Chapter 13
Ebola in West Africa: Biosocial and Biomedical Reflections

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13.1 The Case

This essay is about the scientific and medical response to ebola; and more particularly the actual and potential relationship between biotechnical and biosocial actions. It has been nearly entirely stripped of exposition; nevertheless, the ghost of the critical analysis is, I hope, alive in the narrative choices. This allows great compression of ideas and information within a narrative flow. So it can be read – I hope usefully – as a story.

In it, single paragraphs – sometimes single sentences – could have been elaborated into their own chapter in a more technical presentation. In fact, they would seem to require this. Worse yet, a single paranthetic phrase "(very carefully)" represents an entire book that could be written on the production of pharmaceuticals in plants, and the necessary "humanizing" of protein structures such as immunoglobulins.

The same compression applies to themes from Agassi's work. Most of the relationships to his work are in the structure of choices for a general narrative and in the specific direction taken at the end of the paper. There are some direct clues, partly in the section titles. Let me use three examples to illustrate this.

One of the skeleton key elements goes back to the original draft of *The very idea of modern science* which contained much more of Agassi's original PhD thesis from the 1950s than the final manuscript.

In it, he displayed an amazing critical empathy for an obscure scientific literature written mainly in the language and references of Greek mythology. I don't think the critical analysis was possible without empathy being the key to unlock the door of their language, because one has to enter into their style of thinking that was embedded in their use of mythological themes. It was a stunning interpretive translation,

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fully recognizing the way in which the mode of thought was not simply an Aesopian code but influenced how they thought; one could say became integral to how they thought.

So: cross-cultural thinking of a kind. Within a culture but cross-cultural to us, now. Agassi moved from one temporally bounded subculture to a different temporally bounded sub-culture; let's say modern philosophy and history of science. One of the themes of my paper is the notion of cross-cultural science – from a broader perspective but perhaps with the same approach. The easiest place to see a parallel at work is how I talk, all too briefly, about Amilcar Cabral.

A second hint comes from a section title, in which I use a three word gloss to co-integrate some aspects of Paul Feyerabend's and Joseph Agassi's work: *Anything critical goes*. This is – among other things – both sloganeering and a reference to *Popper and his popular critics*. There is more to say about this in terms of Feyerabend and Agassi, but for this essay I was thinking of the immense distances between conceptions and lives of groups, and the possibility of critical evaluation or science as a meeting ground, outside the boundaries of either.

Actually, the behavior of the international medical responders fit perfectly with the conceptual actions of witches: their masking in personal protective equipment, their obsession with blood and tissue samples, their restrictions on normal social intercourse and so on. It would be like someone in the USA taking their child to a hospital emergency room, only to be met by giant bats in lab coats. It is a kind of tribute to cross-cultural rationality that the entire rural population of all three countries did not, in fact, revolt.

I use the term "convergence" in the paper, instead of discussing "cross-cultural consilience", The great ebola anthropologist Alain Epelboin, who worked mainly in Guinea (Conakry) during this epidemic, seems to maintain a sense of humor about the variety and diversity of human follies. He could probably describe poly-cultural consilience.

I think Agassi actually discussed research programs before Imre Lakatos. I do not discuss this directly, but I do mention that the choice of GP (ebola glycoprotein) for target epitopes was common to most of the vaccine and immunomimetic drugs. At least in some of the drug cases, I thought I could see the determining influence of early rodent trials, even though rodents were not a great model for ebola as a human disease. It seemed to me that research programs could be determined by nearly random events, early in their life-cycles, which then became a fixed part of a program or a field-wide dogma.

A third cryptic Agassi-related remark, is towards the end: "[…] a kind of Prague Spring of science facing a lethal crisis." This was a complex phenomenon that relates to Agassi's interest in the self-organization of science. It went beyond research to the institutional infrastructure of science and technology, including publications, funding agencies, pharmaceutical companies and governmental bureaucracies. Sometimes, as in the case of the World Bank, it seemed that lower level staff were making up for leadership deficiencies in planning, and actually acting. In other cases, such as Merck, it was the corporate leadership that turned ebola response into a company-wide effort.

In may be surprising to many, but the FDA pushed all of its boundaries to facilitate rapid development and deployment of experimental therapeutics and diagnostics. My experience was that people individually responded with great acuity and often forced their agencies and bureaucracies to also respond and actually fulfill their missions. Here, I will just mention some of the changes that were made for communication and publication. At least some journals, such as The New England Journal of Medicine, made all their ebola-related articles open access. Some open access PLoS journals shifted fast publication to their associated (but refereed) blogs, but by Spring 2015 were able to publish new reports fairly quickly. In the meantime many researchers shared data without regard to priority of publication. The social scientists set up something like a temporary fast-publication journal, the Ebola Anthropology Platform in the UK, which played a major role in providing a place for well-researched reports that needed to be put out quickly.

Some of these work-arounds became codified by the time the Zika epidemic hit, with a consortium of major journals specifically exempting priority of publication and confidentiality of data in order to encourage, not inhibit, rapid data sharing. Unfortunately, this did not apply to journals in Brazil, apparently; which was the country hardest hit by Zika in 2016.

Then a new phenomenon became serious enough to be widely recognized: the rise of the false journal and predatory publishers. The problem of access to publication, which Agassi discussed, became a new version of the problem of demarcation instead. Perhaps this is enough of an indication of the work that lies behind this somewhat unusual structure for a paper. The references can provide access to many of the topics that fly by.

Finally, I should say that this was the only way I found I could write about this topic without being lit on fire with fury.

13.2 Ebola That's Enough!

Let's begin at the end. On December 23, 2016, The Lancet published on-line the final report of the "Ebola Ça Suffit!" ring-vaccination trial which took place mainly in Guinea and partly in Sierra Leone (Henao-Restrepo et al. 2016). It showed the successful deployment of a vaccine against ebola and confirmed an interim assessment published in September, 2015 (Henao-Restrepo et al. 2015).

