



ARTICLES

FINES, ORDERS, FEAR . . . AND CONSENT? MEDICAL RESEARCH IN EAST AFRICA, C. 1950s

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ABSTRACT

This article reconstructs the history of medical research in East Africa (Kenya, Tanganyika, Uganda), laying out the lies, rumours, and oppressive techniques that made research such a fraught enterprise during the colonial era. The focus is on the beginning stages of medical research: researchers' arrivals, villagers' responses, the gathering of subjects and consent. New archival and oral sources gathered in East Africa illuminate the research encounter and reintegrate the perspective of villagers cum subjects. Data from the 1950s shows that upon arrival in a village, researchers regularly lied in order to avoid sensitive topics and sidestep potential opposition. Misinformation fuelled villagers' fears, skepticism and rumours of blood stealing researchers. When it came to gathering subjects, researchers were rarely involved in the challenging work of enticing villagers to participate, preferring to rely on chiefs. Chiefs, however, often relied on heavy-handed and ethically questionable techniques. The article concludes by looking at the much-discussed concept of group consent, and showing that historically a chief never had the authority to consent on behalf of villagers.

INTRODUCTION

For more than a century, Africans have been functioning in systems of medical pluralism. Since the first set of Europeans arrived in East Africa in the mid-1800s and began their civilizing campaigns, Africans have been exposed to Western medicine through the introduction of new technologies such as needles and pills and more abstract concepts including informed consent and randomization. Racist ideas about Africans' intellect created a breeding ground for both benevolent and not so benevolent paternalism. Africans were forced to follow pill regimens of untested drugs; provide blood samples; be measured, poked and probed; and allow invasive procedures such as lumbar punctures – all in the name of research.¹

¹ M. Lyons. 1992. *The Colonial Disease: A Social History of Sleeping Sickness in Northern Zaire, 1900–1940*. Cambridge, UK: Cambridge University Press; L. White. 2000. *Speaking with Vampires: Rumor and History in Colonial Africa*. Berkeley, CA: University of California Press;

Large amounts of medical research occurred in the British colonies in East Africa (Kenya, Tanganyika and Uganda) between 1940 and 1960. A conservative estimate has between 30,000–50,000 people participating in some form of human experimentation by giving blood, stool, urine or skin samples; being physically examined for leprosy, sleeping sickness or river blindness; or participating in drug trials related to malaria, tuberculosis or bilharzia.²

It would be easy to write this history by relying only on documents produced by the British colonial government

K. Hoppe. 2003. *Lords of the Fly: Sleeping Sickness Control in British East Africa 1900–1960*. Westport, CT: Praeger.

² This is a low estimate based only on the references to trials I have personally seen in the materials in East Africa. I only counted trials that were clear about the number of subjects they included, and I relied on the estimates of the researchers. The East African Medical Survey alone handled 'tens of thousands of lab exams' between 1948 and 1955. East African Medical Survey and Research Institute. 1955. *East African Medical Survey and Research Institute Annual Report, 1954–55*. Nairobi: Government Printer.

and researchers.³ But this would result in a partial reconstruction of an encounter that involved both medical researchers and East African villagers. To this end, I have gathered oral information from East African researchers, assistants, subjects and observers.⁴ I have tried to integrate local peoples' perspectives to arrive at a more nuanced understanding of how projects actually occurred. The article is built around the chronology of the research encounter. It starts with researchers' arrival in the village and the explanations of their work, and then examines what villagers thought of these researchers, and analyzes recruitment and consent practices.

THE 'EXPERTS' ARRIVE

Medical researchers arriving to small villages in rural East Africa faced a difficult situation. They had to figure out how to explain their work and introduce themselves to the communities. How truthful, honest and forthcoming to be? What kinds of promises to make? Based on researchers' own writings, it is clear they routinely misinformed villagers about the scope of their work and their purpose for being there. This section describes the methods researchers often used during this initial stage of arrival.

Doctors or researchers?

