

Local Understandings of Illness and Disease, and the Impact on Disease Control Programmes

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Public health and disease control programmes undertaken in continents such as Africa and Asia can meet with varied success. Often this is not because of lack of good intent, money or even good science, but failure to take into account local understandings, hierarchies and allegiances to traditional beliefs and its actors. This is especially true when there is a pluralistic medical system, where both biomedical and traditional medical ontologies vie for the control of the people and interpretations of illness events often based on post-colonial thinking.

This article will look at examples in both continents where disease control programmes have proved difficult to implement and sustain, due to an ignorance of the local understanding of the illness by the delivering authorities. It will also show how research by ethnographic methods can work with the biomedical model to increase the success of a disease control programme.

Malaria is the biggest single cause of mortality worldwide especially in Africa where it is estimated that between 700,000 and 900,000 people mainly children under five die of the disease per year (WHO Media Centre 2010). However this could well be an underestimate as it is difficult to obtain accurate figures because many febrile illnesses are treated as malaria without proper diagnosis and many children will die of malaria having no access to hospital treatment or diagnosis. Malaria is also prevalent in other countries such as India.

Over the past years many malaria control programmes have tried to reduce the morbidity and mortality rate from the disease and yet it is still on the increase. This essay will look at two different approaches in India and Africa to reduce the burden of malaria on the people.

The Malaria parasite is spread by the female Anopheline mosquito; she requires a blood meal every time she matures a batch of fertilized eggs. The blood meal often comes from a human as the obligatory species. It is during this meal that the sporozoite stage of the parasite migrates from the salivary gland of the mosquito and enters the victim resulting in malaria, if the human has no acquired immunity. At the same time malaria gametes can be transferred to the mosquito from that person infecting the mosquito which allows the life cycle of the *Plasmodium* parasite to continue.

Treating people who harbour the malaria parasite, to eliminate the 'reservoir', is impossible because of the enormity of the cost and the political and logistic problems it poses. As a result many malaria control programmes are aimed at reducing the number of mosquitoes i.e. the vector, and reducing the ability of the vector to bite.

In 1960 the World Health Organisation (WHO) unrolled a programme to eradicate malaria worldwide by a programme of spraying DDT, a residual pesticide, in order to eliminate the vector. However logistical and political difficulties caused the programme to fail. (WHO 1961). Ethnographic research may have helped in some countries where suspicion and clashes with local beliefs may have allowed more sensitive delivery of the programme.

However the residual effects of DDT and its harm on the wildlife also helped to negate the effectiveness of the programme.

Nonetheless, local programmes of vector control using insecticide treated bed nets have also met with limited success. Drawing on a study done in tribal areas of Orissa India (Jambulinam 2008) based on the knowledge that properly used bednets can reduce the incidence of malaria by up to 50%, and overall mortality in the under- fives by as much as 70% (Alonso *et al.* 1991), a programme of supplying free treated bednets to a number of villages was rolled out.

However problems were encountered with the programme as local understanding of the causes of malaria varied. Some believed that mosquitoes were not involved but that the disease could be caused by drinking or wading in dirty water, by overwork, by too much sun exposure, or by irregular meals, and with 38% professing no knowledge of causation. These causes were also given by people of Tanzania, when asked the same question. (Hausmann Muela 1998). Not surprisingly there was a direct relationship between understanding that mosquitoes were the cause of malaria and the successful use of the bednets.

Bednets required retreating with the insecticide every 6 months or so and although the bednets were provided free, in the study in India the treatment had to be paid for. This payment was beyond the means of many people and the ones who paid did so out of fear that they might lose other welfare benefits. So here was a clear case where the science was sound but the social research and marketing was poor. There is no doubt that prior ethnographic research would have increased the success of the programme by running an education programme alongside the bednet distribution and assessing the beliefs of the people first so the programme could have been delivered with greater sensitivity. The majority of deaths from malaria occur in the under-fives as the children are vulnerable after the passive immunity from the mother has faded. Therefore malaria control programmes have been targeted at the under-fives because the majority of children who survive in an area where malaria is endemic will develop some immunity.

