Annual Lecture on Malaria and Human Rights

Poverty, Malaria and the Right to Health: Exploring the Connections

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Malaria is an extremely serious human rights issue on an enormous scale.

Although preventable and treatable, malaria kills well over 1 million people every year. A child dies from malaria every 30 seconds. It costs Africa US$12 billion every year. Six out of eight Millennium Development Goals cannot be achieved without tackling malaria.[1]

Malaria is both a cause and consequence of poverty. Its impact is especially ferocious on the poorest: those least able to afford preventive measures and medical treatment. The impact is not only felt in terms of avoidable human suffering and death – but economic cost and burden. Malaria impoverishes families, households and national economies. The disease may account for as much as 40% of public health expenditure. In Tanzania, malaria accounts for 30% of the national disease burden. In Ghana, malaria care can cost up to 34% of a poor household's income. Malaria lowers worker productivity. It discourages investment.[2]

Malaria is entirely preventable by way of an integrated package of interventions, including properly treated and maintained insecticide-treated nets, indoor residual spraying, information campaigns, and so on. If diagnosed and treated promptly and correctly, malaria is curable. Resistance to the cheapest drugs (such as chloroquine) is common throughout Africa. New artemisinin-based combination therapies (ACTs) are effective – but expensive and beyond the reach of many.[3]

Recognising malaria as a right to health issue does not provide a magic solution to an enormous, complex problem. But the right to health perspective - the human rights analysis – adds something. It has a constructive contribution to make. My remarks tonight attempt to signal what that contribution is.

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[1] For information about the health and economic burden of malaria see: UN Millennium Project 2005, *Coming to Grips with Malaria in the New Millennium,* Task force on HIV/AIDS, Malaria, TB, and Access to Essential Medicines, Working Group on Malaria (UN Millennium Project 2005), pp 15-18. See also: European Alliance Against Malaria, *Fact Sheet No. 2 - Malaria & Poverty*, September 2007, available online at http://www.europeanallianceagainstmalaria.org/uploads/media/Facts_Malaria_Poverty.pdf.

[2] UN Millennium Project 2005, pp 19-21, above n 1; *Malaria & Poverty*, above n 1.

[3] *The Right Drug at the Right Time. The Power of the Affordable Medicines Facility – Malaria (AMFm) to Save Lives*, Report for the All Party Malaria Group(APPMG), November 2007, available online at http://www.appmg-malaria.org.uk.

What is the right to the highest attainable standard of health?[4]
First, we have to get clear what the right to health means.

The right to the highest attainable standard of health is codified in numerous legally binding international and regional human rights treaties.[5] These binding treaties are beginning to generate case law and other jurisprudence that shed light on the scope of the right to health. The right is also enshrined in numerous national constitutions: over 100 constitutional provisions include the right to health or health-related rights.[6] Moreover, in some jurisdictions constitutional provisions on the right to the highest attainable standard of health have generated significant jurisprudence.[7]

While the right to health includes the right to medical care, it goes beyond medical care to encompass the underlying determinants of health, such as safe drinking water, adequate sanitation and access to health-related information. The right includes freedoms, such as the right to be free from discrimination and involuntary medical treatment. It also includes entitlements, such as the right to essential primary health care. The right has numerous elements, including child health, maternal health, and access to essential drugs. Like other human rights, it has a particular concern for the disadvantaged, marginal and those living in poverty. The right requires an effective, inclusive health system of good quality.

International human rights law is realistic and recognises that the right to the highest attainable standard of health for all cannot be realised overnight. Thus, the right is expressly subject to both progressive realisation and resource availability. Although qualified in this way, nonetheless the right to health imposes some obligations of immediate effect, such as non-discrimination, and the requirement that a State at least prepares a national plan for health care and protection. The right demands indicators and benchmarks to monitor the progressive realization of the right.[8] It also encompasses the active and informed participation of individuals and communities in health decision-making that affects them. Under international human rights law, developed States have some responsibilities towards the realization of the right to health in poor countries. Crucially, because the right to health gives rise to entitlements and obligations, it demands effective mechanisms of accountability.

