Contrasting perspectives from South Africa and the UK

One session of the seminar included a live video link with participants from the University of Cape Town. Jacky Thomas, Research Fellow at the University of Cape Town, gave a presentation on The Women's Circle (TWC), a locally based network of women from 30 communities in Cape Town, who come together to share information, knowledge, skills and experiences with the aim of improving the quality of their lives.

Jacky, with her colleague Vanessa Reynolds, from TWC, pointed out that the right to health and health care is increasingly being recognised in national and international law. The South African constitution, for example, says that everyone has the right of access to health care and to an environment not harmful to their health.

Yet, Jacky said, "the practical realisation of health as a right remains elusive."

Jacky and Vanessa carried out a case study within TWC to explore women's awareness and understanding of human rights, including their own rights, the right to health, and the involvement of TWC in a civil society network to realise the right to health.

Abstract Principles

One of the main conclusions from their study was that people have to know they have rights in order to access those rights. A key challenge facing the advancement of human rights, Jacky said, is that human rights are often viewed as abstract international principles that are divorced from people's daily realities. "People have no common understanding of what human rights mean," she said

As part of the video-linked session, Jeanelle de Gruchy, Consultant in Public Health Medicine at Nottingham City Primary Care Trust (PCT), gave a presentation entitled "Are Human Rights Fair?"

Jeanelle is South African but has worked in the UK since the late 1990s. She currently works in a health authority where there is a 10-year gap in life expectancy between the most affluent parts of the community and the most deprived.

"This difference in survival underlines unacceptable health inequality and central to this inequality is socioeconomic class," Jeanelle said.

Unusually for a PCT, the trust's main vision is to bring an end to the health inequalities that exist within it.

When Jeanelle first moved to the UK, she was, she said, "acutely aware" that the language of human rights was largely absent from this country. In 2000, however, the Human Rights Act became law. "Then I did start to hear people around me talk about human rights, but I was really surprised to find that what I took to be a self-evident congruity between the language of human rights and health equity was not, in fact, the case for many working in the NHS," she said. "Some people interpreted this Act as protecting 'the other' and not 'people like me'."

No Links to Socioeconomic Status

Jeanelle theorises that the reason for the absence of a link between human rights and health inequalities in the UK is because the Human Rights Act and various other pieces of UK human rights legislation do not make any mention of the need to protect the rights of those in the lowest socioeconomic classes. "Likewise, the new Equality and Human Rights Commission, which was set up in October 2007, outlaws discrimination on the grounds of six different strands—disability, age, gender, religion or belief, sexual orientation or race," Jeanelle said. "But there is nothing about class."

Yet, as the Nottingham data on life expectancy show, discrimination is also possible on the basis of class.

Even in the Department of Health document, Human Rights in Healthcare: a Framework for Local Care, which features six case studies, Jeanelle points out, there is no link to socioeconomic status

Despite working where she does, she did not know of the existence of this document until she started preparing her presentation to the seminar

She questioned whether such initiatives are indeed helpful to public health practitioners who are trying to deliver health care to local populations. "Do we need to have human rights discourse in the National Health Service," she asked, "or does the language of health inequalities that we are using in the NHS, which includes mention of socioeconomic status, enable us to get on with the job of eliminating those health inequalities?"

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Exploring the tension between human rights and public health

The right to health is an acknowledged human right; but human rights sometimes make uneasy bedfellows with health issues. Public health policies, for example, which consider a population's collective rights, can conflict with individuals' rights.

What if someone disagrees that fluoride in their drinking water is good for their health, for example? Should their right not to be forced to drink water from a fluorinated supply outweigh the right of the rest of the population to benefit from lower levels of dental caries?

What if someone successfully argues that their local health authority should pay for a very expensive drug that will allow them to live with cancer for a few more months? What about the rights of the people who receive care from the same health authority who will no longer receive chiropody or may be offered inferior mental health services because the money has been spent on cancer treatment for one person?

Do governments have the right to screen people for infectious diseases and to detain them if they are infected? Is it appropriate to treat people like criminals simply because they are ill, and how will this affect their care?

