



## 2<sup>nd</sup> Annual Lecture on Malaria and Human Rights Dr Christoffer van Tulleken



Dr Christoffer van Tulleken opened by explaining that his lecture would touch on the ideas of human rights violations exacerbating malaria and the relationship between rights based approaches and the successes and failings of interaction with western humanitarian aid. He based his discourse on brief experiences in Burma

(Myanmar) and Congo Brazzaville, both of which have high Malaria prevalence rates.

Dr van Tulleken travelled to Burma as a patron of MERLIN in May 2008 shortly after cyclone Nargis had hit the coastal region of the country. The cyclone had already killed 10,000 people. The rest of the population, having lost family and livelihoods, were now very vulnerable to malaria, cholera and dengue fever. The western media reported how the Myanmar government was actively obstructing international aid efforts. Dr van Tulleken was present in many UN cluster meetings discussing how to tackle this issue. He then travelled out on a pilot UN assessment in the company of the Myanmar secret police.

The assessment was a tripartite initiative between the UN, the Myanmar government and the Association of South East Asian Nations (ASEAN) as World Bank representatives.

The coastal area had suffered devastating destruction with the greatest casualties being women and children. From his experiences Dr van Tulleken believes that the western media under reported the positive impact of aid delivered by the Myanmar government itself prior to his arrival in Yangon with the UN. He feels that a surprising amount of aid from the Myanmar government had arrived to those in need and that the aid had saved lives. He described how the relationship between the government agents in the secret police was one based on fear and intimidation and that most agents were forced to join and recruit, they did not do so by choice - they were not necessarily 'bad people'. Nevertheless the media struggle to say good things about bad people. This was a factor in the media reporting of the Myanmar government's aid efforts. Specifically regarding the Nargis cyclone disaster Dr van Tulleken feels that the Myanmar government's vices were passive and their virtues active. He feels that the western media interacted mainly with the NGOs present in the country and not the government which could explain the negative images portrayed.

Dr van Tulleken went on to describe the concepts of prejudicial language used by the humanitarian aid sector and how humanitarian assistance could be interpreted as an extension of foreign policy. An example he used was the term 'beneficiary', implying a successful outcome of a project even before implementation. He went on to explain that the language of human rights is also a complex issue with legal, moral, practical and philosophical concepts. The interpretation of rights varies across these ideas, for example the idea legal rights laid out in the Bill of Rights differs from the moral rights groups such as Amnesty International use.

Dr van Tulleken expressed the importance of incorporating a rights based approach in programme planning. Using the example of a malaria eradication programme he emphasised the need to look at the various rights elements, for example a programme that effectively tackled malaria but was discriminatory or polluted, may have an overall negative effect on supposed beneficiaries.



A Rights based approach as described by Dr van Tulleken would include the following:

- Interdependence
- Participation
- Non - discrimination
- Accountability
- Availability
- Accessibility
- Acceptability
- Quality

He feels that the Myanmar government's response to the Nargis cyclone performed surprisingly well in terms of a rights-based approach. It included factors ensuring participation, non - discrimination, accessibility and acceptability in its delivery of aid.

Dr van Tulleken described how, by some of the principles of a rights-based approach, the health cluster performed poorly; for example not printing translated documentation for local NGOs.

Dr van Tulleken briefly outlined the idea behind the documentary 'Medicine Men Go Wild'. A programme where by he and his brother (also a doctor) lived amongst people who had no contact with Western medicine.

During this experience he spent some time living with the Byaka pygmies in Congo Brazzaville. These people live as semi-nomadic hunter gatherers. The serendipity of this way of life prevents the accrual of wealth and flattens social hierarchy.

Some groups of Byaka may be healthier than their Bantu neighbours who have poor access to, and are heavily reliant upon, western medicines. Dr van Tulleken then discussed the idea put forward by some NGOs who work with indigenous people, which would be to leave tribes such as the Byaka

pygmies alone as contact could do more harm than good (e.g. bringing diseases of the urban poor). He raised debate around the idea of forcing treatment on to people versus the right to treatment and life. An often overlooked issue is that despite the good health of adult Byaka pygmies, for every one adult, three die before their fifth birthday. Many of these deaths are due to malaria.

Dr van Tulleken spoke of the different approaches needed in treating and preventing malaria in Burma and the Congo, for example in Burma mosquitoes generally bite during the evening whereas in Congo Brazzaville they tend to bite at night. He explains that logistical issues arise in Congo Brazzaville given the roaming nature of hunter gatherer groups such as the Byaka. He explains his view that in reality the only way to eradicate malaria is when people are protected from mosquitoes by better housing and modern social infrastructure, however these are accompanied by health problems of the urban poor. He concludes that the successful eradication of malaria is less to do with treatment and more concerned with ensuring the civil and human rights of the people, but in the meantime groups such as Malaria Consortium and other NGOs do the best they possibly can to treat those affected.



