

THE EXPERIMENT MUST CONTINUE

Medical Research and Ethics
in East Africa, 1940–2014

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PREFACE

Gonja, Take One

It was sometime in the 1970s. Or the 1950s. Or maybe even the 1960s. In any case, it happened years ago. “It” happened in the town of Gonja, in the Pare area of northern Tanzania, and started with angry residents who were unhappy with researchers working in their village. The rabble-rousers were either a group of wholesome, yet angry, residents, or a group of unruly, pot-smoking youth who had recently returned from the war with Uganda. Their anger was directed at a set of researchers who were working in the village at night, either collecting mosquitoes or blood samples. Maybe the researchers were *mumiani* (bloodsuckers) and murderers, maybe not. In any case, they had made the bad decision to drive home that night rather than sleeping in the village. Their car was forced to a stop on a blocked road. Villagers appeared and began hurling stones. The car was damaged; the researchers sat inside, afraid. Flames appeared: the car was on fire. The researchers fled, and it was only due to the appearance of the police that no one was killed.

The story of Gonja was the first account I heard when I asked people about the history of medical research in East Africa. Researchers remembered some version of the story, local people in the region knew about it, and, depending on the teller, the story was used to emphasize any number of points. When told by current medical researchers, it was a morality tale of what happened when well-intentioned scientists encountered uneducated villagers. Among a certain group of researchers, the only lesson to be learned from Gonja was that African rural residents were uneducated, unpredictable, and had yet to learn the benefits of biomedicine and scientific investigations. In some of the narratives, the teller continued into the present, explaining how the bad behavior of the Gonja residents resulted in the building of one of the largest police stations in the district. It also meant that there was almost no research done in Gonja for decades, and it wasn't until 1993 that a research team was sent in to “check people's feelings.” Only

at that point—twenty, thirty, or forty years after the initial conflict—had villagers finally learned their lesson and begged for the researchers to return, to help reduce malaria and bring drugs, like in years past.

Although I was happy that people shared their recollections of Gonja with me, I was perplexed by how many competing versions of the story I heard in just a matter of days. It was a story that continued to be told, but it seemed none of the tellers were preoccupied with fine details. The dates changed, the people involved changed, and the rationale and moral changed. I didn't know what to make of Gonja, but I kept asking about it, kept thinking about it, and kept squirreling away references. I knew Gonja was important, but I wasn't sure why. So I set the story aside, continued with my work, and hoped that by the end of my research I'd have untangled Gonja's significance.

Surveying the Pathological Museum

Lieutenant Colonel William Laurie, the Director of the East African Medical Survey, exclaimed in 1952, "The African is a walking pathological museum."¹ Laurie was not the only one to consider the African as such, or to be excited by the myriad tropical diseases found in East Africa. The medical missionary Stanley George Browne used the same phrase when describing his work in the Belgian Congo in the 1940s, remarking, "[The native] is a walking pathological museum."² During a survey project in Kenya in 1937, the researcher in charge declared that each of the Africans was an "ambulant pathological museum."³ In 1944, a colonial worker in West Africa stated, "There is no doubt that the African native is often a pathological museum."⁴ It's unclear how common a refrain it was, but it would appear to be a phrase that circulated among medical researchers—a common remark expressing amazement at the collection of germs, pathogens, viruses, parasites, and other abnormal and unusual diseases likely to be found in a single African body.

The phrase captures much of what was wrong with the East African Medical Survey and belies an expectation of how researchers expected to interact with Africans. It was not unusual or unexpected that medical workers would look at sick Africans as objects. The phrase oriented researchers to focus on pathologies rather than bodies, and on sick body parts rather than sick patients. Research practices and the material culture of medical activities in the 1950s reinforced this tendency to think in terms of objects rather

than people: medical tubes and vials suck and store bodily fluids, scissors snip samples of skin, needles drain blood, tightly lidded jars contain stool samples. These pieces of bodies, floating in formaldehyde, stored in glass, packed in ice, were transformed from being parts of people into data. As a modern manager of an international contract research organization stated dryly, “We don’t see patients, we see data.”⁵ In fact, the objectification of sick bodies has been a central part of the medical profession. Medicalization of the body (defined as seeing something in medical terms, often unwarrantedly) leads easily into seeing the body as a set of objects, and to a general practice of objectification. The goal isn’t just to separate the idiosyncrasies of individuals from the disease, but to seek objectivity and objective truths. Sick people are not necessarily helpful to science, but they are when they can be turned into data.

