



Volume 16 Number 4

Human Rights Abuses and Health Care

INTERIGHTS
The International
Centre for the
Legal Protection
of Human Rights

This edition of the Bulletin was supported by funding from the Open Society Public Health Program, which works to advance the health and human rights of marginalised persons by building the capacity of civil society leaders and organisations and advocating for accountability and a strong civil society role in health policy and practice.

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INTERIGHTS Lancaster House 33 Islington High Street London N1 9LH

Tel:

+44 (0)20 7278 3230

Fax:

+44 (0)20 7278 4334

E-mail: ir@interights.org

Website: www.interights.org

Registered Charity No. 292357

Incorporation No. 1927581

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# Editorial Addressing Abuses in Health Settings: A New Paradigm

Iain Byrne

The association between medical care and adherence to a values-based ethical form of behaviour has a long history – stretching back over 2,500 years to the Hippocratic Oath. At the same time fundamental guarantees, such as the prohibition of torture and cruel, inhuman or degrading treatment, are universal and absolute. In these circumstances one might expect that it should be relatively straightforward to integrate a human rights approach into healthcare settings to both safeguard the interests of patients and ensure effective accountability for abuses.

However, as this edition of the Bulletin, supported by the Open Society Foundations' Law and Health Initiative as part of a campaign to highlight abuses amounting to torture, cruel, inhuman or degrading treatment in healthcare settings, demonstrates, the reality is very different. Across the globe millions of patients frequently experience severe pain and suffering, abuse, neglect and prejudice. Often this occurs out of sight of public consciousness with no possibility for victims to hold anybody to account and secure any form of redress.

Although the focus is on torture and ill-treatment, many other relevant rights – health, dignity, due process, information and participation – are discussed, reflecting both the indivisibility and interdependence of rights and the need for a holistic approach in delivering patients' rights centred healthcare systems.

In a similar vein, viewing abuses in health settings through the lens of torture, cruel, inhuman and/or degrading treatment is not aimed at stigmatising healthcare providers as 'torturers.' Rather, it is to protect patients and ensure that sufficient

safeguards and accountability mechanisms are in place. As Jonathan Cohen and Tamar Ezer, from the Law and Health Initiative, point out, the legal implications of a finding of torture or ill-treatment could be highly significant in ensuring non-repetition.

In their comprehensive overview of the issue Cohen and Ezer place the focus firmly on accountability, particularly in respect of hidden abuses suffered by some of the most vulnerable and marginalised who are often powerless to take remedial action. Yet, despite the clear recognition by the UN Human Rights Committee that patients in medical institutions should equally be protected from torture and cruel, inhuman or degrading treatment as those in prison or police custody, in practice there has been very little attention given to the issue by human rights bodies.

After demonstrating that the legal definition of torture and ill-treatment is broad enough to cover a range of abuses in health settings, Cohen and Ezer analyse a non-exhaustive list of some of the significant examples that need to be addressed – people needing pain relief; people with disabilities; women seeking reproductive health care; people living with HIV; people who use drugs; sex workers; lesbian, gay, bisexual, transgender and intersex; and the Roma – the common factor being their vulnerability to abuse and discrimination due to their status.

Yet, as the authors themselves highlight, the examples given 'likely represent a small fraction of this global problem.' In order to shine a light on this neglected area they urge both official monitoring bodies and civil society to strengthen monitoring and documentation in this area as part of their routine work. The requirement

for preventive visits to places of detention under the Optional Protocol to the Convention Against Torture (OPCAT) process could and should be applied to health settings given the similar nature of abuses and control frequently exerted in such institutions.

Drawing on her significant experience as an African human rights lawyer working at both the domestic and regional level, Judy Oder's article focuses on some of the main challenges facing healthcare systems across the Continent. Oder highlights the lack of accountability as underpinning many of the serious problems encountered by patients. In achieving effective accountability, legal recognition of the relevant human rights guarantees is a necessary first step towards systematic reform of policies, procedures and practices.

One of the most egregious abuses that frequently occurs in many African countries is the detention of poor patients in medical facilities who cannot afford to pay their bills. This includes women who have just given birth, often resulting in them being refused further vital follow-up treatment. It also acts as a significant deterrent to other expectant mothers from accessing the medical help they require. At the heart of the problem is the state's failure to fulfil its obligation to provide free and/or affordable maternal health care and treatment to all regardless of ability to pay.

In some instances the healthcare system appears to have lost complete sight of what it is there to do, placing more emphasis on fulfilling bureaucratic requirements than on treating patients. Nowhere is this more exemplified than in the denial of emergency care to certain vulnerable groups, such as undocumented

migrants who are fearful of being reported to the immigration authorities if they seek to access treatment.

Another serious, but unfortunately all too routine, violation of patients' rights is described by lawyers Solomon Sacco, Allan Maleche and Omwanza Ombati: the forcible isolation of TB patients in Kenyan jails. Their case report highlights the tension that often exists between individual rights and wider public health concerns. However, whilst recognising the serious challenge posed by drug-resistant TB, particularly in Africa with high levels of HIV infection and low levels of state spending on health, the authors argue that the approach adopted by the government Kenyan disproportionate and out of step with global best practice. Although isolation may be required to prevent the spread of the disease and there is a need to monitor and ensure that patients take the appropriate medicines, this should be done within a healthcare setting and not through the use of prisons. In such circumstances extra vigilance is required with human rights dictating, and not being subservient to, public health policy.

In their article on harm reduction Damon Barrett and Patrick Gallahue from Harm Reduction International begin by explaining that, whilst the concept may be unfamiliar to many working in the human rights field, it has a solid basis in many fundamental rights principles such as dignity, universality. transparency, accountability and participation. By definition, harm reduction focuses on reducing the harms associated with drugs and their use, requiring the active participation of patients based on genuine consultation and the provision of objective information. However, as Barrett and Gallahue point out, harm reduction only works if it is not supplanted by the use of draconian and punitive measures.

Clearly, the issue is particularly stark in custodial settings, where disproportionately high levels of drug

use and HIV combined with lack of access to appropriate harm reduction based treatment result in users being placed at risk of, at the very least, cruel, inhuman or degrading treatment or punishment. In some jurisdictions the problem is exacerbated by the use of forcible treatment centres run not by trained medical staff but by security and military personnel. Abuses, including severe beatings, sexual violence, forced labour and other forms of torture have been widely documented. Another completely unacceptable judicially-sanctioned measure is the use of corporal punishment for drug use, purchase or possession, representing everything, as Barret and Gallahue point out, that harm reduction opposes.

The powerlessness and multiple forms of discrimination experienced by women and girls in society often translates into them bearing a disproportionate burden when it comes to suffering abuses in healthcare settings. This is powerfully brought out in Elisa Slattery's article in the context of sexual and reproductive health services.

However, at the same time Slattery, who works for the Center for Reproductive Rights, highlights that the increasing body of case law on reproductive rights such as forced sterilisation and abortion is not only playing a significant role in advancing gender health rights; it is also having a wider impact on litigation of health issues more generally, both in terms of the procedural issues – complex medical fact patterns, time-sensitivity and fundamental principles such as progressive realisation of the right to health and preventing discrimination and torture or cruel, inhuman and degrading treatment.

The article goes on to examine several recent landmark cases from regional and international human rights bodies on maternal mortality and abortion which, as well as addressing violations of reproductive rights, have contributed more broadly to strengthening the human rights and

accountability framework around violations in healthcare settings.

Denial of pain treatment affects millions of people worldwide and yet it could be one of the most easily rectified problems. As Diederik Lohman and Joseph Amon from Human Rights Watch point out, the severe pain suffered by millions of people, including 5.5 million terminal cancer patients, could be prevented through the provision of relatively cheap, safe and highly effective drugs such as morphine. Yet these types of medication are virtually unavailable in more than 150 countries due to overly restrictive drug regulations and/or lack of knowledge amongst medical staff about prescribing them.

Lohman and Amon argue that not only does such a systemic failure breach a state's right-to-health obligations but also constitutes a violation of the prohibition of torture, cruel, inhuman or degrading treatment. Denial of pain treatment clearly fulfils the minimum requirements for suffering - both physical and mental - but there is a comprehensive failure of states to fulfil positive obligations including to adequately respond to complaints and to ensure the availability and accessibility of pain treatment for all those who need it. At a minimum this involves the drawing up and implementation of appropriate national action plans and policies together with the training of medical personnel.

Yet, beyond the recommendations of international and regional monitoring bodies on this issue, it is the case study of a Ukrainian patient which brings home powerfully the reality of the issue for millions of victims. Oleg Malinovsky and the millions of other patients worldwide who are failed by their health systems deserve better: a right not just to appropriate health care but to be treated with humanity and dignity.

Iain Byrne is ESCR Policy Coordinator at Amnesty International

# Torture and Ill-Treatment in Health Settings: A Failure of Accountability Campaig

Campaign to Stop Torture in Health Care

The absolute prohibition under human rights law of all forms of torture and cruel, inhuman and degrading treatment ('torture and ill-treatment') does not apply only to prisons, pre-trial detention centres and other places where torture and ill-treatment are commonly thought to occur. It also applies to places such as schools, hospitals, orphanages and social care institutions - places where coercion, power dynamics and practices occurring outside the purview of law or justice systems can contribute to the infliction of unjustified and severe pain and suffering on marginalised people.

This article focuses on torture and ill-treatment in health settings, including hospitals, clinics, hospices, people's homes or anywhere health care is delivered. It does not seek to stigmatise health providers as 'torturers,' but rather to focus on government accountability for placing health providers and patients in unacceptable situations whereby torture and ill-treatment is neither documented, prevented, punished, nor redressed.

The United Nations Human Rights Committee has explicitly recognised that the legal prohibition against torture and ill-treatment protects 'in particular...patients in...medical institutions.' Yet, national, regional and international mechanisms to promote accountability for and to prevent torture are rarely applied to health settings. Human rights bodies responsible for monitoring compliance with anti-torture provisions should systematically examine health settings in their reports and actionable make recommendations to governments on how to stop this abuse.

#### The Legal Definition of Torture and Ill-Treatment

The legal definition of torture and ill-treatment is broad enough to encompass a range of abuses occurring in health settings. Under international law, any infliction of severe pain and suffering by a state actor or with state instigation, consent or acquiescence can, depending on the circumstances, constitute either torture or ill-treatment.<sup>2</sup>

Whether an act qualifies as 'torture,' 'cruel and inhuman treatment or punishment,' or 'degrading treatment or punishment' depends on several factors, including the severity of pain or suffering inflicted, the type of pain and suffering inflicted (i.e. physical or mental), whether the pain and suffering was inflicted intentionally and for an improper purpose, and whether the pain and suffering is incidental to lawful sanctions. Generally speaking, cruel inhuman treatment or punishment can be intentional or unintentional and with or without a specific purpose, while torture is always intentional and with a specific purpose.3

#### Examples of Torture and Ill-Treatment in Health Settings

Torture and ill-treatment in health settings commonly occur among socially marginalised populations. People who are perceived as 'deviant' by authorities, who pose a 'nuisance' to health providers, who lack the power to complain or assert their rights or who are associated with stigmatised or criminalised behaviours may be especially at risk. The following are selected documented examples of torture and ill-treatment against specific populations.

**People needing pain relief**, whether as part of palliative care or for chronic

disease, injury, surgery or labour may experience ill-treatment if their pain is severe enough and avoidable. Denial of pain relief is a pervasive problem among all of the populations discussed below: people with disabilities, women seeking reproductive health care, people living with HIV, people with tuberculosis, people who use drugs, sex workers, lesbian, gay, bisexual, transgender and intersex (LGBTI) persons, and Roma. Denial of pain relief is also disturbingly common among children. According to the World Health Organization, approximately 80 per cent of the world's population – or tens of millions of people each year - have either no or insufficient access to treatment for moderate to severe pain, leading to profound physical, psychological and social consequences.4

In interviews with Human Rights Watch, people who had experienced severe pain in India 'expressed the exact same sentiment as torture survivors: all they wanted was for the pain to stop. Unable to sign a confession to make that happen, several people [said] that they had wanted to commit suicide to end the pain, prayed to be taken away, or told doctors or relatives that they wanted to die.'5

A 28-year-old former drug user from Kyrgyzstan reported in 2006 that he had been given orthopaedic surgery without anaesthesia because doctors feared it would fuel his addiction. 'They tied me down,' he said. 'One doctor held me down, pushed me to the table, and the second doctor gave the operation. I was screaming, awake, feeling all the pain, screaming and screaming as they hammered the nails into my bones.'

The reasons for denial of pain relief are

many, including: ineffective supply and distribution systems for morphine; the absence of pain management policies or guidelines for practitioners; excessively strict drug control regulations that unnecessarily impede access to morphine or establish excessive penalties for mishandling it; failure to ensure that healthcare workers receive instruction on pain management and palliative care as part of their training; and insufficient efforts to ensure morphine is available.<sup>7</sup>

Having considered these reasons, the former United Nations Special Rapporteur on Torture, Manfred Nowak, concluded that the '[f]ailure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged this obligation [to protect people under their jurisdiction from inhuman and degrading treatment],' and furthermore, that 'the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman, or degrading treatment or punishment.'8 In a joint statement with the UN Special Rapporteur on the Right to Health, he additionally confirmed, 'The failure to ensure access to controlled medications for pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment.'9

People with disabilities are especially vulnerable to torture and ill-treatment in health settings, though this is not the only context where they suffer such abuse. The situation is especially dire for the thousands who are forced to live for decades, and often for life, in longstay closed institutions. Restrictions on legal capacity affecting the right to refuse treatment, mental health laws that override refusal to consent to treatment, laws that suspend the right to liberty and stigmatisation against people with disabilities in healthcare systems are of particular concern.

In 2008, Manfred Nowak concluded, 'The requirement of intent in article 1 of the Convention against Torture can be effectively implied where a person has been discriminated against on the basis of disability. This is particularly relevant in the context of medical treatment of persons with disabilities, violations where serious discrimination against persons with disabilities may be masked as 'good intentions' on the part of health professionals.'10 Nowak went on to say that 'forced and non-consensual administration of psychiatric drugs, and in particular of neuroleptics, for the treatment of a mental condition needs to be closely scrutinized. Depending on the circumstances of the case, the suffering inflicted and the effects upon the individual's health may constitute a form of torture or illtreatment.'11

In a report on Serbia, Mental Disability Rights International alleged torture and ill-treatment against children and adults in institutions marked by 'unhygienic conditions and filth.' Bedridden patients are forced 'to urinate and defecate in metal buckets which are kept under their beds,' locked away in 'tiny isolation rooms' as punishment, subjected to lack of heat during the winter and forced to sleep in bedrooms contaminated by mice and rats. Medical neglect had led to emaciated and dehydrated children lying in cribs, children with untreated hydrocephalus (an abnormal build up of cerebral spinal fluid that causes swelling in the brain and skull and frequent death) and people with open cuts and sores, eye infections and missing or rotten teeth.12 Also documented were dehumanising practices such as shaving residents' heads, denying them access to their personal clothes and effects, and imposing 'work therapy' whereby residents are forced to do chores in exchange for rewards such as coffee. Similarly, in a psychiatric hospital in Kyrgyzstan, the NGO Mental Health

and Society found that patients were forced to bake bread in the name of 'labour therapy.' Though the patients are unpaid for this work, the hospital charges the government market prices for the product.<sup>13</sup>

Another major problem is the widespread and extensive use of physical restraints - sometimes throughout a patient's lifetime without any standards controlling their usage or any justification for using them. The use of cage beds in mental health facilities is a still-documented practice that violates the right to be free from torture and ill-treatment. In a 2003 report, the Mental Disability Advocacy Center (MDAC) documented the routine use of cage beds in Hungary, the Czech Republic, Slovakia and Slovenia. 14 MDAC found that cage beds were routinely being used as a substitute for adequate staffing or as a form of punishment against people with severe intellectual disabilities, elderly people with dementia and psychiatric patients. People were placed in cage beds for 'hours, days, weeks, or sometimes months or years.' A former user of psychiatric services said of the use of cage beds, 'You feel like you would rather kill yourself than be in there for several days.' Another reported having been rendered unconscious by an involuntary injection administered just after giving birth and then placed in a cage bed. When she woke up, she was not permitted to use the bathroom and 'had to do it in the cage bed like an animal.'

Women seeking reproductive health care frequently encounter 'low-quality, often negligent and abusive care and treatment' that sometimes rises to the level of torture or ill-treatment. In a 2011 briefing paper, the Center for Reproductive Rights (CRR) identified several violations of women's reproductive rights, including verbal and physical abuse by health providers, extended delays in care leading to physical and emotional suffering, and involuntary detention in inhuman conditions for failure to pay medical

bills. According to Human Rights Watch, medical staff at hospitals in Burundi have denied post-natal care, such as treating a baby's respiratory problems or removing the stitches from a caesarean delivery, to women who are locked up for failure to pay their medical bills.<sup>16</sup>

Forced and coerced sterilisations are also examples of torture and illtreatment. Such practices have been documented against women living with HIV, Roma women and women with mental disabilities, among other vulnerable and marginalised groups. According to CRR, 'Experts recognize that the permanent deprivation of one's reproductive capacity without informed consent generally results in psychological trauma, including depression and grief.' This issue has recently been litigated in countries as diverse as Chile, Namibia and Slovakia. Both the UN Human Rights Committee and the Committee against Torture have addressed forced and coerced sterilisation as a violation of the right to be free from torture and illtreatment.17

At the other extreme, women may be denied abortion or post-abortion care for the discriminatory and improper purpose of discouraging them from, or punishing them for, terminating their pregnancies, which can result in severe and long-lasting pain and suffering. The Committee against Torture has also considered denial of both abortion and post-abortion care in the context of the right to be free from torture and ill-treatment. <sup>18</sup>

People living with HIV in many countries report being mistreated by health providers or denied treatment in a manner that is cruel, inhuman or degrading. In Vietnam, people living with HIV recently reported being ignored by health professionals, marked as HIV-positive on their clothes, segregated from other patients and denied services such as lymph node incisions, in-patient admission and cleaning. Forced or compulsory HIV testing is also a common abuse that may constitute degrading

treatment if it is 'done on a discriminatory basis without respecting consent and necessity requirements...especially detention setting.'20 Unauthorised disclosure of HIV status to sexual partners, family members, employers and other health workers is a frequent abuse of people living with HIV that may lead to physical violence, especially against women.<sup>21</sup> Illtreatment of people living with HIV in health settings is compounded by the association of HIV with criminalised behaviour such as illicit drug use, homosexuality and sex work. In Ukraine, injecting drug users living with HIV have been 'denied emergency medical treatment. including by ambulances who refused to pick them up,' 'kicked out of hospitals,' and 'provided inadequate treatment by doctors who refused even to touch them.'22 In Jamaica, where HIV is stereotyped as a 'gay disease,' medical professionals have avoided touching the skin of people living with HIV with medical equipment, with one nurse saying she was 'concerned about contracting the virus from patients who... "really hopelessly wanted you to get HIV too."'23 In Namibia, despite a policy of providing HIV prevention and treatment services free of charge to those who cannot afford them, sex workers who meet eligibility requirements are often discriminated against and denied these services.24

People with tuberculosis (TB), a contagious and sometimes drugresistant disease, have unnecessarily detained for 'treatment' in institutions where conditions can amount to ill-treatment. Detaining patients with TB is a form of administrative detention intended to prevent the further spread of disease; thus authorities must demonstrate that the detention is a necessary last-resort and the detention itself should 'respect human dignity, be culturally sensitive, and be periodically reviewed by courts.'25 In practice, this is often not the case, and persons with TB are detained even when they are capable of adhering to infection control regimens and to treatment. In March 2008, The New York Times described the Jose Pearson Tuberculosis Hospital, a detention centre for people with drugresistant tuberculosis in South Africa, as 'a prison for the sick,' with razor wire to prevent patients from escaping, overcrowding, poor ventilation fuelling the further spread of tuberculosis and a single social worker for more than 300 detainees.<sup>26</sup> One detained patient told The New York Times, 'I've seen people die and die and die. The only discharge you get from this place is to the mortuary.' Poor conditions in TB treatment facilities can lead to the development of additional drug resistance and transmission to healthcare workers, resulting in patients that are more difficult and costly to treat.<sup>27</sup> Treatment in the community has been shown to be a more effective and less rights-violating alternative to detention of people with TB, who in any case have an absolute right to freedom from ill-treatment in confinement and to due process to challenge their confinement. 28