At root, the right to the highest attainable standard of health consists of global standards; out of these standards derive legal obligations; and these obligations demand effective mechanisms of accountability. The combined effect of these three

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[4] For a fuller introduction than is provided here, see E/CN.4/2003/58 (dated 13 February 2003) paras 10-36. This - and my other UN reports – are available online at http://www2.essex.ac.uk/human_rights_centre/rth/rapporteur.shtm One report examines the health-related Millennium Development Goals through the lens of the right to the highest attainable standard of health, see A/59/422 (dated 8 October 2004).

[5] The full name of the right is the 'right of everyone to the enjoyment of the highest attainable standard of physical and mental health'. For convenience, this is often shortened to the 'right to the highest attainable standard of health' or the 'right to health'.

[6] Eleanor Kinney and Brian Clark, 'Provisions for Health and Health Care in the Constitutions of the Countries of the World' (2004) 37 *Cornell International Law Journal* 285.

[7] E.g. the Ecuadorian case of *Mendoza and others v Ministry of Public Health and the Director of the HIV-AIDS National Programme*, Resolucion No. 0749-2003-RA, 28 January 2004.

[8] For a human rights-based approach to health indicators see E/CN.4/2006/48 (dated 3 March 2006).

dimensions - standards, obligations and accountability - is the empowerment of disadvantaged individuals and communities.

While the right to the highest attainable standard of health is a powerful campaigning and advocacy tool, it is more than just a slogan, more than just a bumper sticker. Additionally, it has normative depth and something constructive and concise to say to policy makers.

In general terms, what does the right to health bring to policy making?
In general, abstract terms it brings a set of fundamental principles, such as dignity, well-being, autonomy, and equality.

It places the interests of individuals and communities – their dignity and well-being – at the heart of policy making.

It brings a keen preoccupation with the marginal and disadvantaged, including those living in poverty.

The right to health emphasises primary health and it demands effective health systems that are responsive to local priorities.

It places obligations – moral and legal – on States and requires that they be held to account for their conduct.

It insists that rich States have a responsibility to help developing States realise the right to health – in this way responding to the shocking inequality in global health that shames our contemporary world.

More specifically: Uganda, neglected diseases and the right to health
One of my responsibilities as UN Special Rapporteur on the right to health is to clarify what, in more *practical* terms, the right to health brings to a particular health problem.

In 2005, I received an invitation from the Government of Uganda to visit and prepare a report on neglected diseases and the right to health.[9] By neglected diseases I mean those that are mainly suffered by poor people in poor countries. Clearly, the report is relevant to all those countries where malaria is endemic.

Historically, these neglected diseases have attracted little health research and development because those afflicted invariably have negligible purchasing power. The market fails them – although, fortunately, there are some signs that this situation is now improving.[10]

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[9] E/CN.4/2006/48/Add.2 (dated 19 January 2006). This report was informed by parallel research that resulted in Paul Hunt, Rebecca Steward, Judith Bueno de Mesquita and Lisa Oldring, *Neglected Diseases: A Human Rights Analysis*, WHO on behalf of the Special Programme for Research and Training in Tropical Diseases, 2007, available online at http://www.who.int/tdr/publications/publications/seb_topic6.htm.
[10] See, for example, Mary Moran, Anne-Laure Ropars, Javier Guzman, Jose Diaz and Christopher Garrison, *The New Landscape of Neglected Disease Drug Development*, The Wellcome Trust, 2005, available online at http://www.wellcome.ac.uk/assets/wtx026592.pdf.

Examining Uganda’s neglected diseases through the lens of the right to health underlines the importance of a number of policy responses.

First, it underscores the imperative of developing an *integrated* health system responsive to local priorities. Vertical interventions that focus on one particular disease can actually weaken the broader health system. While there might be a place for some vertical interventions, they must be designed, so far as possible, to strengthen, not undermine, an integrated health system.

Second, village health teams are urgently needed to identify local health priorities. Their local knowledge about the prevalence of disease in the community will enhance the perspectives provided by a health official from the regional or national capital.