Of the five malaria parasites known to affect humans *Plasmodium Falciparum* is the species that accounts for the greatest mortality. The mortality is a result of the unique way the 'schizont' stage of the parasite develops in the red cells and causes the red cells to become irregular and sequestered. The irregular cells then clog the small arterioles starving the recipient organ of blood and therefore oxygen. Therefore it can be seen that the presenting symptoms of malaria may be many and varied depending on which arterioles are blocked. For example if the arterioles feeding the kidney are blocked renal failure can ensue, and if those feeding the gut are blocked then diarrhoea and vomiting can ensue. Blocking the arterioles in the lungs can cause severe breathing problems and if the arterioles feeding the brain are blocked the patient may have fits and loss of consciousness leading to death, a complication commonly known as 'cerebral malaria'. Also the destruction of red blood cells and the trapping of red cells in an enlarged spleen, present during the development of immunity, can lead to severe anaemia.

Problems in the rapid treatment of malaria can arise when there is a pluralistic medical tradition. The different presenting symptoms of malaria can allow the symptomatology to be interpreted in different ways, as the ontologies of biomedical and traditional medical practitioners compete for control of the people and their illness. For example, whereas a

biomedical doctor would be suspicious that convulsions and coma could be caused by malaria in Tanzania, this may be interpreted by traditional healers as something completely different, *degedege*. This dual interpretation can be confusing to a mother whose child is seriously ill with malaria, causing her to delay visiting the hospital for treatment, and reducing the chances of her child surviving.

In Tanzania where witchcraft is common, convulsions, *degedege* and the presence of anaemia and a large spleen *bandama* are seen to have supernatural causes (Hausmann Muela 1998). This requires the mother of a child to seek help 'protection' from a traditional healer before going to hospital. Whereas they understand 'normal' malaria *homa*, any symptom that deviates from fever with its associated malaise and myalgia is given a causation derived from traditional beliefs.

The mother may reason that the cause of the convulsions or coma may be due to witchcraft. This may not be directed at the child, but is a direct effect of spirits sent by witches aimed at another member of the family because of envy or revenge. The convulsions are interpreted as *degedege* a traditional illness. There is little doubt that most of the convulsive states are the result of 'cerebral malaria' (Langwick 2007). However traditional healers argue that the needles used to treat malaria can also bring on *degedege* and possibly cause a fatal outcome (Langwick 2007), another argument that often makes the mother take her sick child to the traditional healer first.

There is a fundamental difference in the understanding of the curative cultures. The traditional healer seeks to 'toughen' the exterior body to prevent penetration by spirits, whereas the biomedical doctor looks inside the body to find parasites to eliminate. The healer, whose focus is more on the body, does not have to show the spirits or eliminate them, only prevent them entering.

Malaria parasites can be difficult to detect, even though malaria is present. The failure to find them in a blood film therefore reinforces the belief in a supernatural cause. The spirits *manjini* can do two things. Firstly they can mask the parasites so that the hospital will not be able to detect them on microscopy, not an unusual occurrence as it can take three successive blood films before parasites are identified, and secondly, the *manjini* can cause an illness that mirrors the symptoms of malaria, but is not true malaria, which also explains why parasites may not be detected even though the child displays all the symptoms of *homa*.

Another reason for parasites not being detected in a blood film is the use of anti-malarial drugs given before a hospital visit, as these can eliminate the developing parasite in the red blood cells. Unless the treatment course is completed it will not eliminate the disease. The danger is that failure to detect the parasites under the microscope again, favours the diagnosis of 'witchcraft' and the biomedical treatment is therefore stopped while a traditional cure is sourced.

The traditional medicines and herbs used in the treatment of *degedege* are bitter. It is believed that too much 'bitter' causes the blood to boil (Hausmann-Muela 1998). Drugs that biomedical doctors use to treat malaria such as quinine and chloroquine are also bitter. Therefore, to prevent an 'overdose' of bitterness, western medication may be stopped or reduced allowing the disease to remain or recur. The failure of treatment and recurrences of the symptoms will lead to the suspicion of a supernatural cause.