The trial took place late on the downward side of the ebola epicurve. Later, I will discuss issues from the other side of the epicurve, when cases kept doubling faster and faster and case numbers appeared to be going asymptotic to a vertical: the circumstances from late 2013 to the end of 2014.

As an investigation and intervention Ebola Ça Suffit! got many things right, under still difficult conditions. Ebola Ça Suffit! got trial design right, for the circumstances. A major issue was designing a trial that would be able to capture actual ebola cases. By the time major resources were made available, in 2015, the ebola epidemic was ending and cases were vanishing. Social scientists I knew working on

a proposed multi-vaccine RCT (randomized controlled trial) for Liberia in early 2015 kept hearing the numbers changed: 5000 then 50,000 then 500,000 prospective participants in what was supposed to be a phase II trial and then "a phase II/III trial" trying to capture enough probable cases to have a contrast.

There often seems to be a sub-discipline that has more power and authority in a crisis. During the ebola crisis, mathematical epidemiological modelers seemed to have such a position. They played an ambiguous role. The models encouraged a massive response in the fall of 2014 by their projected unthinkable caseloads, if nothing were done. They also used a random population-exposure assumption that was wrong.

A natural question would be: why weren't RCT vaccine trials (placebo controlled, double-blind, randomly-assigned treatment trials) used before the ebola case numbers had turned so far down? Part of the answer, lies in the time it took to have adequate non human primate (NHP) data on safety and efficacy and human preliminary trials.

Another factor was that objections to the deployment of experimental drugs in RCTs for clinical patient treatment, which had some strong contextual and ethical validity (Adebamowo et al. 2014), spilled over into views of vaccine RCTs, even where the same contexts could be seen as absent.

Vaccine trials were prospective, when participants could make informed choices. Increased care could be planned for patients who developed ebola or other medical conditions as a result of vaccine trial participation. Trials could have been designed for and with volunteering health care workers at high risk, with advanced medical back-up relief options for all participants, for example in the early Fall of 2014.

NIAID, the National Institute of Allergy and Infectious Disease, National Institutes of Health, Department of Health and Human Services in the United States, was one of the strong advocates of RCTs for both drug and vaccine trials, which ultimately they started in Liberia. However, the director of one of the leading vaccine candidates told me in the early fall of 2014, that even mentioning RCT vaccine trials could lead to his vaccine never being trialed in Sierra Leone. There was a clear difference in approaches within the international medical communities.

Guinea (Conakry) fell geopolitically and biopolitically on the other side of the divide from the NIAID approach. This is reflected in the composition of the trial funders, from WHO, Norway, UK, MSF (Médicins Sans Frontières) and Canada.

Ebola Ça Suffit! could be described as a control measure fused with a trial in a skillful combination. This type of design may have broader future use. One of the only ways novel control measures could legally be used was as trials.

Capturing cases was done by defining the participants as contacts and contacts of contacts of remaining ebola cases. These were people at true higher risk of ebola. The trial populations were clusters (actually two rings of risk) of contacts around known cases. The design was based on vaccination procedures used for the final stages of eradicating smallpox under natural (nonmilitary, non-biowarfare) conditions.

Vaccination could occur either immediately or following a two-week delay, and the clusters themselves were randomly assigned to either treatment in a double blind

manner. By the time they reported their interim results (Henao-Restrepo et al. 2015), a separate evaluation team called for the elimination of the delayed vaccination arm of the trial, because sufficient evidence of efficacy of immediate vaccination made it unethical to continue delayed vaccination.

The authors describe multiple teams, including for informed consent, separate from the trial medical team. Informed consent, crucially, included community acceptance as well as individual choice (and the right to withdraw). The trial personnel were predominantly from Guinea itself and other African countries. They harmonized the international regulations, country regulations and local participation.

Perhaps this is too rosy a picture? There were still many issues in Guinea. Planners could have engaged communities on the trial design itself; or allowed choices between pre-designed approaches that already had regulatory approval, and had sufficient statistical power. The resources brought to bear in this trial would have been unimaginable in August 2014, when basic medical supplies were unavailable and even the supply of the most basic sanitation tool, chlorine bleach was out of date and nearly useless in, for example, Sierra Leone. Remarkably, Ebola Ça Suffit! even had electric power, water, and systems for maintaining a cold chain for vaccine deliveries.

In August 2014 Sierra Leone asked the UK military to bring as many helicopters as possible for distribution of supplies to remote areas, and for access to much more of the countryside during the coming rainy season. Roads were often poor at all times. Before ebola, when the critically important Lassa Fever lab was re-equipped in Kenema, Sierra Leone, the only way key components could be brought in was by U.N. troops from Pakistan re-purposing one of the military helicopters (Wilkinson 2016). Helicopters could also deliver vaccine on dry ice in coolers; which was cold enough, a vaccine head told me. Nothing so jury-rigged needed to be contemplated by mid-2015.

In this ebola epidemic there were over 20,000 infected and over 11,000 dead, due to ebola itself. The secondary effects due to the impact on the overall health system may have been equal or worse. In Sierra Leone with a typical extraordinarily low ratio of doctors or health care workers to population, before the epidemic began, at least 14 senior doctors died in the 7 months from July to December 2014; as well as large numbers of other health care workers.

The randomised ring-cluster design probably is statistically under-powered relative to an equal-sized RCT trial, if an RCT could have been finished. Ebola Ça Suffit! is the only phase III vaccine trial to successfully report from the West African ebola epidemic.

13.3 From Agassi to Ebola

By July of 2014 I had been engaged in a multi-year dialog with Joseph Agassi on various aspects of philosophy and history of science. He asked me to read and critique the drafts of two of his books: *The Very Idea of Modern Science* (Agassi 2013) and *Popper and His Popular Critics* (Agassi 2014). Another critical reader was Ian Jarvie.

My professional interests came mainly from plant breeding and genetics in agricultural; the intersection with cross-cultural science; the temporal development and intersecting changes of biology, medicine, nutrition and agriculture in North America; and how these interacted with other cultures and countries. These were actually practical matters, but how one thought about them could be crucial.

