2816

THE UNIVERSITY OF CHICAGO

CENTER IN DELHI

LEGAL WORKSHOP: TUBERCULOSIS, HUMAN RIGHTS AND THE LAW

NEW DELHI, INDIA, 19-20 DECEMBER 2015

DRUG RESISTANT TUBERCULOSIS: THE TEN COMMANDMENTS OF DELHI

The Hon. Michael Kirby AC CMG

THE UNIVERSITY OF CHICAGO
CENTER IN DELHI

LEGAL WORKSHOP: TUBERCULOSIS, HUMAN RIGHTS AND THE LAW

NEW DELHI, INDIA, 19-20 DECEMBER 2015

DRUG RESISTANT TUBERCULOSIS: THE TEN COMMANDMENTS OF DELHI[*]

The Hon. Michael Kirby AC CMG[**]

Tuberculosis (TB) is a major challenge to global health. It is one of the most serious impediments to the attainment of the new Sustainable Development Goals (SDGs) adopted by the Member States of the United Nations in 2015. Like the Millennium Declaration in the year 2000 the SDGs recognised the interdependence of health and development. SDG 3 aims to "attain healthy lives and well-being for all". In 2013 alone, there were approximately 9 million cases of TB and 1.5 million deaths resulting from the disease. This means that many people are being left behind so that inclusive and equitable development is not being realised.

A particular problem presented by TB is that, although it is generally a curable disease, defective healthcare in mostly low and middle income countries accounts for the majority of deaths. Moreover, at this workshop, it has been estimated that 5% of cases of TB worldwide are multidrug resistant. The majority of such cases are undiagnosed and undetected. In India, we were informed that 204,000 people died of TB in the year past. Of these 100,000 died of multidrug resistant TB. Amongst these in 2014, many died of the combined effects of TB and HIV/AIDS. About a quarter of the cases of multidrug resistant TB in the world are found in India.[1]

The inability of the present health system in India to detect cases of TB and to differentiate multidrug resistant TB in large numbers is a major challenge. It is also a challenge that is regional and global. It is at last beginning to reach the general media.[2] It is a problem that has led the Secretary-General of the United Nations

[*] Based on remarks made at the close of the workshop.
[**] Former Justice of the High Court of Australia (1996-2009); member of the UNDP Global Commission on HIV and the Law (2011-12); member of the UN Secretary-General's High Level Panel on Innovation and Health Technologies; Member of the Panel on the Equitable Access Initiative of The Global Fund Against AIDS, Tuberculosis and Malaria (2015-16); Patron of The Kirby Institute, UNSW, Sydney, Australia.
[1] World Health Organisation, *A Brief History of Tuberculosis Control in India,* WHO, Geneva, 2010.
[2] G. Rushton, "Tuberculosis Fight Critical in Asia-Pacific, Advocates Warn", *The Australian,* 31 August 2015, 7. See also "Drug Resistance Grows Menacingly", *Bangkok Post*, 21 December 2015, 10.

(Ban Ki-moon) to establish a High Level Panel on Access to Essential Medicines. According to the Secretary-General:

> *"The availability of health technologies is essential for the achievement of SDG 3. Many of these technologies remain unavailable or inaccessible, such as those needed to treat hepatitis C and HIV, as well as some non-communicable and rare diseases… The [HLP] will comprise eminent leaders from the public and commercial worlds, [be] tasked with making recommendations for how the future of health technologies innovation can be balanced with access for all, so that no one is left behind in the pursuit of a healthy and productive life."*[3]

In the specific context of TB and drug resistant TB, this workshop has demonstrated that specific treatment is specially problematic.

The realisation that many who have obtained the standard treatment for TB in India have done so across the counter of pharmacies or informal shops or in private medical practice lacking public health expertise. They have, when commencing treatment, not been advised to continue to administer the drugs to the completion of the dosage, allowing the development of drug resistant tuberculosis. In some such cases of TB, in the worst instances, varieties of the bacillus develop that are themselves resistant to multiple available drugs. This form of TB is not at all easy to treat and there are many failures. Even the 50% of cases of this kind in which success is claimed, the patient must undergo lengthy procedures of injection, the consumption of thousands of tablets; and run the risk of serious side effects that have included blindness, deafness, extreme nausea and psychotic conditions sometimes leading to suicide.[4] The treatment is also extremely expensive, starting at $USD 5,000/person/year.

A second development arises out of the nature of this new epidemic. Most of the people who are ultimately diagnosed as suffering from multidrug resistant tuberculosis are extremely poor. Indeed, their poverty has resulted in inadequate or incomplete medical advice. Although there are many and growing numbers faced with this predicament, their poverty is discouraging to the investment of capital designed to find more effective and less expensive cures. New pharmaceutical products, produced by the private sector, tend to concentrate on conditions prevalent in middle to higher income countries. There are many neglected diseases. It was, in part, to address this problem as well that the Secretary-General created his High Level Panel.