Third, of course more health workers are essential, but also incentives are needed to ensure that the health workers are willing to serve these remote neglected communities.

Fourth, there are myths and misconceptions about the causes of some neglected diseases: these can be dispelled by accessible public information campaigns.

Fifth, some of those suffering from neglected diseases are stigmatised and discriminated against: this, too, can be tackled by evidence-based information and education.

Sixth, the international community and pharmaceutical companies also have responsibilities to provide needs-based research and development on neglected diseases, as well as other assistance.

Seventh, effective monitoring and accountability devices must be established. Existing parliamentary and judicial accountability mechanisms are not enough in relation to those diseases mainly affecting the most disadvantaged. In my report I suggest a way of enhancing accountability in relation to neglected diseases in Uganda.

I want to return to neglected diseases – and malaria – shortly, but first some general observations about the deepening relationship between health and human rights.

The relationship between health and human rights

Clearly, the right to the highest attainable standard of health depends upon the interventions of public health and medical care. Obviously, the right to health cannot be realised without effective public health programmes and the provision of good medical care.

Equally, the classic, long-established objectives of public health and medical care can benefit from the newer, dynamic discipline of human rights.

My multiple UN reports, such as the one on Uganda, illustrate the common ground between health and human rights.

For example, both health and human rights stress the importance of the underlying determinants of health, as well as health care. Both look beyond the health sector. Both struggle against discrimination and disadvantage. Both demand cultural respect. Both attach great importance to public information and education. And so on.

My UN reports also show how human rights can help to reinforce *existing*, good health programmes. And they show how human rights can sometimes help to identify *new*, equitable health policies.

Human rights strengthen public health and medical care in several ways, not least by introducing guidance for policy-making, as well as by demanding accountability.

The right to health asks awkward questions.

As you devise this new health programme, how will you ensure that the voices of women and girls are heard and respected? How are you ensuring that the poor and marginal have access to these health services? How are you measuring the impact of that new irrigation scheme on the health of neighbouring communities? How are you measuring whether or not access to health care is being progressively improved? If you are using indicators and benchmarks, are they disaggregated on the grounds of sex, ethnicity and other prohibited grounds of discrimination? Why are maternal and infant mortality rates static - or worsening - for some ethnic minorities? Are your health programmes respectful of minority cultures? Are they available in common minority languages?

But human rights not only ask these awkward questions, they also require answers – that is what accountability is all about.

For example, if health outcomes are not improving, we need to know why, so that policy adjustments can be made.

If the evidence shows that a new private sector development is damaging health, we need to identify what is going to be done and by whom. What is the private company going to do about it? What is the local authority going to do? What is the State going to do?

If those living in poverty do not have access to essential medical care, water and sanitation, we need to identify the obstacles so those responsible can take specific, targeted remedial action – and if they fail to take all reasonable steps, the poor need to be told why.

In short, human rights accountability asks questions and requires answers, *not* with a view to blame and punishment, but with a view to finding out what works and what does not. Accountability is a powerful human rights tool for improving the health of all.

Of course, we have not figured out all the implications of the right to health – and we probably never will. The only human right or discipline without dilemmas and disputes is one that has atrophied and died.

But, *for the first time*, the key pieces are now in place for health and the right to health to invigorate and enrich each other in an operational, systematic and sustained way.

In my view, however, we have gone about as far as we can with health and human rights unless we can generate much more support from many more health workers, including those working on malaria.

It is imperative that many more health workers come to appreciate that the right to the highest attainable standard of health is not just a rhetorical device, but also a tool that can save lives and reduce suffering, especially among the most disadvantaged.

If we are to make progress, we have to get across the message much more clearly and widely that human rights, including the right to health, are allies and assets for health workers to use – to devise better policies and programmes; to raise more funds from the Treasury; to leverage more funds from developed countries to developing countries; in some countries, to improve the terms and conditions of those working in the health sector; and so on.

We have to convince many more health workers of the new maturity and rich potential of the right to health and other human rights.

