

# Detention and the Evolving Threat of Tuberculosis: Evidence, Ethics, and Law

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## Introduction

The issue of detention as a tuberculosis control measure has resurfaced following the prolonged detention of a patient with an extensively drug-resistant strain of tuberculosis in a prison cell in Arizona,<sup>1</sup> and the attempted detention in Italy and subsequent detention in Atlanta, Georgia of an American sufferer thought to have XDR-TB in May 2007.<sup>2</sup> These cases have reignited the debate over the evidence that supports detention policy in the control of tuberculosis, and its associated legal and ethical ramifications. This paper considers whether involuntary detention is justified where voluntary measures have failed or where a patient poses a danger, albeit uncertain, to the public, and discusses the need for strengthening evidence-based assessments of public health risk.

Globally, tuberculosis currently infects about a third of the world's population, with an estimated growth of one percent per year for the global incidence of active disease.<sup>3</sup> This increase is driven in part by its association with Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS), both of which predispose their sufferers to tuberculosis through complex epidemiological and socio-economic interactions. Consequently, tuberculosis affects societies' most vulnerable and deprived populations. Of profound concern has been the recent rise in the prevalence of drug-resistant strains of the disease. The causes of this, like the interactions with HIV, are manifest and complex, but fundamentally iatrogenic in nature.

The emergence of an extensively drug-resistant form of tuberculosis (XDR-TB) was reported by the World Health Organization (WHO) in March 2006 following a worldwide survey that examined resistance to second-line drug therapies.<sup>4</sup> Multi-drug resistant tuberculosis (MDR-TB)<sup>5</sup> poses profound challenges, most notably because of the treatment costs and the prolonged duration of infectiousness. XDR-TB amplifies these concerns.

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Drug resistance poses an enormous challenge to ongoing efforts to globally control TB, and raises concerns over a lethal global pandemic of increasingly drug-resistant forms of the disease. Although improved clinical care, strengthened health systems, and access to second line anti-tuberculosis drugs have improved cure rates for MDR-TB in recent years with reported survival rates of 60 percent, in the case of XDR-TB, the pattern is still very worrisome, especially amongst populations where HIV prevalence is high.<sup>6</sup> In a rural area of KwaZulu-Natal, for example, an alarming picture has emerged in relation to an outbreak of HIV-associated XDR-TB.<sup>7</sup> Forty-five percent of the 53 cases occurred in individuals who had not previously been treated for tuberculosis, suggesting active ongoing spread. All 44 individuals tested for HIV were co-infected, signifying substantial rapid progression to disease following infection. Rapid progression to death occurred in 98 percent of patients, with a median survival of only 16 days from the time of diagnosis.<sup>8</sup>

### Responses to the Emergence of XDR-TB

There has been an international response to the emergence of XDR-TB and the issues surrounding it in the context of tuberculosis control. The WHO restated its focus on preventative measures and updated its tuberculosis control strategy to account for XDR-TB, following a meeting of the Global Taskforce on XDR-TB in October 2006. In January 2007, guidance on involuntary detention in the context of human rights was issued in response to a paper by Singh et al., which highlighted the potential role for involuntary detention in the management of XDR-TB.<sup>9</sup> In this paper, involuntary detention was advocated as a last resort where voluntary measures had failed, and where the patient "wilfully" refused treatment and posed a danger to the public.<sup>10</sup> The South African Medical Research Council published a position statement taking a similar approach, in which the need for careful legal and ethical review was emphasized.<sup>11</sup>

### Tuberculosis Control Measures within Europe

Legislation to support tuberculosis control varies across countries in Europe (see table).<sup>12</sup> Some countries, for example Switzerland, legislate for compulsory control measures such as examination, detention, and treatment, in addition to compulsory prevention measures such as screening and vaccination. In contrast, Spain has no compulsory measures for tuberculosis control. A recent review of public health legislation in 14 European states found that eight states sanction detention, either within the home or in an institution, for patients with tuberculosis.<sup>13</sup> Five of these states also sanction compulsory treatment for tuberculosis

