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Competing interests: None declared.

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LIMITATIONS ON HUMAN RIGHTS: ARE THEY JUSTIFIABLE TO REDUCE THE BURDEN OF TB IN THE ERA OF MDR- AND XDR-TB?

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ABSTRACT

Tuberculosis, in all its forms, poses a serious, demonstrable threat to the health of countless individuals as well as to health as a public good. MDR-TB and, in particular, the emergence of XDR-TB, have re-opened the debate on the importance, and nature, of treatment supervision for basic TB control and the management of drug-resistant TB. Enforcing compulsory measures regarding TB patients raises questions of respect for human rights. Yet, international law provides for rights-limiting principles, which would justify enforcing compulsory measures against TB patients who refuse to have diagnostic procedures or who refuse to be monitored and treated once disease is confirmed.

This article analyzes under what circumstances compulsory measures for TB patients may be enforced under international law. Compulsory measures for TB patients may, in fact, be justified on legal grounds provided that these measures are foreseen in the law, that they are used as a last resort, and that safeguards are in place to protect affected individuals. The deadly nature of the disease, its epidemiology, the high case fatality rate, and the speed at which the disease leads to death when associated with HIV are proven.

BACKGROUND

Tuberculosis (TB) is among the most widespread communicable diseases and the world's second most important cause of death from an infectious agent.¹ Between 1995 and 2006, a total of 31.8 million new cases of TB were reported to the World Health Organization (WHO), of which nearly half (49%) were smear-positive cases, and therefore potentially capable of transmitting the disease. Based on surveillance data, WHO estimated that in 2006 alone, there were 9.2 million new cases of TB, of which 4.1 million were smear-positive cases.²

TB caused by bacilli resistant to drugs has been documented in every region of the world and in all countries surveyed so far.³ Multi-drug-resistant tuberculosis (MDR-TB) — that is, TB resistant to at least rifampicin and isoniazid, the two most powerful anti-TB drugs — has been estimated to occur in nearly half a million cases every year and, recently, an even more severe form of drug-resistant TB, named extensively drug-resistant tuberculosis (XDR-TB) — that is, TB resistant to at least rifampicin and isoniazid (MDR-TB), in addition to any fluoroquinolone, and to at least one of the three following injectable drugs used in anti-TB treatment: capreomycin, kanamycin, and amikacin — has been reported in all regions of the world and associated with extremely high mortality among HIV-infected patients.⁴

The burden of TB and MDR-TB and, in particular, the emergence of XDR-TB, which brings with it the spectrum of incurable disease, have

re-opened the debate on the importance of treatment supervision for basic TB control and management of drug-resistant TB.⁵ One sensitive issue raised by this debate is the role of involuntary treatment and other compulsory measures in TB, MDR-TB and, now, XDR-TB control.⁶ Such measures include compulsory medical examination, compulsory quarantine, and compulsory isolation or detention of infected persons.⁷ The lack of voluntary participation may be a substantial obstacle to the success of public health actions. When it comes to the various forms of TB, the public health goal of securing and enhancing the health and well-being of citizens is frustrated if TB patients (who, for the purpose of this article, include patients with contagious forms of TB, MDR-TB, and XDR-TB) do not consent to isolation when they are infectious and/or do not accept treatment. Both of these measures may be needed to prevent the spread of the disease to others.

The use of compulsory measures to achieve public health goals is, however, problematic.⁸ International law, and in particular, human rights law, imposes on governments the duty to promote and protect human rights, such as the right to privacy, the right to be free from inhuman or degrading treatment, and the right to freedom of movement. Human rights impose positive and negative obligations on a state. These include refraining and preventing third parties from interfering with human rights-holders' enjoyment and enacting positive measures so that rights-holders are in a position to enjoy their rights.

Consequently, a tension between collective interests and individual rights may arise. In particular, public health measures could potentially lead to a perceived or real violation of basic human rights. To balance public health concerns and human rights protection, international law provides that public health may be invoked as a ground for limiting certain rights. In other words, the protection of human rights is generally not absolute under international law.⁹ In the remainder of this article, we analyze whether, and to what extent, public health programs aiming at reducing the burden of TB, MDR-TB, and the emergence of XDR-TB justify the limitation of certain human rights.

