Chest Hospital which serves a part of East London with a large Bangladeshi population as well as other ethnic minority groups whose mother tongue is not English. Many patients are women who have recently arrived in the country, speak no English and are virtually housebound. As interpreters are required for the medical consultation, the patients are denied their fundamental right to privacy. To add to their discomfiture, it may, in the absence of an interpreter on the hospital staff, be necessary for the husband, son or other male relative to assume this role. Women patients are understandably reluctant to discuss intimate medical matters in front of male relatives and they may be particularly anxious to conceal a diagnosis of tuberculosis, still a stigma-bearing disease, from their extended family.

3 years ago, an innovative project in the form of a telephone interpretation service called Language Line was introduced to the London Hospital and the London Chest Hospital. The service provides a three-way communication between patient, interpreter and health care provider. Most of the interpreters are women, and pa-

## EDUCATION AND TUBERCULOSIS CONTROL

It is often stated that public health education contributes to the success of tuberculosis control programmes. The relation between educational background and knowledge of the symptoms and significance to health of tuberculosis, however, varies from region to region,<sup>5,6,20,21</sup> and general education and knowledge of tuberculosis does not necessarily result in the earlier presentation of a patient to the appropriate medical services.<sup>22</sup> Locally undertaken surveys on knowledge of tuberculosis and attitudes towards the disease are therefore of great benefit in planning control programmes and, in particular, their educational element. Shashidhara and Krishnamurthy stressed the importance of analysing the thinking processes of patients who fail to comply with therapy despite knowing that they harbour a curable but potentially deadly disease.<sup>23</sup> For example, to many people, disease means *dis-ease* – a sense of a lack of well-being. In the absence of careful explanation and education, a person may fail to accept the need of continuing medication when he or she is feeling perfectly well. In a study of tuberculosis control in a Somali refugee camp, the most frequent cause of default was loss of interest in therapy due to feeling well.<sup>11</sup>

Lower educational levels are not necessarily related to poor compliance provided that the nature of the disease and its therapy is sympathetically explained in a manner suitable to the individual patient.<sup>1,15</sup> Kindness must sometimes be combined with firmness. In one study, the necessity of regular therapy in cases of tuberculous meningitis was emphasised by taking the attendants to the hospital wards and clinics to see patients who had fully recovered and those with the sequelae of poor-compliance.<sup>15</sup>

## OTHER LOCAL FACTORS AFFECTING COMPLIANCE

The extent to which tuberculosis is regarded as a stigmatising condition varies from region to region. One of the great advantages of modern short-course therapy is that patients need not be isolated from society (although the emergence of multidrug resistant tuberculosis in some regions may once again render isolation necessary). Nevertheless the fear of isolation and segregation may be a very real one. In Turkey, even the relatives of absconding patients were often reluctant to have any contact with tuberculosis dispensaries.<sup>13</sup> In such countries, integration of such dispensaries with general medical facilities and changing the name to 'chest clinic' could well dispel these fears.

In some regions the stigma of tuberculosis has been

to pay for their transport – indeed, transport costs may exceed the cost of the drugs. In Ghana, regular home visits by liaison staff, even though they had little medical knowledge and general education, improved compliance significantly.<sup>3</sup> It was noted, however, that success depended on the commitment and dedication of the liaison workers, which was often very high. Likewise, in South Africa, compliance was notably improved by the employment of voluntary health workers to supervise therapy, assist in contact tracing and case finding and to help with community education.<sup>14</sup> The effects of motivation and support of the health worker on the efficacy of tuberculosis control programmes have been assessed in Korea. By the simple process of discussion sessions, regular supervision and audit of performance, treatment completion rates were increased from 65 to 79%, bacteriological conversion at the end of therapy from 62 to 92% and overall efficacy from 46 to 75%.<sup>5</sup>

#### HUMAN FACTORS AT NATIONAL AND INTERNATIONAL LEVELS

Human considerations spread far beyond the contact between patients and health care providers. The course and incidence of tuberculosis in a country depends critically on the interest and commitment by governments to its control. In the developed world, the failure to translate control into elimination stems largely from the false belief that tuberculosis had been 'conquered' by the discovery of effective drugs and BCG. Unfortunately, the decline in the disease was matched by a decline in interest. In the absence of diagnostic awareness, the incidence started to rise in the USA and some other developed nations and interest is now chasing this increase, as eloquently expressed by the title of Reichman's thoughtful paper 'The U-shaped curve of concern'.<sup>24</sup>

Brudney and Dobkin noted that non-compliance in New York City is massive and predictable and remarked that for homeless, unemployed people who are often also drug abusers, alcoholics or mentally ill, pill taking is low on their priority list for sheer survival.<sup>25</sup> The provision of sheltered accommodation for such people often exacerbated the problem by affording opportunities for spread of disease. In this respect, it is noteworthy that tuberculosis has long been associated with social deprivation and that its high incidence in Europe in the latter half of the 19th century was an important factor leading to the improvement of living conditions and the health of the community. It has been remarked that 'without Koch's discovery, the socio-economic character of tuberculosis would have been clearer, and a demand for redistribution of the wealth of the community would have become a much more important issue'.<sup>26</sup> In this

implications for tuberculosis control. Unless novel therapies for HIV infection and HIV-related tuberculosis emerge soon, an unparalleled socio-economic disaster could occur in Africa and, eventually, the whole world.<sup>2</sup> A previously unconsidered factor is that the cost of treating intercurrent infections renders the overall cost of managing HIV-related tuberculosis higher.<sup>8</sup> International aid in tuberculosis services in developing nations will soon be overwhelmed.

Another area of global concern requiring thoughtful attention is the relevance and direction of tuberculosis research. Current pressures on academic researchers in the developed nations are increasingly leading to work that is poorly orientated towards, or even irrelevant to, the pressing needs of the developing world. Administrators and funding bodies tend to regard good research as being synonymous with costly high technology that generates tangible and marketable 'products'. There is a need to combat this attitude and to develop a stronger sense of 'appropriate technology' and to make this a respectable and respected term. It is also necessary to escape from the prevalent concept that real science only takes place in laboratories. There is a tendency to belittle operations research, the social sciences, anthropology and the humanities yet these will be as essential to the success of the global campaign against tuberculosis as the most advanced research into the nature of the mycobacteria and the diseases caused by them.

#### CONCLUSIONS

It is abundantly clear that the global struggle against tuberculosis is not being won. Indeed the incidence of the disease is increasing in several countries. Although better weapons are required for the fight,<sup>2</sup> human considerations, as well as scientific ones, are of crucial importance. With meticulous organisation and support from the relevant authorities, good control can be ensured, even under very difficult conditions such as refugee camps in war-torn regions.<sup>27</sup> Ultimately, it is for the human race to determine whether the battle against tuberculosis will be drawn to a speedy and successful conclusion or whether, in the words of J.R. Bignall,<sup>28</sup> 'it will be a long, long war'.

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