People who use drugs are a highly stigmatised and criminalised population whose experience of health care is often one of humiliation, punishment and cruelty. In Ukraine, Human Rights Watch documented cases of drug users being kicked out of hospitals, provided treatment in an inadequate or abusive manner and denied emergency care.<sup>29</sup> example, one man said he had been denied a hospital room and told by a doctor, 'Why do you come here and make more problems for us? You are guilty yourself for this.' Another person was denied treatment for tuberculosis once the clinic workers found out she was a drug user: 'I was staying at a tuberculosis clinic. My tuberculosis should have been [treated]. As soon as they found out that I was an addict, I was refused.'30 A report by the Eurasian Harm Reduction Network documented similar cases of ill-treatment, including the testimony of an outreach worker who brought a woman to a clinic for a leg abscess related to drug injection, only to be asked by the doctor, 'Why do you mess with her, she's a drug addict!'31 Limited coordination and integration of services in Ukraine and throughout Eastern Europe and Central Asia often forces patients to choose between TB, HIV and drug treatment.32 A particular form of ill-treatment and possibly torture of drug users is the denial of opiate substitution treatment, including as a way of eliciting criminal confessions through inducing painful withdrawal symptoms.33 The denial of methadone treatment in custodial settings has been deemed by both Manfred Nowak<sup>34</sup> and the European Court of Human Rights<sup>35</sup> to be a violation of the right to be free from torture and ill-treatment in certain circumstances. Similar reasoning ought to apply to the non-custodial context, particularly in instances where governments, such as the Russian Federation, impose a complete ban on substitution treatment.<sup>36</sup> In many Asian countries, including Cambodia, China, Laos, Malaysia, Thailand and Vietnam, thousands of children and drugs who use administratively detained without due process in compulsory centres that purport to provide addiction treatment but in fact inflict abuse amounting to torture and ill-treatment. Practices documented in these centres include long hours of forced labour under extremely harsh conditions, partial lobotomy of drug users by inserting heated needles into their brain for up to a week, imprisonment in thorn-tree cages, handcuffing of drug users to beds while they undergo withdrawal, suspension by the arms and legs for hours and beatings on the feet, and sexual abuse of inmates by guards.37 Medical care is routinely denied. A doctor in one drug detention centre in Guangxi Province, China, told Human Rights Watch, 'The purpose of the detox center is really just disciplinary, it's not to give people medical care.'38

**Sex workers**, like people who use drugs, face ill-treatment in health settings stemming from their

criminalised status. A report on sex workers in Botswana, Namibia and South Africa documented negative and obstructive attitudes on the part of medical workers, including denial of necessary healthcare services to sex workers.39 One sex worker said, 'I'm afraid to go to the clinic' because of harassment from nurses and doctors. A male sex worker seeking HIV treatment in Namibia said, 'The nurse called a few other nurses and they were laughing at me.' Another was chased out of a hospital after a doctor screamed, 'You are a prostitute!' to her in front of other staff and patients. A sex worker in Kyrgyzstan said that when she went to the hospital with appendicitis, the nurse 'became rude with me' after learning she worked in a sauna, 'saying that girls like me should be killed or put in jail.'40 She was discharged from the hospital before her stitches were removed. Breaches of privacy and confidentiality are a further indignity experienced by sex workers in health settings. In Macedonia in 2008 police rounded up more than thirty people in an area known for sex work and subjected them to forced testing for HIV, hepatitis B and hepatitis C. Following the arrests, the Ministry of the Interior released a press announcement disclosing personal information about the detainees and media outlets published photos and videos of them. The NGO Healthy Options Project Skopje (HOPS) is supporting several of the sex workers in litigation against the Ministry and the health clinic for breach of privacy and inhuman and degrading punishment.41 In Austria, where registered sex workers are required to undergo weekly medical check-ups and take regular blood tests for sexually transmitted diseases, the Committee against Torture recently noted 'reports of alleged lack of privacy and humiliating circumstances amounting to degrading treatment during medical examinations.'42

**Lesbian, gay, bisexual, transgender and intersex (LGBTI) persons** have reported abuses in health settings that amount to cruel and degrading

treatment. In Kyrgyzstan, doctors have refused to treat LGBTI persons and accompanied this refusal with cruel and degrading comments such as: homosexuality is 'absurd,' 'condemned by Islam' or 'abnormal,' or that LGBTI people are 'not our patients.'43 Health providers in Jamaica have 'refused to treat men whom they knew or perceived to be gay and made abusive comments to them, at times instigating abusive comments by others.'44 In one case, 'a health worker told a gay man with gonorrhea that he was 'nasty' and asked why he had sex with other men.' Some health providers still treat homosexuality as a mental disorder, a form discrimination that may also amount to cruel, inhuman or degrading treatment, and subject them to 'conversion therapy' with severe psychological consequences.45 Transgender people routinely face degrading treatment in health settings stemming from discrimination and prejudice on the basis of gender identity or presentation. In the United States, a 2010 report of the National Gay and Lesbian Task Force and the National Center for Transgender Equality documented cases of transgender people being refused care outright because they were transgender or gender non-conforming, postponing their own care due to fear of disrespect by medical providers, harassment in medical settings and other abuses.<sup>46</sup> One survey respondent reported problems finding a doctor who would treat or 'even look at you like a human being.' A survey from Europe similarly found that transgender people avoided routine medical care because they anticipated prejudicial treatment.47 Transgender people additionally face a particular form of ill-treatment in health settings stemming from arbitrary requirements that they undergo psychiatric evaluation, genital surgery or even sterilisation in order to officially change their gender. Such requirements are inherently a form of coerced medical treatment that may violate the right to be free from torture and ill-treatment. Children born with

intersex conditions or atypical sex organs (also called disorders of sex development) routinely face abuse amounting to ill-treatment in health settings.<sup>48</sup> These include a variety of forced, unnecessary and irreversible medical procedures such sterilisation, hormone therapy and genital-normalising surgeries such as clitoral 'reduction,'49 considered genital mutilation by some intersex people.<sup>50</sup> These procedures are rarely medically necessary, but are performed for social reasons and can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression.<sup>51</sup> They are typically performed without any legal restriction or oversight in an attempt to impose a biological gender of either male or female.<sup>52</sup> Parents are frequently pressured to consent to these procedures for their children without adequate information about the longterm risk to sexual function and mental health.53 Intersex children are also often exposed to humiliating and unnecessary exams<sup>54</sup> or are used as teaching tools or in unethical medical experiments.55 In 2008, a German intersex woman, Christine Völling, successfully sued her surgeon for damages for removing her ovaries and uterus without her informed consent.56

Roma in Central and Eastern Europe face what the European Roma Rights Center (ERRC) has called 'a consistent pattern of discriminatory treatment' by professionals.57 medical Such discrimination may rise to the level of cruel, inhuman or degrading treatment, as when health workers insult Roma patients and their families. In one case documented by the ERRC, a woman whose son had died after being released from the hospital, reportedly in good condition, said that in response to her demands to see her son's medical file a doctor said of her son's death, 'It's not a big thing-one Gypsy less.' Denial of medical care to Roma has taken the form of failure of ambulances to respond to requests for assistance coming from Roma neighbourhoods,

outright refusals by medical professionals to provide services to Roma and demands for payment for services that ought to be provided at no cost. In one case, a 20-year-old Roma woman gave birth to a stillborn child after an ambulance took 90 minutes to arrive at her home in a Roma settlement; one dispatcher mockingly told the woman's husband 'to put his wife into a wheel-barrow and wheel her to the medical center.' In another case. a woman was inappropriately charged medical treatment for a spontaneous miscarriage, apparently because doctors assume that Roma women induce their own abortions to avoid paying the cost of surgical abortions. A particularly humiliating practice is the segregation of Roma patients into rooms called 'gypsy rooms' or the 'Chinese quarter.' According to the ERRC, these Roma wards are of inferior quality 'in material and sanitary conditions and services.' It has also been reported that Roma women accompanying their sick children are made to clean the ward.

#### Conclusion: The Need for Monitoring and Accountability

The preceding examples of torture and ill-treatment in health settings likely represent a small fraction of this global problem. In order to better understand and confront this problem, a necessary first step is for human rights organisations and official mechanisms systematically include health settings among the places they document and advocate against torture and ill-treatment. Courts and tribunals which are confronted with cases of severe abuse in health settings should likewise consider whether these abuses rise to the level of torture and ill-treatment. While some have already done so, this has mostly been in the case of abuses occurring in prisons and pretrial detention centres, not traditional health settings. important way to prevent torture and ill-treatment is to monitor the human rights of people in the settings where such practices are likely to take place. The Optional Protocol to the UN Convention against Torture (OPCAT)

obliges state parties to establish independent 'national preventive mechanisms' to carry out preventive visits to places of detention. For the reasons set out in this article, health settings may well be considered places of detention where people are subject to torture and ill-treatment. For anyone with disabilities, states have further obligations to 'ensure that all facilities and programmes designed to serve persons with disabilities are effectively by independent monitored authorities,'58 and that the implementation of human rights is monitored,59 with the participation of civil society, particularly people with disabilities and their representative organisations.60 The legal implications of a finding that abuse in health settings amounts to torture or ill-treatment are significant. With respect to addressing acts of cruel, inhuman or degrading treatment or punishment, the Convention against Torture requires governments to provide education and information to public officials (including medical personnel), requires a prompt and impartial investigation of allegations, and requires an appropriate complaint mechanism.<sup>61</sup> With respect to torture, governments are additionally obliged to prosecute offences and ensure a civil legal remedy for compensation of victims, among other things. Real accountability for torture and illtreatment in health settings, however, means identifying the laws, policies and practices that lead to abuse, rather than simply singling out individual health providers as 'torturers.' Health providers may abuse the rights of patients because they are ordered to by authorities, because regulations restrict the type of care they can provide or for other reasons beyond their control. These situations are sometimes referred to as dual loyalty, defined as 'simultaneous obligations, express or implied, to a patient and a third party, often the state.'62 As part of their obligation to prevent torture and ill-treatment in health care, governments should take concrete steps to protect health providers from dual loyalty conflicts. Torture and illtreatment are antithetical to every notion of health care and human dignity. Health settings should be places where human rights are realised and fulfilled, not debased and violated. To stop the scourge of torture and illtreatment in health care, health providers and anti-torture advocates must come together to listen to the stories of victims, understand the problem and its roots, and propose solutions.

The Campaign to Stop Torture in Health Care is a global initiative coordinated by the Open Society Foundations to promote accountability for severe human rights violations occurring in healthcare settings. This article is based on a briefing note compiled for the Campaign by Jonathan Cohen, with input from Mary Callaway, Tamar Ezer, Kathleen Foley, Françoise Girard, Matt Goodro, Lydia Guterman, Erin Howe, Judith Klein, Anne Tamar-Mattis, David Scamell, Paul Silva, Elisa Slattery, Rachel Thomas and Jessica Weidmann.

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#### Pay Up or You'll Be Detained! Improved Health Systems and Accountability as a Response to Violations Arising in Healthcare Settings

Judy Oder

#### Introduction

Human rights violations in healthcare settings are illustrative of weak health systems and the failure or lack of accountability mechanisms to deal with rights infringements across Africa. This is reflected by the emphasis placed on accountability by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health in stating that the analytical framework of the right to health includes effective, transparent and accessible monitoring accountability mechanisms available at the national international levels.1

This article seeks to analyse some of the main current challenges in healthcare settings across Africa. In so doing it looks at the principle of accountability and states' regional and international human rights obligations in light of selected serious human rights infringements. It argues that improved healthcare systems and the entrenchment of accountability within processes these potentially reduce the high number of violations taking place in African healthcare settings. Secondly, where violations have taken place, accountability processes should ensure the availability of remedies for victims. It concludes by arguing that minimum resources should not be used as an excuse for failing to address these serious violations, as there are measures states can take even when resources are limited.

#### The principle of accountability in human rights law

Accountability is fundamental to human rights and includes the monitoring of conduct. In the context of a health system, there must be accessible, transparent and effective mechanisms of accountability in order to understand how those with responsibilities in delivering and managing health care have discharged their duties.<sup>2</sup>

Closely linked to the principle of accountability are obligations derived from national, regional and international human rights standards. States are required to institute measures necessary to both prevent and remedy violations arising in healthcare settings. Where violations have occurred, remedies should include the investigation, prosecution and punishment of perpetrators.

A crucial first step is the recognition of the right to the highest attainable standard of health in national law, as this imposes legal accountability on those with responsibilities for health systems.<sup>3</sup> However, legal recognition on its own, whilst important, is insufficient, since it is usually formulated in a very general manner that does not specify what is actually required of those with responsibilities. Therefore, a state must not only recognise the right to health in national law but also ensure detailed provisions clarifying what society expects by way of health-related services and facilities.4

Both regional instruments and national constitutions in Africa include specific provisions on the right to health.<sup>5</sup> In addition, many more national constitutional provisions outline fundamental civil rights provisions such as the right to life, freedom from inhuman and degrading treatment and the principle of equality and non-discrimination, which are applicable in the health context. The African Charter on Human and Peoples' Rights (ACHPR) also

proscribes discrimination, <sup>6</sup> torture and inhuman and degrading treatment. <sup>7</sup> States are also parties to other regional <sup>8</sup> and international <sup>9</sup> human rights instruments that proscribe these types of violations. However, examination of violations that occur in health settings across the region demonstrates that states are far from respecting and implementing their right-to-health obligations.

#### Selected violations arising in healthcare settings Detention of poor patients for failure to pay hospital bills

In Kenya mothers who cannot pay their bills for maternity or other services are routinely detained. Both private and public facilities seek to pressure the patient's relatives into paying, and public facilities will use detention to determine whether a patient is really poor enough to qualify for a waiver. Women who have recently given birth are often forced to sleep on the floor or share a bed with others, are underfed and suffer verbal abuse from staff for failing to pay. For women whose babies have died, there is a particular psychological cruelty to being detained in a maternity ward, surrounded by other mothers and their infants.10

In recent years, public hospitals in Burundi have detained hundreds of patients who were unable to pay their hospital bills, often for several weeks or months and, in one case, over a year. Detained patients without money went hungry if not fed by the charity of others. Some were forced to vacate their beds and sleep on the floor to make space for paying patients. Often, indigent patients did not receive further medical treatment once the bill had reached a large amount, even if they needed only basic follow-up care

such as removing stitches after a caesarean delivery.<sup>11</sup> Other countries where the problem is widespread include Nigeria. The fear of being detained discourages women from seeking skilled maternal care. Even those that do have the courage to seek professional treatment during delivery may risk forgoing post-natal care in order to escape detention.<sup>12</sup>

The detention of poor patients by hospitals is prevalent in numerous African countries where the health system is based on cost recovery. The practice is found in countries including Kenya, Ghana and the Democratic Republic of Congo, and there was at least one instance in Zimbabwe concerning multiple patients.<sup>13</sup>

The detention of persons who are not able to pay their bills raises a number of concerns under international human rights law. This includes the right not to be arbitrarily detained,14 detained as a debtor<sup>15</sup> or mistreated in detention, 16 as protected under the International Covenant on Civil and Political Rights (ICCPR). The impact of the policy on individuals seeking health care also implicates the state's duty to progressively realise the right to the highest attainable standard of health under the International Covenant on Economic, Social and Cultural Rights (ICESCR).<sup>17</sup>

#### Denial of emergency care

In South Africa both documented and undocumented migrants have been denied access to health care. Even when seeking emergency care after xenophobic attacks or rapes, migrants are often turned away by medical personnel who may discharge them prematurely, harass them, charge them excessive user fees and/or call the police to deport them.<sup>18</sup>

Language barriers and lack of information make meaningful counselling and consent all but impossible. Rape survivors, who frequently lack knowledge of the services available to them and often fear deportation, face barriers in

accessing lifesaving post-rape care, including emergency contraception and post-exposure prophylaxis (PEP) within the 72-hour window for treatment after an assault. Some healthcare facilities erroneously require survivors to report the rape to the police before assistance is given. For undocumented asylum seekers and other migrants who fear deportation, such a requirement is frequently prohibitive. <sup>19</sup>

The United Nations Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health has stated that asylum seekers and even illegal immigrants should enjoy the right to health:

States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services.<sup>20</sup>

South Africa has signed, but not ratified, the ICESCR, meaning that it undertakes not to undermine the object and purpose of the treaty.21 Under South Africa's Constitution, everyone has the right to have healthcare services and no one may be refused emergency medical treatment.<sup>22</sup> Furthermore, the South African Constitutional Court has explicitly considered the ICESCR in interpreting the scope of social and economic rights guaranteed by the Constitution.<sup>23</sup> The **ICESCR** guarantees the right of everyone to the highest attainable standard of health.24

In Nigeria, there have been repeated calls for repeal of a defunct police directive which mandates that victims of gunshot wounds, violent crimes and accidents must produce a police report before emergency medical treatment can be administered. Every year many gunshot victims are denied such care and left to die. Every three months at least twenty victims reportedly die in

this way, with many more going unreported. Medical staff who have helped victims without first obtaining these reports have faced arrest and harassment from Nigerian law enforcement agencies.<sup>25</sup>

In September 2009, the death of Guardian journalist Bayo Ohu as a result of this 'No Police Report, No Treatment' policy publicised the issue and prompted calls for the law to be decisively changed. The public outcry caused the police to officially rescind their directive in October 2009, but the outdated law – Section 4(2) of the Robbery and Firearms (Special Provisions) Decree No. 21 of 1984 – officially remains in place.<sup>26</sup>

According to international law, states are required to have in place adequate services<sup>27</sup> medical including 'system(s) of urgent medical care in cases of accidents' with services being 'available, accessible and of good quality.'28 Medical staff in hospitals are also under a corresponding duty to provide the necessary treatment.<sup>29</sup> These provisions shall accomplished within 'available resources,' regardless of the level of economic constraints that the country might experience.<sup>30</sup> As part of its core minimum obligation, the victim has a right of access to health facilities on a non-discriminatory basis.31

With a view to the routine practice of denying emergency treatment, in this case to Roma people in Hungary, the UN Committee on Economic Social and Cultural Rights urged the state party to ensure 'adequate access to health care, including [for] disadvantaged and marginalized individuals and groups.'32

The Human Rights Committee, in the context of prisoners, has repeatedly found that the denial of medical attention amounts to cruel, inhuman or degrading treatment.<sup>33</sup> In *Leehong v Jamaica*, the Committee found violations of Article 7 and 10(1) of the ICCPR since the applicant had 'only been allowed to see the doctors once despite having sustained beating by

the prison staff and having required medical assistance.'34 In *Kelang v Zambia*, there was a breach of Article 10(1) in so far as a 'failure to provide medical assistance when needed' can amount to a failure to be treated with humanity and respect for the inherent dignity of his person.35

In Paschim Banga Khet Mazdoor Samity & Ors v State of West Bengal & Anor,36 where as many as seven government hospitals in Calcutta refused to admit an injured person as they did not have beds vacant, the Supreme Court of India held that the right to life includes an obligation to provide timely medical treatment necessary to preserve human life. Similarly in Pravat Kumar Mukherjee v Ruby General Hospital & Ors<sup>37</sup> the National Consumer Disputes Redressal Commission<sup>38</sup> ruled that a hospital is duty bound to accept accident victims and patients in a critical condition, that it cannot refuse medical treatment and that it cannot demand fees before agreeing to treat.

#### Detention of mental health patients in prisons

People with mental disorders are routinely locked up in prisons in many countries due to inadequate mental health services.39 In April 2011, Human Rights Watch (HRW) reported the continued and protracted incarceration in Uganda of 11 persons with psychosocial disabilities found not guilty by reason of insanity. These individuals have been imprisoned for years awaiting Minister's orders as required by the Trial on Indictments Act. The prolonged delay in notifying them of their legal status is a serious violation of their rights under national, regional and international law.40 HRW also has information that many other victims are in a similar situation and has urged the Ugandan Minister of Justice to take action.<sup>41</sup>

The Ugandan Constitution provides for affirmative action in respect of marginalised groups<sup>42</sup> and for the protection of persons with disabilities.<sup>43</sup> The Uganda Persons with Disabilities Act guarantees persons with psychosocial disabilities

the right to respect and human dignity. In the African Commission case *Purohit and Moore v The Gambia*, the Commission declared that:

Mental health patients should be accorded special treatment which would enable them not only to attain but also sustain their optimum level of independence and performance in keeping with Article 18(4) of the African Charter.44

Yet despite these fundamental rights guarantees, according to Section 48 of Uganda's Trial on Indictments Act a person found not guilty by reason of insanity can be remanded to a prison, mental hospital or other suitable place of safe custody in accordance with the Minister's order until a determination is made on the case. The fact that the detention of these individuals, and others who are being detained pursuant to section 48 of the Act, is dependent upon the decision of a member of the executive and not an independent tribunal also renders their detention arbitrary and unlawful under international human rights law.45

#### Maternal deaths

Across the developing world, maternal mortality levels remain too high, with more than 500,000 women dying every year as a result of complications during pregnancy and childbirth; about half of these deaths occur in sub-Saharan Africa.<sup>46</sup> The results of a study indicated that an effective and efficient health system, especially during pregnancy and birth, are fundamental cornerstones of maternal health, along with access to clean drinking water.<sup>47</sup>

The Center for Reproductive Rights has reported that the lack of financial and political commitment from the Nigerian government has created a number of significant barriers for pregnant women seeking maternity care. For example, pregnant women seeking obstetric care in public hospitals must bring their husbands to donate blood; if the husband refuses or if the woman doesn't have a husband, she is denied care. Women in labour

are forced to travel to hospitals on motorbikes. Public health facilities demand, in exchange for care, that pregnant women purchase basic necessities like antiseptics, syringes and gauze and that these items be a specific brand, thereby increasing cost. Doctors keep flashlights handy in the delivery room for use during regular power outages because health centres are not equipped with alternative sources of power.<sup>48</sup>

Maternal death in Uganda has remained high for many years: maternal mortality figures are at 435 deaths out of every 100,000 live births, which translates to 6,000 deaths annually or 16 per day. Most of these deaths are preventable, caused mainly by the massive shortage of professional health workers and a lack of access to emergency obstetric care, quality antenatal care and family planning services.49

A recent case filed before Uganda's Constitutional Court by human rights activists and relatives of women who died during childbirth argues that the state's failure to provide essential medical supplies and health services to pregnant women and the escalating maternal deaths in Uganda violate the constitutional rights of Ugandans.5°

In a recent decision against Brazil, the Committee on the Elimination of Discrimination against Women (CEDAW) found that the state should ensure affordable access for all women to adequate emergency obstetric care and to effective judicial remedies. It also recommended the state provide adequate professional training for health workers, ensure compliance by private facilities with national and international standards in reproductive health care, and reduce preventable maternal deaths.<sup>51</sup>

The Committee's approach of referencing Article 12 of the ICESCR and General Comment 14 on the Right to Health, in relation to capturing the scope of the rights and obligations at issue in this case was an important step forward in increasing coherence

in international human rights law on women's economic, social and cultural rights. Further, CEDAW's inclusion of factors affecting the victim's access to health services, such as poverty and race, was an important step in further developing an intersectional understanding of women's economic, social and cultural rights.<sup>52</sup> The case is a significant example of how litigation can be used as an effective tool to encourage states to respond to maternal mortality issues.

