

Editorials

Carrots, sticks and tuberculosis

Richard J Coker

Public health authorities have long had at their disposal the authority to impose coercive measures to protect the public from perceived threats. Tuberculosis is a global emergency and the spectre of widespread drug resistance resulting from inadequate treatment is perhaps the most feared vision by those involved in control programmes. To improve treatment completion rates and reduce the development of drug resistance, the World Health Organisation (WHO) and others are advocating the broad use of observed therapy as a central plank in their tuberculosis control programme. Directly observed therapy (DOT) has been shown to be effective in several settings, perhaps most dramatically in New York City.¹ The success of this particular programme has received widespread recognition, but what has perhaps received less international attention is the use of some measures to support this approach.

In addition to a broad array of incentives, including cash payments, food coupons, shelter, and assistance with travel, the city underpinned the expansion of its DOT programme by amending its health codes and authorising the Commissioner of Health to detain both infectious and non-infectious individuals “where there is a substantial likelihood, based on such person’s past or present behaviour, that he or she can not (sic) be relied upon to participate in and/or to complete an appropriate prescribed course of medication for tuberculosis and/or, if necessary, to follow required contagion precautions for tuberculosis.”² This represented a fundamental shift in officials’ authority to include measures directed towards the non-infectious recalcitrant patient. At the time the amended regulations were adopted, concern both from civil libertarians and city officials was focused upon “due process” protections with an emphasis on the use of less restrictive alternatives to detention. Both sides accepted the constitutional and ethical principles underlying the justification for detention of “recalcitrant” individuals and little distinction was made between whether they were infectious or non-infectious.³ Although the primary goal was reduction of threat to public health, little attention was paid to the uncertainty regarding the risk of relapse or the actual magnitude of the threat posed by non-infectious poorly compliant individuals, particularly by those opposing the regulatory changes. The Health Department officials simply suggested that “over time, it is likely that they (poorly compliant, non-infectious individuals) will pose a very serious threat to large segments of the public.”⁴ Since 1993, when the amended regulations were adopted, more than 200 non-infectious individuals have been detained, most for prolonged periods, some for more than two years.

Although patients with acid fast bacillus smear positive pulmonary tuberculosis pose a public health threat, much

of what is accepted dogmatically with regard to the transmissibility of tuberculosis is, in fact, uncertain and it is far from clear what threat smear negative individuals who are non-compliant pose to the public.⁵ When treatment is erratic, when only some drugs but not others are taken, and when there is primary or acquired drug resistance at the commencement of treatment, estimating the risk of relapse and the possibility that further drug resistance has developed (even when the clinical history is reliable) is, in practice, almost impossible. So, if the risks posed to the public health by any individual smear negative poorly compliant patient are small but uncertain, and probably unquantifiable, how should society respond? How might the perception of risk have influenced the response in New York City, and what can we learn from this when considering the adoption or implementation of coercive public health measures?

Societies respond to risk in a value laden manner.⁶ It was widely perceived that tuberculosis in New York City during the 1980s and early 1990s affected principally homeless, alcoholic, drug dependent, and HIV infected individuals. Was the perception of risk from poorly compliant individuals in New York City heightened, for example, by an unspoken fear of these individuals who populate the margins of society, and by certain cases, such as that of the immunocompromised prison guard with cancer acquiring multidrug resistant tuberculosis (MDRTB),⁷ or other nosocomial outbreaks,⁸ including those involving health care workers?^{9–11} Although there was no “signal” event prompting the authorities to respond to the epidemic,¹² some cases certainly generated considerable publicity.¹³

In the USA, unlike in the UK, the “police powers” which provide for and protect the public health are not held centrally but locally (with the Mayor’s appointee, the Commissioner of Health, in the case of New York City) and this system, it could be argued, increases local political awareness, accountability, and responsiveness in the public health arena. Moreover, in the case of tuberculosis where restriction fragment length polymorphism (RFLP) typing provides a mechanism to support the epidemiological linking of cases (and highlights failures in control), concerns over litigation may encourage health officials to respond more assertively in the USA (although, interestingly, cases resulting in litigation from nosocomial hospital spread of MDRTB have been seen in the UK but not in New York City).

