Article

Confinement in the management of drug-resistant TB: The unsavoury prospect of balancing individual human rights and the public good

Leslie London, *MB ChB, DOH, MD, MMed (Public Health)*
School of Public Health and Family Medicine, University of Cape Town
leslie.london@uct.ac.za

In the context of expanding TB and HIV epidemics in South Africa, the decision to enforce non-voluntary admission for XDR TB raises many ethical and human rights dilemmas, principally because it trades off the human rights of individuals against the public good. However, the dichotomy may also involve competing rights claims and rights obligations of the state to control infectious diseases. A more careful rights analysis is provided, using established analytical frameworks, to elicit the possible criteria that could justify limitation of individual rights. Generally, only in very restricted situations where there is a clearly defined risk to one or more third parties, based on evidence, and conditional on thorough consideration of available alternatives, could non-voluntary admission be considered. Community-based strategies will need to be developed to cope with infection control without forced admission for most cases. Even when compulsory admission is needed, strict adherence to administrative justice procedures would be required. Confinement has no place as a strategy for the broader control of an epidemic which should be contingent on improved health system functioning and addressing the abysmal investment in research and development for drugs for neglected diseases worldwide.

South Africa's TB and HIV epidemics continue to confront health care providers and the country's health system not only with enormous clinical and service delivery challenges, but also, more starkly in recent times, with a range of evolving ethical and human rights dilemmas. In particular, rising rates of both pulmonary and extrapulmonary TB, fuelled by a huge burden of HIV in the country,[1,2] have seen growth in the caseload of multidrug-resistant (MDR) TB3 and the emergence of outbreaks of extremely drug-resistant (XDR) TB around the country,[4-7] sometimes characterised in the popular press as the realisation of health workers' 'worst fears'.[8]

XDR TB, defined as resistance to at least the two most powerful first-line anti-TB drugs rifampicin and isoniazid, to any fluoroquinolone, and to one or more of the injectable drugs amikacin, kanamycin and capreomycin,[9] has an extremely poor prognosis.[10] Estimates of cure in XDR TB are speculative (for example, Paul Nunn, coordinator of WHO's TB drug-resistance unit, cited a mortality rate of 80% for XDR TB11) and are certainly much lower than estimates for drug-sensitive TB (which in theory should be 85%), but cure rates in South Africa are approximately 50%[12] or lower than for MDR TB.[9,12] Indeed, of the 53 XDR patients treated at Tugela Ferry in Kwazulu-Natal province, all but one died in <4 weeks, prompting descriptions of incurability.[13-16] Costs of treatment for MDR, and particularly XDR, are also prohibitive, often requiring treatment options that are complicated, difficult to administer and painful and carry high risks of side-effects. Treatment is typically far more prolonged and expensive, requiring admissions for periods of up to 2 years and costing approximately 300 times more than would be the case for drug-sensitive TB.[12] Moreover, TB infection in HIV is associated with increased disease progression such that an increase in XDR-TB could be expected to significantly exacerbate the HIV/AIDS epidemic.[11]

The public health significance of XDR TB is therefore substantial, not just in terms of individual patient survival ('a likely death sentence'[14]), and the potential harm to family members and close contacts, but also in terms of the risks of dissemination into the infectious pool in South Africa and the resulting added burden on the health system. For example, one health official is quoted as describing XDR as 'biological warfare' that carries the risk of 'decimating the population' if let loose.[17] Put simply, an explosion of drug-resistant TB in the South African population, already rendered vulnerable by seroprevalences for HIV in excess of 30% among groups of reproductive age adults, looms like an uncontrollable and untreatable tidal wave that could wreak a scale of social and economic devastation never before anticipated. Such doomsday predictions are not just products of newspaper sensationalism;[8,14,18] the prospects of disaster are also contained in sobering warnings (such as a 'ticking time bomb') issued by a range of scientific sources.[19-22]

Under these circumstances, it is perhaps not surprising that South Africa has seen the re-emergence of coercive public health action (such as court orders) to enforce treatment and/or compulsory admission to hospital for XDR patients.[12] Such court actions have achieved a high press profile, attracting national[23,24] and international[8,11,12,17,18] attention, including wildly misquoted statistics on the frequency of XDR cases,[25] claims of threats to millions of lives in Southern Africa[26] and, for example, special health warnings issued to students coming to South Africa[27] on study-abroad programmes. Moreover, there have also been particular concerns over the violations of human rights inherent in coercive action. Unfortunately, much of the public media coverage has focused on the most sensational aspects of what is a complex dilemma,[28] reducing the choices to a simplistic binary trade-off between the public good and individual patients' human rights.

This article sets out why superficial analyses of the ethical and rights issues in managing drug-resistant TB patients are more likely to do harm than good, and argues for a more nuanced dialogue about these questions. In particular, it focuses on applying a human rights analysis that recognises the rights of individuals and collectives, and acknowledges the protec-

tion of public health as not just a cogent social objective, but also as a very specific rights obligation of the state. This type of model makes it possible to explore when it is legitimate to limit individual human rights in the interest of the public good, clearly exemplified in the dilemmas around compulsory admission for XDR TB. However, using XDR as illustrative of the general case, it is first necessary to reflect on the nature of society's approaches to health and also on what an XDR case implies for the health system.

Public health and the authoritarian tradition

The idea of quarantining patients with infectious disease is perhaps one of the most defining characteristics of the public health tradition,[29] with deep roots in the hygiene movement[30] in industrial Victorian England. Recognition of the transmission routes of contagious epidemics led early pioneers to establish the principles of separating the infected from non-infected as standard practice when facing such epidemics. Indeed, quarantining of sufferers of infectious diseases became the raison *d'etre* of many public health services, and was exported to British colonies through colonial health services staffed by enthusiastic doctors committed to the control of such epidemics.[31] Reliance on segregation as a health response to infectious diseases has been challenged in recent decades by the availability of treatment for many conditions that provide better and more effective alternatives to quarantine. Moreover, the HIV epidemic has particularly driven a realisation that protection of human rights may be necessary for good public health[32] in that it promotes utilisation of health services and has the potential to improve treatment adherence, if health services are trusted and believed to protect patients' rights.[33,34]

Notwithstanding these concessions to recognising the rights of affected persons and populations, public health practice draws heavily on a tradition of control and placing limits on personal autonomy, when seeking to address health problems from a population perspective. For example, almost all public health regulation involves placing limits on individual autonomy in order to protect a public interest – in this case, the health of society.[34] Implicit in such action is always a risk-benefit assessment which inevitably requires judgments and draws on perceptions of risk.[29]

Not surprisingly, some critics have taken the position therefore that public health policies must be assumed to be violatory of human rights, unless proven otherwise.[32] In that sense, the current debates on enforced hospitalisation for XDR TB[21,35-38] signal a key unresolved dilemma for public health: How is it possible to balance the public good against the protection of the rights of individuals infected with XDR TB?