#### Degrading and ill-treatment in mental health institutions

Mental health patients often live in deplorable conditions. The World Health Organization (WHO) has reported that violations within psychiatric institutions include people restrained by rusting metal shackles, kept in caged beds, living in filthy conditions, kept in seclusion for lengthy periods and lacking clothes, clean water, food, heating, proper bedding and hygiene facilities. Patients are often isolated from society and held in institutions far away from their loved ones. Patients experience inappropriate forced admission or treatment and are detained against their will for weeks, months or years.53 These situations are contrary to states' regional and international human rights obligations.54 The WHO recommends that states set up monitoring bodies to ensure that human rights are respected in mental institutions and that mental health care is available at the community level.55

In *Purohit & Moore v the Gambia*, the African Commission reiterated that mental health patients should be accorded special treatment to enable them to attain and sustain their optimum level of independence and performance. This would be consistent with Article 18(4) ACHPR and the standards outlined in the UN Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care. 56

#### Linking the violations to key human rights law principles

Appropriate responses to the above violations require an understanding of how they engage key human rights principles.

#### The right to life

The right to life is enshrined in Article 6 of the ICCPR and in Article 4 of the ACHPR. Under both international and comparative case law, the right to life is seen as not only imposing a negative obligation upon states to not arbitrarily deprive one's life, but also corresponds to a positive obligation to take steps in order to guarantee life, which includes measures to reduce high rates of preventable maternal mortality. Several national and international bodies have also interpreted the right to life or even the right to not be subjected to cruel, inhuman or degrading treatment as including the right to health,57 particularly the right to primary health care and emergency treatments.

#### The obligation to respect, protect and fulfil the right to health

States are required to respect, protect and fulfil the right to health.<sup>58</sup> The obligation to respect requires states to, inter alia, refrain from denying or limiting, directly or indirectly, equal access to the right to health for all persons. The obligation to protect not only entails protecting individuals and communities from violations, but also requires the investigation and prosecution of perpetrators and the provision of legal and other remedies to victims.<sup>59</sup> It is an obligation of immediate effect and thus readily justiciable, though if the positive steps required were resource-intensive the obligation would be qualified by the maximum available resources of the state.60 The obligation to fulfil requires states to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to fully realise the right to health.61

#### Freedom from torture and cruel, inhuman or degrading treatment

The right to be free from torture and cruel, inhuman or degrading

treatment is not only specifically protected by several international and regional conventions but is now widely acknowledged as part of customary international law. It is integrally linked to the right to health. <sup>62</sup> The absolute prohibition of torture entails certain positive obligations that are absolute in nature, such as the duty to provide victims with an effective remedy and full and adequate reparation. The importance of access to a court for torture is reflected across international norms and practice. <sup>63</sup>

#### How should states respond to these kinds of violations?

State parties have immediate obligations to take steps to respect their international obligations. 64 They are obliged to take legislative measures and allocate sufficient resources within national budgets to deal with weaknesses in their health structures. Where states allege resource constraints to deal with violations in healthcare settings, they have the burden of justifying that every effort has nevertheless been made to use all available resources. 65 Similarly, when a state claims that it has failed to realise minimum essential levels of economic, social and cultural rights, it must be able to show that it has allocated all available resources towards the realisation of these rights.66

National plans should be based on human rights principles and states should consider adopting a framework law to operationalise their strategies, 67 which should identify appropriate right-to-health indicators and benchmarks. 68

In terms of healthcare settings, states should realise the minimum core obligation to ensure that no significant number of individuals is deprived of the essential elements of a particular right. 69 The state must ensure access to health facilities, goods and services on a non-discriminatory basis. especially for vulnerable and marginalised groups, and provision of essential drugs. States should also ensure an equitable distribution of all health resources and the adoption and implementation of a national public health strategy and plan of action addressing the health concerns of the population.<sup>70</sup>

An institution as complex and important as a health system requires a range of effective, transparent, accessible and independent accountability mechanisms. There are many options in this regard, including health commissioners, democratically elected local health councils, public hearings, patients' committees, impact assessments and judicial proceedings. media and civil society organisations also have a crucial role to play regarding accountability. Crucially, the requirement of human rights accountability extends to both the public and private health sectors, and also extends to international actors working on health-related issues.<sup>71</sup>

#### Conclusion

Violations arising in healthcare settings continue to have far-reaching repercussions on victims and their families. Deaths, denial of emergency medical care and detention of poor patients all point to the weak health institutions across Africa. These situations also indicate the lack of accountability processes – a key feature of health structures across the continent.

For African states to address these violations, they need to prioritise systematic and structural reform of their health systems. Experts argue that governments and donor agencies tend to focus on specific themes, such as HIV infection, malaria and tuberculosis, while failing to address the general state of Africa's healthcare systems. Strengthening health services generally would be very important for all these programmes. Given that a country cannot develop without a minimal health system, what is needed is long-term investment. However, this is not being done.<sup>72</sup>

While specific violations arising in healthcare settings need to be appropriately addressed, an

assessment of a country's entire health system, involving looking at the shortcomings and devising and implementing solutions, is critical for fundamental change. Ad hoc interventions will not permanently create stronger and more effective health structures.

A country's difficult financial situation does not absolve it from having to take action to realise the right to health. When considering implementation of this right in a particular state, the availability of resources and the development context are taken into account. Nonetheless, no state can justify a failure to respect its obligations because of a lack of resources. States must guarantee the right to health to the maximum of their available resources, even if these are tight. While steps may depend on the specific context, all states must move towards meeting their obligations to respect, protect and fulfil. 73

Accountability mechanisms urgently needed for all those actors public, private, national international - working on healthrelated issues. The design of appropriate, independent accountability mechanisms demands creativity and imagination.74 Creating these mechanisms or, in countries where they exist, ensuring that they adequately respond to violations, would assure individuals of the commitment of their governments to addressing human rights violations in the health sector.

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## Denial of Pain Treatment and the Prohibition of Torture, Cruel, Inhuman or Degrading Treatment or Punishment

Joseph Amon and Diederik Lohman

We must all die. But that I can save him from days of torture, that is what I feel as my great and ever new privilege. Pain is a more terrible lord of mankind than even death himself.

Albert Schweitzer<sup>1</sup>

'I have two of these,' says Artur as he pulls a handgun from under his pillow. 'I keep it to shoot myself when the pain gets too strong...'2 Artur, a decorated former KGB agent, is dying of prostate cancer in his home in a village in central Ukraine. He experiences severe pain but the medications he receives from Ukraine's healthcare system offer him little relief. Under World Health Organization recommendations, he should be receiving morphine six times per day but Ukraine's antiquated drug laws require that a nurse visit him at home for each dose he gets. It's an impossible task for the local nurse who is already overstretched. So Artur receives two doses per day instead. The rest of the time he is alone with his pain. The gun is his insurance policy for when life becomes unbearable.

There should be no need for a gun. Artur's suffering from pain is almost entirely preventable. According to the World Health Organization (WHO), 'most, if not all, pain due to cancer could be relieved if we implemented existing medical knowledge and treatments.'3 Indeed, if Ukraine's drug regulations did not make proper treatment of his pain impossible, Artur would not have to contemplate and plan his own death. He could spend the last months of his life with his family. Instead, he lives his last months isolated in a world of pain and suffering, having moved away from his family because he doesn't want them to hear him scream at night. Eventually, three months after the interview. Artur died of natural causes.

Sadly, Artur's suffering is hardly an Millions of people exception. worldwide suffer from severe pain without access to adequate treatment each year. Although morphine and other strong pain medications are inexpensive, safe and highly effective, they are virtually unavailable in more than 150 countries around the world.4 WHO estimates that tens of millions of worldwide suffer moderate to severe pain without access to treatment every year, including 5.5 million people with terminal cancer.5 Medications like morphine are often simply not available, drug regulations interfere with their accessibility, or doctors do not know how to prescribe them.6

The failure of governments in many countries to ensure the adequate availability of pain treatment services clearly raises questions of whether these countries live up to their obligations under the right to health, which requires states to ensure the availability and accessibility of health services, including, of course, treatment for pain. 7 But could this failure, which condemns patients to what Albert Schweitzer, the great Swiss medical doctor and humanist, called 'days of torture...more terrible than death itself,' also constitute a violation of the prohibition of torture, cruel, inhuman or degrading treatment (hereinafter: torture or ill-treatment)?

At present, no international legal mechanism, whether judicial or quasi-judicial, has settled this question. In some countries, national courts have ruled that pain treatment must be available to patients but these rulings are not based on the prohibition of torture but on the right to health or life. 8 In this article, we explore the

legal basis for the argument that denial of pain treatment can indeed constitute torture and ill-treatment and examine existing case-law to see how judicial mechanisms might approach the question.

#### Applicability of the Prohibition of Torture and Ill-treatment to Denial of Pain Treatment

A first question to answer is whether the prohibition of torture and ill-treatment can be applicable to denial of pain treatment. After all, denial of pain treatment generally involves acts of omission rather than commission (the active infliction of suffering by a state official on the victim). Moreover, in these cases the victim's suffering is caused not by some external source but by the patient's own body.

Article 7 of the International Covenant on Civil and Political Rights (ICCPR) articulates the prohibition of torture as follows: 'No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment...' While in the ICCPR and other international human rights instruments the right is formulated as a negative obligation - a prohibition for states to inflict such treatment jurisprudence has clearly established that the provision also imposes a positive obligation on states: To protect people in their jurisdiction from such treatment as well as to investigate credible allegations of torture or illtreatment.10 In other words, when a state fails to take steps to protect people from torture or ill-treatment an act of omission – it can still be guilty of a violation of the prohibition of torture and ill-treatment.

A review of jurisprudence and authoritative interpretations shows that international human rights bodies and courts have found a great variety of different types of suffering of different origins to potentially constitute torture or ill-treatment. For example, the European Court of Human Rights (ECtHR) has accepted that suffering due to the military burning someone's house;11 a failure to protect someone from environmental pollution;12 a failure by a government to adequately investigate a reported disappearance;<sup>13</sup> a failure to protect someone from domestic violence;14 and a failure to address mistreatment and neglect of children by their parents<sup>15</sup> can all give rise to a violation of the prohibition of torture or ill-treatment.

The Committee against Torture, an independent body that monitors the implementation of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, has stated that member states must prevent torture and ill-treatment in 'all context of custody or control...as well as contexts where the failure of the State to intervene encourages and enhances the danger of privately inflicted harm.' <sup>16</sup>

The UN Special Rapporteur on Torture, Cruel, Inhuman or Degrading Treatment or Punishment has specifically addressed the issue of pain treatment and argued that denial of such treatment can constitute torture and ill-treatment. In a 2009 report to the Human Rights Council, Professor Manfred Nowak, the then-rapporteur, specified that, in his expert opinion, 'the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman degrading treatment punishment.'17

#### Minimum Level of Severity

The next question to examine is whether the suffering caused by untreated pain meets the required minimum level of severity, which most international human rights mechanisms use, to qualify as torture or ill-treatment. This determination is made on a case-by-case basis. The ECtHR, for example, has held that 'the assessment of this minimum is, in the nature of things, relative; it depends on

all circumstances of the case, such as the duration of the treatment, its physical or mental effects and, in some cases, the sex, age and state of health of the victim.' 18

As Artur's case clearly shows, the physical and mental suffering of persons with untreated pain can, like that of victims of traditional forms of torture and ill-treatment, be very severe:

Physical Suffering: Not only can pain due to cancer or other illnesses be very severe, it often extends to many parts of the body, may be constant and without reprieve, and can last over long periods of time. Experts estimate that, on average, a person dying of cancer or AIDS will suffer from moderate to severe pain for a period of three months, far longer than most victims of traditional forms of torture or illtreatment are subjected to abuse. 19 In interviews with Human Rights Watch in half a dozen countries around the world, people with severe pain often expressed a sentiment similar to that of traditional torture victims: They would do anything to stop the pain.20 We have documented numerous cases of suicidal ideation among such patients, as well as various cases of suicides and attempted suicides.

Mental suffering: Severe pain causes significant mental suffering. Patients often experience a profound sense of loss of control, fear, anxiety and isolation. Severe pain tends to render patients bedridden and incapable of being active or even making decisions about their own lives. Frequently, they become completely dependent on relatives while at the same time being unable to interact with them in a meaningful way. Human Rights Watch interviewed various patients who said that they could no longer tolerate having their children around them or became abusive to their spouses as a result of the pain. Finally, pain frequently causes acute deprivation that builds over time and has a profound impact on patients' mental state.<sup>21</sup> According to a WHO study, people who live with chronic

pain are four times more likely to suffer from depression or anxiety than people who do not have chronic pain.<sup>22</sup>

**Long-term consequences**: Finally, untreated pain can have serious long-term consequences for patients. According to WHO, the physical effect of pain can influence the course of the diseases and even result in death.<sup>23</sup> Pain frequently causes immobility, which can result in permanent loss of function in patients.<sup>24</sup>

It is important to keep in mind that a certain degree of suffering, both physical and mental, is inherent in having a life-threatening disease like cancer. In assessing whether the minimum level of severity is met, one therefore needs to examine not the totality of the patient's suffering but the severity of the suffering that may not be regarded as inevitably experienced by a person with a serious, life-threatening health condition.<sup>25</sup> The question is the extent to which the lack of treatment for severe pain unnecessarily prolonged exacerbated the suffering.

#### Torture or Ill-Treatment?

A subsequent question is whether denial of pain treatment would qualify as torture or ill-treatment. Schweitzer uses the word torture to convey the severity of the suffering of patients. But in a legal sense torture requires intent to cause severe suffering and state officials must be directly or indirectly responsible for inflicting the suffering.<sup>26</sup> Typically, however, denial of pain treatment results from neglect, poor government policies, and a lack of knowledge, rather than from an intention to inflict suffering and would therefore constitute ill-treatment and not torture. Theoretically, of course, a healthcare worker or official who deliberately withholds treatment from someone in severe pain with the intent to cause severe suffering could be guilty of torture but this is not a situation we have come across in our work.<sup>27</sup>

The Scope of the Positive Obligation

If we accept that the severe suffering of many patients with pain due to cancer and other health conditions can constitute ill-treatment, the next question to examine is the scope of the positive obligation to prevent such suffering. What steps do states have to take to ensure that these patients do not have to suffer from severe pain without being able to access treatment? Below, we first discuss the positive obligation states have in individual cases of pain treatment denial and then the obligations states may have to protect persons more generally from such unnecessary suffering.

#### Obligation to Adequately Respond to Complaints

It is well established that states have a legal obligation to respond to credible allegations of serious ill-treatment, must take steps to stop the abuse and investigate and, if necessary, prosecute the perpetrators.<sup>28</sup> Failure to do so in itself constitutes a violation of the prohibition of torture and illtreatment. Human Rights Watch believes that this obligation applies to cases where state authorities receive complaints from patients who are unable to get access to pain treatment, or the authorities have other reasonable grounds to believe a patient is suffering ill-treatment due to lack of access to pain treatment.<sup>29</sup> In such situations, states should take expedient steps to examine these complaints and, if it is found that a healthcare institution arbitrarily denied treatment causing severe suffering, it should take all reasonable steps to ensure that the patient gains access to appropriate treatment.30 It should also examine whether legal steps, such disciplinary measures, against the clinic or doctor are appropriate.31

#### The Case of Oleg Malinovsky

Oleg Malinovsky is a 35-year-old man from Kiev who has been diagnosed with chronic hepatitis C and a range of other illnesses. He developed severe pain in various joints shortly after he began treatment for hepatitis C in 2008. As any movement of his hip and knee joints caused severe pain,

Malinovsky was forced to lie completely still in his bed throughout the day. His wife told Human Rights Watch:

The pain was intolerable with any movement and became more severe with every day because of the pathological process in his hip joints. The pain affected his sleep, appetite, and his psychological condition. He became irritable and nothing could make him happy anymore. A normal sneeze or cough caused him terrible pain ... You could knock on the wall, and if he was lying over there, he would scream [in pain]...32

For a period in late 2008 and early 2009, Malinovsky received a small dose of morphine every day which allowed him to sleep at night. Following surgery in March 2009, his pain temporarily subsided. When it came back in September 2009, Malinovsky asked his doctors for adequate pain treatment, expecting to once again receive morphine.

But the government clinic responded without any sense of urgency. It took weeks before examining Malinovsky and then repeatedly ordered new examinations, often after significant intervals, some of which appeared to simply repeat earlier examinations. Ultimately, it determined Malinovsky suffered from persistent pain syndrome but failed to prescribe anything stronger than basic over-thecounter pain medications. Instead of viewing Malinovsky's request for stronger pain medications as a legitimate request for a medication that had helped control his pain before, it interpreted it as evidence of drug dependence. As a result, Malinovsky suffered from debilitating pain for six months. Eventually, Malinovsky's condition improved on its own.

#### Obligation to Ensure Availability and Accessibility of Pain Treatment

Given how severe and extended the suffering is that many patients with cancer and other severe chronic pain face, the large numbers of people affected each year and the fact that this pain can be treated easily with inexpensive and safe medications, Human Rights Watch believes that the state's positive obligation requires reasonable steps to ensure that patients with severe pain can gain access to adequate treatment. This does not mean that every case where a patient with severe pain is unable to get access to pain medications constitutes ill-treatment. Where a country has taken all steps that can reasonably be expected of it to improve access to pain treatment but some patients still do not have adequate access because of the general weakness of the healthcare system or objective difficulties in making services available for people who live far from health centres, there would be no violation of the prohibition of torture or illtreatment. (Of course, if a state became aware of such patients, it would still have to take adequate steps to remedy their situation where it is reasonable to do so.) But there may be a violation of the prohibition of torture and illtreatment where states fail to take even basic steps to protect people in their jurisdiction from preventable suffering from pain.

The ECtHR has used a 'reasonable steps' test in some cases regarding the positive obligation under prohibition of torture and illtreatment. For example, in Opuz v *Turkey*, a case that concerned domestic violence, it examined whether the national authorities had taken 'all reasonable measures to prevent the recurrence of violent attacks against the applicant's physical integrity.' It found that although the national authorities had 'not remained totally passive' they had not 'displayed the required diligence to prevent the recurrence of violent attacks against the applicant...'33

While this jurisprudence emanates from cases related to suffering caused by violence, the reasonable-steps test could be applied by analogy to cases of denial of pain treatment. Indeed, the UN Special Rapporteur on Torture has said explicitly that:

The case summaries in this issue were kindly prepared for the Bulletin by lawyers from Dechert LLP. Those lawyers were:

**Douglas Carleton** 

Matthew Root

Eric Schroeder

Amy Thayer

With many thanks to Douglas Carleton and Suzanne Turner of Dechert LLP for managing the project.