PUBLIC HEALTH AND HUMAN RIGHTS LAW

Human rights are protected under international law, under regional systems, and by national constitutions.

Some of the basic human rights are asserted in the Universal Declaration of Human Rights, adopted in 1948 by the General Assembly of the United Nations. Although the Universal Declaration of Human Rights is a resolution with no explicit force of law, because of its moral and political authority its basic principles are reflected in countless international legal instruments as well as in regional and national legal frameworks. Subsequent international legal instruments have expanded human rights law further. The International Covenant on Civil and Political Rights requires member states to respect and ensure civil and political rights. Echoing the 1946 WHO Constitution, Article 12 of the International Covenant on Economic, Social and Cultural Rights provides that “[t]he States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”¹⁰

Governmental public health actions must “protect and advance the health of the population as a whole, while at the same time protecting basic human rights and social values.”¹¹ Therefore, the protection afforded to an individual's human rights is subject to limitations, and international human rights law authorizes restricting rights in order to protect public health, when necessary. The legal standards for assessing whether limitations on human rights are valid are spelled out in the Siracusa Principles, a non-binding document adopted by the UN Economic and Social Council in 1985.¹² These principles hold that measures restricting human rights should be legal, neither arbitrary nor discriminatory, proportionate, necessary, the least restrictive means that are reasonably available under the circumstances, and based on sound science. Specifically, for a restriction of a human right to be considered legitimate, a government has to address the following five criteria: 1) the restriction is provided for and carried out in accordance with the law; 2) the restriction is in the interest of a legitimate objective of general interest; 3) the restriction is strictly necessary in a democratic society to achieve the objective; 4) there are no less intrusive and restrictive means available to reach the same objective; and 5) the restriction is based on scientific evidence and not drafted or imposed arbitrarily — that is, in an unreasonable or otherwise discriminatory manner.¹³ Moreover, any restriction must be of a limited duration, respectful of human dignity, and subject to review. The following two sections discuss whether limitations on human rights are justifiable

to reduce the burden of TB and MDR-TB, and the emergence of XDR-TB.

THE LEGAL ASPECTS OF INVOLUNTARY CONFINEMENT OF TB PATIENTS

Involuntary confinement is one of the public health measures that governments could implement to manage the public health risks associated with TB and MDR-TB, and the emergence of XDR-TB. This measure is justified primarily to protect both the human right to health and health as a public good. The human right to health is the right of any individual member of the community to be protected from the risk of contracting the disease by airborne transmission if, for instance, an XDR-TB patient not taking adequate treatment and not adhering to respiratory hygiene standards, were to be allowed to freely circulate in a community. The public good is the health of the entire population, which may be at risk if the XDR-TB patient is not confined. Justifying involuntary confinement of specific patients is always controversial, however, because it represents a significant deprivation of an individual's freedom of movement and runs the risk of resulting in limiting other civil liberties, such as privacy, non-discrimination, and freedom from arbitrary detention. Yet, the right to health of other members of the society, and more generally, the interest in having societies that are free from diseases that are difficult to treat and highly lethal, cannot be overlooked. If consideration is given to the welfare of healthy individuals and society at large, then involuntary confinement can be legitimate when public health interests are carefully balanced against individual TB patients' interests. This is also recognized by international human rights law. By requiring measures that limit civil liberties to be prescribed under the law, and to be grounded on evidence-based necessity, to be proportionate and gradual, the least restrictive options available, and based on sound science, the Siracusa Principles provide a workable framework for determining if involuntary confinement is justified. The following sections analyze these criteria set by the Siracusa Principles in detail.