What does XDR TB represent?

Furthermore, it is important to recognise that the emergence of XDR represents essentially a failure of the health system to treat cases of TB effectively.[12,35,38] Typically, XDR patients are individuals who have been treated for TB on multiple occasions but with frequent defaulting or relapses, who may discharge themselves from treatment when feeling better, thereby helping to encourage microbial resistance through partial treatment, often on repeated occasions. Many, though not all, will be vulnerable, homeless, substance abusers or having other forms of social dysfunction. Dependence on social grants as the only family source of income might also have played a role in encouraging non-adherence because of reluctance to lose the grant when cured.[39] The potential for stigmatisation of such patients is therefore high, since XDR infections are associated with problematic or 'recalcitrant' patients.[29,40]

However, it is also important to realise the systemic antecedents to the emergence of XDR. One of the most important factors in maintaining good patient adherence has been demonstrated to be the nature of the provider-patient relationship, and the quality of the treatment environment.[41] Focusing only on patient characteristics, as is typically the case in XDR research and in public policy, misses the context in which patients become non-adherent. Further, institutional deficiencies that may contribute critically to failure to counsel, treat or trace patients, may arise owing to unfilled posts, lack of staff, poor skill levels of existing staff, irregular or inappropriate drug supply, etc. Moreover, the neglect by pharmaceutical companies to research drug development for diseases such as malaria and TB, has left a legacy of limited options for treatment for patients who develop first- and second-line TB drug resistance.[42]

Therefore, in analysing whether a particular policy is justified, a human rights framework demands recognition of not just the immediate antecedents to a problem, but also the institutional and contextual factors underlying that problem.

What are human rights and what do they imply?

Human rights may be described as entitlements that people have by virtue of being human beings. Typically, they take the form of social or material claims from society that are universal across cultures and settings and are codified in national and international laws. They are by nature intended to address fundamental needs, and originated in concerns to protect people from an abusive state by limiting the power of the state over individuals. However, while dignity and freedom lie at the heart of a rights framework, and are manifested in a range of rights protecting civil and political freedoms (so-called first generation rights), it was recognised in the last century that entitlements to social and economic goods and services (so-called socio-economic rights) are equally important; indeed, are indivisible from civil and political freedoms in that they are all interdependent. Exercising one's right to access housing is essential for human dignity, and expressing one's freedom to vote is not possible if one has not received sufficient education to be sufficiently literate to read the ballot paper, for example.

Having a human right therefore implies a duty on a third party – typically, the state – to deliver on that right. State obligations take different forms: (*i*) The state must respect rights by desisting from passing laws that are, for example, discriminatory against certain people or groups. Here, the obligation on the state is a negative one – to desist from certain actions: (*ii*) the state must protect people from violations perpetrated by third parties, such as it does with the many public health regulations to protect people from environmental tobacco smoke or hazardous industrial pollutants etc; (*iii*) the state must promote rights by providing rights-holders with the information and mechanisms that enable them to realise their rights, otherwise rights remain on paper as theoretical entitlements that people do not use; and (*iv*) the state must fulfil rights by taking active steps – such as budgeting, and providing services and infrastructure – to deliver on its rights obligations. Here, the obligation is a positive onus on the state to take specific actions.

Rights often need to be balanced, since rights can conflict, either with each other, or different parties may have conflicting rights. In the former case, it may be that a state action violates someone's rights in the interest of meeting the state's obligation to protect, promote or fulfil other rights. For example, implementing user fees at health facilities may have the effect of violating the rights of some poor people who cannot afford to pay, in order to achieve a more sustainable health system in the long term, and therefore help to realise the right to health for greater numbers of people. Similarly, fluoridating drinking water may violate individuals' rights to choose[43] in the interest of realising the right to health of the population as a whole.[44] Families whose religious and cultural beliefs eschew Western-style allopathic medicine may find their rights to enjoy their culture violated if schools insist on their children being vaccinated before school entry, in the interests of protecting other school-going children from exposure to various infectious diseases.[45]

In all the above examples, a rational basis for decision-making is needed – one that balances the trade-offs in ways that are justified and justifiable. Human rights law addresses this need in three ways:

Firstly, the International Covenant on Civil and Political Rights (ICCPR) recognises circumstances under which rights may be validly restricted, i.e. situations where the restriction is to secure due recognition and respect for the rights and freedoms of others; in the interests of general welfare; and in times of emergency (albeit that some rights, being non-derogable (such as freedom from torture, right to a fair trial, etc.) can never be restricted).

Secondly, the International Covenant on Social, Economic and Cultural Rights (ICSECR) specifically obligates government to take steps necessary for the prevention, treatment and control of epidemic, endemic, occupational and other diseases. Here, far from being asked to abstain from doing the wrong thing (the obligation to respect rights), governments are expected to be active in doing the right thing (obligation to fulfil). What, then, if a statute restricts or violates an individual's rights in order to allow the state to meet its obligation to fulfil rights, is the basis for deciding which rights imperative has priority? Some guidance to this question is found in the Siracusa principles, adopted by the UN Economic and Social Council in 1985, which identified criteria to be met before considering a rights limitation legitimate (Table I). In brief, these principles emphasise the need to confirm that an action that results in a rights limitation (e.g. compulsory incarceration) must be carried out through a legal process that can be subjected to legal challenge, and has both an objective that is genuinely legitimate and must also actually meet the objective it purports to accomplish, which is not achievable through alternative strategies that are less invasive of human rights.