[3] Letter by the Secretary-General to the author and other appointees to his High Level Panel dated 27 October 2015. In the possession of the author.
[4] N.C. Engel, "The Making of a Public Health Problem: Multi-Drug Resistant Tuberculosis in India", *Health Policy and Planning* 2010: 28: 375.

I have been appointed to serve on the new Panel. Its first meeting took place in New York immediately prior to this workshop in New Delhi. It was because that workshop was addressed to a species of the generic problem within the mandate of the HLP, that UNDP has facilitated my attendance at this workshop. In turn, I will report to UNDP and the HLP on our deliberations in New Delhi.

SIGNATURE THEMES

Many themes have emerged during the workshop. They have included:

- The signature theme mentioned by Justice Edwin Cameron in his judicial reasons in a decision before the Constitutional Court of South Africa in *Nexusa*[5]:

  "Law is a scarce resource… Justice [can be] even harder to come by."

- At the outset there was something of a tension between presentations on behalf of the World Health Organisation, suggesting that screening for TB in India has lately increased and is on track to achieve its goals. Opinions expressed for civil society (e.g. by Colleen Daniels and Evan Lyon) claim that the screening, like the advent of new effective drugs, is 'frightening low'. Participants had to consider whether an upbeat stance by institutions can sometimes explain the gulf between such institutional and individual reports.

- Several participants emphasised the complexity of the problem. Effective treatment is bound up in the availability of good food nutrition. Reliance on the informal drug market is imperative because of the effective features of inadequacy in the public health system. (Jacob John and Dr Mira Shiva). Some important actors do not fully realise the challenge of their own situations (Dr Ahmed). Thus, reportedly 80% of deaths in official custody are the result of TB and the instances of drug resistant TB in this cohort are unidentified.

- A scrutiny of the case law that was presented to the workshop shows that, on the whole, the Indian judiciary is sympathetic and sensitive to the predicament of persons living and dying with TB (Noorji Sidhu). A number of innovative judicial decisions and actions that were reported and studied show a capacity and willingness on the part of the judges to be innovative and persistent. These range from decisions of Justices Muralidhur, Manmohan and Gita Mittal (of the Delhi High Court) and the actions of Justice Sinha, exercises his capacity as official inspector of prisons in Bihar State.[6]

[5] See Edwin Cameron, *Justice a Personal Account* (Tafelberg, 2014) 251- 257.
[6] Bihar, India, Bihar State Legal Services Authority: *Prisons of Bihar*, *Status Report 2015*, (Mr Justice V.N. Sinha, Executive Chairman); Smita Chakaraburty, Social Legal Information Center, Delhi.

* Important influences for good can be the awareness of international treaties (Alan Maleche); comparative scrutiny of the situation in other countries such as South Africa (Jonathan Stephens); a deep analysis and diagnosis of the impediments presented by the prevailing political and economic culture in countries at risk (Justice Sinha); and examination of the impact of global intellectual property law (Justice Sridevan, Palavi Singh and Senior Advocate Anand Grover).

* A number of presentations were made to the workshop by people living with TB and by civil society representatives who know and represent them.

* In the closing sessions, the workshop received horror stories from Justice Mittal on the early legislation in India against leprosy and its related condition, TB. Jonathan Stephens dissected the link of economics to TB in the mining industry with its exposure of workers to silicosis; a gruesome account of TB in the Russian Federation was given by Mikhail Golichenko concerning conditions in dedicated facility established to house them in Ekaterinburg. There media criticism of the facility was denounced by media, government and some in the population writing from the standpoint of stigma and prejudice and blaming the victims for their health condition. The urgent need for a truthful and dispassionate examination of custodial institutions in many countries was stressed repeatedly.

* Brian Citro, as leader of the workshop, presented a useful schema for an intellectual approach to legal responses to MDR TB that would be effective but also compliant with international human rights law.

* The importance of legal responses and of judicial leadership was emphasised by the contrast painted between the sensitive and responsive approach of at least some Indian judges who had familiarised themselves with the condition of TB and the unsympathetic, hostile approach of the Russian judge in Ekaterinburg. The Russian judge appeared insensitive to the human rights issues presented to him. But he was also inattentive to the epidemiological implications of his approach and the grave danger it presented to the health of fellow citizens not yet infected with TB.

TEN COMMANDMENTS

1. *Empirical Foundation:*

   The first lesson from the Delhi workshop is, I suggest, a lesson that was also learned in the earliest days of the HIV/AIDS epidemic. It is essential for those who are seeking to establish effective policy for the response to such an epidemic. They must secure the soundest possible empirical foundations for their decisions. Epidemiological, legal and social decision-making must be founded on a thorough knowledge of the nature of the epidemic, its causes, modes of transmission and trends. These rather than assumptions, prejudice, fear or hype must be for the foundation for all laws and policy.