(Estonia, Czech Republic, Norway, Russia, and Switzerland). England, Germany, and Israel provide for compulsory detention but do not authorize compulsory treatment. The authority to detain is not limited to infectious cases, but may, in six countries, be sanctioned when patients refuse treatment. Whilst a court order is generally required to authorize detention, in Norway, however, physicians have the power to detain patients without an order. Norway also legislates for compulsory quarantine of individuals on the grounds of exposure to tuberculosis.<sup>14</sup>

Legislation for the detention of patients with tuberculosis in England and Wales is limited, under sections 37 and 38 of the Public Health Act 1984, to those with tuberculosis of the respiratory tract "in the infectious state." Built-in safeguards from the 1925 and 1936 Public Health Acts were removed in 1968, resulting in no current codified process of review and no limits to the duration of the detention or extension of the order; there is also no automatic right to legal representation.<sup>15</sup> As is the case in numerous states around the world, English legislation is undergoing a process of reform, partly in response to the revision of International Health Regulations. Like many states, English public health laws have been scrutinized and found wanting.<sup>16</sup>

Overarching the application of public health police powers in Europe are people's fundamental rights, which are enshrined in national law and contained in the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR). The question of Convention rights in the context of the exercise of public health powers was raised in the 2005 case of *Enhorn v. Sweden*, in which an HIV positive man successfully challenged his detention by Swedish public health officials.<sup>17</sup> The means of transmission of HIV differ from those of tuberculosis, and it could be argued that the nature of transmitting tuberculosis through simply breathing justifies greater intrusion into private rights for the benefit of the public health. However, the European Court of Human Rights noted in *Enhorn* that there has been little case law on interpretation of the "infectious disease" exemptions in the European Convention, and took the opportunity to lay down some general principles governing those circumstances in which human rights might be infringed in pursuance of infectious disease control. Any exercise of a public health power which resulted in an infringement of the right to liberty contra Article 5 of the Convention, or an infringement of the right to private and family life contra Article 8, must satisfy the requirements that it is proportional to the public health threat, and that there is an "absence of arbitrariness" such that other less severe measures have

Table

**Legal Compulsory Measures for Selected European Countries  
(ranked by number of control measures)**

Country	Screening	Examination	Treatment	Detention	Vaccination	Isolation on the grounds of exposure	Exclusion from activities	Number of control measures
Spain	N	N	N	N	N	N	N	0
France	N	N	N	N	Y	N	Y	2
Germany	N	Y	N	Y	N	N	N	2
Israel	N	N	N	Y	N	N	Y	2
Netherlands	Y	Y	N	N	N	N	N	2
Finland	Y	N	Y	N	N	N	Y	3
Poland	N	N	Y	N	Y	N	Y	3
England	Y	Y	N	Y	N	N	Y	4
Estonia	N	Y	Y	Y	Y	N	N	4
Hungary	Y	N	Y	N	Y	N	Y	4
Switzerland	Y	Y	Y	Y	N	N	N	4
Czech	N	N	Y	Y	Y	N	Y	5
Norway	Y	Y	Y	Y	N	Y	Y	6
Russia	Y	Y	Y	Y	Y	N	Y	6

(Table modified from R. J. Coker, S. Mounier-Jack, and R. Martin, "Public Health Law and Tuberculosis Control in Europe," *Public Health* 121, no. 4 [2007]: 266-73.)

been considered and found to be insufficient to safeguard the individual and the public. The institution where the detention is to take place must be appropriate to the nature of the disease and must provide opportunities for treatment as well as public health protection. It is also the case that Article 6 of the Convention, which protects the right to a fair trial, will invalidate a detention that fails to recognize opportunities for defense, review, and appeal. Although the higher risk of tuberculosis transmission may require proportionally greater restrictive measures than in the case of HIV, it is clear from the decision in *Enhorn* that statutory public health powers in many states of Europe are vulnerable to challenge on human rights grounds. Although *Enhorn* was the first case to reach the courts, many detention practices in Europe would fail to stand up to scrutiny under the ECHR.<sup>18</sup>

### A Role for Involuntary Detention?

Jerome Singh et al.'s paper on the challenge posed by XDR-TB in South Africa stimulated afresh the debate about the use of detention to protect the public's health.<sup>19</sup> The debate originated a decade earlier when New York City, responding to an epidemic of

drug-resistant tuberculosis in the early 1990s, passed laws that facilitated the detention of non-infectious individuals and shifted the burden of proof from an assessment of the risk posed to the public's health to an assessment of likely treatment compliance.<sup>20</sup> Thus, this novel approach did not distinguish between types of tuberculosis (for example, drug-sensitive diseases, MDR-TB, or indeed the as yet to be recognized XDR-TB), but on determinations of compliance and completion of treatment. Periods of detention for those with MDR-TB were longer than those with drug-sensitive disease, not because the threat posed to public health was greater (though it could be argued that this was the case) but because the treatment took much longer to complete. The current New York City law does not respond to differences in transmission dynamics or assessments of risk.