Thirdly, the application of the policy must contain sufficient checks and balances to ensure that it is not arbitrary or discriminatory in its application.

Gostin and Mann[47] developed this framework further into a tool to apply to health policies, to identify the rights impacts of health policies so as to inform decision-making around appropriate policies. The framework poses a set of questions that need to be answered to assess the likely policy impacts (Table II). The purpose of such analyses would be to maximise the human rights and public health benefits within a policy, as located in the top right-hand quadrant in Fig. 1. By setting out an explicit framework, the tool makes the assumptions behind value choices explicit, and forces the policymaker to seek evidence to support claims. Where such evidence is not available, the tool allows one to test the robustness of the assumptions that have to be made in the absence of empirical evidence to support a claim.

TABLE I. LEGITIMATE LIMITATIONS ON HUMAN RIGHTS

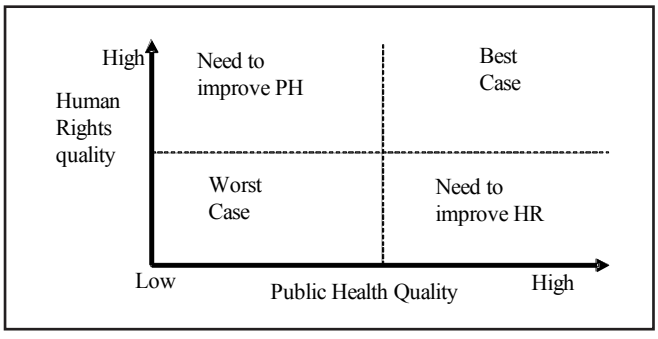
- The restriction is provided for and carried out in terms of law.
- The objective is legitimate.
- The limitation is strictly necessary in a democratic society to achieve an objective.
- There is no less intrusive and restrictive means available to achieve the same objective.
- In its implementation, the limitation is not arbitrary, unreasonable, or discriminatory.

Source: United Nations Economic and Social Council, 1985

TABLE II. A FRAMEWORK FOR ANALYSING THE RIGHTS IMPACTS OF PUBLIC HEALTH POLICIES

1. Clarify the public health purpose.
2. Evaluate likely effectiveness.
3. Is the policy well-targeted?
4. Examine policy for HR burden (benefit?).
5. Least restrictive policy to achieve objective?
6. Base on significant risk standard.
7. Fair administrative procedures.

Source: Gostin and Mann, 1999



Source: International Federation of Red Cross and Red Crescent Societies and the Francois Xavier Bagnoud Centre for Health and Human Rights. (1999)

Fig. 1. A quality matrix: public health and human rights in health policy.

Further adaptations of this model[48,49] have extended this framework to looking beyond the classic limitations of civil and political rights in public health practice, into evaluating health policies' socio-economic rights implications.

This paper now turns to an examination of the question of compulsory admission for XDR TB in South Africa, as outlined by Singh *et al.*,[21] by which XDR TB patients who, after adequate counselling about the importance of admission, refuse hospitalisation could be forced by judicial means to be admitted to a suitable, prepared infection-control TB hospital.

Compulsory admission for XDR-TB

1. Public health purpose

The first step in the analysis is to clarify the public health purpose of compulsory admission of patients with XDR TB. Four possible reasons can be advanced to justify holding patients against their will (Table III). To settle if these constitute legitimate objectives in terms of the Siracusa principles, one needs to consider whether such objectives, independent of the methods chosen to reach them, provide a compelling public health rationale. For all but the last reason in Table III, we would have no argument about adopting policies that aim to prevent patients from infecting others, that limit the transmission of XDR in the population, and which improve adherence to treatment. We may express concern as to whether adopting public health policies solely to reassure the public that something is being done would, in and of itself, represent a legitimate public health action, unless it was effective in reducing a public health burden. For example, banning imports of foreign meat products in the face of a public outcry against reports of food poisoning to assuage public opinion may have little effect on addressing a problem generated by poor regulatory control of domestic food hygiene. Indeed, it may exacerbate the problem in that markets for local production will probably expand. Without evidence that a policy action has some effectiveness, a response solely on the basis of public opinion would be a weak and potentially counter-effective action, providing a false sense of security and opening the door to discriminatory and stigmatising actions. This potential objective will not be considered further in the analysis that follows.

2. Probable effectiveness

The second step is to reflect on the effectiveness of the proposed policy. Here, we need to draw as far as possible on data either from settings directly relevant to XDR or as analogy. Consider, then, the objective of limiting the spread of infection to others. So far as family members or close contacts in the community are concerned, removing infectious patients from contact will reduce the risk of infection. However, two issues then arise:

Firstly, such an action will almost certainly increase the risks of transmission in hospital to other patients and probably to health care providers. For example, the Tugela Ferry outbreak in KZN could clearly be linked to nosocomial transmission, with 85% of patients showing similar strains of mycobacterium.5 The extent to which such risks of transmission within hospital can be reduced by hygiene measures is not entirely evident. While studies on the prevention of nosocomial transmission of TB suggest that risks for patients may be halved, and for health workers reduced by up to 67%,[50,51] it is well recognised that such benefits tend to be more evident in high-income countries.[52] South Africa's health system battles to cope with the demands of health care delivery and has a poor record of implementing infection control measures to reduce TB transmission in its facilities.[12] Therefore, the widespread belief that confinement of XDR patients would be likely to increase nosocomial transmission[12,38] has considerable cogency. Moreover, an unintended consequence of such a policy is to turn the health worker into an agent of social control, with accordant effects on health worker morale. The sustainability of continued confinement of patients who are anxious to es-

TABLE III. POTENTIAL OBJECTIVES FOR A POLICY OF INVOLUNTARY ADMISSION FOR XDR TB

Objective	Public health cogency	Likely effectiveness
1. Prevent patient infecting others (specific individuals at risk)	Yes	Limited effectiveness, contingent on hygiene measures in facilities. Moreover, most transmission will have occurred by the time patients require admission. Only in specific cases. Community-based alternatives urgent and possible
2. Prevent transmission of XDR in population (systems level)	Yes	Nil, given the scale of the TB and HIV epidemic in South Africa
3. Ensure adherence with treatment, which may contribute to (1) and (2) but not inevitably so	Yes	Questionable. Once XDR positive, little prospect of cure
4. Respond to public concerns.	Not as a primary objective	Not considered

cape and often abusive to their perceived captors[7] is perhaps under-estimated by policy makers.