It is also worth remembering that the pathological museum was a real place. Many medical schools in Europe had these museums, and they were places where aspiring doctors and researchers—especially those planning on working in the tropics—could see examples of many diseases that would be impossible to otherwise see in their home countries. As with any museum, the pathological museum was a place to view, to gaze at the exhibits. When walking through a pathological museum, there was a one-way viewership: the objects were dead, cut to pieces, and preserved indefinitely; the medical doctor could view the pathology without shame or self-consciousness, could stare as long as he wanted. It’s also worth remembering that specimens were often collected with the goal of sending them back to a pathological museum. In one sense, the sick African really *was* a walking pathological museum. From the researcher-*cum*-collector’s point of view, the sick person could easily be reduced to a set of sick parts, each deserving of its own exhibit in a far-off gallery.

The samples for the museum, or the pathologies to be recreated as pieces of data, could not be collected without contact, a human interaction. The scholar of photography Christopher Pinney explains the concept of a “dialogic” period, as the space of time when the subject and photographer come together to create an image.⁶ While Pinney references the moment in the creation of a photograph, the same concept applies to medical research. It’s useful to think about research, and even a medical survey, as a discrete moment in time, a dialogic period characterized by exchange and interaction. The encounter relies on the participation of both parties; there must be

a productive give and take. It is a moment that I refer to as a *medical encounter*, and which this book works to reconstruct.

Methods, Sources, and the Challenges of Fieldwork

Prior to beginning graduate school, I spent a year working in Tanzania with the public health organization Population Services International. My current interests in this topic were piqued during that time, especially as I traveled through the region and saw the ubiquitous advertisements soliciting volunteers for HIV/AIDS drug trials. These fliers inevitably advertised the study as the “cutting edge” or something similar, and I viewed them with a combination of frustration, disdain, and sadness. A closer reading of the fliers and background knowledge of the process of human subjects research quickly revealed that few of these trials were beyond the very early phases of testing.

Drugs to be sold in the United States must pass through three “phases” of human testing in order to be approved by the Food and Drug Administration (FDA). Roughly, the first phase tests the drug—often on healthy volunteers—for serious side effects that could preclude its widespread use. In phase one testing, subjects who are taking no other medicines are especially valued because there is less chance of the experimental drug interacting with other drugs in the body and producing unusual side effects. These research subjects are referred to as “drug naive” and it’s much more likely to find drug naive people in the developing world. Phase two tests whether the new drug is better than nothing, and is conducted on sick subjects. Drugs that have “passed” these first two phases by being mostly nontoxic and an improvement on doing nothing are allowed to progress to the final stage. Phase three involves testing the new drug against the best available treatment for the same condition. When there is reference to people participating in a “therapeutic” drug trial, or talk of someone in an experimental drug trial where they are miraculously cured, it is typically in reference to a phase three trial.⁷ This is the only phase in which a sick person gets access to a new drug that has a decent chance of being effective, or at least is likely to be better than nothing. (There is also an informal phase four, when the drugs are already on the market but continue to be monitored.)

The drug trial advertisements in East Africa offended my sense of ethical behavior. While I understood the need to recruit people to these studies and the obvious benefits if effective drugs or a vaccine were found, I wondered if these ads were not falsely raising people’s hopes. Most East Africans

I spoke with believed these projects were giving out *dawa*—medicine. Yet I knew that only people participating in phase three trials had a real chance at receiving new, effective medicines. People participating in phase one and two trials were volunteering to test drugs for potentially serious side effects and to see if the new interventions were better than nothing. It was a dubious use of the word *dawa*.

When I left Tanzania to begin graduate school at Boston University, I knew I was interested in studying the history of human experimentation in East Africa, but I wanted to combine historical training with a better understanding of global public health. After a few years, I had finished my history coursework and exams, earned my Masters in Public Health, and become conversant in Swahili, and I returned to East Africa for a year of research. During those twelve months in the field, and in subsequent summer trips, I conducted forty-three formal interviews, worked in more than a dozen different locations, gathered historical materials from formal and informal archives, and observed medical researchers in a variety of settings. I aimed to be as thorough as possible in researching my topic, occasionally adopting some of the ethnographic and direct-observation techniques of anthropologists. What became most obvious during fieldwork was that it is a difficult activity, full of unexpected challenges and detours.