During the 1950s, researchers were purposefully collapsing doctoring and researching together to put people at ease and make their own work easier. When arriving in a new location, the team would establish themselves at the local dispensary or district hospital. They would introduce themselves as doctors coming to treat the sick. This was a strategic decision since people would line up to see a doctor providing medicine, but would often flee from a foreigner asking for blood samples. As one of the researchers described it:

. . . news was spread, through the Chiefs, that a group of doctors, with a supply of medicines, was working at the dispensary, and that they were prepared to see and treat any sick people who came. Any mention of 'investigation' or 'blood samples' was carefully avoided.⁵

³ Many of the archival materials have sat undisturbed for the past half-century. While working at the Tanzanian National Institute of Medical Research (NIMR) research stations in Mwanza and Amani, I discovered previously un-cataloged materials. When referencing these materials, I cite 'NIMR Mwanza' or 'NIMR Amani'.

⁴ Oral data was gathered through approximately 40 formal interviews and dozens of informal conversations in 15 different locations in Kenya and Tanzania during 2008 while conducting fieldwork for my doctoral dissertation. This research was supported by a National Science Foundation Graduate Research Fellowship.

⁵ R. Moore & A. Roberts. An Investigation of the Pattern of Disease Prevalent in Parts of the Rufiji District. Dr Moore Papers. NIMR Mwanza.

There is no doubt the workers were purposefully concealing their research. They offered medicines to 'treat' sick people and avoided words such as 'blood' that would have tipped villagers off – and caused them to ask appropriate, yet potentially difficult questions like: 'where is the blood going; why do you need it; and what do we get?'.⁶

It could be argued that the researchers were not hiding their work, since they were both researchers collecting samples *and* doctors treating patients. While this is theoretically possible, it was rare in the field. Hope Trant, a long-term medical researcher, wrote bitterly of her inability to properly treat subjects. After being chastised by her boss for giving out basic medicines, she complained that she was becoming 'just a collector of specimens and not a doctor'.⁷

Her frustration, and her inability to adequately treat patients, was the result of conscious decisions by the directors of the medical research schemes. The directors did not want time or money wasted on treatment when they could be collecting data. Trant's boss told her repeatedly that the 'main object is to carry out research: treatment of individuals was only allowed as a method of gaining the confidence of the people' and that her job was 'to carry out research work and that treatment of patients is the responsibility of the Medical Department'.⁸ Given these conditions it seems all the more deceptive that researchers should introduce themselves as doctors to eager villagers.

Big promises

Another way researchers tried to persuade villagers to participate was by coming bearing gifts and making promises. The gifts were small offerings, but the promises were big and sweeping. Unfortunately the claims did not always translate well culturally. In the mid-1950s on the Kenyan coast, the Department of Insect Borne Diseases (DIBD) was running a project on the Lamu Archipelago. The researchers promised to improve people's health by eradicating filariasis (commonly known and presenting as elephantiasis). The boast was not received quite as the researchers had hoped – it did not make sense. Most villagers understood disease much more holistically than the researchers did. Disease was not only caused by 'bugs' infecting one's blood, and doctors were not the only ones

⁶ Blood is intimately linked in peoples' minds with medical research. This may be because many medical researchers explain 'research' to people as the taking of blood and the examination of blood under a microscope to look for the 'bugs' that cause sickness.

⁷ December 4, 1953. From Trant to Director Laurie. NIMR Mwanza.

⁸ February 27, 1951. From Director Laurie to Trant. NIMR Mwanza; November 13, 1950. From Administrative Officer to Trant. NIMR Mwanza.

who could cure. Religious figures, traditional healers or spirit mediums could also provide effective treatment for ill health.⁹

An observant researcher finally figured out that villagers were unimpressed by the eradication promise. He explained to his boss that the project was floundering because people 'believed that elephantiasis is contracted from infected persons, like smallpox. It is not believed to be anything to do with mosquitoes . . . [and] is sent by God.'¹⁰

Since filariasis was not caused by mosquitoes, and was actually divine will, it made no sense that researchers claimed they could eradicate the disease by killing mosquitoes and clearing water containers. Such claims worked to undercut the researchers' believability. It also made it hard to create a viable relationship based on trust. It could have been a different story had they actually succeeded at eradicating the disease, but they did not.

