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Failing Siracusa: governments' obligations to find the least restrictive options for tuberculosis control

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One of the world's leading causes of death, tuberculosis (TB) remains a stigmatized and feared disease. Prevention, diagnosis, and adherence to TB treatment remain a challenge for many people, including migrants, those with alcohol and drug dependency, sex workers, people living with the human immunodeficiency virus, and individuals with disabilities. Low levels of TB treatment literacy and ignorance of transmission risks are common, and—along with inadequate funding for treatment support—contribute to patients' non-adherence to treatment. Recent cases involving the detention of individuals with TB in Kenyan and Canadian correctional facilities illustrate the circumstances under which individuals interrupt treatment and how health authorities seek restrictive measures to oversee and compel treatment. The legitimacy of restrictive measures is often defended by international public health authorities in relation to the non-binding Siracusa Principles. Yet in practice, as illustrated by examples from Kenya and Canada, government authorities and local laws sometimes do not fully meet, or entirely disregard, the requirements in the Siracusa Principles that restrictions on rights in the name of public health be strictly necessary and the least intrusive available to reach their objective. In addition, more specific standards are required at the international level to guide states' development and use of rights-restricting measures to address TB.

Tuberculosis (TB) remains a global threat, and ensuring complete and appropriate treatment is difficult despite declining incidence. In 2010, there were 8.8 million new TB cases, of whom approximately 65% were treated.[1] Even for those who initiate treatment, incomplete and improper care is common, and an increasing number of multidrug-resistant TB (MDR-TB) cases are reported annually.[2]

With rising rates of MDR-TB have come renewed calls for sanatoria,[3] and increased attention to ethical and human rights concerns,[4–7] particularly the question of when compulsory isolation and generally rights-limiting measures can be justified.[8] These measures can range from detention in a prison to forcible admission in a hospital setting, home arrest, or travel restrictions, and implicate a range of human rights, including freedom from arbitrary detention and freedom of movement (the right to freely move or reside within one's country, and to leave and return).

Rights-limiting measures and ethical and human rights concerns are, however, not limited to MDR-TB. Periodic reports suggest that even individuals with drug-susceptible TB are subjected to violations of their rights, particularly, but not exclusively, in the context of non-adherence to treatment. For example, in the United Arab Emirates, evidence of resolved TB infection is routinely used as a basis for barring entry to or deporting migrants.[9] In China, individuals with a past history of TB have faced discrimination in employment and education.[10,11] In California, a TB patient was recently charged and jailed for failing to take his medication.[12] Ignorance of how TB is transmitted leads to fear and stigma of those infected, as illustrated by the experience of a Ugandan woman who described having her belongings burned and being abandoned by her husband after she was diagnosed with TB.[13]

The purpose of the present study was to examine how rights-limiting measures are imposed, and the national and international legal frameworks justifying such measures. A review of court documents related to two recent cases in Kenya and Canada of individuals with drug-susceptible TB who were incarcerated for non-adherence was conducted in conjunction with a review of international instruments and relevant literature. An analysis of these cases suggests the need for new specific international standards related to rights-restricting measures and threats to public health that can aid public health authorities when addressing TB as well as other infectious diseases.

CASE STUDIES: IMPRISONMENT OF TUBERCULOSIS PATIENTS

Kenya

In 2010, DN and PK were TB patients in Nandi County, Kenya. For much of the year they worked on tea farms, and they were required to be away from home for days at a time. In August 2010, after missing several home visits made by TB outreach workers, DN and PK were arrested for defaulting on their treatment and endangering public health. They were held under a court order for purposes of treatment at the Kapsabet GK Prison.[14] When asked why they did not adhere to their TB treatment, they cited lack of food, the need to travel in search of employment, and lack of information about the importance of adhering to treatment.[15] In September 2010, 2 weeks after their detention, advocates petitioned for the patients' release, and 1 month later they were able to secure both patients' release from prison.[16] They then completed treatment at home.