I was also interested in two very different people who specifically credited some of their ideas and methodology to Quine. One was Bob Moses, of the Student Non-Violent Coordinating Committee (SNCC) when he described his later work on math and science education, starting with the Algebra Project (Moses and Cobb 2002). Another was Barry Hallen who, with his colleague John Olubi Sodipo, started a long project on cross-cultural understanding of knowledge (itself) and medicine (as we might say), working as colleagues with Yoruba *onisegun* (Hallen and Sodipo 1997).

Their self-described pragmatic and experimental uses of concepts and methodologies from Quine in these two different contexts were suggestive and intriguing. Their work is reflected in my discussion at the end of this paper.

In early August, 2014, I received a request for assistance on ebola from a colleague who was a senior rice breeder and geneticist, and in fact a World Food Prize laureate. He had returned to Sierra Leone, previously, to accept a position as a Special Advisor to the President and Ambassador-at-Large. I knew Monty Jones from his work at WARDA (the West African Rice Development Association) developing rice varieties (*Oryza sativa*) that were partly based on the indigenous domesticated rice species of West Africa (*Oryza glaberrima*). Now he had the mandate as Presidential liaison for ebola.

We had been talking about the experimental drug ZMapp, and he was looking for how to have it be tested in the (then) two ebola epicenters in Sierra Leone: Kenema and Kailahun. They also were looking for anyone who could help provide badly needed equipment, protective gear, vehicles, ambulances, etc.

The next day I sat in on the CDC conference call to prepare U.S. medical personnel and institutions for the arrival of two ebola patients to Emory University in Atlanta. Attuned to look for anomalies, I noticed the experts who were presenting briefly mentioned the possibility of some evidence for sexual transmission of ebola. We were off.

13.4 On Immunochemistry and International Research Policy

Ebola is considered by the CDC to be a category A bioterrorism agent; meant to be studied only in level IV biosecure facilities. Because of this designation, and perhaps spurred on by recurring episodes of ebola outbreaks in Central Africa, there had been advanced work done on a number of possible interventions. Unfortunately, none of them were actually ready to be used. It may be that a certain lassitude and comfort level had set in, over a decade after the anthrax attacks in 2001. There is a kind of public biowarfare defense community, so to speak, with their own conferences and journals and associated laboratories and companies.

Federal research funding in the United States, in general, includes various small business requirements, and these also apply to funds for biowarfare defense. Such funding can be a useful steady source of income for smaller (or boutique) bioresearch companies. Canada, under the Harper governments, had reached a peak of Thatcher-influenced research policy that required commercial investment, or buy-in, for many areas of public research in the Canadian government laboratories, or their projects would be ended. My guess is that this policy helped lead to the rights to one of the two leading ebola vaccine candidates going from the Public Health Agency of Canada (PHAC) in WInnipeg to NewLink Genetics of the United States for what I recall as two hundred thousand dollars, Canadian. This was rVSV-EBOV, the vaccine that ultimately was used in Ebola Ça Suffit! (by then produced by Merck).

A common approach in vaccine development is to use recombinant technology (the small "r") in a live but innocuous virus (to the human population of interest); in this case a vesicular stomatitis virus (the "VSV") to express antigens of interest from the ebola virus ("EBOV"). One alternative approach is to first silence key genes in a dangerous virus, so it can replicate but not cause damage, and then use it as a vehicle for recombinant antigen expression. In both strategies, the immune system can then react to the antigens of a disease without being exposed to the disease itself, or be harmed by the live virus which is vectoring the antigens.

Heinz Feldmann originally modified VSV in order to study one of the ebola genes for glycoprotein, GP, in mice without needing level IV containment. Gary Kobinger, who also worked on ZMapp, headed the Winnipeg lab after Feldmann moved to the CDC. ZMapp, in contrast, delivers three monoclonal antibodies against GP (glycoprotein) antigens that have been (very carefully) expressed in plants. Like receiving venom anti-toxin or tetanus antitoxin, the monoclonal antibodies should neutralize a key viral function, in this case glycoprotein fusion into a patient's cell membranes, allowing viral entry into the cell. It is passive immunotherapy. This also gives the patient's immune system time to respond to viral antigens.

In general there were three main classes of intervention tools: various means of expressing antigens, leading to an immune system response and defense; various means of providing antibodies to ebola or providing analogs of antibodies for

(temporary) passive immunity; and various means of interfering with (RNA) viral specific replication. Some of these were drugs, some were vaccines. There also were immunology based rapid diagnostics for point of care screening under development. Using transfusions or fractions of ebola survivors' blood, which had been done *ad hoc* in emergencies, was another example of passive immunotherapy. None of them had safety and efficacy data for people. Having rodent data, such as for mice or hamsters, was an advanced stage. Some of them had preliminary small trials of safety or efficacy in nonhuman primates, or these were rapidly undertaken. Proposed repurposed drugs such as favipiravir (Avigan) had extensive human safety data for its intended uses but not in the presence of ebola. There were rodent ebola studies with favipiravir but no human or nonhuman primate efficacy data. Some of the drug classes were so new that I could not find any registered human use in the entire class.

I had been developing a network of people who could help evaluate scientific issues of ebola intervention as well as working with institutions that could or did provide direct aid. By mid-August, with the encouragement of Lawrence Gostin at Georgetown University, I had developed a list of the roughly 19 (then) currently known agents. I also included on the list the notion of social mobilization as an intervention, with some possible examples. These could cut the rates of transmission and give the medical response time to catch up.

Gostin was also the Director of the WHO Collaborating Center on Public Health Law and Human Rights. He emphasized that informed individualized consent was an ethical obligation.

Now, many of the interventions would be hard to explain to anyone not actively working in that particular focused biomedical research subfield. It would be harder to explain to anyone else. It would be harder still to have information translated and explained adequately in a completely different cultural and social context; in the middle of an epidemic.