Some ten years ago, human rights were characterised by the traditional techniques and skills that have served the human rights community very well for many years – 'naming and shaming', letter-writing campaigns, taking test cases to court, demonstrations, slogans, and so on.

Today, the human rights community is developing new skills and techniques so it can engage in national and international health policy-making processes. Today, the human rights community is developing new tools like indicators and benchmarks, impact assessments, and budgetary analysis.[11]

Of course, the traditional human rights techniques - naming and shaming and so on - remain vitally important. But the human rights community recognises that they are no longer enough. Thus, these additional skills are being developed.

Crucially, these new techniques and skills must be developed in close cooperation with health workers. The right to the highest attainable standard of health cannot be realised without their active engagement.

In other words, with the maturing of human rights, health workers have become an integral and indispensable element in the global human rights movement.

More on malaria

One of my messages this evening is that human rights workers and health workers should collaborate to mutual advantage. Together, they can figure out how the right to health can reinforce *existing* anti-malaria initiatives and help to identify *new* effective anti-malaria policies, programmes and projects.

[11] On impact assessments, see Paul Hunt and Gillian MacNaughton, *Impact Assessments, Poverty and Human Rights: A Case Study Using the Right to the Highest Attainable Standard of Health*, UNESCO, 2006, available online at http://www2.essex.ac.uk/human_rights_centre/rth/projects.shtm.

I do not wish to try to anticipate the detailed results of that collaboration which should be considered, thoughtful and evidence-informed.

But, by way of illustration, and for the purposes of discussion, here are some observations about what the right to health has to say about anti-malaria programmes and policies. These comments briefly build on some of the issues already mentioned in relation to Uganda and neglected diseases. The important point is that States and others have a legal obligation to undertake these measures.

Information and education

Under the right to health, individuals and communities are entitled to information and education that bears upon their health. This includes information and education on preventive and health-promoting behaviour, as well as how to access to health services. In the context of malaria, information and education is needed on a wide range of issues from the proper use of anti-malaria drugs, insecticides, indoor residual spraying, and so on. Governments have a duty to adopt public information and education campaigns targeted at the most disadvantaged communities and they should utilise the media, village health teams and health workers, church and other faith networks, schools, and so forth.

Community participation

Another integral feature of the right to health is the active and informed participation of individuals and communities in health decision-making that affects them. People are entitled to participate in the identification of priorities and targets that guide the technical deliberations underlying policy formulation. They are also entitled to participate in the implementation of policies and programmes.

In this context, *home management of malaria* has much to commend it, especially in remote, rural areas where there is no accessible system of health clinics and medical care. Research supported by the Special Programme for Research and Training in Tropical Diseases (TDR) suggests that home management of malaria - community volunteers trained to identify symptoms and provide malaria treatments - have a very positive role to play.[12] Other research by TDR signals that another type of delivery system - *community-directed interventions* - can also increase malaria treatment.[13]

Research and development

The right to health encompasses an obligation to engage in R&D that addresses the health needs of the entire population, including disadvantaged groups. In all countries there is a large number of compelling and competing research and development health needs. Given the burden of malaria, clearly it is a disease that should be prioritised.

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[12] Margaret Gyapong and Bertha Garshong, *Lessons learned in Home Management of Malaria. Implementation research in four African countries*, WHO on behalf of the Special Programme for Research and Training in Tropical Diseases 2007, available online at http://www.who.int/tdr/publications/publications/pdf/lessons_hmm.pdf.

[13] Special Programme for Research and Training in Tropical Diseases, *Eliminating River Blindness*, WHO on behalf of the Special Programme for Research and Training in Tropical Diseases 2007, p 17, available online at http://www.who.int/tdr/topics/ir/oncho_story.pdf.

In recent years, the financial resources devoted to malaria - including R&D – has grown dramatically. All those responsible – some of whom are represented in this meeting – deserve credit for this turn around, although there is no room for complacency. Much more needs to be done.

