LETTER TO THE EDITOR

Lessons from Jonathan Mann: The Ten Commandments on Multidrug-Resistant TB

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I welcome the latest issue of the *Health and Human Rights Journal* with a Special Section on Tuberculosis (TB) and the Right to Health. TB is indeed a major challenge to global health. It is one of the most serious impediments to the attainment of the new Sustainable Development Goals (SDGs) that recognise the interdependence of health and development. SDG 3 aims to "attain healthy lives and well-being for all". As most papers in the Special Issue acknowledged, the statistics are alarming: in 2013 alone, there were approximately nine 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.

The special section drew attention to the extent of multidrug-resistant TB (MDR-TB) and the estimation that 5% of cases of TB worldwide are MDR-TB, that many people with MDR-TB remain undiagnosed. Many of the world's health systems do not have the capacity to detect and treat MDR-TB. It is a problem that has led UN Secretary-General Ban Ki-moon to establish a High Level Panel on Access to Essential Medicines. He stated,

> 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.[1]

In the specific context of TB and MDR-TB, this special issue demonstrated that treatment remains problematic. Most of the people who are ultimately diagnosed as suffering from MDR-TB 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

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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 the High Level Panel.

I have been appointed to serve on the new Panel. Its first meeting took place in New York in late 2015 immediately prior to the "TB, Human Rights and the Law" judicial workshop in New Delhi, India organized by the International Human Rights Clinic at the University of Chicago Law School (UChicago IHR Clinic) and conducted jointly with the All India Institute of Medical Sciences (AIIMS). I attended this workshop, which I reported to the UNDP and the HLP. I first promulgated the following Ten Commandments at this workshop. I also attended a subsequent "TB, Human Rights and the Law" judicial workshop in Nairobi, Kenya co-organized by the UChicago IHR Clinic, KELIN and the Stop TB Partnership. Many of the themes arising at these workshops also featured in the Special Section in the Journal. At the second conference, many of the Ten Commandments were put into practice, including the participation and active engagement with people with TB and survivors. This experience vindicated the wisdom of the Commandments. They are not only right in principle. They improve outcomes.

The Ten Commandments

1. *Empirical Foundation*

It is essential for those who are seeking to establish effective policy for the response to such an epidemic to 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. This first lesson was taught to the international community in the earliest days of the HIV and AIDS epidemic by the late Jonathan Mann. It constitutes his vital legacy for contemporary epidemiology, law and social policy. Our duty now is to extrapolate from our experience with HIV and to spread this message into urgent new health crises, including TB and MDR-TB.

2. *Human Rights 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.[2] 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. *No Time to Lose*

As in the early days of the HIV epidemic, the data placed before the workshop in Delhi and in the papers in the Special Section, frequently stated that there is "no time to lose" in addressing the issues of TB and especially MDR-TB in India and elsewhere. The problem has moved beyond the need for 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
- Healthcare workers
- Hospital treatment officers
- Indigenous peoples
- Particular ethnic groups
- 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 STOP TB Partnership, and 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 straightforward, 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 AIDS Law Project now (Section 27) in South Africa illustrates the successes that can be achieved. So is the work of Lawyers Collective HIV/AIDS Unit, India, of KELIN in Kenya, and of civil society action 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. 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. 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 these Ten Commandments. And in our lives, we should henceforth act accordingly.

References

1. 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.

2. World Health Organization, *A Human Rights Approach to Tuberculosis* (Guidelines to social mobilization) WHO/CDS/STB/2001.