Legality

Legality means that the restriction is provided for and carried out in accordance with the law. In practical terms, legality requires that substantive and procedural safeguards are in place. From a substantive perspective, governments that intend to enforce involun-

tary confinement of XDR-TB patients (or any other TB patient) must enact a law — a statute of general application to the entire affected community — setting forth in general terms, preferably after public consultation, who may be subject to involuntary confinement and the criteria under which a person may be confined against his or her will. From a procedural perspective, governments are required to put in place rules regulating the decision-making process that leads to enforcement of involuntary measures, for instance by specifying the authority that determines who is to be confined and following what procedure. Such process must ensure fairness and prevent arbitrary, unreasonable, or discriminatory actions, for instance, by requiring full disclosure of the reasons for issuing a confinement order. Whenever possible, legal representation should be guaranteed to any individual whose freedom of movement is at stake. In case of emergency, the law should allow temporary orders to be issued whenever delaying the confinement frustrates the public health goals that the law aims to achieve. Procedural safeguards also include monitoring the confinement to ensure that the measure is carried out safely and humanely, with respect for human rights laws and human dignity. Finally, TB patients must have access to the courts to challenge the legality and validity of governmental actions limiting their human rights.

Evidence-based necessity

Necessity requires that any restriction be strictly necessary to achieve the objective. The Siracusa Principles mandate that measures limiting human rights on public health grounds are justified only if a demonstrable public health threat is present. Thus, compulsory measures must be based on scientific evidence, and the public health threat that national authorities assert as the basis for compulsory measures must be demonstrable. Only in these circumstances can the possibility of enforcing compulsory measures be considered. To date, there is no evidence that the transmission dynamics of XDR-TB are significantly different from those of MDR-TB or drug-susceptible TB. Therefore, recommendations to perform TB contact investigation should be applied in all circumstances where the index case is infected by MDR-TB or XDR-TB strains.¹⁴

Necessity also requires that compulsory measures may be enforced only regarding TB patients who pose an actual, demonstrable threat to the commu-

nity. For instance, this could occur when individuals have been either diagnosed with pulmonary TB or are “suspected” of having active disease, and are reluctant either to voluntarily take treatment or to accept a diagnostic procedure. Individual cases require different measures, and a distinction should be foreseen among 1) TB patients with bacteriologic identification of *Mycobacterium tuberculosis* on specimens collected from their lungs (sputum, bronchoalveolar lavage, biopsy), 2) individuals exposed to a serious risk (long-term exposure to a symptomatic sputum smear positive index case in a context of limited ventilation), and 3) individuals who are merely at risk of exposure.¹⁵ Each category is, in fact, associated with a different risk from a public health perspective, and therefore different measures and requirements may be needed. The most problematic case involves individuals who are merely suspected of having TB and being infectious to others. Even in this situation, however, confinement may be justified if a general provision defines beforehand what is meant by “suspected.” For instance, a “suspect” is exposed to a risk factor that is specific to the “suspected” person, such as his/her spouse’s being affected by infectious TB. Additionally, when dealing with a “suspect,” confinement may be initially justified only for the time strictly necessary to establish whether the person is, in fact, affected by infectious TB.

Finally, necessity requires that compulsory measures are not imposed arbitrarily or in an otherwise discriminatory manner, so that no particular group of TB patients would suffer a disproportionate burden of compulsory measures.¹⁶

Proportionality and gradualism

The proportionality and gradualism requirements mandate that 1) the restriction must be balanced against any legitimate objective of general interest that the restriction aims to pursue, 2) the measure must be voluntary whenever possible, and 3) the restrictive measures are justifiable only if there are no less intrusive and restrictive means available to reach the same objective.¹⁷

First, restrictions are more acceptable when a substantial public interest is at stake. XDR-TB is a communicable disease with a high case fatality, especially among those with HIV infection, and for which more effective drugs will likely not be available in the next 5 to 10 years.¹⁸ These features certainly heighten the

interest of the public to contain the spread of XDR-TB, a disease that has the potential to harm a great number of people for a significant time. Therefore, compulsory measures may be justifiable under international law when they are proportionate to protect healthy individuals and the public interest.¹⁹

Second, proportionality requires that confinement be voluntary whenever possible. Governments’ obligation to protect human rights entails respecting rights-holders’ autonomy — that is, the right to make an informed, reasoned, and voluntary decision on whether or not to accept a certain course of action (in this case, the decision of a TB patient to be kept separate from healthy individuals). Although public health concerns are pressing, international law requires that TB patients’ autonomy is respected whenever possible. However, autonomy is not given absolute protection. Preventing harm to third parties is a sufficient ground for limiting the autonomy of a person whose actions may lead to harming such innocent parties.²⁰ Consistently, under international law, the need to prevent healthy individuals from getting sick may provide strength sufficient to override individual autonomy considerations.