The arrests took place pursuant to Section 27 of Kenya's Public Health Act, which permits a local medical officer to obtain an order from a magistrate to isolate and detain a person with an infectious disease.[17] Although the Public Health Act does not explicitly

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require criminal charges prior to detention for treatment,[17] DN and PK were tried, convicted, and sentenced to 8 months in prison, the amount of time estimated to complete TB treatment.[18] Sentencing did not take into account the fact that TB patients become non-infectious soon after commencing treatment. Although the court order specifically directed DN and PK to be held in isolation while infectious, interviews with prison wardens revealed that Kapsabet GK prison had no isolation facilities. The Kenya Prison Act states that when suitable accommodation is not available for a sick prisoner, he or she is to receive services in a hospital at the recommendation of the medical officer.[19]

In the proceedings to incarcerate DN and PK, alternatives provided by Kenya's public health system to facilitate completion of TB treatment in less restrictive ways were not presented to the magistrate, and the option of community-based treatment was not considered in court. No evidence was presented that DN and PK were infectious, that they posed a specific risk to others, or that alternative strategies of delivering treatment had been implemented.[14] In addition, although the Public Health Act allows for isolation, it does not specify that isolation should take place in a prison facility. Ultimately, a Kenyan High Court judge concluded that the measures taken to incarcerate DN and PK were excessive, unconstitutional, and outside legal limits.[16]

Canada

JS, who public health authorities report had a history of involvement in sex work and crack cocaine use,[20] was diagnosed with TB in December 2010. According to court filings by Winnipeg public health officers, she was informed of the infectious nature of her disease and advised to report to the hospital to initiate a 2-week in-patient anti-tuberculosis treatment regimen.[20] She initially declined. However, 2 days later she arrived at the hospital and commenced treatment.[20] After 11 days of her 14-day course of in-patient treatment, she left the hospital against medical orders. Five days later, when she was identified at a government office, health authorities requested an Order to Apprehend under Manitoba's Public Health Act. Police apprehended JS and conveyed her to the hospital. As the end of her hospital stay drew near, JS signed a written agreement to undertake care as an out-patient.[21] However, following her discharge from the hospital, authorities reported that she did not comply with her out-patient treatment obligations, and that she could not be located for the purpose of administering treatment. A second Order to Apprehend was requested and granted.[20]

On 4 March, JS was arrested and taken to a hospital in Edmonton. Prior to her release on 17 March, JS signed an agreement to community treatment. However, she did not arrive for treatment after 11 days.[22] A copy of the agreement itself indicates that JS would receive treatment for TB until the attending physician certified she had finished her treatment and was cured, estimated to take 6 months. JS' signature to the agreement indicated she understood that failure to adhere to her treatment could lead to detention in the corrections system.[23]

On 27 April, JS was arrested by the police, brought before a Justice of the Peace, transferred to a remand center under a 90-day detention order, and restarted on anti-tuberculosis treatment.[20] In July 2011, the health authority applied successfully, under Manitoba's Public Health Act, for JS to be detained at a provincial correctional facility for 90 additional days receiving TB treatment on the grounds that her 'release from detention would present a threat to public health'.[24]

JS was initially held in isolation in the correctional facility, and she was then released into the crowded general prison population for the rest of her treatment, while still receiving clinical assessments at the hospital where she had previously been admitted.[20] Manitoba's Public Health Law does not specify detention for public health purposes in correctional facilities. Rather, the law states that persons infected or exposed to a communicable disease may need to 'present himself or herself for admission to a hospital or other facility, and remain there once admitted', or be isolated, detained, or submit to treatment.[25] Nonetheless, Dr Michael Routledge, lead Medical Officer of Health with Winnipeg Health, explained to the media that JS was incarcerated in a correctional facility because a TB patient detained under the Public Health Act can be hospitalized only if he or she is 'medically unstable'.[26]

DISCUSSION

The detention of DN and PK in Kenya and JS in Canada presents strikingly different examples of government action in cases of drug-susceptible TB patients, with parallel results: incarceration in a correctional facility. Both orders of detention were sought and justified by courts under long-standing local or national law. In both cases, the public health authorities implemented or interpreted the law in ways that exploited ambiguous provisions, resulting in the imposition of rights-limiting measures beyond explicit requirements.[27,28]

Ultimately, both the Kenyan and Canadian patients were deprived of their liberty and freedom of movement, not only while they were infectious, but also throughout the course of their anti-tuberculosis treatment. Yet the International Covenant on Civil and Political Rights (ICCPR), to which both Canada and Kenya are party, guarantees both rights, and prohibits arbitrary arrest or detention.[29] Guidance on when these rights can be restricted is commonly found in two sources: first, in the Siracusa Principles, a non-binding document developed by non-governmental organizations and adopted by the United Nations Economic and Social Council in 1984; and second, in the authoritative interpretations of the United Nations Human Rights Committee, the body charged with overseeing state implementation of the ICCPR.