Seminar Series

Researchers from around the world gathered at the University of Warwick on 26 and 27 June 2008 to discuss the relationship between health and human rights, including debates such as those outlined above. The event was part of the ESRC Research Seminar series on "Global Health and Human Rights: Theory, Process and Substance".

The first seminar, on "Theory" was held in Liverpool in April 2007. One of the delegates was Paul Hunt, the UN Special Rapporteur on the right to the highest attainable standard of health

The second seminar, on "Process", took place in Edinburgh in November 2007. The title of the Warwick seminar, the third and final in the series, was "Global Substantive Health Issues".

The International Covenant on Economic, Social and Cultural Rights (1966) defines the right to health as "the right to the highest attainable standard of physical and mental health". The seminar series set out to examine and discuss the development of rights-based approaches to health, while deepening researchers' theoretical and practical understanding of rights-based approaches to health.

Maria Stuttaford, Assistant Professor in the Department of International Health at Maastricht University, The Netherlands, and one of the convenors of the Warwick seminar, told delegates in the opening session: "Health and human rights is

starting to grow and take off as a field. Until now, there has not been a good opportunity for researchers in the UK to come together to discuss this broad range of issues."

The seminar had been carefully put together, she added, to try to stimulate as broad a discussion as possible—to include presentations by both established academics and PhD students, and contributions from people from both sides of the North/South divide.

The other convenors of the Warwick seminar were Gillian Lewando-Hundt, Professor of Health and Social Studies at the University of Warwick, and John Harrington, Professor of Law at the University of Liverpool.

A Wider Debate

Speaking later, Gillian said: "This seminar represents the continuation of long-standing research in an emergent field, and it is a great way of creating international dialogue about this topic, and of raising its profile. With this meeting, we aim to widen the debate conceptually, between disciplines, between continents and between academics and PhD students."

One of the seeds from which the idea of the seminars grew is a research collaboration between Maria and Leslie London, Professor of Public Health and Family Medicine at the University of Cape Town, South Africa. The two researchers have been working on setting up a learning network on health and human rights, which in turn has links with Equinet, the Network on Equity in Health in Southern Africa.

Growing Inequalitie

Leslie told the seminar that a human rights approach to health is critical if we are to address growing global health inequalities.

Speaking later, Leslie said: "In Africa, a good example of the tension between individual and collective rights is provided by the example of, 'Do we spend money on oral rehydration for infants or on high-tech drugs?' Some people would argue that if you address questions such as these from the human rights angle, it opens the door to people who claim most loudly for resources, whether cancer drugs or antiretroviral drugs to treat AIDS. In contrast, if you take a narrow utilitarian public health approach, this can violate human rights."

Maria added: "The late Jonathan Mann, who had formerly headed the World Health Organization's Global Programme on AIDS, was being provocative when he said that all public health is a violation of human rights, whether it is a case of fluoride in water or surveillance for infectious diseases. But this view touches an important chord, acknowledging the unease of public health advocates with the human rights approach."

continued overleaf

Maria and Leslie hope to explore and extend understandings of individual and collective rights. Both accept that academic theory in support of collective rights is very weak.

For Maria, one of the most exciting challenges is how to move forward to provide health and health care for those who currently do not have it. Maria concludes;

We have had presentations in this seminar on case law and what the judiciary say about determining the right to health, but these laws and judgements will not by themselves make health care, or the underlying determinants of health, a reality for people.

We can work with legal processes, but one really important point is that the notion of collective rights and collective action has to be made stronger.



Maria Stuttaford

Tobacco control: the evolution of a new human right

A new and emerging human right is the right to tobacco control. Stephen Marks, François-Xavier Bagnoud Professor of Health and Human Rights in the Department of Global Health and Population at Harvard School of Public Health, reviewed the evidence that tobacco control can be considered a human right. He also highlighted the problems that result when smokers claim that tobacco control violates their human rights.