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## African Committee of Experts on the Rights and Welfare of the Child

Institute for Human Rights and Development in Africa (IHRDA) and Open Society Justice Initiative (OSJI) on Behalf of Children of Nubian Descent in Kenya v The Government of Kenya

## Committee on the Elimination of Discrimination Against Women

Alyne da Silva Pimentel v Brazil

#### European Court of Human Rights

Al-Skeini & Ors v United Kingdom

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#### Inter-American Commission on Human Rights

Jessica Lenahan (formerly Jessica Gonzales) v United States

#### United Nations Human Rights Committee

LMR v Argentina

#### **Abbreviations**

#### **ACERWC**

African Committee of Experts on the Rights and Welfare of the Child

#### ACHPR

African Commission on Human and Peoples' Rights

#### **ACRWC**

African Charter on the Rights and Welfare of the Child

#### **ADRDM**

American Declaration of the Rights and Duties of Man

#### **CmEDAW**

Committee on the Elimination of Discrimination Against Women

#### **CEDAW**

Convention on the Elimination of All Forms of Discrimination Against Women

#### **ECHR**

European Convention on Human Rights

#### **ECtHR**

European Court of Human Rights

#### HRC

United Nations Human Rights Committee

#### **IACmHR**

Inter-American Commission on Human Rights

#### **ICCPR**

International Covenant on Civil and Political Rights

#### ICI

International Court of Justice

#### CHILDREN; NATIONALITY; HEALTH; EDUCATION; EQUALITY, NON-DISCRIMINATION

Violation of Article 3 – right to non-discrimination, Article 6(2), (3) and (4) – right to name and nationality, Article 14(2)(b), (c) and (g) – right to health and health services and Article 11(3) – right to education – of the ACRWC

Institute for Human Rights and Development in Africa (IHRDA) and Open Society Justice Initiative (OSJI) on Behalf of Children of Nubian Descent in Kenya v The Government of Kenya

Decision No 002/Com/002/2009, Decision of the ACERWC, 22 March 2011

The ACERWC received a communication from the IHRDA and the OSJI on behalf of children of Nubian descent in Kenya alleging that the Nubians in Kenya are descendents of persons hailing from present day Sudan who were forcibly conscripted into the British army in the early 1900s. Upon demobilisation of the British colonial army, these Nubians were denied the right to return to Sudan and forced to remain in Kenya. Although the British colonial authorities allocated land to the Nubians in Kenya, it did not grant them British citizenship, and, upon Kenyan independence in 1963, the citizenship of the Nubians in Kenya was not addressed. The Nubians were consistently treated as 'aliens' by the Government of Kenya since they did not have any ancestral homeland within Kenya. Since many Nubian parents lack valid citizenship documents, it is difficult to register their children's births and the children are left in an ambiguous state of citizenship. Despite an expectation that they will be recognised as Kenyan citizens when they reach the age of 18, since many persons of Nubian descent are denied the identification cards that are essential to prove citizenship, these persons are left stateless. Accordingly the IHRDA and the OSJI alleged violations by the Government of Kenya of Articles 3, 6, 14 and 11 of the ACRWC.

The Committee held that: (1) there were multiple violations by the Government of Articles 3, 6, 14 and 11 of

the ACRWC; (2) the Government should take all necessary legislative, administrative and other measures to ensure that children of Nubian descent in Kenya that are otherwise stateless can acquire Kenyan citizenship and proof of Kenyan citizenship at birth; (3) the Government should take measures to ensure that existing children of Nubian descent whose Kenyan citizenship is not recognised are systematically afforded the benefit of these new measures as a matter of priority; (4) the Government should implement its birth registration system in a non-discriminatory manner; (5) the Government should adopt a plan to ensure the right to the highest attainable standard of health and the right to education for the affected community; (6) the Government should report on the implementation of these recommendations within six months from the date of the decision.

# EXTRA-TERRITORIAL APPLICABILITY OF HUMAN RIGHTS LAW; LIFE; REMEDIES; CRUEL, INHUMAN AND DEGRADING TREATMENT; TORTURE

Violation of Article 2 – right to life (procedural aspect) – of the ECHR

#### Al-Skeini and Others v The United Kingdom

Application no. 55721/07, Judgment of the ECtHR (Grand Chamber), 7 July 2011

The six applicants were relatives of people killed in or near Basrah City, Iraq in 2003 while it was under British military control. The first, second, and fourth applicants' relatives were shot by British soldiers; the third applicant's wife was a third-party shooting victim during a gun battle involving British troops; the fifth applicant's son apparently drowned in a river after being arrested by British soldiers; and the sixth applicant's son died in British military custody. The deaths of the first five applicants' relatives were either investigated only by the commanding officer of the soldiers involved or by the Special Investigations Branch, a part of the army whose findings also were reported to the commanding officer of

the unit involved. In either case, the commanding officer decided whether to refer the cases to the prosecuting authority.

On 26 March 2004, the UK Secretary of State for Defence decided not to conduct an independent investigation into the deaths of the relatives of the six applicants, not to accept liability for their deaths and not to compensate the families. The applicants sought judicial review of the decision.

The Divisional Court reviewed all of the applicants' cases, except for the fifth applicant whose case was stayed pending the outcome of the others. The Divisional Court found that it had no jurisdiction over the claims of the first four applicants under Article 1 of the ECHR because the narrow exceptions to Article 1's territorial jurisdiction did not apply. However, the Divisional Court did have jurisdiction over the claim of the sixth applicant because a death occurring in a British military prison abroad was covered by a narrow jurisdictional exception for locations with 'a discrete quasi-territorial quality,' much like foreign embassies. In the case of the sixth applicant, the Divisional Court found that the UK had breached its investigative duty under Articles 2 and 3 because the results of the investigation were 'unknown and inconclusive' ten months after the killing.

The first four applicants appealed the jurisdictional ruling and the UK Secretary of State for Defence cross-appealed the jurisdictional finding regarding the sixth applicant. The Court of Appeal dismissed the appeals and cross-appeal. The Court of Appeal found that none of the applicants' relatives were under the control and authority of the UK except for the sixth applicant's son, whose claim was within the scope of the Human Rights Act 1998. The sixth applicant's claim was remanded to the Divisional Court for reconsideration after further developments in the investigation.

Following an unsuccessful appeal to the House of Lords, the applicants sought relief from the ECtHR. The applicants argued that the UK had jurisdiction over the applicants' deceased relatives under Article 1 because the UK was in effective control of South East Iraq and had responsibility for public order in that region. The UK argued that only the sixth applicant's relative, who died while in British military custody, fell under its jurisdiction. The UK claimed that, with respect to the relatives of the first to fifth applicants, the acts in

question took place in Iraq, which is outside of the UK's jurisdiction under Article 1, and that, in any event, the UK did not have effective control over any part of Iraq during the relevant period.

The applicants further complained to the ECtHR that the UK failed to fulfill its duty to effectively investigate the deaths of the first to fifth applicants' relatives under Article 2, which prohibits arbitrary killing by state actors and sought a Government investigation into their relatives' deaths and compensation for their distress. The sixth applicant and the UK agreed that the sixth applicant was no longer a victim of an Article 2 violation given the public inquiry underway at that time. The UK argued that any implied procedural duty to investigate the deaths under Article 2 should not place a disproportionate burden on any state and should take into account the relevant circumstances. The UK claimed that it did not have full control over the relevant Iraqi territory and that its personnel were operating under very difficult security conditions. The UK agreed, however, that the investigations into the deaths of the relatives of the first, second and third applicants were not sufficiently independent of the military chain of command under Article 2 because the investigations were conducted by the commanding officers of the soldiers allegedly responsible for the killings. However, the UK maintained that the investigations into the deaths of the fourth, fifth and sixth applicants' relatives complied with Article 2. The UK also argued that the fifth and sixth applicants no longer had victim status.

A joint third-party intervention by the Bar Human Rights Committee, the European Human Rights Advocacy Centre, Human Rights Watch, the International Federation for Human Rights, INTERIGHTS, the Law Society and Liberty argued that a narrow interpretation of territorial jurisdiction for a state under Article 1 would lead to differing standards of accountability based on whether a state's deprivation of human rights occurred at home or abroad, an outcome that was not intended by the parties adopting the ECHR in the aftermath of World War II and would be out of step with the practice of other human rights bodies such as the ICJ, the HRC, the IACHR and the ACHPR. To do otherwise would allow a state to commit violations in a foreign land that it would not permit on its own territory. The interveners argued further that when a state continues to control the conduct of its agents abroad, as in a foreign military

occupation, it is responsible for its agents' human rights violations.

The Court held that: (1) the relatives of the applicants were subject to the jurisdiction of the UK because after the cessation of major combat operations in Iraq in May 2003, the UK assumed authority over security operations in Basrah thereby establishing a jurisdictional link between those killed during British security operations and the UK under Article 1; (2) the fifth applicant has victim status, notwithstanding the applicant's receipt of a substantial settlement for his civil claim and the admission of liability on behalf of the army, because there never was a thorough investigation into the applicant's son's death; (3) the UK violated Article 2 by conducting investigations into the deaths of the first to fifth applicants' relatives that were insufficiently independent of the military chain of command; (4) the sixth applicant was no longer a victim of the procedural obligation under Article 2 due to the near completion of the public inquiry into the applicant's son's death; (5) the UK must pay each of the first five applicants EUR 17,000 for non-pecuniary damage; (6) the UK must pay the first five applicants EUR 40,000 jointly in costs and expenses.

#### LIFE; EQUALITY; REMEDIES

Violation of Article II – right to equality before the law, Article I – right to life, liberty and personal security in conjunction with Article VII – right to protection for mothers and children and Article XVIII – right to fair trial – of the ADRDM

#### Lenghan v United States

Report no. 80/11, Case 12.626, Decision of the Inter-American Commission on Human Rights, 21 July 2011

JL and SG were married but became estranged due to SG's erratic and abusive behaviour. As a result of SG's behaviour, JL obtained a restraining order restricting SG's visitation with their three children. Subsequently, without informing JL, SG picked up his three daughters in his truck and drove away.

JL, concerned that her children were missing, contacted the local police at 7:42 p.m. that day to request assistance. Over the next several hours, JL contacted the police department multiple times informing them that

her daughters were missing, that they may be with SG and that she had a restraining order against SG. At approximately 3:25 a.m. the following morning, SG drove his pick-up truck to the police department and fired his pistol at the police station from the street. SG was killed during the ensuing exchange of gunfire with the police. When the police officers approached the truck following the shooting, they discovered the bodies of the three girls, each of whom who had been shot in the head.

JL brought an action in the United States (U.S.) District Court based on the Due Process Clause of the Fourteenth Amendment to the U.S. Constitution. That case was appealed to the U.S. Supreme Court, which rejected JL's claims. JL subsequently petitioned the IACHR.

JL argued that the State failed to act with due diligence in protecting the lives of her daughters, in violation of their right to life guaranteed under Article I of the ADRDM. JL further argued that such failure was a result of discrimination based on their sex, in violation of Article II of the ADRDM. JL also asserted that her rights under Article XVIII of the ADRDM were violated in that she was unable to obtain a remedy for the non-enforcement of her protection order or a diligent investigation into the circumstances surrounding her daughters' deaths, including SG's ability to purchase a firearm and the inadequate response of the police. JL argued that these claims also implicated a violation of Articles IV and XXIV of the ADRDM.

With respect to JL's claims under Article I and Article II of the ADRDM, the State responded that the danger to JL's daughters could not have been foreseen and, therefore, the State acted with reasonable diligence. With respect to JL's claims under Article XVIII of the ADRDM, the State responded that this Article does not provide a right to a remedy related to non-enforcement of restraining orders, and that the State in fact undertook extensive investigations into the deaths of JL's daughters.

The Commission held that: (1) the State failed to act with due diligence to protect JL and her daughters from domestic violence, which violated the State's obligation not to discriminate and to provide for equal protection before the law under Article II of the ADRDM; (2) the State failed to undertake reasonable measures to protect the life of the children in violation of their right to life under Article I of the ADRDM, in conjunction with their

right to special protection as girl-children under Article VII of the ADRDM; (3) the State violated the right to judicial protection of JL and her next of kin under Article XVIII of the ADRDM; (4) there was not sufficient information to find violations of Articles V and VI of the ADRDM; (5) the claims under Articles IV and XXIV of the ADRDM had been addressed under Article XVIII of the ADRDM.

## WOMEN; HEALTH; EQUALITY, DISCRIMINATION

Violation of Article 12(1) and (2) – access to healthcare services and Article 2 – establishment of policy measures to eliminate discrimination – of CEDAW

#### Alyne da Silva Pimentel Teixera (deceased) v Brazil

Communication No 17/2008, Decision of the CmEDAW, 25 July 2011

AT was a Brazilian national of African descent. In her sixth month of pregnancy, AT went to the health centre complaining of severe nausea and abdominal pain. She was given medication and sent home. Two days later she returned to the health clinic, at which time the doctor could not detect a foetal heartbeat, which was confirmed by ultrasound. AT was then given medication to induce the delivery of the stillborn foetus.

Fourteen hours after delivery, AT underwent surgery to remove parts of the placenta and afterbirth, but her condition continued to worsen. The doctors at the health centre then sought to transfer AT to a hospital. The municipal hospital had available space but was unwilling to use its only ambulance to transfer AT. AT waited in critical condition for eight hours, manifesting clinical symptoms of coma for the last two hours. On arrival at the hospital she was in critical condition and needed to be resuscitated, but the hospital placed her in a makeshift area in the emergency room hallway. She died the next day of digestive haemorrhage caused by delivery of the stillborn foetus.

MT, the mother of AT, submitted a communication with the CmEDAW claiming that AT was a victim of a violation by Brazil of her right to life and health under Articles 2 and 12 of CEDAW. MT argued that Article 2 required immediate action by Brazil to address

discrimination against women when a woman's right to life is violated by failure to secure her safety during pregnancy and childbirth. MT contended that CEDAW required Brazil to ensure practical implementation to combat discrimination, not just legal guarantees.

Brazil argued that a number of public policies aimed at eliminating discrimination against women in the field of health care are under development and that the failures in the medical care provided to AT were not because of discrimination against women but through deficient and low-quality service to the population, specifically by the private for-profit hospital. Brazil did not contest that the services provided to AT were inadequate.

The Committee held that: (1) AT's death was 'maternal' within the meaning of Article 12(2) of CEDAW; (2) AT was not ensured appropriate services in connection with her pregnancy; (3) Brazil is directly responsible for the actions of private medical services outsourced by the State; (4) the lack of appropriate maternal health services fails to meet the distinctive health needs and interests of women, in violation of Article 12(2) of CEDAW, constitutes discrimination against women under Article 12(1) and Article 2 of CEDAW, and has a differential impact on the right to life of women; (5) AT was discriminated against not only on the basis of her sex but also on the basis of her status as a woman of African descent and her socio-economic background; (6) it is recommended that Brazil: provides appropriate reparation including financial compensation, ensures womens' right to safe motherhood and affordable access to adequate emergency obstetric care, provides adequate professional training for health workers, especially on women's reproductive health rights, including quality medical treatment during pregnancy and delivery, as well as timely emergency obstetric care, ensures access to effective remedies in cases where women's reproductive health rights have been violated and provides training for the judiciary and for law enforcement personnel, ensures that private healthcare facilities comply with relevant national and international standards on reproductive health care; ensures that adequate sanctions are imposed on health professionals who violate women's reproductive health rights, reduces preventable maternal deaths through implementation of the National Pact for the Reduction of Maternal Mortality at state and municipal levels, including by establishing maternal mortality committees

where they still do not exist, in line with the recommendations in its concluding observations for Brazil, adopted on 15 August 2007 (CEDAW/BRA/CO/6).

#### WOMEN; HEALTH; PRIVATE LIFE

Violation of Article 8 – right to respect for private and family life – of the ECHR

#### Ternovszky v Hungary

Application no. 67545/09, Judgment of the ECtHR, 14 December 2010

In 2009, T, a Hungarian national, became pregnant and intended to give birth at her home, rather than in a hospital or a birth home. Hungarian law, at the time, provided that a health professional who carries out activities within his or her qualifications without a license, or carries out such activities in a manner which is not in compliance with the law or the license, is punishable with a fine of up to 100,000 Hungarian forints. Hungarian law further provided that the Government would determine (but during the relevant period, the Government had not yet determined) the professional rules and conditions governing births outside an institution.

T filed an application with the ECtHR against Hungary claiming a violation of Article 8 read in conjunction with Article 14 of the ECHR. T alleged that the lack of comprehensive legislation on home birth effectively dissuades health professionals from assisting those wishing home birth because they run the risk of conviction for a regulatory offence. T noted that at least one such prosecution had taken place in recent years. T claimed that her inability to obtain adequate professional assistance for a home birth in view of the relevant Hungarian legislation amounted to discrimination in the enjoyment of her right to respect for her private life.

The Government argued that the right to self-determination under Article 8 was subject to restrictions within a wide margin of appreciation by the Government. The Government argued that there was no consensus among the European member states as to how to strike a fair balance between the mother's right to give birth at home and the child's right to life and health and, in particular, to a safe birth. The Government

further claimed that there was a professional consensus in Hungary that home birth was less safe than birth in a healthcare institution. The Government argued further that home birth was not prohibited and that several instances of death or serious injury had resulted in legislation authorising the Government to regulate births outside a health institution and that the legislation was currently underway.

The Court held that: (1) the complaint should be examined under Article 8 alone; (2) the circumstances of giving birth form part of one's private life protected under Article 8; (3) legislation which dissuades health professionals from providing assistance to a home birth constitutes an interference with the exercise, by prospective mothers such as T, of the right to respect for private life; (4) such interference infringes Article 8 if the interfering law does not satisfy certain qualitative requirements such as foreseeability and an absence of arbitrariness; (5) in the context of home birth, the mother is entitled to a legal and institutional environment that enables her choice (including legal certainty that the choice is lawful and not subject to sanctions), except where other rights render it necessary to impose restrictions on that choice; (6) the threat posed to health professionals by virtue of Hungarian law, the absence of specific, comprehensive legislation on the matter of assisting home births, and the actual institution of proceedings against at least one health professional for having assisted a home birth, enable the Court to conclude that the matter of health professionals assisting home births is surrounded by legal uncertainty prone to arbitrariness; (7) T made no damages claim; (8) the Government must pay to T EUR 1,250 plus any tax that may be chargeable to T in respect of costs and expenses.

## WOMEN; LIFE; EQUALITY, DISABILITY; HEALTH

Violation of Article 7 – prohibition of torture and cruel, inhuman or degrading treatment or punishment, Article 17(1) – right to freedom of thought, conscience and religion and Article 2(3) – obligation on states to provide a remedy for breaches of rights – in relation to Articles 3 – the equal right of men and women to the enjoyment of all civil and political rights in the ICCPR, 7 and 17 – right not to be subjected to arbitrary or unlawful interference with privacy, family, home or

correspondence and to protection of the law against such interference or attacks – of the ICCPR

#### L.M.R. v Argentina

Communication no. 1608/2007

Decision of the HRC, 29 March 2011

LMR is a young woman with a permanent mental impairment, having a mental age between eight and ten years old. LMR was raped and became pregnant. VDA, LMR's mother, sought to have LMR's pregnancy terminated. Under Argentine law, an abortion is permitted if the pregnancy results from the rape of a woman with a mental disability and the woman's legal representative consents.

The staff of the first hospital that LMR visited in June 2006 refused to perform the abortion. VDA took LMR to a second hospital, SMH, which was willing to perform the abortion. LMR was almost 15 weeks pregnant at the time. However, before the procedure could be performed, the juvenile court issued an injunction against SMH performing the procedure on the grounds that a wrongful assault (the rape) could not be repaired 'with another wrongful assault against a new innocent victim, i.e. the unborn child'. On 31 July 2006 the Supreme Court of Justice of Buenos Aires overruled this decision and held that the abortion could proceed. Following the Supreme Court's ruling, SMH came under enormous pressure from sources opposed to abortion (including various Catholic groups) and refused to perform the procedure on the grounds that the pregnancy was, at that time, too far advanced. LMR subsequently underwent an illegal abortion.

VDA filed a communication with the HRC on behalf of LMR alleging that forcing LMR to continue her pregnancy constituted cruel and degrading treatment in violation of Article 7 of the ICCPR. The communication also alleged that, in taking a decision concerning LMR's life and reproductive health on LMR's behalf, Argentina had arbitrarily interfered in her private life, in violation of Article 17 of the ICCPR. VDA complained that Argentina's failure to safeguard LMR's legal right to a procedure required solely by women was discriminatory conduct in violation of Article 3 of the ICCPR, and that Argentina had forced LMR to undergo a risky illegal abortion, in violation of VDA's right to life. The communication further alleged that, because Argentina

lacked the mechanism to ensure that LMR could exercise her legal right to an abortion, Argentina had violated Article 2 of the ICCPR. Finally, VDA complained that the failure of Argentina to protect LMR's rights in the face of coercion by various Catholic groups was a violation of Article 18 of the ICCPR.

Argentina conceded that it could be concluded from the Supreme Court's ruling that the lower court had possibly interfered unlawfully with LMR's right to an abortion in violation of Article 2. However, Argentina argued that the judiciary had acted promptly since the matter was resolved by the Supreme Court in less than four weeks and that the choice by the hospital not to terminate the pregnancy was due to the advanced stage of the pregnancy. Argentina acknowledged that its unlawful interference, through the judiciary, in an issue that should have been resolved between LMR and her physician could be considered a violation of LMR's right to privacy in violation of Article 17. Nonetheless, Argentina argued that forcing LMR to endure a pregnancy resulting from rape and to undergo an illegal abortion did not rise to the level of torture or cruel treatment in violation of Article 7 and that LMR's decision to resort to an unsafe abortion was her own decision, therefore the illegal abortion should not be considered a direct consequence of state action. Finally, Argentina contended that it had not committed a violation of Article 18, in that the activities of the Catholic groups were unconnected to the actions of state officials.