Broadly speaking, however, although there are some differences, national responses to threats—whether they are environmental hazards or new pathogens—are similar on both sides of the Atlantic. For example, when one looks at the public, professional, and media responses to the risk of occupational transmission of HIV from health care

workers, the response to asbestos or cigarette smoking, or homicides resulting from the mentally ill, one sees many similarities. Coercive public health measures have not, however, been a major feature in tuberculosis control programmes outside the USA. In the UK, for example, legislation allows for the detention of an individual with a notifiable disease who is a threat to others, but this legislation is rarely used. Moreover, there is no legislation to detain an individual who may become a threat in the future. Whether this will remain so if rates of tuberculosis, and particularly rates of drug resistance, continue to rise is unclear.

How can public health policy directed towards tuberculosis control, which includes coercive measures and which, by necessity, focuses on a disenfranchised group of individuals whose voice may not be heard in policy debates, be as equitable and as fair as possible? What is clear is that the burden of proof that individuals pose a threat to the public should be more demanding when the consequences of regulation include detention than when economic encumbrances are created.¹⁴ Furthermore, we need to recognise that, when people feel threatened, they focus inappropriately on external sources such as stereotyped minorities and blame them, rather than assessing other threats which are perhaps closer to home.¹⁵

We must further recognise that public health decision making, particularly in a crisis, may be prone to errors, and we must be clear of the goals we are trying to attain. When coercion was used in the South Asia smallpox campaign the goal was different—it was eradication, not control. Although the campaign was successful, concerns have been raised that some of the measures used may hinder future public health campaigns, and that ultimately the use of coercion may be counterproductive.¹⁶

Despite the WHO's assertion that "everyone who breathes air, from Wall Street to the Great Wall of China, needs to worry about this risk", it is clear that the risks to all from tuberculosis are not equal. For example, in New York City, those using homeless shelters in which beds were spaced 18 inches apart and HIV prevalence was high were obviously at greater risk of exposure than those in the leafy suburbs. But the perception was high in New York that all were at risk, and undoubtedly encouraged the response seen.

As new information regarding tuberculosis transmission becomes available, as circumstances alter, and as our understanding of the perceived threats improves or changes, we must alter appropriately our view of the probabilities of potential given events occurring. Policy decisions should involve assessments that are both individualised and weighted to account for expert views on probabilities (and perhaps further weighted on the basis of past predictive success), upon economic calculations, and upon ethical analysis. Furthermore, one should be able to evaluate whether the consequences of policy decisions are similar to or different from those predicted.

An approach to our understanding of risk with regard to tuberculosis must therefore attempt to define the risk of an

event occurring (for example, the transmission of tuberculosis from a smear negative poorly compliant individual), determine the gravity of that event, weight different available measures to be taken, and alter the perception of risk with time both as our understanding improves and as circumstances change. In addition, with the changing perception of that risk, the legislative and regulatory approach to coercive public health measures should be responsive and encourage swift modifications of public health measures. The anxiety over MDRTB in New York has largely abated. It will be interesting to see if either the regulations, or the application of them, is modified in response.

Perhaps more important than any of the above, however, the use of coercive measures to support strategies which improve treatment compliance must be sensitive to national and cultural differences and not simply be based upon perceived successes elsewhere. The global control of tuberculosis may be harmed more than it is assisted by inappropriate, ill judged, culturally insensitive coercive public health measures.

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More carrot or more stick or both?

Richard Coker describes how a system, with a substantial coercive component even for non-infectious patients, evolved in New York based on a perception of risk which was perhaps fuelled by media hype.¹ The reasons why such a system came about can, however, be appreciated from the

state of tuberculosis control—or perhaps non-control—in New York in the early 1990s.

Due to a series of cuts in health funding, routine drug sensitivity testing had been stopped, support systems were slashed, and in some areas only about 10% of patients com-