Secondly, patients with XDR TB will probably have infected their close contacts by the time they reach the diagnosis.[12] Evidence from other settings suggest high transmissibility in both community and hospital settings[53] and clustering of genotypes. Given the poor case-finding record and late presentations in the South African TB programme,[12] it is quite reasonable to infer that the burden of transmission would most likely already have occurred on presentation. For example, evidence from a study of TB patients in Ethiopia suggested that most of the delay to diagnosis is caused not by patient-related factors but by the health providers' and health systems' delays.[54] Given that MDR TB has been shown to be no more infectious than drug-sensitive TB,[55] it seems hard to make a case that XDR TB would transmit more readily.

Nonetheless, an argument may well be advanced that protection of family members may be achieved by removing the patient from the home setting. This will be effective inasmuch as family members are protected by appropriate barrier methods when visiting and patients are retained in facilities. However, as South Africa has seen, an unintended consequence of the policy has been frequent escapes of patients, requiring increased resourcing to keep admitted patients captive,[7,12,56] resources that could be better spent in strengthening basic TB infrastructure. Further, the need to keep patients admitted will fall away if treatment succeeds in rendering the patient non-infective, since the objective of protecting third parties from infection will no longer be served by compulsory admission.

It should be clear that the (third) objective of achieving prevention at the population level through compulsory admission is implausible. Estimates of the prevalence of XDR in South Africa range widely from 2.1% of MDR isolates[57] to 5.6%[3] and even 10%,[12] and it is evident that much of this burden in the population remains undiagnosed.[12,28,38] Given South Africa's huge TB caseload, the sheer volume of XDR patients would clearly exceed the capacity of TB facilities, already overburdened and unable to admit XDR patients,[6,39] no matter how quickly the Department of Health commits to building requisite facilities.[58] Therefore, the probable lack of effectiveness of compulsory admission contributing to population-level control of XDR would negate reliance on this specific objective as a justification for compulsory admission in terms of the Siracusa principles. Indeed, one has to guard against allowing coercive practices to become '… a smokescreen for improved, but more complex or more costly public health responses to the root causes of tuberculosis control failures'.[29]

The third objective of relying on compulsory admission to achieve adequate adherence to treatment is predicated on the assumption that, once a patient is diagnosed with XDR TB, forced hospital admission will somehow improve adherence that has, in all likelihood, been extremely problematic in the past. Firstly, there is evidence that, independent of other risk factors, XDR TB will quadruple the risk of treatment failure, even compared with MDR TB.[59] Secondly, where confinement has been used in the management of drug-resistance, it has been used as a last resort in a selected population,[60] and success rates associated with confinement have been variable and reported only for MDR TB and not for XDR, where questions remain as to its curability at all, even under optimal circumstances. Thirdly, the supposed success of the New York TB programme's use of confinement was more to do with the 'credible threat of detention' rather than its routine use.[61] Further, it is not clear that confinement for MDR TB has been any more effective than well-structured ambulatory care for patients with multiple drug resistance, where DOTS coupled with strong community engagement, training of community health workers and careful organisation has produced impressive outcomes.[62,63] Lastly, use of confinement will in all likelihood deter some patients from seeking health care,[12,34,38] thereby exacerbating an existing epidemic. Using confinement to achieve better treatment outcomes therefore must be of questionable validity.

3. Suitably targeted

The third step in the model is to ask whether the policy is suitably targeted. In other words, does it over- or under-include patients, and does it adequately distinguish risk situations?

Firstly, it has been pointed out that, by focusing on the relatively smaller number of XDR patients who are the end result of a dysfunctional TB control programme, resources are inappropriately directed away from strengthening basic TB control infrastructure.[12,28,38]

Secondly, XDR patients affected by compulsory admission to date have been predominantly poor, working class and black. Is it conceivable that white patients or health care professionals with XDR TB would be permitted to be treated on an ambulatory basis? If so, what distinguishes such patients and assessments of their likely compliance with infection control measures from their poorer counterparts? Implicit in health worker assessments of patient compliance are value judgements coloured with sub-conscious or even conscious stereotypes, thereby inclining to stigmatisation and discrimination.[34]

Thirdly, there is currently no apparent discussion in South Africa about what constitutes a significant domestic or workplace risk and no data to inform such decisions. For example, are all infectious XDR TB patients equally likely to pose a risk to household residents, and is the risk the same for all contacts? Current policy in the Western Cape distinguishes between immunocompromised contacts (i.e. mainly HIV positive) and others, which is some evidence of targeting. But the extent to which hygiene precautions could be taken at home, and their likely success, will vary greatly between households, depending on residential density, size of rooms, ventilation, quality of the structure, presence of outbuildings and other factors. For example, running a spaza shop or shebeen will clearly have implications for transmissibility, should the patient be treated on an ambulatory basis. These factors point to the need for a careful assessment on a case-by-case basis of the real risk of transmission to third parties, and consideration of whether ambulatory treatment is feasible. In the absence of such assessment, the health policy risks over-including patients who could quite easily manage infection control at home, or those for whom domestic contacts can be adequately protected.

4. Human rights burdens and benefits

Regarding patients, the policy of involuntary admission ideally should only limit one right – that of patients' freedom of movement. However, experience in South Africa has indicated that the policy has the potential to, and frequently does, limit many other rights. For example, patients may have their rights to dignity violated if conditions in the health facilities are sub-standard; rights to work violated if they lose their job or access to a

social security grant; rights to raise a family violated if they are forcibly separated from young children who have no alternative carer; and rights to housing violated should they lose their homes as a result of admission and suffer discrimination as a result of stigma.[7,12,24,56] The extent to which these unintended consequences could result in inadvertent rights violations is dependent on the extent of resources invested by the state to put in place measures to respect, protect and fulfil patients' human rights. For example, the state would need to ensure proper confinement facilities and conditions of confinement,[7,56] ongoing maintenance of income, and perhaps incentives to encourage compliance with hospital admission. These are not insubstantial costs,[64] particularly as the XDR incidence escalates. The argument that compulsory admission may provide increased access to health care for XDR patients would only apply if treatment options provided improved prognosis – a contingency not currently evident from the data. Whether the effects are positive or negative, it is imperative that decisions on compulsory admission are based on a full understanding of the complete picture of how patients' rights are affected, supported by clear evidence.