*The Committee held that*: (1) there is nothing in the case file to indicate that LMR's life was exposed to particular danger as a result of the illegal abortion, therefore, the allegation that Argentina violated LMR's right to life under the ICCPR is inadmissible; (2) the author has not adequately substantiated her complaint of a violation of Article 18, therefore it is inadmissible; (3) Argentina's failure to guarantee LMR's right to an abortion caused LMR physical and mental suffering in violation of Article 7; (4) Argentina's unlawful interference through the judiciary, in an issue that should have been resolved between the patient and her physician, violated Article 17(1) of the ICCPR; (5) LMR did not have access to an effective remedy to lawfully terminate her pregnancy in violation of Article 2(3) in relation to Articles 3, 7 and 17 of the ICCPR; (6) under Article 2(3)(a) of the ICCPR, Argentina is obligated to compensate LMR and to take steps to prevent future violations; (7) within 180 days,

Argentina is to provide information to the HRC about the measures taken to give effect to the HRC's views.

#### **WOMEN; LIFE; HEALTH**

Violation of Article 3 – prohibition of torture or inhuman or degrading treatment (substantive aspect) and Article 8 – right to respect for private and family life – of the ECHR

#### R.R. v Poland

Application no. 27617/04, Judgment of the ECtHR, 26 May 2011

During the 18th week of her pregnancy, RR underwent an ultrasound scan which indicated that her foetus may have been affected with an undetermined malformation. RR was informed that genetic testing was required to confirm this diagnosis. RR told her physician that she wanted to undergo genetic testing, and that she wished to have an abortion if the foetus was in fact malformed. Abortion in Poland is available only in limited circumstances, including when prenatal tests indicate a high risk that the foetus will be severely and irreversibly damaged.

Over the next several weeks, RR persistently sought to undergo genetic testing, seeking the procedure from various doctors, hospitals and clinics, only to be denied for various purported reasons. Six weeks after the ultrasound which gave rise to the concerns about the foetus, RR was finally able to obtain the genetic testing, the results of which indicated that her foetus was affected by Turner syndrome, a chromosomal abnormality. However, RR was unable to obtain an abortion at that time, as Polish law prohibited a woman from obtaining an abortion under the given circumstances after the 22nd week of pregnancy. RR subsequently gave birth to a daughter affected with Turner syndrome. RR initiated legal proceedings in the Polish courts, which resulted in her being awarded monetary damages pursuant to a final judgment. During these proceedings, RR rejected a settlement proposal by the Government.

RR applied to the ECtHR, complaining that her doctors' intentional failure to provide timely prenatal testing, as well as the dismissive and contemptuous manner in which the medical professionals communicated with her

during her ordeal, gave rise to a violation of Article 3 of the ECHR. RR further complained that the failure of the Government to implement regulations governing access to prenatal examinations, abortions and the exercise of conscientious objections by medical professionals gave rise to a violation of Article 8 of the ECHR. Finally, RR submitted that the Government's failure to create a legal mechanism for her to challenge her doctors' decisions concerning access to prenatal examinations constituted a violation of Article 13 of the ECHR.

As a threshold issue, the Government argued that RR had lost her status as a victim of a breach of her rights under the ECHR by rejecting the Government's settlement proposal and by receiving a monetary award from the Polish courts. The Government submitted that the manner in which RR had been treated by the various medical professionals did not rise to the level of a breach of Article 3. In addition, the Government took the position that Turner syndrome did not rise to the level of severe and irreversible damage that would permit RR to seek a lawful abortion, thus the delay in genetic testing did not result in any denial of RR's right to a lawful abortion under Polish law. Finally, the Government argued that Polish law provided for adequate procedures governing the taking of medical decisions concerning abortion on medical grounds and thus there had been no breach under Article 13.

The Court held that: (1) RR's refusal to settle the case has no affect on her victim status under the ECHR; (2) the award by the Polish courts was insufficient financial redress and did not result in her losing her status as a victim under the ECHR; (3) RR's suffering reached the minimum threshold necessary to result in a breach of Article 3; (4) the Government's failure to create a procedural framework enabling a pregnant woman to exercise her right of access to lawful abortion (including access to information on her foetus' health to determine whether an abortion is legally available) is a breach under Article 8; (5) RR's complaint regarding the breach of Article 13 overlaps with the issues the Court examined under Article 8, therefore it is not necessary to examine separately whether there has been a violation of Article 13; (6) the Government must pay RR EUR 45,000 for non-pecuniary damages and EUR 15,000 for costs.

Governments also have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises whether questions they adequately discharged this obligation.34

The European Court of Human Rights has held that vulnerable individuals, such as children, are particularly entitled to state protection.<sup>35</sup> In an authoritative interpretation of the Convention against Torture, the Committee against Torture specifically cites the protection of 'marginalized individuals or populations' against torture or ill-treatment as an obligation for state parties and identifies health status as a category for vulnerability.<sup>36</sup> A strong case can be made for considering patients with incurable illnesses vulnerable individuals as well.

So what are the reasonable steps a government should take to protect patients with severe pain from unnecessary suffering? We can look for guidance at the right to health. A key duty under the right to health is the obligation to respect which requires countries to 'refrain from interfering directly or indirectly with the enjoyment of the right to health.'37 In Artur's case, Ukraine's drug control policies made it practically impossible for healthcare workers to properly manage his pain. As the legal requirement that a healthcare worker administer every dose of morphine is unnecessary from both a medical and drug control perspective - it is standard practice worldwide that patients who are at home or their families administer morphine themselves - there is no justification for a regulation that so severely impedes appropriate pain care, which thus violates the obligation to respect. Another example: In Guatemala, drug control regulations require that every prescription for morphine be validated at a government office in Guatemala City before a pharmacy can fill it. This requirement, again unnecessary from a drug control or medical perspective, for all practical purposes makes morphine inaccessible for many patients, particularly those in rural areas.

The Committee on Economic, Social and Cultural Rights, the body that monitors the implementation of the right to health as articulated in the International Covenant on Economic. Social and Cultural Rights (ICESCR),<sup>38</sup> has identified a number of core obligations under the right to health, which it holds all countries must meet regardless of resource availability. First, the Committee articulates the general principle that 'the right of access to health facilities, goods and services on a nondiscriminatory basis, especially for vulnerable or marginalized groups'.39

A crucial core obligation for this topic holds that states must ensure the availability and accessibility of medications included in the WHO Model List of Essential Medicines, which includes morphine. In fact, countries also have an obligation to ensure the availability of morphine under the 1961 Single Convention on Narcotic Drugs, to which 184 countries are party and which 'establishes a dual drug control obligation: to ensure adequate availability of narcotic drugs, including opiates, for medical and scientific purposes, while at the same time preventing illicit production of, trafficking in and use of such drugs.'40 Thus, ensuring the accessibility of morphine is not just a reasonable step toward preventing unnecessary suffering from pain, it actually is a legal obligation.

A second core obligation holds that states must adopt and implement a national public health strategy and plan of action.<sup>41</sup> This core obligation is closely aligned with a recommendation by the WHO that countries adopt national or state policies that support pain relief and palliative care.<sup>42</sup> A

second reasonable step to prevent unnecessary suffering from pain is therefore the adoption of health policies that address the palliative care needs of the population. If national health policies fail to do so, the state will fall foul of this core obligation.

Finally, the Committee has held that providing appropriate training for health personnel is an obligation of 'comparable priority.'43 Again, this obligation coincides with WHO's recommendation that countries ensure healthcare workers are trained in provision of palliative care.44 Thus, a reasonable third step toward preventing unnecessary suffering from pain therefore involves ensuring that healthcare personnel, particularly those likely to regularly encounter patients who need such health services, such as oncologists, have at least basic training in palliative care provision.

When the failure of states to take these positive steps or to refrain from interfering with healthcare services condemn large number of patients to unnecessary suffering from pain, they will not only fall foul of the right to health but may also violate the positive obligation under the prohibition of torture and ill-treatment. In an example of this in India we found that more than half of the country's regional cancer centres, which see tens of thousands of cancer patients per year, do not offer adequate palliative care services. In fact, many do not even have morphine or doctors trained in using it, despite the fact that 70 per cent or more of their patients have advanced cancer and are likely to require pain treatment. Although the Indian government bestows the prestigious designation of regional cancer centre on hospitals and provides some financial support, it has not used its leverage with these hospitals to ensure that they offer palliative care and pain treatment services. As a result, tens of thousands of patients of these cancer centres suffer unnecessarily from severe pain every year. A doctor at a regional cancer centre that does offer palliative care recalled how he and his colleagues dealt with patients in pain when they did not have morphine:

We used some drugs ... For example, weak opioids... But our patients' pain was [often] much beyond [those medications]. So we tried to avoid the patients: "Don't come to us. Go and take treatment at your local [doctor]." That was the attitude. "Our treatment is exhausted. We completed radiation, chemotherapy. We did everything we could for you. Nothing more is possible. You need not come here. You go and show to your local doctor." The local doctor says, "This is not my specialty. Cancer is like a superspecialty. I don't know anything about this cancer. So go back to your treating doctor." So in between the patient suffers and they die with suffering.45

This kind of gross neglect of the needs of large numbers of patients who face severe suffering as a result violates the prohibition of torture and ill-treatment and states should be held accountable accordingly.

Joseph Amon is director and Diederik Lohman is senior researcher at the Health and Human Rights division of Human Rights Watch.

The authors would like to acknowledge the contributions to this article of three former interns or externs with HRW's HHR division: Florian Kastler, Jimmy Pan and a third person who requested to remain anonymous.

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- 8 See, for example, All India Lawyers' Forum for Civil Liberties v Union of India, (1998), WP 942/98.
- **9** See, for example, Sadykov v Russian Federation, judgment of 7 October 2010.
- 10 UN Human Rights Committee, General Comment 20, para. 8, <a href="http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/6924291970754969c12563edoo4c8ae5?Opendocument">http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/6924291970754969c12563edoo4c8ae5?Opendocument</a>, (accessed 29 August 2009). See also the judgment of the European Court of Human Rights in Z v United Kingdom (2001) 34 EHHR 97.
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- **12** Lopez Ostra v Spain, judgment of 9 December 1994, para. 60.
- 13 Kurt v Turkey, judgment of 25 May 1998, para. 134.
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- **15** *Z. v UK*, judgment of 10 May 2001, para. 75.
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- **23** WHO, 'National Cancer Control Programme: Policies and Managerial Guidelines,' 2002, p. 83.

- **24** Supra note 21.
- **25** The ECtHR uses a similar approach in cases of enforced disappearances, where it examines whether the suffering caused to relatives of a disappeared person is exacerbated by the failure of the government to conduct an adequate investigation into the incident. See for example, *Kurt v Turkey*.
- **26** Article 1 of the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (hereinafter: Convention against Torture) stipulates that torture means 'any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.'
- **27** In our research, we have found cases where police deliberately denied treatment to drug users, using resulting painful withdrawal symptoms to force them to sign confessions. See: Human Rights Watch, Rhetoric and Risk: Human rights abuses impeding Ukraine's fight against HIV/AIDS, March 2006.
- **28** See, for example, Articles 12 and 16 of the Convention against Torture; *Assenov v Bulgaria*, ECtHR judgment of 15 July 2005.
- 29 See Article 12 of the Convention against Torture.
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- **31** *Ibid*.
- 32 Human Rights Watch, *Uncontrolled Pain*, supra note 20.
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- 35 Opuz v Turkey, para. 159.
- 36 Supra note 16, para 21.
- **37** Supra note 7, para. 33.
- 38 International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted 16 December 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, entered into force 3 January 1976, Art. 11; also in the Convention on the Rights of the Child (CRC), G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force 2 September 1990, Art. 12.
- 39 Supra note 7, para. 43.
- **40** INCB, 'Availability of Opiates for Medical Needs: Report of the International Narcotics Control Board for 1995,' <a href="http://www.incb.org/pdf/e/ar/1995/supplien.pdf">http://www.incb.org/pdf/e/ar/1995/supplien.pdf</a>, (accessed 15 January 2009), p.i.
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- **42** WHO, 'Cancer Pain Relief, Second Edition, With a guide to opioid availability,' 1996, p. 3.
- **43** *Supra* note 7, para. 44f.
- 44 Supra note 42, p. 3.
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# Out of the Silo: Using Reproductive Rights Jurisprudence to Litigate Abuses in Healthcare Settings

Elisa Slattery

Women and girls seeking sexual and reproductive health services frequently experience abuse and mistreatment at the hands of healthcare personnel, who hold clear positions of authority and often exercise significant control over women in these contexts. Reproductive rights violations in healthcare settings include: verbal, physical and sexual abuse; coercive practices, such as forced sterilisation; and denial of abortion and post-abortion care services. These abuses are often exacerbated when the health services they seek, such as abortion, are highly stigmatised or the women themselves belong to a marginalised group.<sup>2</sup>

Many of these issues, such as coercive sterilisation, denial of legal abortion services and failure to provide quality maternal health care have been, and are being, litigated in national, regional and international fora.<sup>3</sup> While this jurisprudence, especially abortion jurisprudence, is not widely drawn upon in the wider body of efforts to seek accountability for abuses in healthcare facilities, it can be extremely relevant to the litigation of healthrelated cases which are often accompanied by stigma, complex medical fact patterns and timesensitivity. Furthermore, much of this jurisprudence claims rights violations beyond the right to health, moving the discussion out of the realm of progressive realisation to immediate governmental obligations, such as preventing discrimination and torture or cruel, inhuman and degrading treatment. For example, as discussed in this article, recent jurisprudence from the Human Rights Committee and the European Court of Human Rights (the European Court) have analysed violations in the abortion context through a cruel, inhuman and degrading treatment lens.

This article discusses several recent pioneering cases from regional and international human rights bodies which strengthen the human rights and accountability framework around violations in healthcare settings; establish limits on providers' ability to place their own beliefs and biases above the well-being of their patients; and affirm the importance of timely and effective measures to both prevent and redress violations.

#### Addressing Maternal Death as a Systemic Problem Which Violates Fundamental Human Rights, Including the Right to be Free From Discrimination

In August 2011, the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) Committee became the first international human rights body4 to issue a decision on maternal mortality, Alyne da Silva Pimentel Teixeira v Brazil (Alyne).5 Alyne, a young Afro-Brazilian woman, was denied timely medical care for a high-risk pregnancy, including a timely referral and transfer to a facility better equipped to handle her complications. Even when she was finally transferred to a higher level facility, she 'was left largely unattended in a makeshift area of the hospital for 21 hours until she died., The Committee analysed the individual medical circumstances of the case as well as the broader systemic factors surrounding the provision of, and access to, quality maternal health care in both public and private health facilities in Brazil.

#### Compounded Discrimination

In assessing the interlocking factors that led to Alyne's death – the substandard care, her family's inability to obtain an ambulance to transfer her to the hospital and the unequal

geographical distribution of higherlevel health facilities in Brazil – the Committee concluded that Alyne 'was discriminated against, not only on the basis of her sex, but also on the basis of her status as a woman of African descent and her socio-economic background.'7

#### State Responsibility for Violations in Private Healthcare Facilities

The CEDAW Committee rejected the Government's claim that it was not responsible for Alyne's death because she had received sub-standard care in a private health facility. The Committee observed that 'the State is directly responsible for the action of private institutions when it outsources its medical services' and ʻalways maintains the duty to regulate and private health-care monitor institutions.' The state, it added, 'has a due diligence obligation' to ensure 'that the activities of private actors in regard to health policies and practices are appropriate.'8 This language is crucial in further articulating state responsibility for violations which occur in private healthcare facilities,9 as health care continues to be increasingly privatised, and where in many parts of the world, the sparse distribution of public facilities may mean that people only have access to private facilities.<sup>10</sup>

#### Individual and Systemic Remedies

The CEDAW Committee's recommendations to the Brazilian Government recognise both the harms suffered by Alyne's family and the need for systemic change and are groundbreaking in their specificity to bring about this change. In addition to calling for reparations, including financial compensation, for Alyne's mother and daughter (who was five when her mother died), the Committee

also called for ensuring affordable access to adequate emergency obstetric care; providing adequate training for health workers and imposing sanctions on health professionals who violate women's reproductive rights; ensuring that private healthcare facilities comply with national and international reproductive healthcare standards; and ensuring access to effective remedies for reproductive rights violations.<sup>11</sup>

#### Abortion Jurisprudence

Because abortion is often subject to legal and procedural restrictions, heavily stigmatised and highly timesensitive, violations in the abortion context are frequent. In the process of protecting access to safe and legal abortion, a growing body of jurisprudence is articulating how denial of medical treatment violates fundamental rights and that states are obligated to institute procedural protections to prevent these violations.

#### Denial of Key Medical Services and Information as Cruel, Inhuman and Degrading Treatment

In its groundbreaking 2005 decision, KL v Peru, the Human Rights oversees Committee. which compliance with the International Covenant on Civil and Political Rights, held that denial of a therapeutic abortion violates the right to be free from torture, cruel, inhuman and degrading treatment.12 It noted that Article 7 'relates not only to physical pain but also to mental suffering'13 and that KL's suffering was foreseeable.14 In 2011, the European Court found in RR v Poland<sup>15</sup> that denial of essential medical information in the abortion context can violate the right to be free from cruel, inhuman and degrading treatment. While the decision is not yet final as Poland has appealed to the Grand Chamber, the reasoning in the case is instructive. RR was consistently denied the genetic testing she needed to make an informed decision about whether to terminate her pregnancy and to demonstrate that she qualified for a legal abortion under Poland's highly restrictive abortion law. RR's

doctors denied the testing precisely because they believed RR would use the information to terminate her pregnancy. By the time RR received confirmation of the foetal anomaly, it was too late for her to obtain an abortion. The European Court rejected the Polish Government's claim that RR's doctors were entitled to refuse to provide these services on the grounds of conscience, affirming that states are obligated to organise their health services 'to ensure that an effective exercise of the freedom of conscience of health professionals...does not prevent patients from obtaining access to [legal healthcare] services...'16

In concluding that RR had been subjected to inhuman and degrading treatment, the European Court analysed the relationship between access to reliable medical information and RR's ability to exercise her right to a legal abortion, and the mistreatment RR experienced at the hands of her healthcare providers. The Court noted that it has found violations of Article 3 where authorities showed 'a callous disregard for [the] vulnerability and distress' seeking 'information of crucial importance' to the applicants. 17 recognised Court vulnerability and 'acute anguish' caused by her inability to obtain accurate information about her pregnancy and that the health professionals treating RR did not take into account 'the temporal aspect of the applicant's predicament' or acknowledge or address her concerns. 18 It noted that RR was 'shabbily treated by the doctors dealing with her case' who criticised and belittled for considering terminating the pregnancy and that RR had been 'humiliated.'19

#### Meaningful Procedural Protections and Timely Remedies

Access to abortion is highly timesensitive because of the nature of pregnancy, but there are many situations where medical information and treatment must be provided in a timely fashion to protect a patient's rights and to prevent lasting harm. In those instances, abortion-related jurisprudence affirming the importance of procedural protections and timely remedies could be applicable.

In determining exhaustion of domestic remedies in KL v Peru, the Human Committee noted that Rights meaningful remedies had to be attuned to the time-sensitive nature of terminating a pregnancy and remarked on the absence of an 'administrative remedy which would enable a pregnancy to be terminated on therapeutic grounds, or any judicial remedy functioning with the speed and efficiency required to enable a woman to require the authorities to guarantee her right to lawful abortion within the limited period...'20

Similarly, in Tysiac v Poland, another European Court decision involving the denial of a legal abortion in Poland, the Court emphasised the importance of clearly defined procedures to ensure that healthcare providers can perform abortions without fear of legal penalties and to ensure that redress procedures are in place for women who have been denied an abortion.<sup>21</sup> The European Court recognised the 'chilling effect' that largely criminalising a medical procedure can have on its provision and stated that: 'The provisions regulating the availability of legal abortion should be formulated in such a way to alleviate this effect. Once the legislature decides to allow abortion, it must not structure its legal framework in a way which would limit real possibilities to obtain it.'22 The European Court noted that 'the concepts of lawfulness and the rule of law in a democratic society command that measures affecting fundamental human rights be, in certain cases, subject to some form of procedure before an independent body....'23 In such instances, the procedure should at a minimum provide the pregnant woman with a chance 'to be heard in person and to have her views considered.'24 The relevant body 'should also issue written grounds for its decision.' The importance of these procedural protections are reiterated in *RR v Poland* and in both cases the European Court stated that retrospective measures alone are not sufficient, as by that point, the harm has already occurred.<sup>25</sup>

The cases in this article establish important protections and standards to ensure access to quality and respectful healthcare services in a timely manner.

