FROM ANONYMITY TO NOTORIETY.

HISTORICAL PROBLEMS ASSOCIATED WITH OUTBREAKS OF EMERGING INFECTIOUS DISEASES; A CASE STUDY: EBOLA HAEMORRHAGIC FEVER.

by

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ABSTRACT

Ebola Haemorrhagic Fever is an acute viral disease with a lethality rate ranging from 50% to 90%. Although first reported in 1976, it only emerged in the public consciousness in the early 1990s. This work explains the reasons behind this sudden change, and examines the modifications that arose in the transition from scientific texts to popular articles. My analysis reveals that this newfound notoriety has had direct and indirect effects on the control and management of Ebola epidemics.

The initial reactions of Europeans and Africans in epidemic sites are reconstructed using oral interviews, published material, as well as surveys sent to 33 Ebola researchers. Using this evidence, the thesis explores a variety of issues: how afflicted communities interpreted the outbreaks, the role of Western and traditional medicine, the various ways in which local populations resisted control measures, and the different attitudes of Western health personnel towards the disease and each other. The result is a deeper understanding of the considerable social impact of Ebola epidemics, and an awareness of certain problems entirely neglected by the media.

Finally, this thesis turns its attention to the mystery surrounding the disease and to scientists' attempts to solve some of the unknown elements, such as the identity of the natural reservoir. I argue that the scientific uncertainty has affected popular perceptions of the disease, and, as a result, increased the amount of funds invested into Ebola research. A section devoted to broader issues, such as the difficulty of reconciling deforestation and economic growth in impoverished African countries, and the deleterious effects of political instability, concludes the work. The thesis argues that the publicized drama of Ebola outbreaks has obscured these fundamental problems.

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CHAPTER 1

Introduction

'I will show you fear in a handful of dust'

T.S. Eliot, *The Waste Land* (1922)

Background on Ebola

Ebola Haemorrhagic Fever (EHF) is an acute viral illness with a lethality rate that ranges from around 50% to 90%. With the exception of Rabies and HIV/AIDS, no other viral disease has such a high case fatality rate. The Ebola viruses are one of two genera of the family *Filoviridae*.[1] The symptoms of Ebola infection vary from case to case, but generally involve fever, headache, joint or muscle pains, sore throat, vomiting, diarrhoea, bleeding, shock and other neurological symptoms. Patients usually die six to nine days after the appearance of the first symptoms. At the time of writing, there exists no treatment against the disease. Transmission of the virus occurs through contact with infected blood or body fluids. One species of the genus, Reston Ebola Virus (REBOV), is believed to be spread by aerosol, but is nonpathogenic to humans. Despite a number of investigations, the organism in which the virus resides in nature - the reservoir – is not known.[2]

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[1] The other genus comprises the Marburg virus. There are four species of Ebola, named after the country or site of their first recorded appearance: Zaire, Sudan, Reston and Côte d'Ivoire Ebola Virus.
[2] Colebunders, R., and Borchert, M., 'Ebola Haemorrhagic Fever', *Journal of Infection*, 40 (2000), 16-20.

The first reported cases of EHF appeared in the Sudan and the Democratic Republic of the Congo (DRC) in the middle of 1976, when 602 people were reported to have contracted the disease. Since then, there have been about a dozen further outbreaks, totalling 1638 identified cases, and 1104 deaths (67% case fatality rate). It should be noted, however, that retrospective evidence of Ebola infections, as shown by Tignor *et al*., and the non-identified or misidentified cases are likely to make this total a gross underestimate.[3] The new agent was named Ebola, after a river in northern DRC.

The Ebola Phenomenon

With 1104 documented deaths since 1976, and even if the figures are wrong by a factor of a hundred, Ebola is a statistically trivial disease. Malaria, for example, kills over two million people each year, and Tuberculosis makes three million victims annually.[4] Yet 'Ebola' is a household name. It was not always so. One purpose of this thesis is to examine the immediate questions and observations raised by scientists on the nature of this new disease. Chapter one explains the disease's meteoric rise in the early 1990s from anonymity to notoriety in the public consciousness. The consequences of this rise to fame are also discussed.