With regard to third parties, protection from infection with a potentially incurable and life-threatening disease is obviously a key human rights benefit. However, inasmuch as the patient may be a breadwinner or parent, the burdens of loss of income, housing, family integrity and stigmatisation may apply as much to the individuals whom the policy seeks to protect, and the amelioration of such effects is again dependent on the extent of resources accordingly provided by the state. Clearly, the state has obligations to take steps necessary for prevention, treatment and control of epidemic, endemic, occupational and other diseases (ICESCR article 12) and may be justified in limiting some rights in order to meet other rights. However, unless the protection of third parties' rights and the state's obligation to fulfil and protect rights outweighs the patients' rights and the state's obligations to respect rights, such a policy could not meet international human rights standards. This issue is discussed in more detail in Point 6 below. However, a key step prior to this evaluation is the consideration of potential alternatives to complulsory admission.

5. Less restrictive alternatives that achieve the same objective

From the perspective of preventing transmission to third parties, home confinement has been suggested as a workable alternative, particularly if coupled with barrier measures and health services support.[38] Evidence in the Western Cape points to successes with the use of lay health workers to enhance TB adherence among farm workers[65] (a traditionally very difficult patient population), and excellent treatment outcomes for MDR TB were reported from Peru, using similar approaches involving community health workers.[62] Médecins Sans Frontières has similarly demonstrated the effectiveness of careful community-based protocols to maximise ARV adherence.[66] Similar kinds of intervention may work as well for implementing infection control at home and the workplace to limit transmission. Indeed, Goemare[12,38] points out the contradiction that patients are trusted sufficiently to take ARV treatment at home, but are not trusted sufficiently to adhere to infection control at home. Extensive evidence points to the importance of the treatment environment and health system factors amenable to interventions[41] as being key to enhancing TB treatment adherence. Rather than 'holding' patients in the literal sense of being incarcerated, we should interpret 'holding' as reflecting the process of providing support, containment and care needed to ensure overcoming the barriers to adherence.[40]

Clearly, this is not an all-or-none approach. Where there are immuno-compromised persons at home (or children), one may be less willing to risk domestic confinement and more likely to choose hospitalisation. However, it is evident that such decisions must be on a case-by-case basis, on the best evidence at hand, rather than being the result of a blanket policy that may undermine the ostensible objective.

From the perspective of prevention at a population level, it should be clear that a wide range of strategies provide alternatives that are both more effective and less invasive of patients' rights. These include improved management of drug-sensitive TB (especially at district level), building the capacity to manage drug-resistant TB outside of specialist centres, development of laboratory capacity to effect prompt surveillance, improved access to treatment for sexually transmitted infections and antiretroviral medications, where indicated, and health systems changes to effect these strategies. In addition, community-based interventions, raised community awareness and action, and adoption of social welfare policies that encourage adherence are all underlying steps that need to be taken.[12]

6. Significant risk standard

Given the above analysis, how do we judge the legitimacy of a decision to forcibly admit a patient to hospital? As an action towards decreasing disease transmission in the community, the analysis above clearly points to a rejection that this could constitute justification for compulsory admission. However, as a step needed in order to protect third parties, the assessment depends on the case assessment and specific evidence provided. Are there clearly defined risks to specific persons that cannot be addressed through alternative means of infection control? Such a process would reduce the number of cases from the general (XDR) to the specific (an XDR patient where a specific risk exists to a defined third party) and force us to look carefully at alternatives. Such approaches are widely applied in other settings,[67-69] and the strict application of the requirement to examine alternatives to justify involuntary admission has been shown to reduce the number of cases requiring court-mandated confinement.[69] Therefore, one would expect the number of cases where such confinement meets the criteria for legitimacy to be extremely few in number. Here, the issue is directly focused on whether the magnitude of the risk, as defined as objectively as possible, is such as to justify admission, taking account of all positive and negative externalities.[29]

Where patients are not obviously infectious but are suspected of converting, it would be a dangerous value judgement to forcibly admit them on the basis of a presumed anticipation of infectiousness. The unpredictability of risk requires as much effort as is reasonable to determine objective evidence of risk[29] rather than rely on assumptions vulnerable to stereotyping. Moreover, governments have the responsibility to ensure that research generates empirical evidence to inform decisions about the likelihood and extent of risks of, for example, domestic transmission and the effectiveness of hygiene control measures.

A further consideration would be whether patients have been given full opportunity to exercise their responsibilities. Has the state done all that would be considered reasonable

in terms of counselling, information, and adequacy of service provision? If not, the health services are guilty of shifting responsibility onto the patient and adding a level of unfairness to the decision that may undermine the legitimacy of any legal action.[34] As argued by the New York City Working Group, 'It is unethical, illegal and bad public health policy to detain "non-compliant" persons before making concerted efforts to address the numerous systemic deficiencies that make adherence to treatment virtually impossible' (cited in Lerner[67]).

7. Fair administrative procedures

Lastly, in the event that a compulsory admission is deemed legitimate, public health policy has to meet the requirements for fair administrative procedures. This step implies that, for example, the procedure by which the decision was reached, allowed for adequate assessment of all necessary evidence. If a committee were responsible for making such a recommendation, would it be considered to have the requisite skills to carefully assess the patient's social background and the real risks of transmission to others, as well as the likelihood of non-compliance with hygiene measures at home? In as many ways as possible, the policy needs to be structured to avoid any arbitrariness.