It is also believed that *Majini* can cause the elimination of western medication by vomiting or toughening the skin to prevent needles entering or causing them to break, thus necessitating a visit to the witchdoctor before visiting the hospital.

Therefore, because the symptoms of 'severe complicated malaria' can be interpreted as a traditional illness, it allows the traditional healer, *mganga*, to be a major player in the treatment of the sick child, often delaying curative biomedical treatment. Even though, in Tanzania, educational programmes allow the people to have a good understanding about the aetiology of malaria, it does not answer the question 'why me?' In a culture where beliefs in witchcraft are strong and suspicion and superstition are prevalent, the people turn to witchcraft to answer those questions. Hausmann Muela (1998) gives an example in her paper when she tells of a woman that understands that mosquitoes spread malaria but wants to know 'who sent that mosquito'. A theme I shall return to later.

There is also a battle of the ontologies for the control of the people and their illness. The traditional and long held beliefs, around *degedege*, belong to the traditional healer and the observation of parasites in the blood is the domain of the biomedical doctor. While it is important for the two medicine cultures to work alongside one another in order to preserve the pride and ego of all players, there is the potential that the traditional system can cause serious and possibly fatal delay in treatment.

The ethnological research suggested the promulgation of two messages. Firstly, not completing the course of biomedical treatment may lead to recurrence of malaria, and secondly, taking malaria medication before a hospital visit may temporarily eliminate the parasite from the blood preventing the diagnosis. However ethnographic research suggests that the main cause of poor treatment-seeking behaviour may be economic because of the lack of money or the lack of time due to agricultural work (Hausmann-Muela 1998 Langwick 2007).

In another example, of the conflict between two competing medical cultures, Heald (2002) describes how HIV/AIDS, in Botswana, has been reinterpreted as *tswana* a traditional disease, and a progression of other venereal diseases. 36.1 million people are estimated to be living with HIV/AIDS in sub-Saharan Africa (UNAIDS 2000). Against this background a disease control programme was launched in Botswana.

Botswana is one of the richest countries in Africa largely due to both the diamond mines at Orapa, and a relatively stable government with a small population of 1.4 million people. It has a well run health service and has the enviable ability to be able to provide anti-retroviral drugs to sufferers of HIV/AIDS. However it is still the case that 50% of 15 year olds will die of AIDS or AIDS related illnesses. There was an exceptional rise in people with HIV/AIDS with the number doubling between 1992 and 1997 and 43% - 50% of pregnant women testing positive for the virus. During ethnological work it was discovered that HIV/AIDS was not necessarily seen by some of the people as a new disease, but rather a new presentation of an old traditional disease, *tswana*.

HIV/AIDS was initially described by the government as mainly a disease of white homosexuals and therefore was ignored for some time by the local population (Heald 2000). The language of AIDS was always that of Western science and biomedicine which excluded the traditional healers and marginalised them within the management of the disease. Even the government slogan ABC," Abstain, Be faithful and Condomise" was written in

'white man's' English rather than Setswana the traditional language. However further ethnological investigation revealed deep flaws in this strategy. It was not understood that in Botswana kinship, discourse around sexual matters was not encouraged and that advocating the use of condoms was seen as an invitation to promiscuity causing a backlash that saw the condom as a cause of HIV/AIDS.

In Botswana there are many spiritual churches that support the traditional healers, *Tswana* doctors. These traditions are normally hostile to western medicine. In Botswana, females are more likely to follow the churches with their spiritual healers whereas males are more likely to follow the traditional healers. (Hausmann Muela 1998). Most of the traditional medical cultures rely on diviners, throwers of bones, to diagnose and treat illnesses. It is true that the majority of people use the well established western medical facilities (Seely 1973). However western medicine offers a treatment regime but does not explain the underlying reasons why the person contracted the disease. A view reflecting similarities in the example of 'the directing of the mosquito' mentioned above and a point made by Evans-Pritchard (1976) in his book 'Oracles, Witchcraft and Magic among the Azande'. The traditional beliefs offer a rationale for the contracting of an illness and explains the chance nature of illness in terms of witchcraft, which may be as a result of anger, moral misdemeanours or breaking taboos. This view of witchcraft is reinforced when western medicine fails to cure or prevent HIV/AIDS.