#### Elisa Slattery is Regional Director of the Africa Program at the Center for Reproductive Rights.

- 1 For examples of reproductive rights violations in health-care settings and how they can constitute torture, or cruel, inhuman or degrading treatment, see: Center for Reproductive Rights, Reproductive Rights Violations as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment: A Critical Human Rights Analysis, 2011, available at <a href="http://reproductiverights">http://reproductiverights</a>. org/sites/-crr.civicactions.net/files/documents/TCIDT.pdf >.
- 2 Ibid.
- 3 For recent developments in litigating forced sterilisation, see P. Nair, 'Litigating against the Forced Sterilization of HIV-Positive Women: Recent Developments in Chile and Namibia', Harvard Human Rights Journal, vol. 23 (2010) available at <a href="http://harvardhrj.com/wp-content/uploads/2010/10/223-232.pdf">http://harvardhrj.com/wp-content/uploads/2010/10/223-232.pdf</a>. See also note 4.
- 4 Preventable maternal deaths are also being litigated at the national level, in India and Uganda, for example. The work of the Human Rights Law Network in India can be found at: <a href="http://hrln.org/hrln/index.php?">http://hrln.org/hrln/index.php?</a> option=com\_content&view=category&layout=blog&id=109&ltemid=197>. For information on the litigation in Uganda, see A. Weseka, 'Activists Storm Court Over Maternal Deaths', The Monitor, 29 May 2011 at <a href="http://allafrica.com/stories/20105300084.html">http://allafrica.com/stories/20105300084.html</a>>.
- **5** Alyne da Silva Pimentel Teixeira v Brazil, CEDAW Committee, Communication No. 17/2008, Views adopted on 25 July 2011. The case was brought on behalf of Alyne's family by the Center for Reproductive Rights and Advocacia Cidadã pelos Direitos Humanos.
- 6 Ibid., para. 3.6.
- 7 Ibid., para. 7.8.
- 8 Ibid., para 7.5.
- 9 See also: Committee on Economic, Social, and Cultural Rights, General Comment 14: *The right to the highest attainable standard of health* (22nd Session, 2000); *Ximenes Lopes v Brazil*, 2006 Inter-Am. Ct. H.R. (ser. C) No. 149,para. 103 (4 July 2006) and *A.S. v Hungary*, CEDAW Committee, Communication No. 4/2004, Views adopted on 14 August 2006, para. 11.5.
- 10 For example of a large percentage of reproductive healthcare services being provided in private facilities, see, Center for Reproductive Rights & Federation of Women Lawyers-Kenya, Failure to Deliver: Violations of Women's Human Rights in Kenyan Health Facilities, 66 (2007), available at < http://reproductiverights.org/sites/crr.civicactions.net/files/documents/pub\_bo\_failu retodeliver.pdf>.
- **11** *Alyne, supra* note 5, paras. 8.1-8.2.
- 12 KL v Peru, Human Rights Committee, Communication No. 1153/2003, CCPR/C/85/D1153/2003, Views adopted on 24 October 2005.
- 13 *Ibid.*, para. 6.3.
- **14** *Ibid*.
- **15** *RR v Poland* (Appl. No. 27617/04, 26 May 2011). For further analysis of abortion-related cases against Poland,

- see Center for Reproductive Rights and Federation for Women and Family Planning, On the Case: R.R. v. Poland, S & T v. Poland, Z v. Poland and Tysiac v. Poland, available at <a href="http://reproductiverights.org/en/rr-v-poland-st-v-poland-z-
- 16 Ibid., para 206.
- 17 Ibid., para. 151.
- 18 Ibid., para. 159.
- 19 *Ibid.*, para. 160.
- 20 KL v Peru, supra note 12, para. 5.2.
- 21 Tysiac v Poland, (Appl. No. 5410/03, 20 March 2007).
- **22** *Ibid.*, para. 116.
- 23 *Ibid.*, para. 117.
- 24 Ibid
- **25** Tysiac v Poland, supra note 21, paras. 124-127 and RR v Poland, supra note 15, para. 114.

Endnotes continued from page 200

- 25 See Amon et al, *supra* note 11, quoting Republic of South Africa, National Health Act, No. 61 of 2003 (2004), s. 7; Republic of South Africa, Regulations Relating to Communicable Diseases and the Notification of Notifiable Medical Conditions, Government Notice No. R2438 (30 October 1987), available at <a href="http://www.doh.gov.za/docs/regulations/1987/reg2438.html">http://www.doh.gov.za/docs/regulations/1987/reg2438.html</a>; and 'South Africa: XDR-TB: Is forced isolation the cure?', *IRIN News*, 14 January 2009. See also AIDS Law Project, *Human rights in the response to TB in South Africa: State and individual responsibilities*, 2009.
- 26 Supra note 11.
- **27** *Ibid.* Nosocomial infection also known as a hospital-acquired infection is an infection whose development is favoured by a hospital environment.
- **28** Even in developed world settings and with developed world facilities the Australian government notes that 'Again, prisons may not have the expertise or time to devote to management of this type of case. Also it is likely that even in prison the person may continue to be a risk, in this case to other inmates. Mechanisms may need to be explored to carry over case management into this setting.' See New South Wales Government Policy Directive, *supra* note 18.
- 29 Section 27 provides: 'Where, in the opinion of the medical officer of health, any person has recently been exposed to the infection, and may be in the incubation stage, of any notifiable infectious disease and is not accommodated in such manner as adequately to guard against the spread of the disease, such person may, on a certificate signed by the medical officer of health, be removed, by order of a magistrate and at the cost of the local authority of the district where such person is found, to a place of isolation and there detained until, in the opinion of the medical officer of health, he is free from infection or able to be discharged without danger to the public health, or until the magistrate cancels the order.'
- **30** See open letter by civil society organisations to the Government of Kenya at <a href="http://kelinkenya.org/wpcontent/uploads/2010/10/Advisory-Note-on-Arrest-of-T">http://kelinkenya.org/wpcontent/uploads/2010/10/Advisory-Note-on-Arrest-of-T</a> B-Patients-in-Kapsabet.pdf>.
- 31 An argument could also be made that the initial arrest and detention of the patients was unlawful under s 28 as an order for their isolation had not yet been made. However, this argument was not made and perhaps is not crucial considering the bigger issues in the case.
- **32** Available at <a href="http://kelinkenya.org/wp-content/uploads/2010/10/Ruling-on-Petition-No.-3-of-2010.pdf">http://kelinkenya.org/wp-content/uploads/2010/10/Ruling-on-Petition-No.-3-of-2010.pdf</a>.
- 33 A reading of the Act implies that it does not since isolation is defined as the 'segregation and the separation from and interdiction of communication with others, of persons who are or are suspected of being infected.' This cannot be read to include detention in gaols unless special measures are put in place to provide TB wards in jails, which would seem a misdirection of resources when civilian hospitals do not have isolation wards.
- 34 Section 17(1).
- **35** Serious concerns with the effect and implementation of this section are beyond the scope of this article.
- 36 KELIN's pro bono Lawyer's interview with client in Nanyuki SPM CR. No 856 OF 2011 Republic v James Kasena.
- **37** The Kenyan Government uses ss 27 and 28 interchangeably and charges patients who fail to take their medicine with exposing the public to the danger of infection.
- **38** There are three courts cases in the Kenyan High Courts of Eldoret, Embu and Meru that are seeking to challenge the arrest and detention of TB patients on the basis of provisions of the Public Health Act and the Penal Code. More information on these cases can be accessed from <a href="https://www.kelinkenya.org">www.kelinkenya.org</a>».

## Harm Reduction and Human Rights

#### Damon Barrett and Patrick Gallahue

'Harm reduction' is a phrase that may be unfamiliar to many in the human rights field. Alone, it is not the most descriptive of terms, and doesn't immediately direct people to its subject matter – drugs. So let us begin with a definition. According to Harm Reduction International:\*

Harm reduction refers to policies, programmes and practices that aim to reduce the harms associated with the use of psychoactive drugs in people unable or unwilling to stop.<sup>1</sup>

This is fairly clear and succinct, but not enough by itself to capture what harm reduction represents or what people have, over the years, come to understand as not just a range of interventions but an ethos and way of working. People in the field, who care less about definition than getting the job done, have long known exactly what harm reduction is about: pragmatism and evidence; social justice and compassion; taking people as they are and dispensing with judgments about how they got there; together with involving people who use drugs or are dependent on drugs in the decisions that affect them.

As such, the brief definition above is backed up with the principles of harm reduction, rooted not just in public health, but in human rights: dignity, universality, transparency, accountability and participation. In addition, in the requirement of a strong evidence base for drug interventions, harm reduction warns against arbitrariness.<sup>2</sup> These are important underlying principles in a field characterised by law enforcement, stigma, political sensitivity, crime, illhealth and widespread misunderstanding.

Harm reduction gathered steam in the

1980s and 1990s in the context of HIV/AIDS as it became clear that an exceedingly efficient way of contracting HIV is to inject drugs with unsterile equipment. Today it is estimated that unsafe injecting contributes to approximately 30 per cent of new HIV infections outside of sub-Saharan Africa, and in some regions and countries this transmission route represents the main driver of HIV (and hepatitis C) epidemics.3 Some of the known harm reduction interventions are therefore aimed at reducing unsafe injecting practices and reducing injecting as a method of consumption. They include needle and syringe programmes (NSPs) and opioid substitution therapy (OST) with, for example, methadone or buprenorphine (both on World Health Organization (WHO) model essential medicines list for this reason).4 These interventions form part of the nine core interventions for HIV prevention among injecting drug users endorsed by WHO, the UN Office on Drugs and Crime (UNODC) and UNAIDS.5 Others, which have proven effective but are more controversial and not included in the nine interventions. include heroin prescription programmes and safe injecting facilities. The core interventions also fail to mention the participation of people who use drugs, a glaring omission from a human rights perspective.

There is, however, far more to harm reduction than HIV prevention, both in terms of the health harms to be mitigated (e.g. overdose, abscesses and co-infections) as well as the social harms associated with drug use and, importantly, drug policies. Central among these harms are the negative effects of contact with the police and the criminal justice system, including

violence, criminal records, incarceration and restrictions on social welfare. From the earliest days, it became more than clear that for drugrelated harms to be addressed, including HIV transmission, drug policy and law enforcement practices would have to change. (It is a central reason why harm reduction has been and remains a flashpoint in national and international drug policy discussions).

In this understanding we again see similarities and convergences between human rights and harm reduction. Just like human rights abuses, drugrelated harms do not occur in a vacuum or solely as a result of individual action. What is now widely known as the 'risk environment' for drug-related harms refers to the laws, structures, polices and actions that surround drug use and health interventions.<sup>6</sup> Punitive drug laws, restrictive policies, abusive policing, stigma and discrimination among many other factors all weigh heavily on risk and harm in relation to drug use. and on the success or failure of harm reduction interventions. 7 As such, the definition of harm reduction set out by Harm Reduction International also makes clear the importance of 'challenging policies and practices that maximise harm'.8

Harm reduction, unfamiliar in name to the human rights field, becomes very familiar in substance.

#### The Right to the Highest Attainable Standard of Health

Readers of this journal may have spotted harm reduction arising in two separate articles in Vol. 15 No. 2 (2005) which focused on HIV/AIDS and human rights. 9 At that time calls for harm reduction interventions from human rights mechanisms were rare.

In its General Comment No. 3 on HIV/AIDS from 2003, for example, the Committee on the Rights of the Child noted that, 'Injecting practices with unsterile equipment further enhances the risk of HIV transmission' and that '[I]n most countries, children have not benefited from pragmatic HIV prevention programmes related to substance use, which even when they do exist have largely been targeted at adults'. 10 The Committee stopped short of spelling out what those pragmatic services might be.

Since then, however, commentaries relating to harm reduction from special procedures and treaty bodies, including the Committee on the Rights of the Child, have developed significantly. These have been most prominent in the context of the right to health.

As noted by Professor Paul Hunt in 2008, while Special Rapporteur on the right to health:

In seeking to reduce drug-related harm, without judgement, and with respect for the inherent dignity of every individual, regardless of lifestyle, harm reduction stands as a clear example of human rights in practice. What began as a health-based intervention in response to HIV must today be recognised as an essential component of the right to the highest attainable standard of health for people who inject drugs.<sup>11</sup>

This comment followed his mission to Sweden in 2006 in which he recommended the national scale up of harm reduction programmes.<sup>12</sup> (It should be noted that no new needle and syringe programmes have begun in Sweden since that visit).

Professor Hunt's views are shared by Anand Grover, the current incumbent of the post, who has looked into issues relating to drugs in country missions, made a series of related recommendations to governments<sup>13</sup> and adopted the issue of drug policies as a thematic report to the UN General Assembly.<sup>14</sup> It contained a detailed section on harm

reduction and called for significant changes to drug laws and policies in order to realise the right to health of people affected by drug dependence and drug-related harms, including that states:

Ensure that all harm-reduction measures (as itemized by UNAIDS) and drug-dependence treatment services, particularly opioid substitution therapy, are available to people who use drugs, in particular those among incarcerated populations.

Decriminalize or de-penalize possession and use of drugs.

Repeal or substantially reform laws and policies inhibiting the delivery of essential health services to drug users, and review law enforcement initiatives around drug control to ensure compliance with human rights obligations.<sup>15</sup>

Manfred Nowak, while Special Rapporteur on torture, looked at harm reduction in the context of prisons, reporting to the UN Human Rights Council on the need for a human rights based approach to drug policy<sup>16</sup> and recommending the introduction of prison OST and NSPs on his mission to Kazakhstan.<sup>17</sup> Prisoners' right to health, of course, has considerable jurisprudential support in the context of freedom from cruel, inhuman or degrading treatment or punishment.<sup>18</sup> This includes preventative health care. In Pantea v Romania, the European Court of Human Rights (the European Court) stated that Article 3 of the European Convention on Human Rights 'compels the authorities...to take the practical preventive measures necessary to protect the physical integrity and the health of persons who have been deprived of their liberty.' In Benediktov v Russia, the European Court found it 'most probable' that the applicant was infected with hepatitis C while in prison. While this in and of itself did not constitute a violation of Article 3, particularly as the prisoner was given effective treatment, the European Court considered it a contributing factor to its finding that the overall conditions of confinement were degrading. In *Kalashnikov v Russia*, the fact that the applicant contracted a series of skin and fungal infections while incarcerated was an element cited by the European Court in finding the State in violation of Article 3.<sup>19</sup>

Following the 2003 General Comment on HIV/AIDS, the Committee on the Rights of the Child (CRC) had remained relatively silent on the issue of drug-related harms. The Convention on the Rights of the Child is the only one of the nine core UN human rights treaties to refer explicitly to drugs (Article 33), but the CRC's Concluding Observations had tended to be general in nature and focused on prevention of drug use and treatment of drug dependence (both certainly vital, especially in relation to children and young people). In 2009, however, the CRC recommended that Sweden provide the 'necessary evidence-based support, recovery and reintegration services to all children affected by substance abuse...aimed at effectively reducing the harmful consequences of such abuse' [emphasis added].20 It was the closest the CRC had come to saving 'harm reduction' since its 2003 General Comment on HIV/AIDS. In 2011, however, in its report on Ukraine, the CRC delivered a detailed set of recommendations including a specific call for youth-focused harm reduction services. The CRC also called for the reform of criminal laws so that children and young people who use drugs are not criminalised.<sup>21</sup>

Some of the most significant progress on harm reduction and the right to health has been in relation to the UN Committee on Economic, Social and Cultural Rights. Prior to 2006 the Committee had never made recommendations on harm reduction in the context of Article 12 of the International Covenant on Economic, Social and Cultural Rights (CESCR). But in 2006 in its Concluding Observations on Tajikistan, the Committee recommended 'that the State party establish time-bound targets for extending the provision of free testing services, free treatment for HIV and harm reduction services to all parts of the country.'2.2

This was followed by similar recommendations on Ukraine in 2007, this time focusing on OST and on prisons.<sup>23</sup> In 2009 the scale up of OST was again recommended, this time in relation to Poland,<sup>24</sup> and again in relation to Kazakhstan in 2010.<sup>25</sup>

In 2010 the Committee released its Concluding most detailed Observations to date on the issue, this time in relation to Mauritius, a country with high per capita rates of opiate use and injecting drug use. The recommendations are worth reading in full as they cover a lot of ground, from youth-focused harm reduction services, to prison needle and syringe programmes, to access to domestic violence shelters for women who use drugs, to the decriminalisation of the OST medication buprenorphine.<sup>26</sup>

Many of these represent the first such recommendations by the CESCR Committee. But the recommendations on Mauritius were novel for another reason. The Committee explicitly brought in Article 15(1)(b) which guarantees the right to benefit from scientific progress and its applications, recognising the scientific backing for harm reduction interventions and the clear relationship between Articles 12 and 15.<sup>27</sup>

The CESCR Committee has since followed this with recommendations on Russia in 2011.<sup>28</sup> Russia has one of the worst injectiondriven HIV epidemics in the world and the Government has for many years refused to adopt OST as a prevention measure. Needle and syringe programmes are barely tolerated and by NGOs entirely run with international support. The Committee criticised this state of affairs and recommended the scale up of the nine core interventions as set out by WHO, UNODC and UNAIDS and referred to above.<sup>29</sup> This was the first mention of these guidelines by a human rights treaty body. Another novelty was the Committee's first reference to overdose prevention.

As such, from the last five years of Concluding Observations of the Committee on Economic Social and Cultural Rights, we now have a better idea of the requirements of Article 12 of the CESCR as it relates to drug use and harm reduction. Where injecting drug use and/or opiate use are identified, Article 12 requires, at the least:

- Needle and syringe programmes (Mauritius 2010, Russia 2011)
- Opioid substitution therapy (Tajikistan 2006, Ukraine 2007, Poland 2009, Kazakhstan 2010, Mauritius 2010, Russia 2011)
- Overdose prevention (Russia 2011)
- Youth-focused harm reduction services (Mauritius 2010)
- Specific protections for women at risk (Mauritius 2010)
- Prison OST and NSPs (Ukraine 2007 and Mauritius 2010 respectively)
- Law reform to facilitate harm reduction (Mauritius 2010, Russia 2011)

#### Harm Reduction, HIV and Progressive Realisation to the Maximum of Available Resources

The recognition of harm reduction as a component of the right to health for people who use drugs is an important and recent development, but, of course, not enough. Despite the overwhelming evidence in favour of harm reduction as an effective HIV prevention strategy, the global state of harm reduction is poor. This is especially true in countries where these services are needed most urgently.

According to research by Harm Reduction International in 2010 (currently being updated for 2012),30 there are at least 76 countries where injecting drug use has been documented and where no harm reduction services are available, several

of which are discussed below.

In many countries where they do exist, needle and syringe programmes are run entirely by NGOs with, at best, grudging acceptance by the government (e.g. Russia), and, even though they are legal, are targeted by police. Coverage levels sufficient to avert or reverse HIV epidemics have thus far only been implemented in parts of Western Europe, Australia and New Zealand.

In the region of South-East Asia, only 3 per cent of people who inject drugs have access to harm reduction programs. In East Asia, this figure is 8 per cent. Needle and syringe programmes and OST sites are currently limited to pilot programmes in the majority of countries, reaching very small numbers.

Central and Eastern Europe and Central Asia witnessed the fastest growing HIV epidemics in the world. As a response to rapidly expanding HIV epidemics, almost all states in the region have needle and syringe programmes, and the majority of states (23 of 29) prescribe OST for drug dependence. Russia, however, is home to around two million people who inject drugs, but the use of OST is still prohibited, and will remain so until at least 2020 according to Government policy.<sup>31</sup>

While injecting is rare in the Caribbean, recent research highlights a link between non-injecting drug use and sexual HIV transmission in several Caribbean countries, with HIV prevalence estimates among crack cocaine smoking populations reaching those found among injecting populations elsewhere. This linkage is not being adequately addressed and national drug and HIV policies remain largely unrelated in the region.

In Latin America, needle and syringe programmes are available in five countries, although the vast majority operate in Brazil and Argentina. Mexico, with substantially more heroin users than other Latin American countries, is the only state which

prescribes OST, although coverage is low.

In the Middle East and North Africa, six countries, including Iran, have needle and syringe programmes and three have OST, although none have responses sufficient to meet identified need. Across the region there is a low awareness of risks associated with injecting drug use. Few NGOs are working on harm reduction in the region, and in several countries restrictions on NGOs further limit the harm reduction response from civil society.

Although data on drug use in the region are limited, injecting has been reported in 31 of 47 sub-Saharan African states. Where data are available, they suggest high HIV prevalence among people who inject drugs. A Kenyan study, for example, found that six of every seven female injectors were living with HIV. Responses to HIV in the region currently include little focus on people who inject drugs. Mauritius, where an estimated 17,000-18,000 people inject drugs, is the only country where needle and syringe programs are operating.

It should be noted with some concern, that in international political forums, harm reduction has been weakened in the past year. At the General Assembly in the context of the 2011 political declaration on HIV/AIDS, harm reduction, previously seen as an obligation in declarations of 2001 and 2006, was relegated to an optional consideration.<sup>32</sup> This is largely as a result of the weakening of the European Union on the issue, the unwillingness of many countries to expend political capital arguing about it and the staunch views of a handful of countries opposed to harm reduction. These include Russia, Iran, Egypt and the Holy See.