As I discovered repeatedly, success in the field relied upon plenty of preparation; the work also benefited from a dash of serendipity. My first piece of luck came when I was allowed to participate in the Mosquito Ecology and Control Course in Tanga, Tanzania (run jointly by the Danish Bilharziasis Laboratory and Tanzania's National Institute for Medical Research, Amani Research Centre). The two-week course gave me newfound appreciation for the work of entomologists, and firsthand experience doing the research that I often read about in historical documents. Our entomological research work involved the physical labor of trekking through thick mud to find mosquito breeding sites and stomping around cesspits, the challenges of convincing homeowners to allow mosquito traps in their homes at night, and the tedious laboratory work of mosquito identification and dissection to establish whether the mosquitoes were malarial. Perhaps just as important, the course introduced me to a set of well-educated East Africans who worked in science and alerted me to the existence of valuable historical materials not in the national archives. They also provided invaluable introductions to colleagues throughout the region.

My time living and researching in East Africa made me much more aware of all the ways doing “good” (or at least accurate) history could be threatened. While in the port city of Mwanza, in the western part of Tanzania, I began reading about the work of the Filariasis Research Unit and its attempt to eliminate filariasis from Ukara Island in Lake Victoria. The documents were plentiful, and detailed a very obvious break in 1959. From 1956 until 1959, residents on the island had willingly participated in drug trials and other research activities. After that date, participation rates dropped off staggeringly. In a matter of a few years, Ukara went from being an ideal testing place to one where researchers loathed working. Through careful reading of the documents, I had figured out the main reason why: the Wakara had been accepting experimental drugs that the researchers had been advertising as “medicine” for over four years, but very few people had been cured. People were tired of receiving ineffective drugs and being lied to, and refused to participate. Since Ukara Island was only about forty miles north of Mwanza, and was reachable by boat, I decided to take a trip to flesh out my understanding.

A few weeks later I was on Ukara Island, speaking with two older men who remembered the filariasis project. When I asked about 1959, and why people suddenly stopped participating, they gave a simple answer: there was a new *mtemi* (local leader) who was not as excited about the research project as the old leader, and he had not instructed residents to cooperate. Although I asked the two men directly about whether the “medicines” given out by the researchers were effective, or whether the Wakara people were angry about being lied to, they looked at me quizzically.

The experience on Ukara Island reemphasized the importance of actually visiting a place and talking with the people who had lived through these events, and of searching out materials in more unusual places. I didn’t entirely ignore traditional archives. I spent weeks and months in the Kenyan National Archives, the Zanzibar National Archives, the Public Records Office in London, and the Wellcome Library in London, in addition to accessing digital materials of the World Health Organization. But I quickly realized that materials in these places were unlikely to answer the questions about human experimentation I was most interested in. I didn’t want to rely on official reports housed in the national archives, and be left “listening for the silences” of African voices. In this spirit, I prioritized visiting places where research stations were located, or where large-scale projects had taken place. After fourteen months of research in East Africa, I had

gathered archival and oral data in a dozen different locations, ranging from mission hospitals to remote islands in Lake Victoria.

Two of the colonial-era research stations were in the northern Tanzanian town of Amani and in western Tanzania in Mwanza. (Amani has a fascinating, long history, having originally been built by the Germans as an agricultural and forestry research station.⁸) These two places ended up providing thousands of pages of uncatalogued documents that few—if any—other scholars have used and written about. The materials included the private papers of medical researchers who worked for the Pare-Taveta Malaria Scheme, the East African Medical Survey and the Filariasis Research Unit. There were confidential research reports, letters written by frustrated field workers to their bosses in the cities, notes in Swahili from angry residents who objected to research being done in their villages, and newspaper clippings reporting both the organizations' press releases and residents' reactions.⁹ Very few of these documents exist in duplicate in other archives; many documents only reside in Mwanza and Amani.

I stayed for weeks in each location, and it was invigorating work, since each day led to new discoveries. But, for all the excitement of historical discovery, working in Mwanza and Amani was not without challenges. The documents were entirely disorganized, and after receiving approval to work with materials in Mwanza, I was furious when a mid-level bureaucrat denied me entry. When I found a sympathetic co-worker to unlock the room where the documents were, I spent another day working through the materials. I did, however, wonder if I had actually become a “thief”—which was what the angry bureaucrat yelled at me when he returned the next day to find me inside the office.