Tricky tactics

In some cases, researchers did explain their work as research, without hiding behind a veil of doctoring. In these cases, they had to decide how much to explain about their work and how to get community approval. During the filariasis eradication attempt in Lamu, the plan was to use primarily entomological methods to eradicate the transmitting mosquitoes. People were never the primary focus, but even a bug-oriented research program involved humans at some stage.

Although researchers had quickly boasted to villagers that their work would eliminate elephantiasis, they were less forthcoming with information about *how* that attempt would be made. The researchers knew they would need villagers to cooperate by giving access to their bodies, homes, and property, yet that information was never clearly conveyed. Blood samples would be required to determine filariasis prevalence rates and the scope of the problem, and testing would be particularly difficult since venous blood had to be taken after 10:00 pm.¹¹ Traps also had to be set inside homes and land had to be walked to check for mosquito breeding areas.

Within hours of the researchers' arrival, there were problems. Villagers argued that researchers were lying about their true intentions and that the work was just an excuse for the government to enter the village to tax and fine them. The DIBD workers encountered well-organized community opposition: there was a public rally

with hundreds of people, physical threats were made against the African research assistants and community leaders threatened to throw the whole team of researchers out of the village.

In light of this opposition, researchers had to proclaim their good intentions (and put on hold activities like taking blood samples at night). But villagers remained suspicious and decided that while the researchers could stay, '*only* the search for and collection of mosquitoes . . . was permitted'.¹² There were to be no human examinations, and certainly no blood sampling.

For the researchers, a start with mosquitoes was fine, but it wasn't going to allow for the project to be complete. Any eradication attempt would require cleaning up buildings, modifying water storage practices and reorganizing sewage disposal. There would also be a need for large-scale blood taking and a treatment campaign to measure and then eradicate the disease's human reservoir. The DIBD knew that 'a further approach to the public will have to be made'.¹³

In order to remain in the village, the researchers agreed to limit their actions to mosquito collection and consciously concealed their larger research agenda. The strategy was to get people to agree to one tiny piece of research at a time. The whole project was rarely explained, so the community's approval was based on partial, incomplete information. In the case of Lamu, this technique soured community-researcher relations on the archipelago for the next two decades.¹⁴ It also fuelled many stories of lying, blood stealing researchers.

VILLAGERS RESPOND

When researchers arrived, people observed, listened and formed their own opinions. The fact that researchers regularly lied about their goals and intentions – to collect mosquitoes, when really blood samples were needed; when they claimed to be doctors but really did research – only fuelled villagers' fear and skepticism. Concerns were given voice in stories questioning the *real* goals of research and what would be done with all of the collected samples of blood, urine, skin and stool. Were 'white experts' there to steal blood, steal people or kill people? The foreign-ness of researchers, their international ties and their wealth, just made them more suspect.

Researchers also suffered by being linked with the colonial government. Villagers did not perceive

⁹ M. Malowany. 1997. *Medical Pluralism: Disease Health and Healing on the Coast of Kenya, 1840–1940* (Ph.D. Dissertation). Montreal, QC: McGill University.

¹⁰ March 2, 1956. From Brayne Nicholls to Provincial Commissioner, Coast. 'Elephantiasis Survey: Pate Island.' DC/LAMU/2/23/29. KNA.

¹¹ Daytime blood tests for filariasis will produce false negatives; only in the evening do the micro-filare become active in the peripheral blood.

¹² March 13, 1956. Letter from Brayne Nicholls to Senior Parasitologist. 'Elephantiasis Survey Pate Island.' DC/LAMU/2/23/29. KNA (emphasis added).

¹³ Ibid.

¹⁴ The botched attempt in the 1950s soured medical researcher-villager relations throughout the 1960s and 1970s. DC/LAMU/2/23/29 and BY/13/44. KNA.

researchers as being part of autonomous inter-territorial research units or private universities (as many were). They were just another manifestation of the Government. And since local people did not trust the colonial government, they were suspicious. People's fear and distrust of the government were explained using a play on words in KiSwahili. 'Serikali' means 'government' but it sounds and looks remarkably similar to the words 'siri kali', which means a potent/dangerous secret. The very word to describe Government implied to people it was made up of dangerous secrets. The work of researchers was often referred to as just one of the 'secrets of the government' (siri ya serikali).