One of the lead tropical disease specialists in the United States commented to me, in early September, that the three most promising interventions on the list were:

(A) Immunoglobin purified from ebola survivors (passive immunity).
(B) Favipiravir from Fuji/Toyoma (inhibitor of RNA virus replication).
(C) The GSK investigational ChAd3-EBOV vaccine.

This vaccine was from GlaxoSmithKline: ebola GP antigen carried on chimpanzee adenovirus type 3. It was originally developed by NIAID and Okairos, which later became part of GSK. Two forms were initially proposed and tested: monovalent, carrying GP antigen from the Zaire outbreak strain of ebola; and bivalent, carrying GP antigen from both the Zaire and Sudan ebola outbreaks.

Many of the eventual vaccines and immunomimetic drug candidates could be presented in multiple versions depending on these kinds of choices of antigen sources, vaccination schedule, or combinations with other vaccines or related drugs. Almost all of the immunological drug and vaccine interventions were targeted at epitopes (antigenic areas) from forms of the GP ebola protein and not any of the other six ebola proteins.

ZMapp was not on his list of high priority interventions to try. This was partly based on his own experience with plant-derived vaccines and their problems. In particular, there was the difficulty in production scale-up during an escalating epidemic even if ZMapp should prove to be clinically successful.

When asked what I would choose personally, I said either the GSK or Canadian vaccines, and ZMapp as part of clinical treatment. However, the international interest in ZMapp, starting in August 2014, was based on an anomaly: a single dose, with a long backstory, given to Dr. Kent Brantly in Monrovia. Looking back, it was probably late in his disease course to have expected much, but ZMapp is associated with an immediate (transient) reduction in viral load followed by an increased level of a patient's own IgG response (Zeitlin et al. 2016).

Brantly had contracted ebola while working for the missionary charity Samaritan's Purse. Later both he and a volunteer colleague, Nancy Writebol were flown to Emory University for advanced medical care under high biocontainment. Nancy Writebol had turned down the ZMapp treatment because Kent Brantly was sicker. Their clinical case history and treatment at Emory are in the *New England Journal of Medicine*, where they appear thinly disguised as Patient 1 and Patient 2 (Lyon et al. 2014).

Looking back, the observation of greatest importance to the most patients in West Africa was buried in the case histories and may appear trivial. In Monrovia, Patient 1 tried to maintain fluids and electrolytes by drinking Tang and Gatorade. This was commonly done by Westerners as self-treatment for a number of similarly presenting tropical fevers. It was inadequate for clinical care of ebola. Nutritional support, correct oral hydration therapy (ORT) and (eventually) maintaining intravenous electrolytes (etc) were key to patient survival of ebola in a wide variety of circumstances and facilities (Lamontagne et al. 2014). A curious international pattern developed.

International medical workers who developed ebola were flown to Europe or the United States, where they received the highest level of monitored intensive care. And they also received one, two or even three of the experimental drugs, with no discussion of enrollment in trials. West African ebola patients, including doctors and medical workers received none of this. This was the context in which MSF, which led the on-the-ground battle against ebola, as well as others, rejected using patients in West Africa as experimental subjects in RCT drug trials as medically unethical.

RCT vaccine trials were collateral damage. Well-informed volunteer trials of medical workers were rejected. RCT vaccine trial co-designed with participants, with acceptable risk and conditions from their own perspectives never came up. I was told an RCT of as few as 200 people could give up to 90% confidence of a drug being effective, in the context of projected hundreds of thousands of cases without effective control measures in September, 2014. I wondered about the politics and ethics of the ethical debate itself. Trial designs themselves are imposed as fiats rather than co-designed with the people most at risk. People at risk, including medical workers, were not participants in the ethical debate; nor in the assessment of tolerable risks versus possible benefits of particular trial designs. They were not

participants in the decisions to not have RCT trials, even of vaccines. In vaccine trials participants are not under the threat of imminent death; they are healthy and at risk of infection.

Drug trials require a constant background of uniformly adequate palliative care to even determine if a treatment is effective This would have been difficult under chaotic medical conditions. Vaccine trials do not. It was perplexing. My initial reason for contacting social scientists, mainly anthropologists, was motivated by the technical concerns about informed individual consent for any of the experimental interventions, however they were deployed. There was an added issue of the need for social or community consent in some contexts. Individual consent could be required by the international community, and that looked hard enough; while some level of social or group consent was a cultural and social requirement for the potential participants. This quickly became subsidiary to much broader issues of social and cultural aspects of disease transmission, prevention, and deliverable clinical care.

13.5 The Social Epidemiology of Being Dead

An ebola disease course starts with fever and mostly non-specific symptoms, which could indicate other diseases, about 8–12 days after effective exposure. The second phase, with the highest classic risk of transmission, starts about 5 days later and includes, notably, massive diarrhea and vomiting. Viral concentration needed for infection is very low (Vetter et al. 2016) while blood and other fluids have very high viral concentration (CDC 2016).

Unfortunately, so do corpses. The handling of ebola corpses can be extremely difficult even under United States' conditions (CDC 2015). Consider the impact of just one example of cultural difference: when is a marriage complete? In some Sierra Leone societies a marriage takes years to be complete, involving obligations to both the spouse and her family. When a married woman dies of ebola, where is she buried? It may require near or long distance transport of the body depending on her family of origin and the status of the marriage. Transmission can occur everywhere along the journey.

The social scientists I was working with often had decades of experience in West Africa. Many were integrated into the societies they worked with; some because it was their society. Many had medical, biological, ecological or agricultural backgrounds. They had lived through the violent convulsions of West Africa (Richards 1998; Suluku et al. 2012), the AIDS crisis (Nguyen 2010; Benton 2015), the crises of governance, and the complex social communication (Ferme 2001) elaborated under permanent structural violence (Bardosh et al. 2016).

They had critical information about the tremendous social impacts of illness care, dying, death, mourning, preparation for burial, burial and post-burial ceremonies. All of these involved high ebola risk to different types of contacts and associates of the dead. My closest anthropology colleague, Professor Paul Richards,

prepared a summary of key information which I sent to retired senior CDC staff as a reality check. We then had a formal conference call with active CDC ebola-response staff, in Atlanta, who were joined by multiple other agencies. A later summary was published in 2015 (Richards et al. 2015).