I wasn't so blind as to be ignorant of the irony, or the myriad ways my own challenges mimicked those of earlier medical researchers. There I was, accused of being a “thief” and “stealing” documents, writing about the challenges of medical researchers who were also called thieves and accused of stealing blood. The challenges of field research in East Africa often created morally ambiguous situations: situations where I had to figure out how to translate formal ethics into field ethics. Should I bribe someone to get access to materials? (No, but a heavy dose of persuasion and pestering was acceptable.) Was I a “thief” for figuring out a way to use documents one man had prohibited me from seeing? (No, because he had no formal authority to make that decision, and I had been granted access by those in charge.) Did people actually understand and value my project, or were they



FIGURE 1.1. Uncataloged archival materials at Amani Medical Research Station, Amani, Tanzania, 2008. Photo by author.

just letting me do what I wanted because I was a white foreigner handing out gifts? (Hard to say.) There were no easy answers, but this discomfort and self-questioning bred a deeper appreciation of the challenging situations any type of researcher encounters.

In addition to the archival materials, oral sources derived through semi-structured interviews were my other source of information. I conducted a total of forty-three formal interviews with people who participated in medical research (as subjects or members of the community who assisted in the research), professional medical researchers during the colonial or post-colonial eras, missionaries who helped researchers gather participants, and with East Africans who lived in communities where medical research had been conducted. Interviews typically lasted about an hour, although a few of the livelier ones went on for two to three hours. I asked questions about what “research” was; past experiences with medical researchers, or working as medical researchers; and opinions about difficult medical scenarios I described. Asking about research was complicated since the topic was not well understood by people. That usually led me to ask if the person had ever given blood, taken pills or received shots outside of the hospital, or met a roving “doctor” or “expert” who was doing “research” or an “investigation.” Although I spent a lot of time conducting formal interviews, many of my best insights came from conversations with a mix of health professionals, young people, amateur historians, and the best chicken fryer in Zanzibar. These informal exchanges gave me a chance to talk about my research and have lively discussions without falling into the rigidity of a formal interview.

I analyzed the oral and written sources in dialogue with each other and paid close attention to places of discord—when the oral and archival sources were in clear conflict. In some cases, I was able to “right” these disagreements; in other cases, a level of ambiguity remains. I did not begin by assuming that my oral sources were any less accurate or “factual” than the written sources, nor that the value of my interviews was only in preserving people’s opinions, impressions, or understandings of past encounters. In this way, I depart from the approach taken by Luise White in her groundbreaking and creative work on blood rumors in East Africa—a topic I discuss more fully in the conclusion of chapter 2.

Everyone formally interviewed consented orally after receiving a written description of my research and listening to me read the document aloud. When I audio-recorded interviews, I asked permission at the start and again at the end of the interview, offering to delete the recording if the person felt we had discussed overly sensitive topics. I took it as evidence that my consent process was working when some people refused to be interviewed. At the conclusion of the interview, I presented a gift that was typically worth

about five US dollars—often sugar, soap, or tea, although it was sometimes cash. I typically conducted the interview in Swahili, although there was often another person present (usually an older male) who had facilitated the introduction and helped clarify any questions or confusions that came up. The interviews were transcribed with the help of Tanzanian research assistants in Mwanza and Zanzibar. I was responsible for all translations from Swahili into English, although I have double-checked difficult passages with native speakers. As for interviews not done in Swahili, a few were conducted in KiKara or KiKerewe and required an intermediary translator, and a few others were in English.

I was surprised to rediscover, even while speaking Swahili and coming with contacts, how hard it was to show up in a new place, establish yourself, explain your project, and hope people would at least tolerate—if not accept—you. As my interviewees reminded me, *I* was a researcher and struggled with many of the same issues researchers over the past half-century have struggled with—consent, benefit, and clarity of explanation—even if I was only asking questions and not collecting blood. And, just as with researchers from decades past, my methods in practice were quite different from what I had theorized. My questions (lovingly crafted in Boston with the oversight of many experienced professionals) were designed to be nonbiased, culturally sensitive, and nonthreatening. Yet those questions were tossed to the side as I saw their inefficacy firsthand. My *haute* methodology met its match in rural Tanzania through a series of challenging interviews full of evasive answers and misunderstood questions.

This research occurred under the watchful eye of Boston University's Institutional Review Board (IRB). The university's interpretation of federal guidelines meant that I initially collected signatures from nonliterate people and kept interview transcripts under "lock and key," even though I couldn't stop people from walking into my hotel room and out with my laptop. My methods produced viable results and a long list of things to do differently in the future. Most notably, I will keep in mind the conclusions I reached for this book. There is often a profound gap between formal ethics and field ethics; one must be nimble, adapt to local conditions, and take cues from the subjects one is working with, who must always be considered active and vital participants in the research enterprise.