While researchers were not responsible for creating villagers' views of the colonial government, they played into these fears and took advantage of the benefits. Their lack of clear information, evasive answers and techniques for presenting research projects in incremental bits rather than explaining the whole meant that many aspects of the work remained a 'secret'. And many of the practices and people involved in the research encounter were described with the adjective 'kali' – 'fierce'. A tough researcher was 'kali', and a heavy-handed chief who aided the researchers was 'kali'. It all worked to reinforce connections between government, secrets, tough measures and research.

Another illustration of how people's impressions of researchers were shaded by their views of the Government comes through the use of phrase 'amri, si ombi'. It translates as 'orders, not requests' and was used to describe what the Government (and its functionaries) issued. The District Commissioner, the Chief and the researchers did not *request* that people participate in research trials, they *ordered* it. A statement from the chief did not have to be prefaced by the words 'This is an order' – it was understood that the government only gave out 'amri, si ombi'.

Mr. Elephantiasis

Throughout East Africa, and Africa more widely, rumours have circulated for decades about blood sucking researchers.¹⁵ There were, however, local variations of this story. While interviewing people about the history of medical research in Mwanza region, Tanzania, nearly

everyone mentioned 'Bwana Matende' – Mr. Elephantiasis. People described him as a government-affiliated researcher, who worked in an office in Mwanza near the hospital, did research about elephantiasis, and also killed people and stole their blood. He was a foreigner, had strong ties with Europe and was always on the look out for Africans to capture.¹⁶

A typical story about Bwana Matende usually had the following elements: Bwana Matende is a white doctor/researcher. (People were undecided about his profession, noting that he worked in a laboratory, but also offered 'medicine' to sick people.) He steals and deals in blood and in the process kills people. He sells African blood internationally, which white people use for transfusions or to make medicine. Bwana Matende relies on sneaky tactics, and hides his bad intentions behind a veneer of politeness, often arriving in villages calling himself a doctor and dispersing free medicines. Frequently he is driving a car and offers lonely pedestrians a ride. Once the hapless African is in the car, Mr. Elephantiasis sucks his blood – not to drink, but to sell. The passenger is 'finished' and the body is disposed of. Bwana Matende is not a 'vampire' but an intermediary, earning his way in life through peddling other peoples' fluids.

This broad outline of the story is amazingly consistent with the history of medical research in the area. People said that Mr. Elephantiasis was most active in the 1950s and 1960s, and no longer worked in the area today. It was in the late 1940s that the East African Medical Survey and Filariasis Research Unit were established in Mwanza. It was during the 1950s that large elephantiasis research projects involving thousands of people were run in villages around Mwanza and on islands in Lake Victoria. Stories of Bwana Matende circulated and gained relevancy as white researchers entered villages to take blood samples under the cover of darkness and used cars to take villagers away for multi-day hospital stays. Research related mishaps and deaths in the region only strengthened Bwana Matende's relevance.¹⁷

Is Mr. Elephantiasis fact or fiction, mere metaphor or something more tangible? Certainly Bwana Matende functions partially in the realm of fact, as the alignment of dates and locations indicates. The story was originally based on the work of a real man employed by the Filariasis Research Unit. Even local people agree the original

¹⁵ J. Comaroff & J.L. Comaroff. Occult Economies and the Violence of Abstraction: Notes from the South African Postcolony. *Am Ethnol* 1999; 26: 279–303; J. Fairhead, M. Leach & M. Small. Where Techno-Science Meets Poverty: Medical Research and the Economy of Blood in The Gambia, West Africa. *Soc Sci Med* 2006; 63: 1109–1120; P.W. Geissler. Kachinja are Coming! Encounters Around Medical Research Work in a Kenyan Village. *Africa* 2005; 2: 173–202; B. Weiss. 1996. *The Making and Unmaking of the Haya Lived World: Consumption, Commoditization, and Everyday Practice*. Durham, NC: Duke University Press.

¹⁶ The information presented in this section is a compilation of information I gathered in 20 interviews and dozens of informal conversation with people in Mwanza region of Tanzania in July and August 2008.