Funding for harm reduction is very low globally and is neither representative of what is needed to address the HIV epidemic among injecting drug users, nor proportionate to injection-driven HIV transmission versus sexual transmission. Harm Reduction International estimates that just three US cents per day per injector is spent on HIV prevention in low and middle income countries.33

One of the most positive developments of recent years, however, has been the change in position of the US Government. From opposing and blocking resolutions at the UN Commission on Narcotic Drugs that referred to HIV prevention for injecting drug users and to human rights, the US has begun cosponsoring them. Even more importantly the US has lifted the ban on federal funding for needle and syringe programmes. At the time of writing, however, the President's Emergency Plan for AIDS Relief (PEPFAR) has yet to purchase any needles. That money, from the world's largest donor to HIV/AIDS, would go a long way to improving the scale-up of harm reduction where it is most needed and realising the right to health of those affected.34

With this in mind, it is important to note that global funding for health-based interventions related to drug use is vastly outstripped by the tens of billions of dollars spent annually on police, courts, prisons and military actions as part of law enforcement and other counter-narcotics initiatives. And it is in this context that many human rights abuses against people who use drugs and others are committed.

# Human Rights Abuses Against People Who Use Drugs in the Context of Health Care

# Criminal Laws and Policing

In almost every country in the world, possession of drugs for personal consumption is a crime. In many, drug use itself is a crime.<sup>35</sup> The implications for those who have a dependency – a chronic, relapsing medical condition – are particularly serious. Individuals have a right to obtain lifesaving health services without fear of punishment or discrimination. In some countries, many people who inject drugs do not carry sterile syringes or other injecting

equipment, even though it is legal to do so, because possession of such equipment can mark an individual as a drug user and expose him or her to punishment on other grounds.<sup>36</sup> Many do not seek treatment or attend harm reduction services, again, for fear of arrest and conviction.<sup>37</sup>

Appropriate, human rights compliant policing is essential for effective drug policies and positive health outcomes for drug users. Unfortunately, in country after country, the experience is often the opposite, partly due to the poor laws being enforced and partly due to policing practices. In many places, police target drug users and harm reduction services, seeing easy opportunities to harass, entrap and extort clients – or simply to fill arrest targets.<sup>38</sup>

Police presence at or near harm reduction programmes drives people away from these services due to fear of arrest or other punishment. In Ukraine, for example, drug users have reported being arrested multiple times at legal needle exchange sites. 39 Individuals have been severely beaten for possessing syringes at or near needle exchange points. 40 Withdrawal has been used as a means to extract evidence or to extort money once detained. 41

In Georgia, drug crackdowns in 2007 resulted in 4 per cent of the country's male population being tested for drugs, many under forced conditions. Thirty-five per cent of these went on to be imprisoned on a drug-related charge. 42

In Thailand, the 2003 'war on drugs' that resulted in more than 2,300 extrajudicial killings has had a lasting impact on drug users' access to fundamental health care services. 43 Studies reported a significant decline in the number of people seeking treatment for drug use during the 'war on drugs,' and also reported that a significant percentage of people who had formerly attended drug treatment centres went into hiding. 44 Years later, many people who use drugs still

refrained from seeking treatment at public hospitals for fear that their drug use (past or current) would be shared with police. This fear is not unfounded. Public hospitals and drug treatment centres collect and share information about individuals' drug use with law enforcement, both as a matter of policy and in practice.

# Drug User Registries

Once they come to the attention of health services, drug users in many countries are added to 'registries' where their status as a drug user may be made known to others. Drug user registration serves as a form of state control over people who are dependent on drugs and imposes restrictions on their rights. The process brands people as drug users for years, sometimes indefinitely, regardless of whether they have ceased using drugs. In China, for example, methadone treatment patients are added to government registries linked to their identification documents and accessible to the police.45 In Thailand, once registered, drug users remain under surveillance by police and anti-drug agencies, and information about patient drug use is shared.46 Fear of registry discourages individuals from accessing care, even though it is free. In Russia, people who enrol in public drug treatment programmes are added to registries (those who can afford to seek private drug treatment are not).47 Being listed on the registry can lead to loss of employment, housing and even child custody.48 Faced with consequences, many people don't see public drug treatment as a viable option.

### Prison Health Care

According to the International Centre for Prison Studies there are more than 10.1 million people held in penal institutions throughout the world.<sup>49</sup> In many environments drug offenders make up the majority of people incarcerated.<sup>50</sup> Many of these, in turn, are drug dependent.

The WHO writes that prisons are places where, 'Two of the greatest public health problems facing all

societies overlap: the epidemic of HIV/AIDS and the pandemic harmful use of psychotropic substances such as alcohol and illegal drugs.'<sup>51</sup> In closed settings where there is a risk that prisoners will share paraphernalia such as needles this intersection can be a major driver of high rates of blood-borne diseases, such as HIV and hepatitis C, among prisoners who inject drugs. Infections in prisons and places of detention may be significantly higher than the general population and can spread with alarming speed.<sup>52</sup>

All health personnel working with prisoners 'have a duty to provide them with...treatment of disease of the same quality and standard as is afforded to those who are not imprisoned or detained', according to the UN Principles of Medical Ethics.<sup>53</sup> The principle that people deprived of their liberty have the right to the highest attainable standard of health is articulated within mechanisms overseeing the implementation of economic, social and cultural rights as well as civil and political rights.

The Human Rights Committee, for example, has raised concerns over the well-being of prisoners under the right to life (Article 6) or the right to humane treatment (Article 10).54 Both of these rights impose positive obligations on state parties to protect the lives and/or well-being of people in custody.55

State failure to implement measures that protect people from blood-borne viruses, bacterial infections and overdose – such as a harm reduction measures including needle/syringe programs and opioid substitution therapy – violates their obligations in international human rights law. Despite this, and despite the sheer numbers of people who use drugs incarcerated globally, evidence-based harm reduction services in prisons are severely lacking.

Effective treatment and medically assisted detoxification are also lacking. The UN Special Rapporteur on Torture

and Other Cruel, Inhuman or Degrading Treatment and Punishment found that, '[W]ithdrawal symptoms can cause severe pain and suffering if not alleviated appropriate medical treatment' and that 'denial of medical treatment and/or absence of access to medical care in custodial situations may constitute cruel, inhuman degrading treatment or punishment and is therefore prohibited under international human rights law.'56

Indeed, prisoners are entitled to timely medical attention and appropriate monitoring of medical conditions as found in multiple cases at the European Court of Human Rights and the UN Human Rights Committee, and supported by international prison standards.57 That this applies to withdrawal was clear from McGlinchy & Ors v United Kingdom. In that case the withdrawal was being appropriately treated, but a deterioration in McGlinchy's health over a period of days was not appropriately responded to, resulting in her death and a violation of Article 3.58

# **Drug Detention Centres**

In many environments drug users are forced into compulsory treatment centres. While the conditions in these centres vary, it is clear that patients have no right to choose their treatment or have input into their treatment plans, contrary to an ethical requirement which improves treatment outcomes, according to UNODC.59 WHO and Drugdependence treatment is a form of medical care and the quality of care in these centres does not meet the standards as other forms of health care. As such, human rights advocates now refuse to apply the term 'treatment' to them, focusing instead on the reality of detention and abuse.

Though practices vary, in many countries once drug dependence has been established – through very questionable methods – 'treatment' orders can be made that can last months or even years. 60 In many environments this comes with weak or

non-existent judicial review or any opportunities to challenge the detention, raising considerable concerns with respect to due process protections and arbitrary detention.

Treatment centres are often run by the military or security services with little or no training in health care. Severe beatings, sexual violence and other forms of torture have been documented as well as widespread forced labour. 63

In Cambodia where Human Rights Watch documented sexual assaults, people being shocked with electric batons and beaten with twisted electrical wire, nearly one-quarter of detainees in government treatment centres were under 18-years-old. 64 In another 'treatment centre' in Laos that was lined with razor wire fences and guards to prevent escapes -Human Rights Watch noted that the facility served as a 'dumping ground' for the homeless, street children and people with mental disabilities. 65 In Vietnam, where tens of thousands of drug users are held in detention at any one time, people were forced to work under threat of violence or isolation. 66 Even those who entered voluntarily for treatment were not allowed to leave sometimes for years.<sup>67</sup>

# Corporal Punishment

Judicial corporal punishment - the state-sanctioned beating, caning or whipping of a person for drug use, purchase or possession - represents everything harm reduction opposes.<sup>68</sup> It is a cruel and inhuman punishment and is absolutely prohibited in international law. 69 Despite this fact, institutionalised, state-sanctioned, violence is commonly applied to drug and alcohol offences. Whipping, flogging or caning is often carried out in public to escalate feelings of shame and humiliation. It is intentional degradation. Aside from the physical damage, the result can be long-lasting psychological trauma for those punished in this manner.<sup>70</sup>

Harm Reduction International has produced a study of the legal basis for

judicial corporal punishment for drug and alcohol offences in twelve jurisdictions. In relation to drug and alcohol offences, including those for consumption and for relapse from treatment, corporal punishment is prescribed in some jurisdictions as either a main punishment or in addition to imprisonment. Judicial corporal punishment for drugs and alcohol offences is applied in both secular and religious states.<sup>71</sup>

By definition, harm reduction centres on reducing the harms associated with drugs and their use. It requires engaging drug users in order to understand their needs for their health and for the general well-being of their families, communities and society. However, it can only function if people are not fearful of suffering negative consequences or outright abuse; if people are not frightened of being whipped or caned, forced into detention against their will, subject to forced labour, placed on registries that can negatively impact their own wellbeing and that of their families, or suffer from extortion or other abuses by those in power. These practices serve as structural barriers to engaging with people who use drugs, to providing services that will promote their health and well-being and benefit society at large, and to realising their right to health.

### Conclusion

Harm reduction has over two decades of scientific evidence supporting it. But evidence has never been enough. Human rights support for harm reduction is newer and still developing. But it is an important development, engaging international law and new mechanisms, and involving new partners and ways of advocating for those interventions that are known to work best.

Drug policies should be seen as a thematic issue in human rights discourse. It is a surprise that they still are not. But as the issues above and others are focused on more and more it is in increasingly likely that this will happen. People who use drugs do not forfeit their right to health, life, privacy or humane treatment nor does the presence of drugs in society serve as a legitimate exception to a state's obligation to respect citizens' freedom from arbitrary detention and other abuses. This has been made explicit by international bodies entrusted with the implementation of human rights treaties. The jurisprudence and scholarship around the human rights dimensions of harm reduction will be a critical component in understanding not just what works to protect people and society from drug-related harms, but what is appropriate and necessary in a democratic society to achieve this legitimate aim.

# Damon Barrett is Senior Analyst: Human Rights and Patrick Gallahue is Human Rights Analyst at Harm Reduction International.

- \* Formerly the International Harm Reduction Association.
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- 19 Ibid. pp 25 & 26. Pantea v Romania (2005) 40 EHRR 26 para. 189; Benediktov v Russia Application No. 106/02 (judgment of 10 May 2007) para. 40; Kalashnikov v Russia (2003) 36 EHRR 34, para. 98.
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- **21** Committee on the Rights of the Child, *Concluding Observations: Ukraine*, UN Doc No CRC/C/UKR/CO/3-4, 21 April 2011, para. 61(a).
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- **25** UN Committee on Economic, Social and Cultural Rights, *Concluding Observations: Kazakhstan*, UN Doc No E/C.12/KAZ/CO/1, 21 May 2010, para. 34.
- **26** UN Committee on Economic, Social and Cultural Rights, *Concluding Observations: Mauritius,* UN Doc No E/C.12/MUS/CO/4, 8 June 2010, paras 27 & 28.
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- **28** UN Committee on Economic, Social and Cultural Rights, *Concluding Observations: Russia*, UN Doc No E/C.12/RUS/CO/5, 20 May 2011.
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- **52** WHO, UNODC & UNAIDS, Effectiveness of interventions to address HIV in prisons, 2007.
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- 69 See for example: UN Human Rights Committee General Comment no. 20, Prohibition of torture or cruel, inhuman or degrading treatment or punishment, 10 March 1992, para. 5; UN Human Rights Committee Concluding Observations: Sudan, UN Doc No CCPR/C/79/Add.85, 5 November 1997, para. 9; UN Human Rights Committee George Osbourne v Jamaica, UN Doc No CCPR/C/68/D/759/1997, 13 April 2000, para. 9.1. This jurisprudence has been further expanded in Higginson v Jamaica, 792/1998; Sooklal v Trinidad and Tobago, 928/2000; and Errol Pryce v Jamaica, 793/1998; UN Human Rights Committee Concluding Observations: Iraq, UN Doc No CCPR/C/79/Add.84,19 November 1997, para. 12; UN Human Rights Committee Concluding Observations: Sudan, UN Doc No CCPR/C/79/Add.85, 19 November 1997, para. 9; UN Committee against Torture Concluding Observations: Namibia, UN Doc No A/52/44, 6 May 1997, para. 250; UN Commission on Human Rights, Report of the Special Rapporteur on Torture, UN Doc No E/CN.4/1997/7, 10 January 1997, para. 6; UN General Assembly Report of the Special Rapporteur on Torture, UN Doc No A/60/316, 2005, paras. 19, 26, 28; UN Human Rights Council Report of the Special Rapporteur on Torture, A/HRC/13/39, 2010, para. 63.
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# Forcible Isolation of Tuberculosis Patients in Kenyan Jails Solomon Sacco, Allan Maleche and Omwanza Ombati

Drug-resistant tuberculosis (DRTB)1 constitutes a serious challenge to health systems across the world, but particularly so in Africa with high levels of HIV infection and low levels of state spending on health. TB is highly infectious and the failure to adhere to treatment regimens is a prime cause of the development of DRTB. In many states public health authorities may apply to a court, or act on their own authority, for the isolation of patients with highly infectious and drug-resistant strains of TB. While such detention should and usually does take place in hospitals, in some countries, including Kenya, patients are detained in prisons. States have a legitimate interest in ensuring that individuals with DRTB take their medicines correctly and take the necessary precautions not to spread the disease. However, when they develop a public health policy they have to take into account the rights of the individual to liberty and freedom of movement and balance this against the legitimate governmental interest in maintaining public health. This article will examine this balance under international law as well as in a number of selected countries. We will also identify particular problems in the legal response to the problem in Kenya.

# Rights Engaged by the Coercive Detention of TB Patients

The rights to liberty and freedom of movement are protected by Articles 9 and 12 of the International Covenant on Civil and Political Rights (the ICCPR) and Articles 6 and 12 of the African Charter on Human and Peoples' Rights (the African Charter) – both treaties have been ratified by Kenya. The Kenyan Constitution protects the right to liberty (or freedom as it is termed) in Article 29, freedom

of movement in Article 39 and the right to human dignity at Article 28. The Kenyan Constitution 2010 also provides that every person has the right to the highest attainable standard of health, which includes the right to healthcare services. However, it should be noted that the African Charter, the ICCPR and the Constitution of Kenya all allow limitations on most of the rights protected therein, including on the rights to liberty and freedom of movement. 3

The extent of limitations is closely circumscribed by international law. The basic principles guiding a consideration of whether a limitation on the basis of public health is legitimate are whether it is:

- strictly provided by the law...;
- neither arbitrary nor discriminatory;
- based on objective considerations;
- necessary to respond to a pressing public health need (such as the prevention of TB transmission and the development of the disease following infection);
- proportional to the social aim;
- no more restrictive than necessary to achieve the intended purpose;
- •...(and) of limited duration and subject to review.4

Protection of public health is an important government interest on which the state is entitled, within certain limits, to rely when limiting rights. Thus s 25 of the Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights states that:

Public health may be invoked as a ground for limiting certain rights in

order to allow a state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured (Emphasis added).

Commenting on the general principle of the necessity of detention the European Court of Human Rights (the European Court) has noted that:

The detention of an individual is such a serious measure that it is only justified where other, less severe measures have been considered and found to be insufficient to safeguard the individual or the public interest which might require that the person concerned be detained. That means that it does not suffice that the deprivation of liberty is in conformity with national law, it must also be necessary in the circumstances and in accordance with the principle of proportionality.<sup>5</sup>

The European Court has gone on to elaborate on the specific test regarding detention for the prevention of the spreading of an infectious disease:

The essential criteria when assessing the "lawfulness" of the detention of a person "for the prevention of the spreading of infectious diseases" are whether the spreading of the infectious disease is dangerous to public health or safety, and whether detention of the person infected is the last resort in order to prevent the spreading of the disease, because less severe measures have been considered and found to be insufficient to safeguard the public interest. <sup>6</sup>

For the purposes of this paper it will be accepted that control of persons infected with DRTB is directed towards

the legitimate objective of controlling the spread of highly infectious, difficult to treat and fatal diseases.<sup>7</sup> The question will be whether the procedure utilised to ensure forcible isolation of persons infected with DRTB is necessary and a proportionate limitation of the rights to liberty and freedom of movement in Kenya and whether the limitation includes sufficient safeguards to prevent abuse.

# WHO Standards on Coercive Isolation of TB Carriers Only as a Last Resort

While the World Health Organization (WHO) advises that XDRTB patients should be isolated until they are no longer contagious, 8 it has also established guidelines on treatment of DRTB that emphasise that coercive isolation and detention must only be used as a last resort where other methods of treatment and control have failed.9 The WHO notes that treatment at home is usually perfectly safe and that well-counselled patients are unlikely to seriously deviate from their treatment regimes. The WHO thus recommends that:

...community-based care should always be considered before isolation or detention is contemplated. Countries and TB programmes should put in place services and support structures to ensure that community-based care is as widely available as possible.<sup>10</sup>

Indeed it has been shown that community-based care will in most circumstances be the appropriate method of treatment for all forms of TB:

Ambulatory and community-based treatment models for MDR- and XDR-TB have been successfully implemented in a number of settings— ranging from Lesotho to Latvia, Estonia, Georgia, Peru, the Philippines, Nepal, and the Russian Federation— without having to resort to extraordinary measures that infringe on a patient's human rights.<sup>11</sup>

In most circumstances home-based care would be the least restrictive and most effective measure and therefore forced isolation would be inappropriate (neither necessary nor proportionate). The WHO does, however, accept that in certain very limited circumstances it may be necessary to forcibly isolate TB patients<sup>12</sup> and sets out the following as circumstances in which isolation and detention of TB sufferers can be considered an appropriate public health response:

Isolation or detention should be limited to exceptional circumstances when an individual:

- is known to be contagious, refuses treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful;
- is known to be contagious, has agreed to ambulatory treatment, but lacks the capacity to institute infection control in the home;
- is highly likely to be contagious (based on symptoms and evidence of epidemiological risk factors) but refuses to undergo assessment of his/her infectious status.<sup>13</sup>

The first scenario, where a TB patient refuses treatment, is the appropriate one for consideration within the scope of the Kenyan situation. Where TB patients have refused to adhere to treatment regimens it may be acceptable to isolate them. However, this would not be appropriate under the WHO guidelines if other less invasive efforts have not been tried. The first would necessarily include counselling and attempts community-based care (see below particularly with respect to the experience in Australia). The WHO's guidance on ethics also notes that before a detention order is made the patient should be warned that his behaviour might necessitate detention.14

Even where the detention of TB patients is considered necessary the WHO advises that it should only happen if health authorities:

can ensure it is done in a transparent and accountable manner. If it can be

through evidence-based proved. analysis, that forced isolation is temporarily required, patients must be provided with the high-quality care that includes, among other rights, free access to secondline drugs, laboratory support including effective DST and social support, and be treated with respect and dignity. Patients should be informed clearly, in their language, of the decision and its details, and of their rights and responsibilities, as outlined in the Patients' Charter, accompanied by a peer supporter and/or family member.15

# Comparative Responses to TB Isolation

In the United Kingdom (UK) the legislature allows the local authority to apply to a justice of the peace (a lay magistrate with legal advice) for an order allowing the forced isolation of persons suffering from notifiable diseases, which include TB patients. This power is contained in ss 37 and 38 of the Public Health (Control of Disease) Act 1984. The powers granted to the justice of the peace allow him to make the determination that an infectious person be taken to a hospital ex parte. However, the powers are restricted to situations where other precautions to prevent infection cannot be taken, or are not being taken, where there is a serious risk of infection to other persons, and there is accommodation available in an appropriate hospital. The justice of the peace may also order, again ex parte, that a person suffering from TB be continued to be detained in hospital if he/she is satisfied that his/her accommodation outside the hospital would not be conducive to preventing the spread of the infectious disease. This order may be repeatedly extended by any appropriate justice of the peace. A person who breaches such an order may be subjected to a fine and returned to the hospital but may not be subjected to a term of imprisonment under the terms of the section.

There are a number of positive aspects of this legal regime: the order is made by a magistrates' court on application

(ensuring judicial oversight), a removal order can only be made where alternative arrangements are not available or are not being implemented and there is appropriate accommodation in a hospital. Importantly, there is no power to detain or imprison the patient in prisons, whether as part of the preventive order or as a punishment for failing to abide by a removal or detention order. A number of criticisms can be made however regarding the ex parte power, which allows the justice of the peace to make an order without hearing the TB patient's side of the story, the power to indefinitely extend the detention orders and the absence of automatic reviews of the order (the infectious stage of TB may be over before the period of detention is completed).<sup>16</sup> The excessive discretion granted to the justice of the peace and the local authority mean that TB patients who are no longer highly contagious may be detained for fear that they become highly contagious in the future.