Third, gradualism requires that confinement be justified only if there are no less intrusive and restrictive means available to reach the same objective. The least restrictive measure should be considered first, and more restrictive forms of confinement should be adopted only if dictated by necessity. An example of a mildly restrictive measure is requiring patients living alone, or otherwise in a position to not transmit TB to healthy individuals, for instance by mandating patients not to leave their residence.

Finally, whenever restrictions on the freedom of movement or privacy are imposed, their enforcement must always respect human dignity, be culturally sensitive, and be periodically reviewed by the courts to ensure respect of the proportionality and gradualism requirements over time. If gradualism is applied with reason, even in the case of involuntary confinement, only the freedom of movement is restricted, allowing the exercise of other civil liberties during the confinement.

Are compulsory diagnosis and treatment ever justified?

Early diagnosis and appropriate treatment are critical to limit the duration of contagiousness, and con-

sequently the number of contacts of an infectious TB case. Good adherence to TB treatment is then necessary to limit the selection of strains resistant to medicines and thus the development of drug-resistant TB.²¹

Health being a public good, individuals with TB owe a duty to limit the spread of TB and the development of drug-resistant TB. Compulsory diagnosis and treatment entails limiting the right to be free from non-consensual bodily invasion, which forms the basis of the informed consent doctrine. Involuntary confinement, in itself, does not justify also treating or monitoring the health of those that are confined. Although public health authorities may have the authority under certain circumstances to confine individuals at risk of transmitting a communicable disease, they do not necessarily have the authority to treat them or monitor their health. Parallel, yet separate, evidence, with respect to involuntary confinement, must be produced showing that the requirements set forth by the Siracusa Principles are respected. However, the nature of the analysis does not change. Therefore, compulsory diagnosis and treatment are justified if the measure is legal, not arbitrary, not discriminatory, based on a demonstrable threat, necessary to respond to a pressing public health need, and proportional and gradual. What is distinctive about compulsory diagnosis and treatment is that they may result in the TB patients' becoming healthy again. This would be an important public health interest because it may significantly reduce the period of isolation for the patient and also reduce the risk of TB spreading further in the population, within national boundaries and abroad.

CONCLUSION

The burden of TB and MDR-TB and, in particular, the emergence of XDR-TB pose a serious, demonstrable threat to the health of countless individuals as well as to health as a public good. Enforcing compulsory measures regarding TB patients raises questions of respect for human rights. Yet, international law provides for rights-limiting principles, which would justify enforcing compulsory measures against TB patients who refuse to have diagnostic procedures or who refuse to be monitored and treated once disease is confirmed. Compulsory measures for TB patients may, in fact, be justified on legal grounds provided these measures are foreseen in the law, used as last resort, and that safeguards are in place to protect

affected individuals. The deadly nature of the disease, its epidemiology, the high case fatality rate, and the speed at which the disease leads to death when associated with HIV are proven. This is a serious disease that may lead to death and entails substantial suffering. International human rights law is primarily concerned with balancing the human rights protection with public health concerns. As the respect of human rights is at the basis of modern public health, compulsory measures needed to protect the public from severe health threats should be such that they withstand the scrutiny of the law. They can be justified, under the conditions discussed in this article, to protect the population at large, and prevent the consequences of drug-resistant TB.

Authors' contributions: A. B. conceptualized and compiled the first draft of this article. M. Z. substantially contributed to subsequent drafts. E. J., P. N., G. P., and M. R. revised it critically and approved the version to be published.

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