One-third of the global population over the age of 15 are smokers. Tobacco is the principal cause of preventable death worldwide, killing 5 million people every year.

One major challenge to tobacco control is, of course, that tobacco is a legal product—the only legal product that, when used as intended, kills 50 per cent of users.

Stephen drew an analogy between the human right to tobacco control and the human right to water. "In terms of recognising the right to tobacco control, we are now about where we were 10 years ago on the right to water," he said.

The campaigns by smokers to have their "rights" recognised muddy the waters for those public health practitioners who consider that taking notice of human rights poses an impediment to good public health. "But a proper understanding of the issues shows that a human rights approach should not have this effect on public health," Stephen said.

Smokers' Limited Rights

Smokers' campaigns abuse the word "right", which in truth is a legally protected interest. Smokers' legally protected interests (or rights) comprise only the following:

- Privacy; the right to smoke at home;
- Free expression; the right to advertise;
- Property; the right to purchase tobacco.

In contrast, Stephen said, there are the following overriding social interests (or legitimate limitations on human rights) of the population as a whole:

- Limitation on privacy, in order to protect the right not to be exposed to second-hand smoke;
- Limitation on commercial free expression, in order to ensure the right to be notified about the harmful effects of tobacco;
- Limitation on property through the right of governments to implement heavy taxation on a harmful product.

Speaking after the seminar, Stephen drew attention to the process by which "new" human rights become acknowledged as such. He said: "We see resistance to new human rights coming from people who are not aware of the shifts in understanding relating to what is important to societies. Some examples are slavery, equality for women, even torture. These examples have been recognised only recently in human history as violations of human rights. Even today, we are witnessing a shift in thinking about the death penalty, and about discrimination on the basis of sexual orientation. These are emerging important human rights, but they are currently far from universally acknowledged as such."

A Slow Progression

The human rights to water and to tobacco control are at an even earlier stage in the process towards their acknowledgement as human rights, Stephen added.

In the case of tobacco control, the research that has been done into the adverse health effects of tobacco usage has provided a firm foundation on which to lay other achievements. "We have the trend towards smoking bans in many countries, the Framework Convention on Tobacco Control of the World Health Organization, and other legislative and judicial recognitions of the imperative of protecting people, especially children, from the harmful effects of tobacco."

The next step, Stephen said, will be the expansion and consolidation of existing tobacco control measures to the point where these measures are regarded as a necessary component of the human rights to health.

Stephen acknowledged that it is understandable that smokers and the tobacco industry both see continued access to tobacco products as a matter of right. "The industry takes the view that it has the 'right' to continue to manufacture these products, while consumers believe that they have the 'right' to continue to smoke because they are addicted," Stephen said. "But neither of these beliefs is founded in human rights."

He concluded: "Human rights are social imperatives recognised in law and, in the popular conscience, as fundamental to life and dignity. The right to health is one of those rights, and its realisation requires restrictions on the so-called rights of smokers."

Dealing with pandemic influenza: rights and responsibilities

Some national plans to cope with pandemic disease, such as an outbreak of pandemic influenza, may breach a range of human rights if they are ever implemented, Robyn Martin, Professor of Public Health Law in the Centre for Research in Primary and Community Care, University of Hertfordshire, told the seminar.

Robyn highlighted inconsistencies, gaps and unintended consequences of contingency plans, many of which also have the objective of how to respond to bio-terrorist attack. The threats posed by terrorist attacks involving infectious agents and those flowing from an outbreak of pandemic influenza seem to have become confused in policymakers' minds, she noted, citing one document submitted to the US Government that had the title "Biosecurity and Bioterrorism: Biodefence Strategy and Science. Disease mitigation measures in the control of pandemic influenza".

Currently, a new influenza virus subtype is able to cause disease in humans, but is not yet spreading efficiently and sustainably between humans. The World Health Organization has issued a pandemic alert, taking the view that there is a higher risk now of an outbreak of pandemic influenza than at any time since 1968 when the last pandemic occurred.