This is an example of one kind of important but passive engagement. Social scientists from Sierra Leone had useful epidemic-related information needed for planning effective epidemic interventions. Active integration of social scientists with medical intervention was more encouraged by the UK. Several key incidents of social scientist intervention between communities and the medical response were fairly well known, after violence by governments or violence by communities. Active integration of social scientists with communities on epidemic response also occurred but is less well known.

Social and cultural issues of burial ranged from the ritually covert and secret to the social, legal and ritually overt and public. Both had to be accommodated. With information on ebola transmission, the physical covert ritual actions could be adjusted to block transmission, for example by women in sodalities such as the *sande*. The more overt and socially public aspects of burial could also be modified to accommodate both epidemic control and the social requirements of death. This included proposing the use of trained local burial teams. The modification of both social burial and "medical" burial is an area where mutual accommodation eventually succeeded in many areas.

The social scientists described people in rural areas who would never have timely access to effective ebola treatment. They still needed assistance. Professor Marianne Ferme, Department of Anthropology, University of California, Berkeley described one of her own journeys to health care (Ferme 2014): "When I first did fieldwork in Sierra Leone I came down suddenly with a combination of illnesses that made me completely delirious and incontinent within a few hours (malaria, amoebic dysentery, a staff infection). I was a total mess. I couldn't believe what the two women who took care of me had to do to keep me clean and care for me. They were not only sponging and changing me, they also were constantly laundering all the bed sheets and clothes I was soiling, until I was 'med-evacuated' the indigenous way: the Paramount Chief sent his ceremonial hammock with 4 hammock bearers (who worked in pairs, running at a regular jog up and down hills to keep the momentum, and relieving each other at regular intervals), and I was out of there in no time at all, and on a main road where they flagged down a passing vehicle".

This was a walk-in village with no regular transportation, but I was completely in awe at the ingenuity of people in figuring out how to make do with what they had: from fashioning a little "porto-let" on a bucket for me, to figuring out when I was ill enough to need immediate hospitalization. Even with my ready cash to pay for transportation it took me and the man delegated by the village elders to accompany me about 12 h to get to the Serabu hospital emergency ward, which gives you some sense of how unrealistic it may be to expect isolated rural folks who may not have the means to pay for double transportation all the way there to get to hospitals (in my case, 4 different vehicles/legs to the journey, in addition to the bit with the hammock)." We will return to the hammock bearers later.

Some of the social scientists saw very early that people were condemned for not bringing ebola patients to medical isolation, even when transportation was impossible and medical centers were nonfunctional. I read medical team reports from all three countries that also recognized the failures in each stage of transportation, facilities, adequate material supplies and successful clinical care that were supposed to make clinical-isolation work. Medical messaging castigated the most basic human need to care for loved ones, rather than providing assistance with material and guides for home or local health care of ebola. It was isolation that was needed, whether the setting was a medical facility, community, social group or at home; not just medical isolation, even when it was unobtainable.

In order to break transmission chains *in situ*, roughly "at home", this meant a patient would have to be isolated, and a single care-giver had to be semi-isolated, physically but not socially from the surrounding community. Many farms had isolated field shelters used at harvest which could have been used. This was similar to social practices used for containing smallpox in Zaire (now DRC) that were repurposed during the first ebola outbreak in 1976. Similar practices had been used historically for other epidemics in West Africa as well. Basic palliative care at home had to be done in a clinical manner, to give caregivers a chance at survival. But these were homes without running water, power, and in significant numbers not even two plastic buckets for water or bleach solution. People could contain the epidemic and break chains of transmission (epidemic intervention) by isolation (patient) and semi-isolation (caregiver) without outside aid. But without that aid, both caregiver and patient would probably have died. With improved communication about burial, at least they could have been buried safely (burial teams or local burial teams) with socially adjusted medical burial.

In late August 2014 the U.S. military was going to provide several hundred thousand home health care kits for Liberia. This never happened. The decision making was opaque.

No one ever developed a manual for home health care for ebola. The closest I could ever find was an older CDC and WHO manual *Infection Control for Viral Haemorrhagic Fever in the African Healthcare Setting* (Lloyd and Perry 1998) which discusses the layout of care, innovation in personal protective equipment (PPE) and making maximum use of minimal access to supplies in a low resource setting.

It took about half a year but eventually the CDC put out a poster giving home caregiving advice while waiting for transportation (CDC 2014). I remember similar advice from one MSF facility for people who were waiting for a space to open. At the end of 2015 MSF's internal research unit published a review, in very French-inflected cautious English: noting that home care isolation had been used in other filovirus outbreaks, that they had older guidances for home-based support and risk reduction, that the pragmatic limits of using facility isolation had been reached in 2014, and that perhaps facility isolation was not the only option (Calain and Poncin, December 31, 2015). This is in section four: "Facility isolation: an onerous public health measure".

13.6 Closer to the People: Technologies of Bodies

Broadly speaking, social engagement strategies can be monologues and directed from the top down, or dialogues which require mutual recognition. Social science methodology can also reflect these two orientations. In surveys based on questionnaires people were adept at repeating back the ebola messages that came from governments and international medical groups. *Don't eat bushmeat* along with other more useful messages. Often the surveys were seen as part of the government. When engaged by longer-form more open-ended investigations and asked, for example what they would actually *do* in response to ebola the answers could be quite different. Medical work in foreign-supported centralized hospitals could involve gruesome triage decisions and 70% death rates in 2014. There were two waves of the international response trying to bring isolation and health-care closer to people: first in what were called Ebola Treatment Units (ETUs) which were relatively more advanced, and then in what were called Community Care Centers (CCCs). These may have suffered from the sociological consequences of top-down implementation.