¹⁷ As just one example, a woman told me how researchers (possibly Bwana Matende) had come to her primary school in the early 1960s to steal blood and had killed students in the process. While there were never any deaths at her school, archival records show that six children did die at a nearby school after being injected with an experimental bilharzia drug. Annual Report, Ministry of Health, Mwanza Region, Tanzania. 1965; August 6, 2008. Mama Christine Paolo. Bukumbi, Tanzania.

Bwana Matende is gone, yet the story remains because it accurately captures aspects of the research encounter. It has become a metaphor, idiom and analog for *all* unequal, unfair, suspicious research encounters.¹⁸ A reference today to Bwana Matende does not mean the original man has returned to steal blood, only that a researcher is around, engaging in dangerous, extractive and hidden activities.

As a researcher, Bwana Matende was also seen as being in cahoots with the government. This connection was emphasized in multiple interviews. When I asked if Bwana Matende worked for the government, people responded: 'Eh – the Government? He *is* the government!'¹⁹ People argued that when you were dealing with a 'secret' like the Government, you could never believe what you were told. You always had to be skeptical, and that when bad things did happen (for example, a person was killed) the real story would never be revealed. As one man explained, if you were unlucky enough to be taken by Bwana Matende, you could be sure the police would not help you. The police case would be closed, you would be dead, and the police officer would write that you had died due to 'bad luck'.²⁰

Due to researchers' close connections with the Government, villagers often felt compelled to participate, out of fear of what 'Government' could do. While no one claimed government control was so complete as for every act of defiance to be punished, they did emphasize the strength of the Government and how closely people paid attention to orders. One woman described how during the colonial period even babies sucking at the breast would stop to pay attention when the Government spoke.²¹ The assumption was that if you ignored an order there was going to be a price to pay.

GATHERING SUBJECTS: FINES, ORDERS AND THREATS

In rural parts of East Africa, the relationship between the colonial government and villagers was not always clear. Frequently, there was no obvious physical evidence of the state – no health clinics, courts or cars. But that did not mean people did not feel the state. For Africans, the state was often felt through taxes, fines, forced labour and their appointed intermediaries – the chiefs. The British ruled East Africa through a system of indirect rule, which relied heavily on the perceived 'traditional' authority of local leaders. Rather than using British officers, African men

became part of the colonial government as intermediaries, translating orders and enforcing rule of law in distant places.²² The system was often referred to as colonialism or 'hegemony on a shoe-string'.²³

The system of indirect rule meant researchers were rarely involved in the challenging work of enticing villagers to participate in their projects. Researchers preferred to cultivate a naive oblivion about the heavy-handed methods being used by African chiefs and 'middle men' to gather subjects.²⁴

Chiefs

'No matter how deep the suspicion of the native this can generally be overcome when we have the enthusiastic co-operation of the local authorities'.²⁵

Researchers believed chiefs – the 'local authorities' referenced above – were golden. They were much valued for the results they produced, if not for the techniques they used. Chiefs were an odd mixture of controllable and uncontrollable figures in the medical research context. The government expected the chief to explain the research to his people, 'overcome suspicion' and most importantly, 'obtain their cooperation'.²⁶ No details were ever given about how the leader should accomplish these things. The British evidenced no preference for honey or vinegar, but they were partial to good results.

After the researcher arrived and handed over government stamped and approved letters, the individual researcher would tell the chief what she needed: space to work, literate assistants and plenty of subjects. She would then turn away and wait while the chief did his 'chiefly duties'. This was a cultivated oblivion since she was smart enough to sense that the techniques being used were likely unpalatable, and she would not be able to change this behaviour.

Hope Trant lived through this experience many times during her 20 years of work on the continent. In 1954, she was employed by the East African Medical Survey to collect 3,000 samples of blood, urine and stool from a village in western Tanganyika. She was assisted by the

¹⁸ Geissler uses the concept of 'idiom' to describe how people use blood stealing stories. Geissler. *op. cit.* note 15, pp. 174–175.

¹⁹ August 7, 2008. Mzee Thomas Inyassi. Kigongo, Tanzania.