Furthermore, safeguards need to be built into the process, such as, for example, a notice of detention given to the patients, legal representation and an opportunity for a hearing before admission so that factual inaccuracies that underlie the decision may be corrected. These provisions, frequently under the ambit of the court, would need to satisfy the requirement that review by an uninterested party is fair and transparent, and provide for re-review at time intervals that are realistic and protective of the patients' rights. The policy would also need to guard against loopholes that allow discretion on the part of public officials to skip steps, as has been critically noted in the New York experience.[67] In general, compulsory admission policies that comply with the Siracusa principles mandate public officials to exhaust all less restrictive measures before resorting to compulsory admission.[68,69]

Additionally, family members, as the persons most likely to be the intended beneficiaries of a policy of compulsory admission, should be in a position to make inputs to the process, perhaps through a patient advocate specifically for that purpose. Lastly, beside reviewing individual cases, monitoring and review of the whole process is essential to ensure that, for example, new developments in the science related to XDR, its transmission and its management can inform decisions around compulsory admission. Without such review, systematic bias in the application of the policy can give rise to discrimination that is hidden from the public eye.

Conclusion

The foregoing analysis has provided some pointers to making sense of the question of compulsory admission. Firstly, as a strategy for reducing risk to identified third parties, the public health purpose may be cogent but the effectiveness uncertain. Alternatives should be explored and, only in those specific cases where evidence of direct harm to third parties is demonstrable and not possible to address by alternatives, could the relative balance of human rights burdens and benefits implying compulsory admission be considered. Even then, the process by which admission is implemented should provide sufficient administrative checks and balances to avoid unfair discrimination. To a large extent, current recommendations from the Medical Research Council[70] provide guidance consistent with these principles and will hopefully serve to inform national practice in this regard.

In contrast, compulsory admission for purposes of effecting treatment or as part of preventing population transmission must be considered ineffective and an unreasonable burden on the patient's rights, especially in the presence of alternative strategies to reach these objectives.

However, one key aspect of the current discussion on XDR and compulsory admission that is frequently neglected is the recognition of the structural determinants in the global system of drug development that have created the phenomenon of neglected diseases. It is well recognised that the market economy has failed to foster research and development into those diseases suffered by the poorest populations in the world, who are unable to pay.[42,71] This is as much a human rights violation as is any arbitrary confinement of XDR TB patients. Indeed, it could be said that accountability for human rights violations should not vest only with nations, who are being increasingly disempowered under globalisation, but also with transnational institutions, such as drug companies, whose practices and omissions have a huge impact on the survival of people in the poorest countries of the world.[72]

Therefore, inasmuch as the South African government faces hard choices over enforcing hospitalisation of untreatable XDR patients to protect others' health, they do so as a direct result of a global system of drug development that prioritises shareholder profits over public benefits, which has resulted in the absence of meaningful drug development for TB over the past 50 years. It would be an incomplete human rights analysis that did not link global injustice to the difficulties of preserving human dignity in the face of such reprehensible behaviour. For this reason, the obligations on governments to take positive measures to promote effective access to pharmaceutical products, to protect this right from limitation by third parties, and to take measures to promote research and development of new and more effective pharmaceuticals[73] acquires further cogency in the face of the unsavoury prospect of balancing individual human rights and the public good when facing the dilemmas posed in managing XDR TB today.

References

1. Lawn SD, Bekker LG, Middelkoop K, Myer L, Wood R. Impact of HIV infection on the epidemiology of tuberculosis in a peri-urban community in South Africa: the need for age-specific interventions. *Clin Infect Dis* 2006; 42: 1040-1047.
2. Zwang J, Garenne M, Kahn K, Collinson M, Tollman SM. Trends in mortality from pulmonary tuberculosis and HIV/AIDS co-infection in rural South Africa (Agincourt). *Trans R Soc Trop Med Hyg* 2007; 101: 893-898.
3. World Health Organisation. *Anti-tuberculosis drug resistance in the world. Fourth Global Report. The WHO/IUATLD Global Project on Anti-tuberculosis Drug Resistance Surveillance 2002-2007.* WHO/HTM/TB/2008.394. Geneva: World Health Organization, 2008.
4. South African Press Association (1 September 2006) *New deadly TB strain detected in SA.* http://www.iol.co.za/index.php?set_id=1&click_id=125&art_id=qw1157125502467B243. (accessed 12 April 2008)
5. Gandhi NR, Moll A, Sturm AW, et al. Extensively drug-resistant tuberculosis as a cause of death in patients co-infected with tuberculosis and HIV in a rural area of South Africa. *Lancet* 2006; 368: 1575-1580.
6. Andrews JR, Shah NS, Gandhi N, Moll T, Friedland G; Tugela Ferry Care and Research (TF CARES) Collaboration. Multidrug-resistant and extensively drug-resistant tuberculosis: implications for the HIV epidemic and antiretroviral therapy rollout in South Africa. *J Infect Dis* 2007; 196 Suppl 3: S482-490.