In Liberia, many of the facilities were still being built in 2015, even as case numbers dissolved to nothing. They were burned to the ground for ebola containment reasons and could not be re-purposed for general medical care, following protocol. When the UK teams asked for an ETU plan review, I was able to point out that it *might* be more appropriate if the patient flow-chart schematics did not have the only outcome, or end-product, be disposing of the patient's body by incineration. They could, for example, show the patient cured and returning home. Incinerating the body, in any case, may have been biologically safer but socially disastrous.

What does it mean to be cured of ebola, or ebola-free? Originally it meant that a patient had survived and no longer had detectable virus when blood was tested. This was the diagnostic sign of being ebola-free. It was presumed that this sign derived from blood testing applied to the patient's entire body. However, sexual transmission of ebola developed harder and more convincing evidence. Ebola survival in semen turned out to vary widely and could go on for an indeterminate time in some patients. Gradually it became clear that there were multiple kinds of immune-protected tissues where the virus could remain, be detected, and sometimes be culturable (Vetter et al. 2016). Although sex, usually semen, was the main cause of secondary infections, infection of other tissues could cause long-term problems, for example in eyes. Sex was a real but relatively rare means of transmission compared to, say, Zika. Nor was being ebola-free (by blood testing) the end of long-term physical and mental consequences for patients (Etard et al. 2017).

On the other hand, physical objects from patient-care settings (fomites) did not seem strongly linked to transmission despite the great attention paid to them in all patient-care facilities and the detection of ebola RNA. Ebola was notable for its very high death rate, but people had different risk levels, for example by age. There also were cases of high and intimate exposure followed by minimal symptoms. We received one of these rarer atypical case description from a colleague, Lina Moses

working in Kenema, Sierra Leone, at the height of the epidemic. She is Research Assistant Professor in the Department of Global Community Health and Behavioral Sciences, Tulane University (Moses 2014): "[…] In the three and a half months doing this Ebola response, I was very surprised to see several cases of what I thought was mild disease. One case in particular, the contact of a case that died with severe hemorrhaging, vomiting, diarrhea, had a fever one day, came in for testing and was positive with low viral load. By the time we got the results he was feeling better, but we had to admit him because he had detectable virus. He was not too happy about this as he never developed any further symptoms. In fact, he occupied his time with push-ups, sit-ups, and pull-ups and was considerably bigger when he was discharged four days after admission. We tested him several times just to be sure it wasn't a lab error."

There is a history of some intimate caregivers of ebola patients surviving with only mild ebola symptoms, for example during an earlier outbreak in Gabon. I use the neutral terminology of an atypical disease course, which does not imply any particular mechanism. When blood samples from the Gabon caregivers were tested later they showed anti-ebola antibodies but, interestingly, not to the GP protein. We recommended special attention be paid to the low percentage of West African ebola epidemic survivors who had been identified with an atypical disease course.

Some new vaccine and antibody-like drug development strategies are being modeled on a particular survivor's antibodies from prior outbreaks. Others have the goal of broad-spectrum vaccination, seeking exactly those epitopes that could control a range of filoviruses at once. There may be an analog in the natural history and ecology of filovirus exposure that patients with mild symptoms exemplify. Prior exposure to some other disease, which must be rare, may have cross-protected them from most ebola symptoms. A mild disease reaction in enough people could create similar dynamics to immunization in dampening the rate of transmission.

Personal protective equipment was critical for medical workers but it was never designed for tropical conditions. In a sense they were being cooked sous vide while they tried to work. Typically a two-hour shift was the longest people could work competently, which meant the effective staffing rate needed was at least four times normal. The large, relatively well-trained Cuban medical teams were reported to have kept to shifts of from 40 minutes to an hour (Kirk and Walker 2016). The most dangerous time was disrobing, when liquid contaminating the impermeable surfaces of the PPE could transfer from PPE to exposed skin.

It would have made sense for materials science and PPE design teams to have worked with West Africans on better combinations of protection, particularly affordable protection, to reduce the risks and to reduce the heat stress. Cheap single use, absorbent disposable aprons could help when disrobing, for example.

PPE designs also made patient interaction difficult. Even medical workers who came down with ebola and were treated by their own friends and peers reported feeling humanly cut off. The very welcome relief offered by the international community at the end of 2014 was always additive in nature. If the epidemic had kept growing exponentially, this too would have been rapidly overtaken and swamped. Tropical adapted PPE would at least have had a clinical-personnel multiplier effect,

with better odds of holding the line until vaccines or other effective biotechnical tools were available.

On the other hand, something about the pace and conditions of work was quite different for members of the burial teams. Despite the high risk from corpses, and often less adequate PPE, I do not know of any burial team member who contracted or died from ebola. Nevertheless, the team members often faced tremendous social stigma for their work.

The clinical-isolation model of epidemic control had two internal contradictions at all levels. First, medical transportation and facilities, if available, were themselves major sites of transmission. Careful design and training could reduce within-facility transmission but peri-nosocomial transmission from transportation, waiting to be admitted, and screening at admission remained. Very effective point-of-care rapid screening diagnostics were needed, with near-zero false negative results. These were under development but not available during the epidemic. Second, access to effective medical treatment, indicated by survival rates, was always unequal; and the more effective the medical care, the more unequal the access.

Dr. Olivet Buck was the fourth senior doctor to die in Sierra Leone. When she was diagnosed with ebola, a Level 4 hospital in Germany offered to treat her if she could get there. President Ernest Bai Koroma personally called WHO in Geneva to ask for airplane medical evacuation to Germany. They refused. This was remarkably covered by Joseph Harker in an article in The Guardian newspaper (Harker 2014) headlined: "Why are western health workers with ebola flown out, but locals left to die?" In response, we spent quite some time on how to access the two U.S. SARS-ready emergency planes, but the systemic issue remained.

13.7 The Turning Point

There was a nodal point between two very different phases of the epidemic and response; between 2014 and 2015. It was the first questionable possibility of the beginning of the end. Reports that the epicurve was leveling off and perhaps turning down came first from Liberia. This was still uncertain, over the late winter and New Year's holidays, 2014/2015. I could not find anyone who knew whether to believe the reported Liberian numbers, or not. The major aid had only begun to arrive so it seemed too early. On the other hand, the methodology of reporting cases in Liberia seemed to have some strong disincentives, so perhaps it was a methodological artifact.