²⁰ Ibid.

²¹ August 8, 2008. Bibi Agnes Kagera. Bukumbi, Tanzania.

²² F. Lugard. 1923. *The Dual Mandate in British Tropical Africa*. London, UK: Blackwood and Sons; B. Berman. 1990. *Control & Crisis in Colonial Kenya: the Dialectic of Domination*. London, UK: James Currey.

²³ S. Berry. Hegemony on a Shoestring: Indirect Rule and Access to Agricultural Land. *Africa*. 1992; 62: 327–355.

²⁴ 'Middle men' included chiefs, elders and others with political power in the village—not just those who were employed by the colonial government.

²⁵ East African Medical Survey and Research Institute. 1954. *East Africa Medical Survey Annual Report, 1953*. Nairobi: Government Printer.

²⁶ September 5, 1958. Letter from District Commissioner, Lamu To Mudir of Faza and Witu. 'Filariasis Investigation.' DC/LAMU/2/23/29. KNA.

sub-chief, who was responsible for delivering 25 to 30 people each day. Trant considered him 'quite good' at bringing her a steady stream of subjects, but he eventually ran into problems. Rumours began to swirl that the researchers were sucking blood, and the community began to shirk.

The sub-chief informed Trant that he would get around villagers' reluctance by issuing a 'fine [to] those who refused' to participate.²⁷ While she had never inquired about his methods in their months of work together, she was forced to comment once he let it slip. She admonished him: 'fining is out of the question' even though the reality was she had little authority to complain or change his behaviour.²⁸ Furthermore, her complaints were half-hearted since if the chief failed to convince people the project would be delayed or even cancelled.

Trant's work in central Tanganyika is just one archivally documented case, but oral evidence shows that threatening punishment as an 'incentive' to participate was a widespread practice. In interviews, people described how 'kupiga faini' (to fine) was one way a chief could 'encourage' villagers to participate.²⁹ In some places, chiefs would also forcibly collect people from their fields, and threaten physical beatings or banishment from the village.³⁰ Possibly because of the ubiquity of these techniques, projects rarely floundered. Yet within the landscape of fines, orders and government fierceness, it would be hard to claim that these recruits were willing subjects.

GROUP CONSENT: A STRAW MAN

It has always been convenient for researchers to believe that group consent was a 'traditional' African practice and that getting consent from a chief was equivalent to the will of the people. Such a belief meant consent could be gained faster and culture could be respected by deferring to traditional African systems of authority. But despite the convenience of group consent (and the concept's continued circulation), there is no historical evidence to show that it ever really existed. Much of the literature about group consent was written decades ago

and little of it was grounded in actual data from the continent.³¹ During the 1950s, chiefs were often relied on to gather subjects – voluntary participation was hoped for, but not asked about. The reality was that most subjects were *not* informed, *not understanding* and *not* participating voluntarily. If group consent existed mid-century, it did not share many – or any – of the traits we value for individual consent today.

'Group consent' could describe one of two things. The whole community could come together and decide collectively that they will participate in a project. The chief then 'presents' this decision, as the head of the village. Or, the chief has the traditional authority to consent on behalf of his subjects, regardless of their individual opinions. The first of these scenarios qualifies as voluntary – a form of collective decision-making; the second does not. And a review of the historical and contemporary data shows that chiefs never had the authority to consent for people.

One of the ways we know this was not a traditional authority is because nothing like medical research existed prior to colonization. While there were sophisticated methods for healing in pre-colonial Africa, they did not include the scientific method, statistical significance or running large-scale research trials. If medical experimentation went on pre-colonially, it happened on a small scale, and most likely on sick patients appealing to the healer or herbalist for help. The type of medical experimentation brought from Europe was something entirely new.

The question, then, is what authority chiefs had in the realm of health and disease. Prior to colonization, chiefs were responsible for ensuring the overall 'health' of a village and had authority to make sweeping decisions during times of crisis, such as epidemics of smallpox or sleeping sickness.³² Chiefs were known to quarantine houses with sick people, ban sick people to the outskirts of the village, or demand that the entire village be moved to a safer area.³³ But even in these times of distress, the chief did not have the authority to decide treatment for individual patients. Whether a sick person went to an

²⁷ August 17, 1954. Letter from Trant to Senior Medical Officer, Tabora. Dr Trant Papers, NIMR Mwanza.