The second chapter deals with the reactions of Africans and Westerners to Ebola outbreaks. Using extracts from a survey conducted among 16 field epidemiologists and 17 laboratory researchers, all of whom have worked with the virus, as well as

[3] Tignor *et al*.'s study, based on serological evidence, claims that victims of a Yellow Fever epidemic ravaging parts of Ethiopia in the early 1960s died not only of Yellow Fever, but also of Ebola. Some scientists, however, question the findings, as Tignor used error-prone indirect immunofluorescence tests to obtain the results. Tignor, G., *et al*., 'The Yellow Fever Epidemic in Ethiopia, 1961-2', *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 87 (1993), p. 162.

[4] World Health Organization Fact Sheet Number 189. Available Online: http://www.who.int/inf-fs/en/fact189.html

personal communications and published material, chapter two reconstructs the actions and reactions of victims, community members and health personnel in the field.[5] The result is a vivid tableau of what occurred during past outbreaks, and a deeper understanding of the immediate social impact of Ebola epidemics. A detailed summary of the survey results is included in the Appendix.

Finally, we shall turn our attention to the mystery surrounding Ebola, and the broader issues associated with the disease. We follow the elusive search for the reservoir, the debate on the underlying causes of the epidemics, and the effects of politics on African governments' responses to Ebola outbreaks. What becomes apparent is that the scientific uncertainty complicates an already elaborate web of issues surrounding Ebola.

Unlike firmly established diseases such as Cholera, Plague and Yellow Fever, Ebola is a recent addition to the pantheon of dreaded afflictions. This thesis attempts to untangle strands of the 'Ebola web', and to illuminate neglected aspects of the disease's history.

[5] Between March and July 2002, two different surveys were sent to field and laboratory scientists. As promised to the respondents, their identity is undisclosed.
Certain scientists have given me information on the condition of anonymity. Citations from these sources will be referenced simply as 'Personal Communication'.

CHAPTER 2

From Anonymity to Notoriety

The Ebola virus has been lurking in the forests of Africa for thousands of years, contained within a still unknown reservoir.[6] Before 1976, the year the virus left its niche to infect 602 human cases in the Sudan and the Democratic Republic of the Congo (DRC), Ebola was probably responsible for the sporadic deaths of both human and non-human primates for centuries. A recent serological study has shown that some Pygmy populations and farmers of the Central African Republic possess filovirus antibodies in their blood, suggesting previous encounters with Ebola and Marburg.[7] Following the reported eruptions of Ebola in the late 1970s, a haemorrhagic fever surveillance program was conducted in the DRC between 1981 and 1985. The program led to the identification of 21 cases of Ebola. These few cases, which would probably have passed unnoticed in the absence of surveillance, provide evidence that small-scale and self-limiting outbreaks of Ebola have been occurring in the past. It is easy to imagine, in areas of very low population density, a hunter entering the forest, contracting the disease through the bite or blood of an infected animal, and in turn transmitting the disease to the rest of his family. The

[6] Suzuki, Y., and Gojobori, T. 'The Origin and Evolution of Ebola and Marburg Viruses', *Molecular Biology and Evolution*, 14, 8 (1997), 800-806.
[7] Gonzalez, J-P., *et al.* 'Ebola and Marburg Virus Antibody Prevalence in Selected Populations of the Central African Republic', *Microbes and Infection*, 2 (2000), 39-44.

outbreak would stop at the hunter's doorstep, and would not be reported to the health authorities.

Chimpanzees and gorillas have also been victims of Ebola. As early as 1931, Charles Elton, an Oxford zoologist, stressed the importance of studying animal epidemics. Such studies, he argued, would allow us to trace human diseases to their reservoir in the wild and to examine the forerunners of an epidemic. In short, they would provide a greater understanding of the mechanisms underlying epidemics in general.[8] At the close of the 20th century, the rise in emerging infections meant a leap out of obscurity for the disease ecology of animals. The possibility of total species extinction through disease, long thought nonsensical in terms of population biology, is perhaps the most notable - and alarming - finding.[9] In 2002, the US Institute of Medicine published a report on the emergence of zoonotic diseases, pointing to the avalanche of emerging zoonotic infections of the last decade, and addressing the need for better prevention and control strategies to combat such diseases.[10]