Here I draw attention to just one part of the R&D challenge. R&D must be understood to encompass classic medical research and development into drugs, vaccines and diagnostics, as well as operational or implementation research into the social, economic, cultural, political and policy issues that determine access to health care and protection. In the malaria context, applied social science for public health is therefore crucial with a view to dismantling societal obstacles to health interventions and technologies.[14]

Donors and the international community

The primary responsibility for implementing the right to health falls upon the State in question. However, States have an obligation to take steps individually and through international assistance and cooperation towards the full realisation of various rights, including the right to health. Thus, developed States have a human rights responsibility to help developing States deliver the right to health. These transboundary human rights obligations reinforce MDG 8 (a global partnership for development).

In the malaria context, there is an epidemic of initiatives. On the one hand, this is welcome because it signals concern and commitment. On the other hand, these initiatives can place a very considerable administrative burden on the national authorities. The human rights responsibility of international assistance and cooperation is not confined to financial assistance – it also requires donors and others, including pharmaceutical companies, to coordinate effectively and align their initiatives with a country-owned national plan for malaria.

Monitoring and accountability

While it is commonplace for the impact of health policies to be monitored, it is less common for a health policy to be assessed against a right to health standard, or for those responsible for the policy to be held to account for the discharge of their right to health duties.

From the human rights perspective, all malaria initiatives must be subject to effective, accessible and transparent monitoring and accountability – not just to ensure financial propriety but also to ensure that the initiatives are conforming to human rights standards and delivering to all without discrimination.

Accountability mechanisms can take several forms, including parliamentary select committees, national human rights institutions, and judicial processes. However, I do not know of any effective, transparent, accessible and independent accountability mechanism that is reviewing malaria initiatives in relation to human rights standards.

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[14]"Applied Social Sciences for Public Health (ASSPH). Higher Degree Training for Implementation Research on Tropical Diseases", *Report of the International Health Group of the Centre for Public Health Research, Brunel University, London*, WHO on behalf of the Special Programme for Research and Training in Tropical Diseases, 2007, p 6-7, available online at http://www.who.int/tdr/publications/publications/pdf/higher_degree.pdf.

In my view, this is one of the most signal defects in the current infrastructure that has grown up around malaria.

Crucially, this human rights requirement of effective accountability extends to donors and the international community. It also extends to public and private actors, including pharmaceutical companies.

Others
These issues – information, education, community participation, research and development, donors and the international community, monitoring and accountability – signify the reach, concerns and role of international human rights.

Of course, there are other vital right to health issues, such as the gender dimension. The traditional role of girls as carers has major implications when malaria episodes are high among families and households. Also, pregnant women – particularly during their first and second pregnancies – and their unborn children are especially vulnerable to malaria.

Another right to health issue concerns the vital importance of an effective, integrated health system – a point I will now turn to.

An integrated health system responsive to local and national priorities
Like many others, the Millennium Project Working Group on Malaria emphasises that the weakening of health systems since the 1980s has exacerbated the "malaria conundrum".[15] It recommends a global plan that includes building stronger national health systems.[16]

From the right to health perspective this recommendation is of the first importance.

The right to health can be understood as a right to an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to national and local priorities, and accessible to all.

If we look at a health system - that is both health care and the underlying determinants of health – through the right to health lens, what are the key features that we would expect to see? What are the key right-to-health features of a health system?

Of course, from a right to health perspective, a health system needs a minimum basket of facilities and services. In the context of malaria, this basket must include preventive measures and ACTs. The system needs to deliver adequate water and sanitation services, and so on. The heart of these health facilities and services is integrated primary health care, with an adequate referral system to secondary and tertiary care. Moreover, these health facilities and services must be accessible to all, culturally sensitive, and of good quality.

This is all fine – as far as it goes. But it fails to capture some of the essential right-to-health features of a health system, such as the following.

[15] UN Millennium Project 2005, above n 1, p 2.
[16] UN Millennium Project 2005, above n 1, pp 2-3.