7. Bateman C. XDR TB – humane confinement 'a priority'. *S Afr Med J* 2007; 97: 1026, 1028, 1030.
8. Carter S. *Worst Fears Realized In S. Africa TB Scare.* CBS News. 31 May 2007. http://www.cbsnews.com/stories/2007/05/31/health/main2869685.shtml (accessed 12 April 2008).
9. World Health Organisation. (2006). *Report of the meeting of the WHO Global Task Force on XDR-TB. WHO/HTM/TB/2007.375.* http://www.afro.who.int/tb/res-pub/report_of_a_global_xdr_tb_task_force.pdf (accessed 12 April 2008).
10. Yew WW, Leung CC. Management of multidrug-resistant tuberculosis: Update 2007. *Respirology* 2008; 13: 21-46.
11. *Kaiser Daily HIV/AIDS report.* HIV Fueling Deaths From XDR-TB In South Africa, Researchers Say. 26 Feb. 2007. http://www.kaisernetwork.org/daily_reports/print_report.cfm?DR_ID=43138&dr_cat=1. (accessed 12 April 2008).
12. *IRIN/Plus News.* (2007). The new face of TB: Drug resistance and HIV. http://www.irinnews.org/pdf/in-depth/PlusNews-the-New-face-of-TB-March-2007.pdf (accessed 12 April 2008).
13. Boseley S. Global alert over deadly new TB strains. *The Guardian* Wednesday 6 September 2006. http://www.guardian.co.uk/world/2006/sep/06/health.aids (accessed 12 April 2008).
14. *BBC News.* A "virtually untreatable" form of TB has emerged, according to the World Health Organization (WHO). Wednesday, 6 September 2006. http://news.bbc.co.uk/2/hi/health/5317624.stm (accessed 12 April 2008).
15. Centers for Disease Control and Prevention (CDC). Emergence of Mycobacterium tuberculosis with extensive resistance to second-line drugs--worldwide, 2000-2004. *MMWR Morb Mortal Wkly Rep* 2006; 55: 301-305.
16. Moll T. TB on the back burner, losing curable status. *Int J Tuberc Lung Dis* 2007; 11: 355.
17. Dugger CW. Patients chafe under lockdown in South Africa. *New York Times* 25 March 2008. http://www.nytimes.com/2008/03/25/world/africa/25safrica.html?_r=1&oref=slogin# (accessed 12 April 2008).
18. McGregor S (22 January 2007) South Africa urged to isolate "killer" TB patients. *Mail and Guardian* http://www.alertnet.org/thenews/newsdesk/L23916489.htm (accessed 12 April 2008).
19. Loddenkemper R, Sagebiel D, Brendel A. Strategies against multidrug-resistant tuberculosis. *Eur Respir J Suppl* 2002; 36: 66s-77s.
20. Wells CD, Cegielski JP, Nelson LJ, et al. HIV infection and multidrug-resistant tuberculosis: the perfect storm. *J Infect Dis* 2007; 196 Suppl 1: S86-107.
21. Singh JA, Upshur R, Padayatchi N. XDR-TB in South Africa: no time for denial or complacency. *PLoS Med* 2007; 4(1):e50.
22. Koenig R. Drug-resistant tuberculosis. In South Africa, XDR TB and HIV prove a deadly combination. *Science* 2008; 319: 894-897.
23. Bateman C. Living the TB resistance nightmare. *S Afr Med J* 2006; 96: 1014-1016.
24. Flanagan L. 'XDR-TB may be bigger risk than Aids'. *Independent Online,* 11 January 2008. http://www.iol.co.za/index.php?set_id=1&click_id=125&art_id=vn20080111033336532C636940 (accessed 12 April 2008).
25. Stuijt A. (undated). XDR-TB surging through South Africa. http://www.rense.com/general76/xdr.htm (accessed 12 April 2008).
26. Wines M. Virulent TB in South Africa May Imperil Millions. *New York Times,* 28 January 2007. http://www.nytimes.com/2007/01/28/world/africa/28tuberculosis.html?ex=1170651600&en=9161dee013c43476&ei=5070 (accessed 12 April 2008).
27. Michigan State University. (2007). Health Advisory for MSU students, faculty and staff traveling to South Africa. University Physicians Office. http://studyabroad.msu.edu/safety/MSU-OSA_Health_Advisory_XDR-TB.pdf (accessed 12 April 2008).
28. Bateman C. XDR-TB or not XDR-TB? That is the question. *S Afr Med J* 2007; 97: 318-322.
29. Coker R. Just coercion? Detention of nonadherent tuberculosis patients. *Ann N Y Acad Sci* 2001; 953: 216-223.
30. Hamlin C. *Public health and social justice in the age of Chadwick Britain 1800-1854.* Cambridge, UK: Cambridge University Press, 1998.
31. Bashford A. *Imperial Hygiene. A Critical History of Colonialism, Nationalism and Public Health.* Basingstoke: Palgrave-McMillan, 2003.
32. Mann J. Human rights and the new public health. *Health Hum Rights* 1995; 1(3): 229-233.
33. Gruskin S, Mann J, Tarantola D. Past, present, and future: AIDS and human rights. *Health Hum Rights* 1998; 2: 1-3.
34. Doyal L. Moral problems in the use of coercion in dealing with nonadherence in the diagnosis and treatment of tuberculosis. *Ann N Y Acad Sci* 2001; 953: 208-215.
35. Wise J. Southern Africa is moving swiftly to combat the threat of XDR-TB. *Bull World Health Organ* 2006; 84: 924-925.
36. Sakoane R (2007) XDR-TB in South Africa: Back to TB sanatoria perhaps? *PLoS Med* 4(4): e160. doi:10.1371/journal.pmed.0040160.
37. Andrews J, Basu S, Scales D, Smith-Rohrberg Maru D, Subbaraman R. XDR-TB in South Africa: Theory and practice. *PLoS Med* 2007; 4(4): e163. doi:10.1371/journal.pmed.0040163.
38. Goemaere E, Ford N, Berman D, McDermid C, Cohen R XDR-TB in South Africa: Detention is not the priority. *PLoS Med* 2007; 4(4): e162. doi:10.1371/journal.pmed.0040162
39. Bateman C. 'One shot' to kill MDR TB -- or risk patient death. *S Afr Med J* 2007; 97: 1233-1236.
40. Williams G. Holding the patient. Ann N Y Acad Sci 2001; 953: 199-207.
41. Munro SA, Lewin SA, Smith HJ, Engel ME, Fretheim A, Volmink J. Patient adherence to tuberculosis treatment: a systematic review of qualitative research. *PLoS Med* 2007; 4(7): e238.
42. Pécoul B. New Drugs for Neglected Diseases: From Pipeline to Patients. *PLoS Med* 2004; 1(1): e6 doi:10.1371/journal.pmed.0010006.
43. Cross DW, Carton RJ. Fluoridation: a violation of medical ethics and human rights. *Int J Occup Environ Health* 2003; 9: 24-29.
44. Burt BA. Fluoridation and social equity. *J Public Health Dent* 2002; 62(4): 195-200.
45. Powell A. Rasta kids told to stay away without clinic cards. *Cape Times,* 18 January 2006.
46. Nations Economic and Social Council (UNECOSOC). *The Siracusa Principles on the Limitations and Derogation Provisions in the International Covenant on Civil and Political Rights.* UN Document E/CN.4/1985/4, Annex. Geneva: UNECOSOC, 1985.
47. Gostin L, Mann JM. Towards the Development of a Human Rights Impact Assessment for the Formulation and Evaluation of Public Health Policies. *In Health and Human Rights.* A Reader. Mann JM, Gruskin S, Annas GL, Grodin MA, eds. New York, NY: Routledge, 1999: 54-71.
48. International Federation of Red Cross and Red Crescent Societies and the Francois Xavier Bagnoud Centre for Health and Human Rights. The Public Health – Human Rights Dialogue. In *Health and Human Rights. A Reader.* Mann JM, Gruskin S, Grodin MA, Annas GJ. New York, NY: Routledge,1999: 46-53.
49. London L. Human Rights and Public Health: Dichotomies or Synergies in Developing Countries? Examining the Case of HIV in South Africa. *Journal of Law, Medicine and Ethics* 2002; 30: 677-691.
50. Maloney SA, Pearson ML, Gordon MT, Del Castillo R, Boyle JF, Jarvis WR. Efficacy of control measures in preventing nosocomial transmission of multidrug-resistant tuberculosis to patients and health care workers. *Ann Intern Med* 1995; 122: 90-95.
51. Wenger PN, Otten J, Breeden A, Orfas D, Beck-Sague CM, Jarvis WR. Control of nosocomial transmission of multidrug-resistant Mycobacterium tuberculosis among healthcare workers and HIV-infected patients. *Lancet* 1995; 345: 235-240.
52. Menzies D, Joshi R, Pai M. Risk of tuberculosis infection and disease associated with work in health care settings. *Int J Tuberc Lung Dis* 2007; 11: 593-605.
53. Vázquez-Gallardo R, Anibarro L, Fernández-Villar A, et al. Multidrug-resistant tuberculosis in a low-incidence region shows a high rate of transmission. *Int J Tuberc Lung Dis* 2007; 11: 429-435.
54. Yimer S, Bjune G, Alene G. Diagnostic and treatment delay among pulmonary tuberculosis patients in Ethiopia: a cross sectional study. *BMC Infect Dis* 2005; 5: 112.
55. Teixeira L, Perkins MD, Johnson JL, et al. Infection and disease among household contacts of patients with multidrug-resistant tuberculosis. *Int J Tuberc Lung Dis* 2001; 5: 321-328.
56. Makinana A. South Africa: Runaway TB Patient Blames Hospital. *Cape Argus* 9 April 2008. http://allafrica.com/stories/200804100111.html (accessed 12 April 2008).
57. World Health Organization. *The Global MDR-TB & XDR-TB Response Plan 2007–2008. WHO/HTM/TB/2007.387.* Geneva: World Health Organization, 2007.
58. World Health Organisation. (2007b). *XDR-TB: Extensively drug-resistant tuberbulosis.* http://www.who.int/tb/xdr/news_mar07.pdf (accessed 12 April 2008).
59. Kim HR, Hwang SS, Kim HJ, *et al.* Impact of extensive drug resistance on treatment outcomes in non-HIV-infected patients with multidrug-resistant tuberculosis. *Clin Infect Dis* 2007; 45: 1290-1295.
60. Gasner MR, Maw KL, Feldman GE, Fujiwara PI, Frieden TR. The use of legal