In relation to XDR-TB in South Africa, Singh et al. propose that under some circumstances, individuals might be isolated whilst awaiting susceptibility results. They advocate an initial voluntary isolation of patients with drug-resistant tuberculosis, separating those with multi-drug resistance from those with extensive drug resistance, and recommend coercive measures where

voluntary isolation is declined, acknowledging that the duration of isolation may potentially be indefinite or until death in some cases of XDR-TB. The authors conclude: "Although such an approach might interfere with the patient's right to autonomy and will undoubtedly have human rights implications, such measures are reasonable and justifiable, and must be seen in a utilitarian perspective. Ultimately in such cases, the interests of public health must prevail over the rights of the individual."<sup>21</sup>

This statement raises a number of ethical issues. While considerable attention has been paid to the purpose and boundaries of human rights, the nature and scope of public health ethics have received less consideration. Human rights jurisprudence emerged from Western political philosophy, which prioritizes individual autonomy and the protection of individual physical, personal, and proprietary rights from interference by the state. Medical ethics, as distinct from public health ethics, have developed both temporally and substantively with human rights jurisprudence, resulting in principles of medical ethics also being underpinned by this central recognition of autonomy and private rights. For this reason, human rights and Western norms of medical ethics do not always sit comfortably in some cultures, such as Asian, African, or Islamic cultures, that prioritize the good of society or the community over the individual.

Public health practice, which has its roots not in medicine but in the work of early welfare reformers such as Edwin Chadwick, is premised on the philosophies of utilitarianism and social responsibility, or what we might now term communitarianism, rather than autonomy. Consideration of involuntary detention will thus require some reconciliation between the principles of human rights and autonomy on the one hand, and public benefit on the other. Such reconciliation is not an impossible task. John Stuart Mill's "Harm Principle" makes provision for the restriction of an individual's right to autonomy and self-determination in order to prevent harm to others and benefit liberty overall. This is a central tenet of the position taken by those advocating for the detention of individuals with tuberculosis who are perceived to pose a public health threat. In recognition of this principle, many human rights documents recognize that the public's health might justify some qualification of rights. Article 5(1) of the European Convention, for example, which is designed to protect liberty, allows for "the lawful deten-

tion of persons for the prevention of the spreading of infectious diseases." Similarly the Siracusa Principles, drawn up in 1984, contain a provision for departure from the 1966 International Covenant on Civil and Political Rights in situations of public emergency, including public health emergencies.<sup>22</sup> However, the scope and limits of the power to infringe upon the right to liberty in pursuance of infectious disease prevention and control need further clarification.

### Public Health and Risk

An approach, which might enable the formulation of a body of public health ethics acceptable to human rights jurisprudence, is to introduce into the language of ethics and rights the notion of evidence-based assessment of risk. Singh and colleagues note in their argument for involuntary detention that detention "has met with some degree of success in the U.S., where it helped bring down TB infection rates in states such as New York in the 1990s." Yet this important assertion was unsubstantiated and no evidence was provided. Indeed, there appears to be very limited evidence to support a causal relationship between increased detention and reduction of TB incidence, a somewhat ironic position given the burden such interventions place on individuals in this age of evidence-based medicine.<sup>23</sup>

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Public health regulation essentially constitutes an attempt to control risk by balancing the threat to the public's health against the limitations imposed on the individual by measures implemented to limit the overall risk. Inevitably, regulation constrains the rights of the individual in order to benefit the public interest and the greater good.<sup>24</sup> In the context of detention, it can be argued from a utilitarian perspective that if the utility gain to the greatest number exceeds the utility loss across society, then coercive measures are justifiable.<sup>25</sup> It follows that a risk assessment is necessary to determine this balance. This consideration of risk should inform determinations of whether involuntary detention should play a role in the control of

tuberculosis, and objective evidence of the risks posed by tuberculosis is required to inform rational policy-making. The evidential standard supporting a policy of detention in tuberculosis control should surely be high in order to justify the infringement of human rights that detention entails.