In the Australian state of New South Wales<sup>17</sup> s 23 of the Public Health Act 1991 (NSW) allows an authorised medical practitioner to issue a detention order for up to 28 days if an individual suffering from a notifiable disease such as TB is acting in ways that endanger public health. An application can be made to a specialist court to extend the detention period for up to six months. In exact terms the section allows the medical practitioner to order the patient to 'undergo specified treatment and be detained at a specified place while undergoing the treatment.' This implies that treatment is an inherent aspect of the order and simple detention without treatment would be unlawful. While the legislation itself is silent on the nature of the detention, the government policy is for detention in a hospital when these powers are exercised.<sup>18</sup> The Act and policy both make the distinction between detention (which would be in a hospital) and imprisonment after conviction of a criminal offence, which could include violating a public health order (which would be in prison).

While the Act allows an authorised medical practitioner to issue the initial public health order, in practice these decisions are made by a panel that is comprised of the Medical Officer of Health (a statutory position whose purpose is to enforce the Public Health Act), the Chairman of the NSW TB Advisory Committee, the Statewide Coordinator of TB Services, a physician, social worker or counsellor, and a representative of the patient's community or peer group. There are other important safeguards contained in the Act and the state policy. Section 23(3A)(b) of the Act provides that detention may only be permitted 'if it is the only effective way to ensure that the health of the public is not endangered or likely to endangered.'

While there is no automatic review of a detention order for TB patients the Act does allow an application to the specified court. This is not ideal as it depends on the patient accessing competent legal representation within the 28 days. However, the more important protections are in the policy directives which state that detention:

should be used as a last resort and only be exercised on the following criteria:

- the person has in the past wilfully or knowingly behaved in such a way as to expose others to the risk of infection,
- the person is likely to continue such behaviour in the future,
- the person has been counselled but without success in achieving appropriate and responsible behavioural change.

In addition, the policy guidelines specifically state that, 'The first steps in the management of a person with active, untreated infectious TB thought to be knowingly running the risk of infecting others are counselling, education and support.' This must be thorough and include psychosocial evaluation and support, official warnings that behaviour could lead to

detention, and material and social support (housing assistance, homebased care, emotional support etc). If this fails, limited orders restricting the movement of the patients will be tried until detention is truly tried as a last resort. Partly as a result of the procedure adopted in New South Wales, and partly no doubt as a result of the fact that XDRTB and MDRTB are not as common in New South Wales as in say South Africa or Kenya, there were a total of ten patients coercively detained between 1999 and 2004.

In the United States (US), 'Section 361 of the Public Health Service Act authorizes the Department of Health and Human Services...to apprehend, detain, and forcibly examine persons to prevent certain communicable diseases...from entering the country or travelling across state lines.' States also have the power to detain and isolate individuals under their general police powers and public health legislation. However:

patients who are isolated by law have many procedural due-process rights, including the right to counsel and a hearing before an independent decision maker. States must also provide "clear and convincing" evidence that isolation is necessary to prevent a significant risk of harm to others. Most important, some courts have held that isolation must be the least restrictive alternative for preventing such a risk. If the government can protect public health without relying on involuntary detention, it must and should do so.<sup>20</sup>

US law is not clear on all aspects of the process and one aspect that is still unclear is a crucial one:

...courts have not explained what must be shown to conclude that a patient is noncompliant so that detention is the least restrictive alternative. In tuberculosis cases, courts have upheld detention when a patient has failed...to follow medical advice. But they have not considered how forcefully that advice must be given or what, if anything, the government has to do to facilitate compliance.<sup>21</sup>

Another concern in the US has been the lack of an automatic review system. Unless a patient decides to ask for a court hearing the detention order will be implemented without judicial oversight. Where deprivation of liberty of the most vulnerable is concerned it is important that there be an automatic review of the decision.<sup>22</sup> Of more concern is the fact that in California as late as 1999 TB patients were being tried and detained in prisons.<sup>23</sup>

In Ireland s 38 of the Public Health Act of 1947, as amended, allows two authorised medical practitioners to order the detention of TB patients if 'such person is a probable source of infection with an infectious disease and that his isolation is necessary as a safeguard against the spread of infection, and that such person cannot be effectively isolated in his home.' The section allows an appeal to the Minster of Health and Article 40.4.2 of the Irish Constitution entitles all persons in detention to apply at any time to the High Court for a review of their detention. Section 38 has serious gaps in that it allows medical personnel, without court supervision, to order detention, there is no automatic and periodic review of the detention and there is no statutory provision of legal aid. However the High Court has upheld s 38, despite criticising it for a lack of internal safeguards and the manner in which the particular case was managed by the medical staff, based on presumption of constitutionality, holding that the hospital and medical practitioners in charge should have developed a rights-based plan to ensure that the patient's case was reviewed periodically (both in terms of the legality of her detention and her continued infectiousness).<sup>24</sup> The judge also emphasised other methods of enforcing the patient's rights, which in this case included the ability to petition the High Court under Article 20.4.2 of the Constitution. Therefore, although it is desirable that safeguards

be contained in legislation (and it can be argued that the judge in this case was excessively deferential to the legislature) the decisive question will be whether they exist at all, whether in legislation, policy or administrative action.

In South Africa 'authorities may detain an individual suffering from an infectious disease until the disease ceases to present a public health risk; draft government policy guidelines call for the isolation of all MDR- and XDR-TB patients in a specialist facility for a minimum of six months.'25Unlike in the UK, US and Australia, where isolation is utilised as a last resort and modern and up-to-date where treatment is available, thousands of patients in South Africa are detained in specialised TB hospitals, where many die:

(I)ndividuals with drug-resistant TB (are isolated) for as long as two years, often in conditions closely resembling prisons. In other locations, XDR-TB patients are discharged after six months to "make room for new patients." In both cases, no assessment of infectiousness is made, and throughout their confinement, most patients do not have access to many second-line drugs, resulting in almost universal mortality. In March 2009, the AIDS Law Project reported that approximately 1,700 people, including children, were then detained in TB isolation facilities, many of them in substandard conditions that violated South African constitutional rights and national health legislation.<sup>26</sup>

Importantly, many of the safeguards guaranteed under international law are ignored under South African legislation: the determination to forcibly isolate a patient is made by a health official, who is not required to consider whether less intrusive methods would be more appropriate; there are insufficient procedures to allow judicial review of the decision to detain (there is no automatic review and access to legal representation is limited); most people forcibly isolated are not refusing to take treatment

(meaning that isolation is not necessary to ensure compliance); most are only isolated fourteen weeks after first being tested (allowing them to spread the disease before they are isolated) and the process discriminatory as it only applies to individuals accessing the public health system since patients who can afford private doctors are treated at home. In addition, when considering whether the limitation is proportionate, a determining factor may be that, 'public health experts note that holding MDRand XDR-TB patients in overcrowded hospitals with inadequate ventilation increases the risk of nosocomial disease transmission and crossinfection.'27 In these circumstances it would be difficult to defend the South African programme of detaining TB patients in overcrowded hospitals as a legitimate limitation to the right to liberty under the South African Constitution and international and regional human rights law.

# General Principles From International Practice

The comparison of various approaches towards coercive isolation for patients with MDRTB indicates that there are some basic conditions for the legality of the process. Coercive isolation must always be a last resort after other measures, such as directly observed therapy, have been attempted. Social support, including economic assistance and counselling, should be provided to patients who should be warned of the possible ramifications of default before any action is taken. The process itself must ensure protection of fair trial rights with either administrative or judicial supervision of the decision to detain and on-going review of the detention. Finally patients should be detained in hospitals or other facilities for their treatment and not in open prison with convicted criminals. While not all these principles are fully met in each of the countries studied, the procedure adopted in each country, including to some extent South Africa, demonstrates an attempt to balance the rights of the individual patient with the legitimate state interest of preventing the spread of MDRTB. Below we look at whether legislation and practice in Kenya has made a similar attempt.

# Detention of Patients with DRTB in Kenya

In Kenya there are two key legislative provisions that relate to the detention or imprisonment of persons with TB: ss 27 and 28 of the Public Health Act (the Act). Under s 28 TB patients who deliberately risk the infection of other persons may be convicted of a crime. A thorough analysis of the legitimacy of this provision is beyond the scope of this article except to note that imprisonment of such persons would most likely breach WHO guidelines against detaining persons as a punishment, leaving aside that it makes no sense from a public health perspective as detention in prisons almost inevitably increases the rate of infection in prisons.<sup>28</sup>

Section 27<sup>29</sup> has been used by the Kenyan Government to imprison TB patients who have failed to comply with treatment regimens for whatever reason in police and prison cells. In one case three TB patients were arrested on 12 August 2010 and held in police cells. The next day one was very ill and was removed to hospital while the other two were brought before a magistrate who, on the application of the public health officer, ordered that they be confined in prison for eight months.<sup>30</sup>

The patients, with the assistance of the Kenyan NGOs KELIN, AIDS Law Project and NEPHAK, and public interest lawyers and INTERIGHTS, challenged their detention as a violation of the Kenyan Constitution's protection of the rights to freedom of movement and personal liberty, primarily on the basis that detention in overcrowded prisons for a period of months was 'excessive. unreasonable and even arbitrary.' Even though preventing transmission of DRTB is a legitimate aim, the action taken was not proportionate to the goal. This was for a number of reasons including that the patients were detained for a long period in open prison in conditions that would exacerbate their condition and where they were likely to further spread the disease to immune-compromised prisoners. There was no information regarding the contagion level of the patients; whether they had DRTB or not, which is important because it is not necessary to detain patients who do not have DRTB; whether alternative methods of ensuring compliance had been attempted (including directly observed therapy and communitybased care and economic and social support) and what medical facilities were available in prison.<sup>31</sup> On 29 September 2010 the High Court ordered that the patients be released and be treated at home.32 However, the constitutional questions remain for determination, including the crucial one of whether s 27 of the Act empowers the magistrates' court to order 'isolation' in a prison.33

There are a number of other arguments that could be raised with regard to s 27. While the power to isolate person with notifiable infectious diseases is an important one the section gives too much discretion to the public health officer and to the magistrates and there is insufficient guidance on when a person with an infectious disease should be isolated. It is also questionable whether the powers in s 27 are necessary and nonarbitrary, first because the power is not restricted to the most dangerous infectious diseases. All forms of TB are covered: the Public Health Act defines notifiable diseases to include 'all forms of tuberculosis which are clinically recognizable apart from reaction to the tuberculin test.'34 This would mean that a patient with TB that is not drug resistant and therefore who is not a public health threat could be detained under the authority of the section. This is both unnecessary and arbitrary. In addition there already exist powers under s 26 of the Act to detain patients in hospitals and criminal sanctions (including imprisonment) under s 28 for wilfully exposing the public to the

chance of infection.<sup>35</sup> Broader powers under s <sup>27</sup> are therefore not necessary.

While the legislation does provide that isolation can only be ordered by court, which in theory ensures due process rights, the absence of legal aid and the failure by medical staff to give clear warnings prior to the application for detention negate these procedural protections. Although the legislation provides that the detention order can be cancelled at any time by a magistrate there is no provision for automatic review of the detention or periodic testing of the detainee's contagion levels. Again, in the absence of legal aid this power of review is made nugatory.

There is no requirement in s 27, national policy or subsidiary legislation that other methods of control, such as community-based care, isolation at home or directly observed therapy, be attempted before coercive isolation. Detention under s 27 is therefore not the least intrusive limitation of the rights to liberty and freedom of movement. Many of the patients with DRTB are poor and vulnerable members of society who find it difficult to take medicine without social and economic assistance. Thus in a different case, the patient explained his failure to take the medicines for ten days on the basis that:

due to hunger he would get dizzy and even at times collapse after an injection. He insisted to his family that he would only accept the medication if he is afforded at least two (2) meals a day. He used to work as a casual labourer having dropped from school in class five (5) and on account of his ill health he has been unable to engage in menial jobs.<sup>36</sup>

It is not a proportionate limitation of such a person's right to liberty and freedom of movement to either detain or imprison (he was convicted under s 28)<sup>37</sup> him. Provision needs to be made to provide food and other necessities to persons with DRTB as well as counselling and directly observed therapy. The criminalisation of poverty

and disease will have the effect of discouraging other persons with TB and other infectious diseases (such as HIV/AIDS) from being tested.<sup>38</sup>

### Conclusion

The power to detain individuals to protect the general public from health risks is open to abuse particularly because it is a popular response to health emergencies allowing politicians and civil servants to portray themselves as taking public health seriously. Society must take care that this power is used only in the most extreme cases. It is for this reason that human rights law must be given prominence in the development of any public health policy. While the Government of Kenya has emphasised the importance of patient rights it continues to rely on outdated and draconian powers of detention. There is a promise that the Government will implement community-based directly observed therapies for TB patients with isolation in pressure controlled wards in specialised hospitals only being used for exceptional cases. However, while the hospitals remain unfinished and TB patients continue to struggle with poverty and lack of social support there is a risk that detention will continue to be used in violation of the rights to liberty, freedom of movement and dignity protected under the Constitution. Kenvan Detention should be a last resort to control MDRTB but, in Kenya, it is unfortunately too easy for public health officials to obtain an order for the prolonged detention of TB patients in open prisons, where they are subjected to life threatening conditions and where they may spread the disease to vulnerable prisoners.

Solomon Sacco is a lawyer at INTERIGHTS, Allan Maleche is a lawyer at the Kenya Legal & Ethical Issues Network on HIV/AIDS and Omwanza Ombati is a lawyer at Nchogu, Omwanza & Nyasimi Advocates.

- 1 Clinicians distinguish between extremely drug resistant and multidrug resistant Tuberculosis (XDRTB and MDRTB respectively) but the distinction, although relevant to the clinical determination of which patients should be isolated, does not affect relevant human rights argument and therefore will be ignored for the purposes of this paper.
- **2** Article 43 of the Constitution. See also Article 12 of the International Covenant on Economic, Social and Cultural Rights also ratified by Kenya.
- 3 The right to freedom of movement in the ICCPR may be subjected to limitations 'provided by law,...necessary to protect national security, public order (ordre public), public health or morals or the rights and freedoms of others, and...consistent with the other rights...' The right to liberty under Article 9 of the ICCPR does not contain an overt limitation clause but reference to 'arbitrary' detention has been interpreted to include the power to impose limitations. See Kenneth Davidson Tillman v Australia, Communication No. 1635/2007, U.N. Doc. CCPR/C/98/D/1635/2007 (2010). The Committee has emphasised however, that non-arbitrary is not be equated with 'within the law' and must be 'interpreted more broadly to include such elements as inappropriateness and injustice. Furthermore, remand in custody could be considered arbitrary if it is not necessary in all the circumstances of the case, for example to prevent flight or interference with evidence: the element of proportionality becomes relevant in this context.' See A v Australia, Communication No. 560/1993, U.N. Doc. CCPR/C/59/D/560/1993 (30 April 1997) and *Hugo van* Alphen v The Netherlands, Communication No. 305/1988, U.N. Doc. CCPR/C/39/D/305/1988 (1990). While the African Charter does not contain a general limitation clause the African Commission on Human and Peoples' Rights has held that s 27(2) serves this purpose. See Communications 105/93-128/94-130/94-152/96: Media Rights Agenda, Constitutional Rights Project, Media Rights Agenda and Constitutional Rights Project / Nigeria, the Commission explained the circumstances under which limitations of the rights will be permissible: '68. The only legitimate reasons for limitations to the rights and freedoms of the African Charter are found in Article 27.2, that is, that the rights of the Charter "shall be exercised with due regard to the rights of others, collective security, morality and common interest." 69. The reasons for possible limitations must be founded in a legitimate State interest and the evils of limitations of rights must be strictly proportionate with and absolutely necessary for the advantages which are to be obtained. 70. Even more important, a limitation may never have as a consequence that the right itself becomes illusory.'
- **4** WHO, Guidelines for the programmatic management of drug-resistant tuberculosis Emergency update 2008 (2008 WHO Guidelines). See also the United Nations Economic and Social Council UN Sub-Commission on Prevention of Discrimination and Protection of Minorities, The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights, U.N. Doc. E/CN.4/1985/4.
- **5** Enhorn v Sweden (Application no. 56529/00).
- 6 Ibid.
- **7** See for example *S. v H. S. E. & Ors* [2009] IEHC 106, an Irish case relating to the implementation of Article 38 of the Public Health Act, 1947 which allows two public health officers to order the detention of an infectious person if certain procedural protections were met. The case confirmed that forcible detention of a patient with MDRTB was acceptable in certain circumstances to protect the public from infection.
- 8 Supra note 4, paragraph 15.2.1.
- **9** WHO, Guidance on ethics of tuberculosis prevention, care and control, 1 December 2010 (the 2010 WHO Guidelines). The 2008 WHO Guidelines (supra note 4) also refer in paragraph 19.7 to the fact that 'forcibly isolating people with DR-TB must be used only as the last possible resort when all other means have failed, and only as a temporary measure.'

- **11** See J. J. Amon, F. Girard and S. Keshavjee, 'Limitations on human rights in the context of drugresistant tuberculosis: A reply to Boggio et al', *Health and Human Rights*, 7 October 2009. The paper describes in detail the successes in implementing a home based care approach in Lesotho, a country facing a level of XDRTB and MDRTB similar to South Africa, while having a markedly lower GDP per capita than Kenya. It appears from their article and sources cited therein, including WHO guidelines, that home based care is the preferable strategy for medium and low income countries.
- 12 It appears that coercive isolation has been successful, particularly in the US, in reducing non-compliance and reducing infection rates. See W. J. Burman, et al, 'Short-Incarceration for the Management of Noncompliance With Tuberculosis Treatment', CHEST 1997;112;57-62 CHEST 1997;112;57-62. However, it appears that coercive detention in the US has generally been adopted, at least since 1992, as a last resort, with emphasis placed on directly observed therapy and that in fact the number of patients coercively isolated was quite low [Denver (20 patients detained from 1984 to 1994) Massachusetts (166 patients from 1990 to 1995), California (67 patients in 1994 and 1995), and New York City (46 patients in 1993 and 1994) New York's report was preliminary; the city has detained more than 250 patients since 1993], see B. H Lerner, 'Catching Patients: Tuberculosis and Detention in the 1990s' CHEST January 1999 vol. 115 no. 1 236-241.
- 13 Supra note 9, p. 23.
- 14 An example of the importance of such warnings can be found in *S. v H. S. E. & Ors* (*supra* note 7). One of the factors determinative of whether the state had acted lawfully by ordering the patient's coercive isolation in hospital was that the medical officers had attempted directly observed therapy at her home and had repeatedly informed her of their powers under s 38 and she had still refused to abide by her treatment regime. It can be argued that even where there is no statutory provision requiring pre-detention warning in practice it will be an unreasonable limitation of the individual's rights to detain her without first warning her of the consequences of her actions.
- 15 WHO, Guidelines for the programmatic management of drug-resistant tuberculosis Emergency update 2008, para. 19.7.
- **16** For a more detailed human rights critique of the powers in ss 37 and 38 see J. Coker, 'The law, human rights, and the detention of individuals with tuberculosis in England and Wales', *Journal of Public Health Medicine* Vol. 22 No. 3 pp 263 267. See also A. Harris and R. Martin, 'The exercise of public health powers in an era of human rights: The particular problems of tuberculosis', *Public Health* 188 (2004), pp. 313–322.
- 17 Other states have varying rules and regulations, which while similar may have stronger or weaker protection of the rights of the individuals to movement and liberty
- 18 New South Wales Government Policy Directive, Tuberculosis Management of People Knowingly Placing Others at Risk of Infection – Guidelines, 25 January 2005, accessible at <a href="http://www.health.nsw.gov.au/policies/PD/2005/pdf/PD2005\_068.pdf">http://www.health.nsw.gov.au/policies/PD/2005/pdf/PD2005\_068.pdf</a>.
- **19** *Ibid*.
- **20** W. E. Parmet, 'Legal Power and Legal Rights Isolation and Quarantine in the Case of Drug-Resistant Tuberculosis', N Engl J Med 2007; 357:433-435, 2 August 2007.
- **21** *Ibid*
- **22** B. H. Lerner, 'Catching Patients: Tuberculosis and Detention in the 1990s', *CHEST* January 1999 vol. 115 no. 1236-241.
- **23** Lerner, *ibid.*, and T Oscherwitz, et al, 'Detention of Persistently Nonadherent Patients With Tuberculosis', *JAMA*, 1997;278(io):843-846.
- 24 Supra note 7.

10 *Ibid.*, p. 7.

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Rachel Fleetwood, Information and Publications Officer INTERIGHTS, Lancaster House, 33 Islington High Street, London N1 9LH, UK Telephone +44 (0)20 7843 0496 Email rfleetwood@interights.org

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INTERIGHTS
Lancaster House
33 Islington High Street
London Ni 9LH, UK
Tel:
+44 (0)20 7278 3230
Fax:
+44 (0)20 7278 4334
E-mail:
ir@interights.org
Website:
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