²⁸ Ibid.

²⁹ Interviews in Mwanza, Ukara and Ukerwere Islands. Further evidence that the practice of fining was used by chiefs during the colonial era comes by looking at the KiSwahili word. 'Kupiga faini' is derived from the English word 'fine' which is added to the multi-purpose KiSwahili verb 'kupiga' – to do or make.

³⁰ Interviews in Mwanza, Ukara and Ukerwere Islands. July and August 2008.

³¹ M. Barry. Ethical Considerations of Human Investigation in Developing Countries: the AIDS Dilemma. *NEJM* 1988; 319: 1083–1086; N.A. Christakis. The Ethical Design of an AIDS Vaccine Trial in Africa. *Hastings Cent Rep* 1988; 18: 31–37; C.E. Taylor. Clinical Trials and International Health Research. *Am J Public Health* 1979; 69: 981–998; Ijsselmuiden and Faden are an exception to this rule, and present a thoughtful analysis of the inappropriateness of the concept. C. Ijsselmuiden & R. Faden. 1999. Research and Informed Consent in Africa – Another Look. In *Health and Human Rights: A Reader*. Mann, Gruskin, Grodin & Annas, eds. New York, NY: Routledge: 363–372.

³² S. Feierman. 1990. *Peasant Intellectuals: Anthropology and History in Tanzania*. Madison, WI: University of Wisconsin Press.

³³ H. Kjekshus. 1977. *Ecology Control and Economic Development in East African History: The Case of Tanganyika, 1850–1950*. London, UK: Heinemann; J. Giblin. 1992. *The Politics of Environmental Control in Northeastern Tanzania, 1840–1940*. Philadelphia, PA: University of Pennsylvania Press.

herbalist, spirit medium, witch doctor, or refused all treatment was the decision of the sick person and the family.

Researchers arriving and asking for access to bodies and blood was a new phenomenon, a product of the colonial era. There is no question that chiefs *did* recruit (and implicitly consent for) people to participate in medical research. Under threat of fines or beatings, thousands of people participated, but they still complained bitterly. No one but the chief recognized this as traditional authority, and no one but the researchers would have dared call it 'consent' or these people 'volunteers'.

Even shortly after European arrival in East Africa, a chief giving consent on behalf of his subjects was not the norm. In 1908, the medical missionary Albert Cook sat down at his desk in Uganda and wrote a letter to *The Lancet*. He was responding to an article in which the writer claimed it would be easier to do medical research in East Africa than in India, since doctors could rely on 'complete control over the patients . . . [due to] the influence of the chief over his people'.³⁴

In his response, Cook noted that a chief's influence 'is rapidly dying out and I fear that the hold of the chiefs over their people in such a matter as periodical injections for syphilis would be extremely small'.³⁵ Even a hundred years ago, less than a decade after substantial European contact in the area, the 'hold' of the chief was perceived to be small. More likely, such an authority never existed.

Moving ahead nearly a century, recent data gathered from East Africa confirms this historical evidence. During focus groups held by the Kenya Medical Research Institute in coastal Kenya, one woman pointedly told the interviewer, '[the researchers] have to ask permission from *me* before they do anything or we'll quarrel . . . If *I* agree they can go ahead, but if they do it without asking *me* then they're in the wrong'.³⁶

Another woman, when asked whether the chief could give permission for all people in the village gave the following response:

It's important for the fieldworkers to get permission from the chief to move around the area, but the chief cannot decide for my child. No way!³⁷

What these two contemporary quotes illustrate is that the concept of informed consent is not a foreign one to modern East Africans, and that many scholars have over-emphasized the difficulties of balancing community and

individual consent. As the woman said in the final quote, it *is* important to get approval to enter a community from the chief. However, if you were to tell an East African that because her chief agreed, she was forced to participate in a trial, you would be greeted with disbelief and anger.