Scientific investigation into tuberculosis greatly diminished during the 1970s, when the disease appeared to be effectively controlled and potentially eliminated. Much of the current knowledge regarding transmissibility is derived from studies of outbreaks and animal studies. Although the presence of the acid-fast bacilli in sputum is known to be highly predictive of infectiousness, drawing on advances in molecular analysis, we also know that smear-negative individuals can pose a risk, albeit substantially reduced.<sup>26</sup> Considerable uncertainty remains concerning the risk of transmission and the duration of this risk; thus, risk prediction is still an uncertain business. With the available evidence, we are not acting completely in the dark and may make inferences,<sup>27</sup> but if we wish to justify interventions on utilitarian grounds, we cannot continue to impose measures which infringe upon rights without rigorously pursuing further evidence to support utilitarian calculations of benefit.

In the context of uncertainty, policy decisions commonly rely on the perception of risk to the public health. This notion, if applied rationally, acknowledges both the probability and gravity of harm, while still considering personal, social, and cultural values. Even in the hands of "experts," interpretation of statistical data is subjective and liable to bias and error. This well-documented phenomenon becomes amplified by the incorrect use of statistical data in the determination of risk in other contexts. For example, in England, misinterpretation of statistics by a professor of paediatric medicine led to an overestimation of the risk of two cases of sudden infant death syndrome occurring in the same family, an error that led to a murder conviction for the infants' mother.<sup>28</sup>

A consensus is needed on what may be considered appropriate in balancing the common public health good with individual rights. There is insufficient evidence that a policy of detention is, in aggregate, beneficial to public health.<sup>29</sup> This does not mean, of course, that isolating an individual has no impact on transmission dynamics. Historically, isolation and quarantine *have* been effective in containing the spread of infectious disease and are among control measures recommended in the revised International Health Regulations. But coercive measures could impact positively or negatively on the behavior of those who are threatened with sanction, either by encouraging them to comply with treatment, or, in contrast with a

public health perspective, by causing them to delay in seeking diagnosis and treatment.<sup>30</sup> While the impact on the individual might be readily determined, understanding the public health impact of these wider factors is more challenging.

A further consideration is the risk of stigmatization and discrimination.<sup>31</sup> The greatest burden of disease lies with socially disadvantaged groups: physical overcrowding, HIV, low income, and malnutrition all contribute to the susceptibility of the responsible organism. Tuberculosis stigmatizes,<sup>32</sup> and involuntary detention measures may serve to further stigmatize and marginalize the person, an issue potentially exacerbated if the place of detention is a prison rather than a health care setting.

### Human Rights and the Siracusa Principles

The Siracusa Principles offer a useful framework by which to examine whether coercive public health interventions are justified. The first of the principles is the notion of whether any proposed restriction on liberty is a legitimate objective of general concern. The objective of controlling tuberculosis and limiting drug resistance is undeniably both legitimate and in the public's interest. Is the restriction provided for and carried out in accordance with the law? Many democratic countries have legal structures in which coercive public health interventions are sanctioned. However, much of the public health legislation around the world was drafted before the development of contemporary medical responses to tuberculosis, notably the advent of effective anti-tuberculosis drugs, and before the development of contemporary human rights jurisprudence. Thus, it is often the case that public health legislation contains neither adequate legal safeguards to prevent inappropriate detention, nor adequate opportunities to defend, appeal, or review detention orders.