I went back and read Camus' *The Plague*, this time as a kind of field handbook to an epidemic. So did others: an article in *Emerging Infectious Diseases* from April 2015 on ebola in Liberia, mid-year 2014, introduces each section with a quote from *The Plague*. (Arwady et al. 2015). As it happened, the downturn was true, and the same decline in the rate of increase and then the number of new cases would also occur in Guinea (Conakry) and Sierra Leone. One of the under-examined questions

of the epidemic is what actually caused the epidemic to slow down, ending the growth phase.

I separate social epidemic control measure from classic clinical control measures (medical isolation and contact tracing). They interact: positively when there is adequate medical care for the scale of the outbreak, but negatively when the scale of the epidemic over-runs medical capacity, or medical capacity is limited from the beginning. The outbreak could, possibly, have been controlled early-on by a clinical isolation-contact tracing model, if there had been a timely response to MSF's (Medecins Sans Frontières) first calls for assistance in March, 2014. Later, with comparatively ample resources and many adaptations, the model worked as the epidemic was ending; on the downside of the epicurve controlling re-emerging cases, when single cases or small clusters could have reignited an outbreak.

The containment of ebola as an epidemic to Liberia, Sierra Leone and Guinea (Conakry) was a major success due to classical medical isolation and contact tracing. There were only small, brief, outbreaks in Nigeria, Senegal and Mali, for example. Sometimes this was by a combination of preparation, skill and good fortune. Urban Nigeria could have been the beginning of a world-wide epidemic (Shuaib et al. 2014). Sometimes, as in Guinea-Bissau, which seemed to have escaped transmission, success may have been due mainly to luck. The international response teams of the Centers for DIsease Control, coordinating with national health systems, had a major role.

Jeremy Farrar and Peter Piot described the vastly expanded scope of engagement needed for an ebola epidemic, when classical outbreak control is no longer sufficient (Farrar and Piot 2014). As the epidemic expanded exponentially, throughout 2014, clinical isolation was still the main model for epidemic control; ignoring conditions of unsafe or non-existent transportation to inadequately staffed and supplied facilities, with high mortality rates. MSF, whose capacity had been over-run, for first time in its history called for military intervention and assistance, but with the same model for epidemic control. There has been a recurrent amnesia about key social lessons learned about both clinical and epidemiological engagement during ebola outbreaks. The lessons forgotten include the social design of care facilities and community isolation and treatment, among many others (Bremen and Johnson 2014; Bremen et al. 2016; Hewlett and Hewlett 2007; Hewlett 2016). The lessons are learned and then forgotten, repeatedly since 1976. This is a bureaucratic and institutional mystery (Abramowitz et al. 2015). On the other hand, some key lessons learned, or imagined to have been learned, from the much smaller ebola outbreaks in central Africa were remembered all too well, where they did not apply. For example, messaging on bats, in particular, and bushmeat in general (Frieden et al. 2014) were contradicted by what people saw. Hunters and their families were not dying in West Africa; clinic and hospital staff were. In a factually human-human transmission epidemic, this damaged the credibility of international actors and of health program messaging.

One hypothesis for the turning of the epicurve is that social epidemic control measures had increasing effectiveness. Examples include social distancing; personal sanitation (chlorine solutions everywhere); mourning and burial changes

adapted to local cultural and social requirements; and community-organized isolation control. Temporary shelter-in-place programs, such as in Sierra Leone are another example, although controversial. A variation on the hypothesis stresses community and individual innovation. When there was no effective medical response, I argued that for social epidemic control measures to work: communities needed to think like epidemiologists, and epidemiologists needed to think like villagers and communities.

There was, in fact, a process of convergence that could have been much more supported and emphasized. Issues of convergence included evaluation of clinical risk and benefits: which procedures were critical to use in ebola care and worth the risk to health care workers (Ansumana et al. 2015) That's part of a longer story. The failure to provide basic supplies to people who would never be able to access any functional or timely clinical care is close to the heart of the matter.

13.8 Anything Critical Goes!

Paul Richards' book on the ebola social response is titled *Ebola: how a people's science helped end an epidemic* (Richards 2016). This was very kindly and favorably reviewed by Peter Piot, for some time now the Director of the London School of Hygiene and Tropical Medicine (Piot 2016). Richards describes the case for how rapid community learning and social adaptation on ebola was a major cause for the turning of the epicurve and for control of the epidemic. These changes appear to be mainly what I call epidemic measures, that limit or end transmission, as opposed to clinical care. His own specific examples come from villages studied in depth in 2014 and 2015 by the team he works with at Njala University in Sierra Leone, including Esther Yei Mokuwa. A large number were in Jawei chiefdom, the hardest hit chiefdom of Kailahun District, the epicenter of the epidemic. In general, he thinks that across Sierra Leone, areas that were hit first and hardest put the greatest adaptive measures in place. How rapid learning was adapted in urban and peri-urban areas, will have to be set aside.

Interaction with the epidemic control teams, in these examples, is shown as more of a dialog. Epidemiologists learned from the community and the community learned from medical and epidemic experts. The team set up workshops at Njala specifically for these interactions. Richards' view is that the fact that this was the first epidemic of ebola, as opposed to the smaller prior outbreaks, meant everyone had to learn how to fight and control the epidemic together. Peter Piot agreed (in his review and elsewhere) that there were similar experiences to what he and his team faced with the first ebola outbreak in Yambuku, in what is now the DRC. This included supporting villages using prior social models for fighting small pox.

For context, it is worth recalling the nosocomial origins of the first ebola outbreak, where the virus was spread by the use of unsterilized needles at Yambuku Mission Hospital. Eleven of the staff, then the medical director and three Belgian

missionaries died. The hospital closed and patients and their contacts fled to their homes, bringing ebola with them (Bremen et al. 1976; Breman and Johnson 2014).