During an influenza pandemic, a second generation of patients can appear within 2 days of exposure to the virus. Infected people can shed virus and be infectious for 2 days before they become symptomatic; some infected people may never be symptomatic.

Many governments and international bodies have therefore drawn up plans to say how they would handle such a situation. Robyn identified some of the types of measures proposed in national plans:

- Isolation of non-nationals;
- Suspension of flights and closure of airports;
- Control of the media:
- Enforcement of public health powers by the police or the army;
- Restriction of travel, trade or movement;
- Closure of education and work facilities;
- Isolation of infected people;
- Quarantine of healthy people who have been exposed;
- Suspension of health care for non-nationals;
- Health care workers obliged to work with affected people;
- Authorisation of the use of unlicensed medicines and unlicensed staff.

Closer examination of these policies, however, may raise difficulties, Robyn pointed out. If airports are closed, how will this affect importation of food supplies? If people are no longer allowed to visit inpatients in hospitals, how would someone cope with not being allowed to visit their critically ill child? If schools and offices are to be closed, what will happen to education and commerce given that pandemic influenza can last for years? If non-nationals are to be denied health care (and may be isolated), exactly what would happen to them and how would they be treated?

Such strategies may be contained in contingency plans, but they are not necessarily underpinned by national public health laws, Robyn added.

Some countries have, however, drawn up new laws to cover the eventuality of pandemic influenza. In England, the Health and Social Care Act 2008 provides new quarantine powers, allows for compulsory

quarantine for groups, and outlines a new 28-day public health emergency procedure. The French code of public health also now authorises isolation and quarantine of infected or exposed people.

Robyn said that many countries are assuming that laws outlining emergency powers will provide authorisation for public health interventions. "But an emergency is unforeseen and temporal, and pandemic influenza does not fit the definition of an emergency," she said. "I would argue that we should not use emergency powers to deal with pandemic influenza. Pandemic influenza would develop slowly and recede slowly—at what point would it become an emergency?

"These emergency powers assume that public health laws are insufficient and, on the whole, emergency powers were written with terrorism in mind. They assume that the public will be uncooperative during a pandemic and that Government will need to take a public order approach. Many human rights articles could be breached by implementation of the regulations and plans that I have mentioned."

The SARS outbreaks in Toronto and Hong Kong had shown, Robyn concluded, that voluntary quarantine was adequate. Hong Kong had used quarantine and isolation, and did not impose compulsory treatment on people who fell ill. Although the Hong Kong authorities had screened thousands of people at their borders, they had picked up only one case of SARS this way.

Simulation exercises have shown that survival in pandemic influenza would depend on trust, Robyn added. "We should be drawing up new public health laws if we need them, and if we have done that, then we won't need to use emergency powers."

In brief

Istvan Pogany, Professor of Law at the University of Warwick, gave a presentation on the low level of access to health care experienced by the Roma people who live in some Eastern European countries—mainly western Romania, Bulgaria and Hungary. He presented data showing that the Roma are experiencing worsening poverty. While European Union laws outlawing discrimination may be in existence, he said, it is an enormous leap for a Romany to: first, be aware of those rights; and secondly, have the confidence, resources and ability to visit a lawyer in order to ask for those rights.

Evgeniya Plotnikova, a PhD student at the University of Edinburgh, examined the trends in international migration of health professionals from the perspective of human rights. Such migration poses difficult dilemmas: while patients in the "source" country have the right to health, the health professionals also have rights to freedom of movement and to make career choices. Evgeniya summarised the policy responses to these issues, including the ethical recruitment policy that has been developed in the UK.

Aoife Nolan, Assistant Director of the Human Rights Centre and Law Lecturer at Queen's University Belfast, considered the way in which the child's right to health has been interpreted and applied by a wide range of domestic courts and various international judicial and quasi-judicial decision-making bodies.

Duncan Matthews, Reader in Intellectual Property Law at the School of Law, Queen Mary, University of London, explained the link between intellectual property rights, access to medicines and human rights. As a practical example of these links, Duncan described how the right to health has played a crucial role in the campaign for access to medicines in Brazil.

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