The Siracusa Principles state that restrictions on human rights under the ICCPR must meet standards of legality, evidence-based necessity, proportionality, and gradualism. Specifically, limitations on rights must be, among other provisions, 'strictly necessary', meaning that the limitations respond to a pressing public or social need and proportionately pursue a legitimate aim, and are the least restrictive means required for achieving the purpose of the limitation. Additional protections include that the restriction is provided for and carried out in accordance with the law, that it is neither arbitrary nor discriminatory, and that the burden of justifying a limitation upon a right lies with the state seeking to impose the limitation.[30] Specific to limitations on the basis of 'public health', the Siracusa Principles note that public health can be used as a ground for limiting certain rights if the state needs to take measures 'aimed at preventing disease or injury or providing care for the sick and injured'.[30]

In 1999, the Human Rights Committee published a General Comment related to freedom of movement, which includes an analysis of the criteria for justifiable limitations on movement, including for public health reasons.[31] The General Comment, like the Siracusa Principles, stresses the need for restrictions to be provided for by law, demonstrably necessary, consistent with other rights in the ICCPR, and non-discriminatory.[31] In particular, the Committee dwells on the requirement of necessity for a proposed restriction.

Applying the Siracusa and Human Rights Committee's criteria

to both Kenyan and Canadian cases, it appears that other, less restrictive options should have been explored prior to imprisonment. The requirements of 'strictly necessary' and 'least intrusive' care available were not met, and suggest certain obligations of each government beyond those taken prior to rights-restricting imprisonment. In addition to provision of community-based DOTS-based treatment, these obligations might include, for example, provision of appropriate counseling, so that patients understand the risks of failing to adhere to treatment; nutritional supplements to mediate the side effects of the medicine; and the option of limited in-patient treatment in a hospital or clinic, when clinically necessary, rather than detention and treatment in a prison setting. In the Kenyan cases, none of these additional measures were apparently adopted prior to imprisonment. In Kenya, poor adherence and incomplete treatment are common, and in one study were most significantly associated with lack of knowledge about TB transmission.[32] In this context, jailing a small minority of TB patients for non-adherence has little public health impact, and disproportionately affects those individuals with the least education and social support. Furthermore, detention in the overcrowded environment of Kenya's prisons[33] could not be considered 'appropriate to achieve their protective function', from the perspective either of providing an adequate treatment environment to the detained patients themselves or of preventing the spread of the disease.[34]

While the Canadian example is more complicated, as efforts were clearly made to enroll JS in community-based treatment prior to seeking her incarceration, even affidavits presented by government health workers indicate that JS had recently been adherent to in-patient hospital treatment. In-patient hospital treatment, even in a secure medical facility, is arguably less restrictive and intrusive than imprisonment in a correctional facility, and could have achieved the same end. More extensive counseling, patient support and extended in-patient hospital treatment could have been explored further prior to JS' incarceration and, furthermore, greater consideration should have been given to the limited risk of transmission posed by JS while in the community, particularly following the initial phase of treatment.

The failure of both states to fully follow the guidance of the Siracusa Principles and the requirements under the ICCPR may be related to the fact that neither document was designed to be specific to disease transmission, treatment, and public health risks. The Human Rights Committee in General Comment No. 27 only briefly mentions public health amidst consideration of possible justifications for limitations on rights.[31] Nevertheless, the human rights implications of rights-restricting measures in the case of a public health threat demand specific attention and guidance. Effective treatment for certain diseases can last for months or years, or be unknown or unavailable, and the risks to public health vary greatly according to the manner and ease of transmission, the severity of the disease, and the availability of treatment.