action in New York City to ensure treatment of tuberculosis. *N Engl J Med* 1999; 340: 359-366.

61. Frieden TR, Fujiwara PI, Washko RM, Hamburg MA. Tuberculosis in New York City--turning the tide. *N Engl J Med* 1995; 333: 229-233.
62. Farmer PE, Kim JY, Mitnick C, et al. Responding to outbreaks of MDRTB: introducing "DOTS-Plus." *In Tuberculosis: A Comprehensive International Approach.* 2nd ed. Reichman LB, Hershfield ES, eds. New York: Marcel Dekker, 1999: 447-469.
63. Shin SS, Furin JJ, Alcántara F, Bayona J, Sánchez E, Mitnick CD. Long-term follow-up for multidrug-resistant tuberculosis. *Emerg Infect Dis* 2006; 12: 687-688.
64. Moore-Gillon J. Multidrug-resistant tuberculosis: this is the cost. *Ann N Y Acad Sci* 2001; 953: 233-240.
65. Clarke M, Dick J, Bogg L. Cost-effectiveness analysis of an alternative tuberculosis management strategy for permanent farm dwellers in South Africa amidst health service contraction. *Scand J Public Health* 2006; 34: 83-91.
66. Coetzee D, Boulle A, Hildebrand K, Asselman V, Van Cutsem G, Goemaere E. Promoting adherence to antiretroviral therapy: the experience from a primary care setting in Khayelitsha, South Africa. *AIDS* 2004; 18 Suppl 3: S27-31.
67. Lerner BH. Catching patients: tuberculosis and detention in the 1990s. *Chest* 1999; 115: 236-241.
68. Senanayake SN, Ferson MJ. Detention for tuberculosis: public health and the law. *Med J Aust* 2004; 180: 573-576.
69. Weiler-Ravell D, Leventhal A, Coker RJ, Chemtob D. Compulsory detention of recalcitrant tuberculosis patients in the context of a new tuberculosis control programme in Israel. *Public Health* 2004; 118: 323-328.
70. South African Medical Research Council. *Detention of patients with extensively drug-resistant tuberculosis (XDR-TB). Position Statement by the South African Medical Research Council (SAMRC).* January 2007. http://www.mrc.ac.za/pressreleases/2007/1pres2007.htm (accessed 12 April 2008).
71. Trouiller P, Torreele E, Olliaro P, et al. Drugs for neglected diseases: a failure of the market and a public health failure? *Trop Med Int Health* 2001; 6: 945-951.
72. Loff B, Heywood M. Patents on drugs: manufacturing scarcity or advancing health? *J Law Med Ethics* 2002; 30: 621-631.
73. United Nations High Comission for Human Rights. *Access to medication in the context of pandemics such as HIV/AIDS, tuberculosis and malaria.* Commission on Human Rights resolution 2003/29. http://www.unhchr.ch/Huridocda/Huridoca.nsf/(Symbol)/E.CN.4.RES.2003.29.En?Opendocument (accessed 14 April 2008).