A second principle questions whether available alternatives that are less intrusive and restrictive have been tried. The weak evidence base noted above profoundly tests this notion of proportionality in regards to detention. Moreover, the evidence necessary to support other less restrictive interventions is also insufficient.<sup>33</sup>

Another principle addresses the arbitrary, unreasonable or discriminatory manner in which a sanction might be imposed. The detention of any group of tuberculosis patients may appear arbitrary without a fuller understanding of the risks.<sup>34</sup> More evidence is required in order to identify the individuals or groups to be targeted by these restrictions, and the optimum duration of detention. This is compounded by the fact that the prevalence of tuberculosis, particularly drug-resistant forms of tuberculosis, is not distributed

evenly throughout society, resulting in detention measures that may in practice appear to be focused on particular ethnic groups or strata of society.<sup>35</sup>

Underpinning the Siracusa Principles is the explicit demand for evidence of public health benefit. A lack of evidence when attempting to justify an action is not a

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problem that is unique to communicable disease control. In other areas, however, notably in the context of environmental protection, the precautionary principle carries weight. But environmental protection does not test human rights in the same way as communicable diseases. Use of the precautionary principle to justify the detention of sufferers of disease has the potential to result in a significant invasion of individual rights. If we are to justify overriding human rights for the public good in the absence of evidence, we must do so within another framework of protection, protection against the abuse of power by the state. Such a framework must contain an acknowledgement of the duties incumbent not only upon individuals, but also upon public health agencies, and must address the manner in which society's most marginalized and vulnerable are treated. These are issues that have an implicit impact on an unwritten social contract between individuals and society.

Implicit in the Siracusa Principles is the little explored notion of how much burden or risk, if any, society is prepared to shoulder if basic individual rights and freedoms are to be protected at society's expense. In the absence of evidence, is coercion acceptable for the objective of public health protection? Social and cultural values determine where this balance is to be drawn.

While a utilitarian perspective, from which much debate draws, is dependent upon an evidence base that is yet to be established, Kantian or Rawlsian positions might justify interventions provided that societies accept that acting for the benefit of the public's health is right regardless of the outcomes. In societies where the determination of morally acceptable behavior is determined by a higher law, such as religious belief, it has been easier for states to impose interventions for the public good which result in a sacrifice of the individual. In some states, for example Malaysia, a

state where English common law traditions are superimposed with Islamic law, there are statutory powers of compulsory vaccination and medical treatment. In secular societies however, where autonomy is prized, restrictions on rights that cannot be justified by rational argument will inevitably be controversial. In the

U.K., for example, there are no powers of compulsory vaccination or treatment, and recent law reform proposals have rejected the introduction of such powers. History suggests that making vaccinations or treatments compulsory in the U.K. would be socially and politically unacceptable, unless they could be justified by scientific evidence and rational argument. A new consid-

eration of the philosophy underpinning public health in the context of communicable diseases is needed before we can engage in a meaningful debate about the arguments for and against involuntary detention.

### Conclusion

Controlling the spread of tuberculosis and preventing the development of drug resistance are legitimate public health objectives, but do not in themselves justify interventions which infringe upon human rights. Determination of the legitimacy of a coercive measure demands an analytical framework, and that framework should be underpinned by philosophical and scientific reasoning. Traditionally, in Western societies, public health interventions have been examined from a utilitarian perspective.<sup>36</sup> The Siracusa Principles and other interpretations of human rights, such as those by the European Court of Human Rights, draw upon utilitarianism to provide a coherent framework for analysis. But this framework is of limited value when considering the detention of individuals with tuberculosis because the evidence base is weak. In order to make consistent and coherent decisions in "hard cases," we need to develop an evidence base through research and to consider employing an alternative philosophy as the theoretical foundation of reflections on legitimacy. Otherwise, we will continue to muddle along, directed by "expert" opinion and political imperatives. If we remain wedded to the Siracusa Principles and their utilitarian justification, then the evidence base concerning tuberculosis must be strengthened to inform rational policymaking. In particular, information on the impact of the threat of detention on treatment compliance and the benefits gained from the detention of patients, particularly non-infectious patients, as well as its subsequent effects on the evolution of drug resistance, is vital. Such evidence should be provided by experimental work, formal theoretical

risk analyses, and modelling. Legislation underpinning the detention of patients with tuberculosis must be reviewed in the light of advances in knowledge, and the requirements of due process must be clarified.

Public health requires the development of a coherent and discrete body of public health ethics. The involuntary detention of individuals with tuberculosis tests traditional medical ethical approaches that, broadly, are framed to govern the relationship between health care providers and patients, and which offer little in the way of guidance for the public health imperatives associated with communicable diseases. In particular, norms of public health ethics need to be grounded in well-developed social, political, and philosophical theory so as to provide a robust framework to support public health practice.

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