The previous literature suggesting that consent cannot be gained in East Africa because it is too foreign, and that individual consent would be an aberration from 'tradition' are both false. There is no historical evidence from villagers to indicate that they recognized the practice of 'group consent' as part of a chief's responsibilities. It is far more likely that enterprising local leaders saw the arrival of researchers as a golden opportunity. These men flexed their 'chiefly/ traditional' authority by gathering people for researchers to use, kept villagers moderately docile by threatening fines or punishment and put researchers' minds at ease by invoking language describing 'traditional' practices. The only problem with justifying such practices as traditional is that traditions change.³⁸ They are mutable and malleable and can be invented as convenient.

CONCLUSION

There is a deep history of medical research encounters in East Africa. Many East Africans are 'drug naïve' but they are not naïve about medical research. A century of contact has alerted people to the fact that even when the word 'investigation' is not used, it may still be an 'investigation'; that 'researchers' may masquerade as 'doctors'; and that they may be coerced or threatened into participating.

As just one example of history seeping into the present, researchers' practice of introducing themselves as doctors has further muddled the differences between doctors and researchers, treating and researching. While therapeutic misconception exists even in developed countries, it is particularly troublesome in the developing world where people are less familiar with Western medicine and have less experience with research. A majority of the people I interviewed could not explain the difference between a doctor and a researcher. One Tanzanian, a retired researcher, told me how while working in the 1970s, a villager had come and asked him earnestly if the pills he was handing out were 'dawa' (medicine) or not 'dawa'.³⁹ Such confusions are not the result of a single researcher, but of decades of misinformation, and jeopardize the validity of consent today.

³⁴ A.R. Cook. Syphilis in Uganda. *Lancet*, December 12, 1908: 1771.

³⁵ Ibid.

³⁶ C.S. Molyneux et al. 'Even if they ask you to stand by a tree all day, you will have to do it (laughter) . . .!': Community Voices on the Notion and Practice of Informed Consent for Biomedical Research in Developing Countries. *Soc Sci Med* 2005; 61: 443–454: 446. Emphasis added.

³⁷ Ibid.

³⁸ E. Hobsbawm & T. Ranger, eds. 1992. *The Invention of Tradition*. Cambridge, UK: Cambridge University Press; T. Spear. Neo-Traditionalism and the Limits of Invention in British Colonial Africa. *J Afr Hist*. 2003; 44: 3–27.

³⁹ Mzee Matola. Amani, Tanzania. October 17, 2008.

Misinformation and lack of transparency led to the creation and circulation of stories about blood stealing researchers like Bwana Matende. The fact that these accounts continue to circulate should give researchers pause. Other scholars have argued that they 'contain local interpretations of medical research ethics' and can be mined to better understand subjects' perspectives.⁴⁰ It is convenient to dismiss these stories, but the history of medical research in East Africa shows that what many shrug off as fiction swerves into the realm of fact. Although Bwana Matende was only one man, he has become an analog to discuss shady research encounters, full of fierce Government workers, threats and forced participation.

The importance of the past cannot be overstated; people do not just forget their history; and researchers would do well to remember this. In 1956 a researcher, planning on eradicating filariasis on Kenya's coast, arrived and proudly announced his intention to better peoples' lives and improve their health. Villagers curtly informed him that researchers had been there ten years prior, had made the same promise, had failed and had slunk out of town. He ploughed ahead without finding

out more about this past attempt, and was surprised to find 'violent opposition . . . hostile attitudes' and hot tempers still simmering from ten years prior.⁴¹ Just because he was unaware of this local history did not mean it did not matter. If anything, his oblivion rankled residents even more and led to misunderstandings and conflict. Researchers today have a much longer history to remember, but being attentive to it will surely result in better understanding on all sides.

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Biography

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⁴⁰ P.W. Geissler & R. Pool. Popular Concerns about Medical Research Projects in sub-Saharan Africa – a Critical Voice in Debates about Medical Research Ethics. *Trop Med Int Health* 2006; 11(7): 976.

⁴¹ No date [late January 1956]. From Goiny to Senior Parasitologist. 'Activities during January 1956 – Lamu Pit Latrine Campaign, Patte Island Filariasis Investigations.' DC/LAMU/2/23/29. KNA.

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