Some traditional healers blamed AIDS and the breakdown of traditional culture and loss of traditional values on the white man. Pills, condoms and contraceptive coils related to the HIV/AIDS programme were seen as symbols and tools promoting this change. The spread of HIV/AIDS was a white man's way of reducing the population, a view almost certainly born from colonialism and a theme I shall return to later.

The traditional healers have an understanding of HIV/AIDS and venereal diseases that does not totally match the Western model and although it is believed that venereal diseases are spread by sexual intercourse, it is believed that they can mutate for example gonorrhoea after a time can become syphilis harboured secretly in the woman, or that it is intercourse with the wrong woman at the wrong time that causes the disease rather than the transfer of an infecting organism. Examples of causes could be breaking the taboos around not having intercourse in the three month period following birth, or intercourse after an abnormal birth before ritual cleansing. This view of the aetiology of HIV/AIDS locates the blame firmly in the woman. Man's role serves only to transmit the 'pollution' from one woman to another.

Another belief explains how the health of the body can be weakened, allowing the contracting of HIV/AIDS, and how wearing a condom can create that weakness. In Botswana, the traditional understanding of the body is of a tube full of blood, the blood needs to be kept thin, red and flowing. During the union between a man and his wife, blood, semen and vaginal fluids need to be mixed to create a 'good' blood flow, which maintains health. Preventing such 'flows', as when wearing a condom, creates blockage and causes bad health and disease such as AIDS. (Heald 2000).

The ethnographic research revealed something far deeper than just the mistrust of western tradition which may be a reaction to colonial days and its reinterpretation of the disease. It revealed a society where the poor and uneducated saw their traditional culture being eroded accompanied by a loss of power of the elders and chiefs, and the loss of power of men over

women. The increase in diseases like HIV/AIDS, the rise in teenage pregnancies and the breakdown of traditional social structure, especially the loss of control of women was blamed on supernatural causes, confirming the belief that witchcraft must be to blame and therefore propelling people towards traditional healers.

There was also a new order of wealth developing in Botswana producing envy and suspicion, the very conditions that encourage the use of witchdoctors to avenge differences. It is clear that if the HIV epidemic is to be halted, an 'African' understanding of the disease needs to be considered both in a political sense and in a practical way that allows the western message to be understood.

Footnote:

When I was working in Botswana in 2005 I had occasion to speak with the health minister regarding HIV/AIDS. She told me of a new HIV culture that was developing. In Botswana all people who are HIV positive receive anti-retroviral drugs and regular hospital follow up. Also they receive a state pension. It is believed, by the people, and it may be true, that the survival rate amongst that group is greater than that of the local, uninfected, population. There is now a culture where young people are now purposely infecting themselves with HIV to achieve 'citizenship' of this group. One girl told me; 'my boyfriend 'dumped' me because I was not infected with the virus and therefore I was no good to him'.

Other well meaning health campaigns in Africa have failed because of the lack of 'local' understanding. In her paper (Feldman-Savelsberg 2000) describes a programme of vaccination against tetanus for young girls in Cameroon in 1990.

The anti-tetanus vaccination of young girls produces anti-bodies in future mothers which would protect their unborn babies against tetanus. Tetanus is a fatal disease caused by an infection with the tetanus bacteria which neonates can acquire from dressing the umbilical cord with ash or cow dung.