The Siracusa Principles call for due regard for the World Health Organization's (WHO) International Health Regulations (IHR), which specify that individuals be treated in a way that respects their dignity, human rights and fundamental freedom, while minimizing discomfort and distress.[30] However, the IHR primarily address disease surveillance and notification related to transnational health threats.[35] Deference to WHO guidance beyond the IHR could help countries develop more rights-respecting approaches. For example, current WHO guidance emphasizes the 'exceptional' circumstances under which forcible detention of TB patients may be considered appropriate, and the importance of community-based care and adherence support.[36]

CONCLUSION

The failure of both Kenya and Canada to fully follow the guidance of the Siracusa Principles and requirements under the ICCPR illustrate the need for new specific international standards related to rights-restricting measures and threats to public health. A General Comment from the Human Rights Committee or a set of principles from an independent body of experts could more specifically define criteria for rights-restricting measures in the face of public health threats, and ensure that national laws and practices recognize and comply with existing human rights obligations and WHO guidance. New standards at the international level clearly specifying how rights-limiting steps should be employed could help states' development and reform of laws and policies related to detention, compulsory treatment, and additional rights-restricting measures for TB and existing and emerging infectious diseases more generally.

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La tuberculose (TB), une des principales causes de décès dans le monde, reste une maladie stigmatisée et redoutée. La prévention, le diagnostic et l'adhésion au traitement de la TB restent un défi pour de nombreuses personnes, notamment les migrants, les sujets dépendants à l'alcool et aux drogues, les travailleurs du sexe, les sujets atteints par le virus de l'immunodéficience humaine et les individus atteints d'invalidité. Le faible taux de connaissance du traitement de la TB et l'ignorance des risques de transmission sont courants et contribuent, en plus d'un financement inadéquat pour le soutien au traitement, à la non-adhésion des patients au traitement. Des cas récents impliquant la détention d'individus atteints de TB dans les services correctionnels du Kenya et du Canada illustrent les circonstances dans lesquelles les individus interrompent le traitement et celles où les autorités de santé recourent à des mesures restrictives pour surveiller et imposer le traitement. La légitimité des mesures restrictives est souvent défendue par les autorités internationales de santé publique en lien avec les Principes non-contraignants de Syracuse. En pratique, comme l'illustrent les exemples du Kenya et du Canada, parfois les autorités gouvernementales et les lois locales ne répondent pas complètement, voire méconnaissent totalement les exigences des Principes de Syracuse selon lesquels les restrictions appliquées aux droits au nom de la santé publique doivent être strictement nécessaires et le moins intrusives possible pour atteindre leur objectif. En outre, des standards plus spécifiques s'imposent au niveau international pour orienter au niveau des Etats l'élaboration et l'utilisation de mesures restreignant les droits pour faire face à la TB.

La tuberculosis (TB), una de las principales causas de muerte en el mundo, representa aun una enfermedad estigmatizada y temida. La prevención y el diagnóstico de la TB y el cumplimiento con el tratamiento antituberculoso representan todavía un reto en muchas poblaciones, sobre todo en los inmigrantes, las personas con dependencia al alcohol o las drogas, los trabajadores del sexo, las personas aquejadas de infección por el virus de la inmunodeficiencia humana y las personas discapacitadas. Es frecuente la carencia de conocimientos en materia de tratamiento y se suelen ignorar los riesgos de transmisión, lo cual, aunado a la escasez de financiamiento destinado al apoyo del tratamiento, favorece el incumplimiento terapéutico de los pacientes. Los casos recientes de detención de personas con TB en centros correccionales en Kenia y Canadá constituyen un ejemplo de circunstancias en las cuales los pacientes interrumpen el tratamiento y las autoridades sanitarias ejercen medidas restrictivas con el fin de supervisar el tratamiento y forzar su continuación. Con frecuencia, las autoridades internacionales de salud pública defienden la legitimidad de las medidas restrictivas, en nombre de los Principios de Siracusa, los cuales no presentan un carácter vinculante. Sin embargo en la práctica, como lo pone de manifiesto el ejemplo de Kenia y Canadá, las autoridades gubernamentales y las legislaciones locales en ocasiones no cumplen a cabalidad las exigencias de los Principios de Siracusa o los desacatan totalmente; según estos principios, solo se pueden restringir los derechos en nombre de la salud pública cuando es estrictamente necesario y las restricciones aplicadas deben ser las menos intrusivas existentes que permitan lograr los objetivos. Además, se precisan normas más específicas a escala internacional, que orienten a los estados en la formulación y la ejecución de las medidas de restricción de los derechos encaminadas a luchar contra la TB.

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