The Chair then introduced a question and answer session.

#### Questions and Answers

Q - More money is being put into areas of lower prevalence (of malaria) as a strategy to eliminate malaria in certain areas, at the cost of targeting areas with the most malaria. Coming from a human rights perspective how do you feel about this?

A - Public health programmes always have a conflict between the rights of the individual to self-determination and the rights of the population to health, even in the UK with vaccination programmes. A rights based approach does not necessarily have to be, for example, non-discriminatory, but it must ask this question prior to acting. In some cases being discriminatory is the correct way to proceed. A rights based approach should never force us to bad programming.

Q - What is the Byaka pygmies understanding of malaria?

A - My understanding of this is necessarily limited; we lived with the Byaka for a few weeks and obviously all communication was through a translator. They describe it as a 'heat from inside the body' and treat it with herbal medicines. They seemed to have quite a mechanistic understanding of disease as caused by foreign agents within the body that can be treated with plant derived chemicals.

Q - Although many indigenous communities with high infant mortality rates can only survive at current population levels with the resources they have, and bringing healthcare would disturb this natural balance, they naturally want all their children to survive. This raises a difficult human rights question, how can we question whether supplying them healthcare is a good or bad thing? A mother will always want her child to get the best possible chance to survive.

A- I wholeheartedly agree, a rights based approach to treatment is needed. You would have to consult the people and treat them if they wanted it. You would not force treatment upon people, the key is to consult with people and work to help them get what they want.

Comment from floor - A huge amount of money gets spent on specific programmes by large agencies, but when they don't work and the agencies simply walk away, they are not held accountable. Nobody seems to be advocating that these agencies be held accountable for this money.

Q - Comment arose about the dramatic affect that malaria has on the genome of the body and its relationship to sickle cell anaemia.

A - Yes malaria is a very unique and complicated disease.

Q - What are you feelings towards local production of pharmaceuticals?

A - Local production in some circumstances works quite well. It creates personal confidence, benefits the community and stimulates the local economy but I couldn't comment specifically on the local production of pharmaceuticals as its something I don't know much about.

Q - What do you think the private sectors role should be in the rights based approach?

A - I don't see why the private sector approach should be any different from the public sector or the NGO sector. But I don't have a particularly strong view on the matter apart from to say that the private sector can be very effective e.g. ARV distribution.

Q - Malaria is considered part of life to African people and it is a western perception that it is a problem. There should be more research into a vaccine.

A - I am less confident that a malaria vaccine is the solution. The best vaccine for malaria is malaria when immunity is built up. However Africans returning to Africa from time outside malaria prevalent countries should be aware that they will no longer have the same immunity. Only political and economic change can lead to malaria eradication.

Q - Disease specific funding could be considered a violation of human rights and NGOs should be investing in health system strengthening.

A - it can be argued that the right to health is a subsidiary right, that follows with other rights being implemented that improve basic facilities such as sewage. In the meantime we need to attack the problem from both ends - both disease specific and in health system strengthening.

Q - Health system strengthening approaches only work if people are given equal access and opportunities.

A - I Agree! But I can only comment on my own experiences.

Chair - a key issue is that both system strengthening and disease specific approaches must be backed, but we cannot implement either maximally with continuing change in decision makers. We must accompany both with long-term aims and programmes.

Q - In terms of the hunter gatherers - if the woman in the picture (holding her sick child) asks you 'what do you recommend I do?' - either leave her to her own way of life or advise her to seek westernised medical care - what would you do?

A - I would inform people so that they could make their own choices. It is difficult to envisage a situation whereby remote indigenous peoples have access to western medicine without it changing their way of life and often this can do more harm than good. A rights based approach would aim to inform as best as possible the people we are trying to help and try to implement the changes they desire. An innovative approach grounded in rights is needed.

### **Chair Summary**

The primary right that we must consider is the right to survive. Should it be available to all? The second issue is to decide whether to target low prevalence of malaria areas that we can quickly tackle and wait to deal with the more difficult areas, or to target the most difficult areas first. Regarding the private sector we must explore the possibility that they can play a key role in affording more people the right to access healthcare. It is important to decide which our priority is - to provide healthcare without consulting indigenous people, or to find out exactly what they want?

There are two key questions to leave here with: does the overindulgence of some people exercising certain rights limit the possibility for others to exercise their rights? The second question is how do we keep in mind both ideas of equality and dignity? Not necessarily our understanding of dignity, but the understanding of those we are striving to help.

*All photos by Jon Challicom*