From the point of view of human rights, a State must formally recognise the right to health. Additionally, the State has to clarify what the right means – by way of guidelines, codes of conduct and regulations. It must undertake a needs assessment or situational analysis, as well as prepare an overarching national plan for the organisation and development of the health system. It must have detailed strategies and policies, with timeframes, reporting procedures, indicators and benchmarks. It must have a methodology for health impact assessments, so Ministers know the likely impact of a projected policy on the right to health, especially of disadvantaged individuals and communities. There must be as much participation as possible in health policy formulation, implementation and accountability. There must be an effective system for the collection of disaggregated data. Because the health system is not the sole responsibility of the Ministry of Health, there must be an effective mechanism for intersectoral coordination. Rich States have a human rights responsibility to provide international assistance and cooperation in health to low-income countries. There must be effective monitoring and accountability mechanisms, including redress for when things go wrong.

And so on and so forth - this is not an exhaustive list of the key right-to-health features of a health system.

In the malaria context, the list is instructive. The right to health demands a basket of health facilities and services but, additionally, it demands a needs assessment, a malaria plan, an impact assessment methodology, participatory mechanisms, disaggregated data, intersectoral coordination, monitoring and accountability mechanisms, and so on.

Moreover, these key right-to-health features are underpinned by law. A State is required to take all reasonable steps to implement the key right-to-health features of a health system. It is not just a matter of good management, justice or humanitarianism. It is a matter of international legal obligation.

Conclusion

I am impressed by the range and depth of organisations and initiatives - too numerous to list here - that are taking malaria seriously. Governments have signalled their determination to achieve MDG 6. More funds are being committed. Some progress is being made, some lives are being saved. For example, a recent UNICEF report showed that Ethiopia recently reduced deaths from malaria in young children by 20%.[17]

I am also impressed by the United Kingdom's leadership role on this issue.

But it is also extremely striking that malaria is rarely – if ever – recognised as a human rights issue. Yet there can be no doubt that it is. There can be no doubt that endemic countries have binding human rights duties to vigorously tackle malaria; to improve water management and other preventive measures; to enhance access to anti-

[17] UK Coalition Against Malaria, *Global malaria community in Ethiopia to plan intensified battle against disease*, 28 November 2007, available online at http://www.coalitionagainstmalaria.org.uk/news/00055.html.

malarial treatment, especially for infants and pregnant women; to prepare malaria plans; and so on.

Equally, developed States have a binding human rights duty to do all they reasonably can to assist malaria endemic countries. There continues to be a huge financial gap between what is pledged and what is needed. Other actors, including pharmaceutical companies, also have human rights duties.

Yet malaria is still not seen as a human rights issue, even though the scale of preventable malarial mortality and morbidity is catastrophic.

Among the reasons for this myopia is the reluctance of the classic human rights movement to go beyond civil and political rights and to embrace economic, social and cultural rights, such as the right to the highest attainable standard of health.

Another reason is that most health workers have yet to grasp that human rights can help them fulfil their professional objectives. Most health workers have not yet understood that human rights are a useful advocacy and campaigning tool; a device for sharpening malaria policies; a way of underpinning policies with legal obligation; and a method of ensuring effective, independent accountability of all parties, including donors and pharmaceutical companies.

It is time for a ‘Human Rights and Malaria Call to Action’ to make plain that malaria is a very grave human rights issue. Every day, thousands suffering from malaria are denied their fundamental human rights. The traditional human rights movement must take malarial mortality and morbidity as seriously as they take death penalty cases and ‘disappearances’. Health workers and human rights workers must work together in their common cause. They must identify a sensible, practical human rights-based approach to malaria that strengthens prevention and treatment, including for infants, pregnant women, and those living in poverty. All parties working on malaria, including pharmaceutical companies and public-private partnerships, have human rights duties. Key objectives must be the strengthening of health systems, and the introduction of effective, independent accountability mechanisms for all those working on malaria.

Human rights do not provide magic solutions because there are no magic solutions. But human rights have a distinctive, constructive contribution to make. In the struggle against malaria, it is time for the human rights contribution to be made -- without exaggeration, but with clarity and conviction.

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