The government and NGO burial teams in Kailahun made some adjustments to the social need of burial but much more could have been done. It was very difficult for the local communities to get support and training for their own burial teams, which they wanted.

Where dialog slowed down or disappeared, across the epidemic countries, was over clinical care: supporting the basic palliative care patients need to survive, in a rural community hut as well as in a place designated as a medical facility, or an advanced medical hospital. At a minimum this means, nutritional support (food, broths), oral rehydration therapy (ORT), disinfectants (usually chlorine) and how to prepare them, some PPE, and guidelines on the geometry and procedures of safe patient care to avoid contact with or spread of ebola virus.

Facility layout and movement in good ebola patient care has analogies to safe handling of radioisotopes, requiring a notion of the correct structure for the physical environment and how to move through it in sequence. One could say it is a kind of dance. Although ebola patient-care as dance would have made perfect sense for cross-cultural medical training I did not see a discussion in Richards of this kind of interaction.

Dance, drumming, and masquerade all have specific cognitive content and communicate structured information in this culture; they are languages as well as other things. Talking drums may be more familiar, and Richards gives examples from fieldwork when planting rice. The Paramount Chief Mussa Kallon and two sande (women) elders went to the Njala meetings, but there were disagreements about what should happen next. When Paul asked Chief Mussa Kallon how this was resolved he replied that the elders went into the bush and danced a solution.

Epidemiological concepts became integral to how people approached ebola. The communities Richards worked with were aware of, and developing procedures to prevent, the possibility of ebola transmission when carried by stretcher-bearers. No foreign or domestic medical group ever discussed this. After the epidemic receded, survivors were discussing using ebola, and the history and experience of ebola in their communities, as an important way of teaching science in their children's educational curriculum.

When thinking about strengthening a people's science in the context of the West African ebola epidemic, Richards defines the fundamental idea of science, in passing (!), as: prior judgements must be abandoned in the face of compelling empirical evidence. My interpretation of his work is that convergence of understanding and action could happen, even though the knowledge of the social meaning of death, which had to be understood, started more on one side (in communities) and understanding of the nature of the ebola virus and its transmission, which also had to be understood, was more on the other side (the international medical teams). Dialog can lead to cross-cultural convergence. People have a remarkable capacity to maintain prior judgements in the face of compelling empirical evidence. Here, I have been more interested in showing how this warped the international medical response. More broadly applied, cross-cultural convergence can lead to remarkably interesting

and enriched kinds of science. Most of the examples I know of come from cross-cultural agriculture, so to speak.

Twenty years ago, two of the social scientists we later worked with on ebola, James Fairhead and Melissa Leach, published Misreading the African landscape: society and ecology in a forest-savannah mosaic. A time sequence of aerial photographic surveys of Guinea, which began after the First World War, documented that the integrated cultural use of slash-and-burn annual cropping was part of increasing forest cover and not desertification. Kat Anderson's *Tending the wild* (Anderson 2005) describes the complex indigenous non-farming cultivation of plants and animals in California. The epistemology, ontology and categories used are different. This is part of a longer story. Medical, epidemiological, ecological and agricultural fields come together in the disease control strategies called one-health (Cohen 2013; Rubin et al. 2013), which may be a particularly useful area for investigating cross-cultural science.

13.9 For Amilcar Cabral, Who Would Have Been 76 in the Year 2000

In the Spring of 2015 a fisherman who was a primary contact of an ebola patient disappeared from Guinea (Conakry) into Guinea-Bissau. The CDC social sciences coordinator asked for contacts in Guinea-Bissau; and we had a whole second round of work on the same issues. The medical and governmental conditions were worse. The social scientists now were Portuguese-speaking or from Portuguese language countries. There also were a high proportion of scientists from Nordic countries. Most of this has to be set aside.

The history of Guinea-Bissau made it, if anything, even more socially, culturally and ethnically complex than the three primary ebola epidemic countries. Amilcar Cabral had carried out the first agricultural census of Guinea-Bissau, after 500 years of Portuguese rule, published in 1956. Some of this was now available in English translation. Almost all of the population were farmers so an agricultural survey had to deal with most of the complexity of the country. It was still very useful background information 60 years later.

Cabral was literally one in a million, one of the very few Africans from then Guinea-Bissau and Cape Verde Islands who received a college education. One can imagine if the United States had only 300 people with bachelor degrees. I read as much of his agricultural work as I could find and re-read the political writing and commentary.

Cabral had a very unusual and sophisticated view of critical cross-cultural science, technology, ecology and knowledge. It is framed first within the context of farming, and then in his approach to liberation from Portugal and international support. I could see this in his critical evaluation of rice farming between ethnic and cultural groups, as well as the evaluation of the impact of colonial cash crops. It is

nearly completely overlooked in the political literature, except for two cases that could not be ignored but were never analyzed or, I think, understood. He had interesting methods of using theater for education and practice in cross-cultural work. He died before he could use this approach in post-colonial national development. This needs to be followed up.

Ebola was not reported found in Guinea-Bissau. They were not so fortunate with (Pacific-Brazilian) Zika virus, which went from Cape Verde to Bissau in 2016. Zika may be harder than ebola to control.

Ebola had a striking effect on international biomedical research and development capacity for combatting neglected tropical diseases. It also showed that, in many cases, individuals could wrestle control of scientific, development, government and corporate institutions in a kind of Prague Spring of science facing a lethal crisis. Even advanced biomedical tools have to be used in context.

Ebola went undiagnosed in Guinea for over three months. Dr. Michael Van Herp, MSF Brussels, suspected ebola after receiving case reports that included rapid death, probably too rapid to be Lassa fever, and hiccups (Stern 2014). Hiccups were toward the bottom of signs and symptoms presented by ebola patients; 17th on the WHO Ebola Response Team table of West African patients, reported in October, 2014 (Team WE 2014). But hiccups were associated with ebola among the hemorrhagic fevers.

And so it all began.

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