The poorly advertised and explained campaign caused panic because it was thought that the vaccine was being used to sterilise young women. This view may be a result of post-colonial thinking following the French vaccination campaigns against smallpox and efforts to eliminate sleeping sickness and leprosy. There was also confusion when the vaccination and birth control campaigns were linked erroneously. 'Superstitions and rumours arising from misconceptions and miscommunications emerging from a clash of interests and perspectives' (Geertz 1973) caused the campaign to be cancelled. It was unfortunate that the anti-tetanus campaign was announced concurrently with the Government's contraceptive campaign. In the minds of the people the two became linked, a suspicion reinforced by the fact that only females were offered the vaccine. There were also political struggles between various churches and the government which increased the suspicion. Rumours spread initially that the vaccine was 'bad' and unhealthy, and, when the anti-abortion groups became involved, rumours began to circulate that the vaccine made girls sterile. Soon the suspicion that the vaccine was 'sterilising' spread throughout the whole country.

There were differing perspectives on the vaccination campaign. The health workers had a mission. They were following an ideal, to vaccinate 80% of young girls and reduce or eliminate neo-natal tetanus in line with the Universal Child Immunisation Programme. Their zealous approach to achieve their target rode rough-shod over local sensibilities. The

girls' perspective came out of misunderstanding and ignorance. The education programme prior to the vaccination was poor and only 18% of girls remembered that the vaccine was against tetanus (Feldman-Savelsberg 2000). The girls felt they were being forced to have the vaccine and had to submit to authority otherwise they would have their education withdrawn. Also, in one school, the gates were locked in order to make sure all pupils were vaccinated. This created panic as they thought they were being forcibly sterilised by the vaccination. The fear of being rendered sterile forced 10% of the vaccinated girls to consult a biomedical doctor for reassurance and many took medications they thought would neutralise the vaccine. Some believing that they were now sterile failed to continue to use contraceptive measures. Others sought pregnancy in order to reassure them that they were not sterile. As a result during the following two years there were many extra unwanted pregnancies and the abortion rate increased significantly (Heald 2007).

Rumour was described by Allport and Postman (1947) as 'A specific proposition for belief, passed along from person to person, usually by word of mouth, without secure standards of evidence being present' (1947:ix) This was certainly the case with this campaign and, in the end, rumour and suspicion halted the campaign. In a way this was not surprising as, historically, rumours of sterilising and poisoning in sub-Saharan Africa are not uncommon. For example in 1990, residents avoided smallpox vaccination as it was thought to be poisonous (White 1995). Smallpox vaccine was also rumoured to be a plot to collect blood and bewitch the African labour force (Packard 1993). Five years later it was rumoured that vaccines were a way of producing bottled babies thus dispensing with the need for African women (White 1997). Also the people equated the injection with the way witchdoctors can introduce substances into wombs (Feldman-Savelsberg 1999).

So with little pre-campaign education and old symbolic beliefs surfacing, it was not surprising that the uptake of vaccine was poor. As a result, five years later, only 13% of girls were vaccinated against tetanus (WHO 1996) and confidence in vaccination was undermined as was trust in the health personnel. This caused health workers to be stoned when they entered villages (Van Geldermalsen 1991). Again prior research into sensitive areas of relevant beliefs by ethnography and education might have increased the success of the vaccination campaign and upheld the trust of the health workers.

In conclusion, I have considered four different disease control programmes in India and Africa and how success was tempered by ignorance, superstition, rumour and traditional beliefs. In all cases there were themes which were shared. Pluralistic medical traditions with different interpretations of illnesses caused confusion amongst the people. This was further fuelled by a battle for control of the illness and the patient as traditional healers tried to relocate themselves and their relevance, while western biomedicine tried to take over their traditional role. Common sensitivities were uncovered, such as control or loss of fertility, much of which relates to post-colonial thinking and could have been predicted with ethnographic research.

There were two other themes. Firstly there was a lack of prior education programmes to explain the aims of the medical interventions in a culturally sensitive way. Secondly, the limitations placed on health control programmes by the economics of the state and the family. It is to be hoped that, in future, addressing these problems by a partnership between medicine and anthropology will allow health intervention programmes to meet with full success.

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