2. *Coercive Paradox:*

   Secondly, it is necessary, as in the response to HIV, to address the TB epidemic (especially MDR TB) in a paradoxical manner. This requires overcoming the ineffective hostile, punitive approach to people living with the condition. It is necessary to adopt a human rights respecting approach to the condition to secure some hope of dealing with it effectively. Guidance is available concerning a human rights approach to TB.[7] Adopting this approach is in the interests not only of those infected but also of those who are unaffected and governments and institutions that wish to establish an effective strategy for prevention, containment and treatment.

3. *Participatory Approach*:

   As in the HIV epidemic, it is essential, in responding to the problem of TB, to engage with and involve persons living with TB. This must be done upfront, from the outset and with proper respect and interaction with such persons. In fact, the design of policies should grow out of the experience and demands of such persons. Conferences and workshops should not speak of and to people living with TB alone. They should speak with them and always listen to their voices.

4. *Not Time to Loose:*

   As in the early days of the HIV epidemic, the statistical material placed before the workshop in Delhi established, as was frequently stated, that there is "no time to lose" in addressing the issues of TB and especially multidrug resistant TB in India and elsewhere. The problem has moved beyond the need for

[7] World Health Organisation, *A Human Rights Approach to Tuberculosis* (Guidelines to social mobilization) WHO/CDS/STB/2001.

further generalised conferences. The focus of all such meetings and discussions should be the development and follow up of plans for action to address the epidemic quickly and effectively.

5. *Engaging Vulnerable Groups:*

   It is essential for an effective strategy of dealing with TB and MDR TB to engage with groups that are most vulnerable to infection. Those groups have already been identified. Without limiting them, they include:

   * Prisoners and detainees;
   * Children and disadvantageous environments;
   * People living with HIV (thought to have 10% living with HIV and TB);
   * Healthcare workers;
   * Hospital treatment officers;
   * Indigenous peoples;
   * Particular ethnic groups; and
   * People suffering poor nutrition, lack of adequate housing and basic needs.

6. *International Engagement*

   It is essential to avoid reinventing the wheel of responses. Close attention should be paid to engaging with international bodies concerned with the issues of TB, MDR TB and access to therapy. Engagement with the international community should include:

   * WHO;
   * UNDP;
   * The Global Fund against AIDS, Tuberculosis and Malaria;
   * The Secretary-General's HLP.

7. *Identify Large and Small Strategies:*

   It is important to identify the large contours of the challenge presented by MDR TB and TB generally. Some particular strategies may be comparatively particular, such as the etiquette of coughing and public spitting. However, other strategies will require nationwide and international initiatives.

8. *Addressing the Triage:*

It will be important to face up to the problem of the triage in this as in other instances of disease control and public expenditure. Although to loved ones a human life is priceless, realities oblige governments and health administrators to face the obligation of choosing immediate and long-term strategies most likely to help the greatest number to the greatest degree. Making such decisions can be difficult, painful and controversial. In a democracy, it is desirable that the choices should be publicly ventilated and that those who make them should be accountable, ultimately through the democratic political process. They should not be unaccountable, secret or unknown. The consequences of attempts to make them thus were revealed in the case of the neglect and indifference to patients in Ekaterinburg.

9. *Pro Bono Lawyers:*

It is important to acknowledge the significant and continuing role in human rights and epidemics of pro bono lawyers. This is as much true in the case of TB as of HIV. The work of the Treatment Action Campaign now (Section 27) in South Africa illustrates the successes that can be achieved. So is the work of Lawyers' Collective in India and of civil society action described to the workshop from Russia, Kenya and India.

10. *Media Engagement:*

The final commandment is that good will and good hopes are not good enough for effective strategies to deal with TB generally and MDR TB in particular. To raise public knowledge is an obligation when faced with a challenge like this. That can only be done by engagement with the media. Where wrongs (even if only of omission) are occurring, it is essential to raise awareness. That means engaging with the media. This includes newspapers (especially in a country like India); television; cable news; international news outlets; social media; specialist and expert journals. Doing good things in private, cloaked in secrecy, is never going to change public knowledge and promote effective action. Of course, there are dangers in media engagement. They include trivialisation, error, sensationalising topics and creating celebrities. However, only by raising the issue of TB and especially MDR TB, will political and professional pressure arise. Only then will public funds be deployed. Only then will action be taken to reverse indifference. Only with publicity will the tide of inactivity be turned. On the day of the conference in New Delhi, a medical conference to address the problem of providing affordable treatment for Indian citizens suffering from Hepatitis C (HCV) gained strong publicity in the print and electronic media. Those who are

working in this field must become better at engaging with the media. In the end, it is also good for the relevance of the universities and institutions that are involved.[8] But most of all it brings hope, prevention and treatment to the aid of people living with TB and especially MDR TB.

We should spread the news of these Ten Commandments. And in our lives, we should henceforth act accordingly.

[8] "Doctors Pitch for Affordable Drugs to Fight Hepatitis C", *Hindustan Times*, New Delhi, 21 December 2015, 6.