The death of non-human primates has often preceded outbreaks of human disease. The human epidemic of Kyasanur Forest disease in India (1957), for example, was announced by an unusually high number of monkey deaths.[11] In many African countries, monkeys are commonly hunted for food and trade and present a risk of infection to humans. Peeters *et al*. analyzed the blood of 788 monkeys captured in the

[8] Elton, C., 'The Study of Epidemic Diseases Among Wild Animals', *Journal of Hygiene*, 31, 4 (1931), 436-437.
[9] Daszak, P. 'The Emergence of Infectious Diseases Among Wildlife', *International Conference on Emerging Infectious Diseases 2002*, Atlanta, USA, 25 March 2002. Daszak cites Australian gastric brooding frogs, Hawaiian birds and Partula tree snails as examples of total species extinction through disease.
[10] Burroughs, T., Knobler, S., and Lederberg, J. (eds) *The Emergence of Zoonotic Diseases* (Washington D.C., 2002).
[11] Banerjee, K., 'Emerging Viral Infections with Special Reference to India', 103 (1996), 177-200.

rainforests of Cameroon. They found that 13 of the 16 monkey species were infected with *Simian immunodeficiency virus* (SIV), including four species not previously known to harbour the virus. They conclude that 'humans who hunt and handle bushmeat are exposed to a plethora of genetically highly divergent viruses'.[12] Dr William Karesh, of the Wildlife Conservation Society, estimates that humans and great apes commonly share 150 diseases.[13] Yet there exists evidence of possible longstanding knowledge of the dangers of primate bushmeat, or at least cases when the consumption of such meat is forbidden. In 1933, Humphrey Gilkes, a medical officer working in Zambia, published an article on native customs in Africa. Writing on the tribes living near the Luangwa valley in Northern Rhodesia (now Zambia), he notes that people of child-bearing age must not eat the 'flesh of monkeys because it will make their children be born mad'.[14] Such a rooted taboo, associating monkey meat with infant dementia, suggests that monkey pathogens were transferred to man at some time in the population's history.

On a number of occasions, the deaths of monkeys preceded or co-occurred with human outbreaks of Ebola, including one instance where a 34-year-old ethologist was directly infected after performing an autopsy on a wild chimpanzee.[15] A month later, in December 1994, the first reported outbreak of Ebola erupted in Gabon. On arrival at the site, investigators received reports of unexplained deaths among gorillas and great apes, although they found no carcasses. In February 1996, before the second epidemic in Gabon, 18 people who had skinned and chopped a dead chimpanzee fell

[12] Peeters *et al*. ' Risk to Human Health from a Plethora of Simian Immunodeficiency Viruses in Primate Bushmeat', *Emerging Infectious Diseases*, 8, 5 (2002), p. 451.
[13] Personal Communication, 16 August 2002.
[14] Gilkes, H. 'Native Customs in Africa and the Medical Officer', *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 28, 3 (1933), p. 319.
[15] Formenty, P., *et al*., 'Ebola Virus Outbreak Among Wild Chimpanzees Living in a Rain Forest in Côte d'Ivoire', *The Journal of Infectious Diseases*, 179 (supplement 1, 1999), S120-S126.

ill with the disease.[16] In the most recent outbreak in Gabon (2001/2), the Gabonese Research Minister announced that the government had been informed of 'the discovery in the forest of the corpses of many great apes, gorillas, chimpanzees and so on'.[17] Veterinarians found the remains of over 30 gorillas and a dozen chimpanzees.[18] In the absence of a known reservoir, these epizootics could be considered useful forerunners of human outbreaks and incorporated into surveillance programs.

The Puzzle of Ebola

When the village elders near the affected Yambuku mission in 1976 were asked by epidemiologists if they had ever seen a similar affliction, they unhesitatingly replied in the negative. To these villagers, Ebola was new. And so too was it for the medical community, although they had previously encountered cases of Marburg - another member of the filovirus family. Yet Marburg, since its first recorded appearance in 1967, had only caused eight deaths. What, then, was the reaction of the medical community upon discovering the virus? Dr. P. Brès writes that 'the lack of previous experience with such sudden outbreaks and of such magnitude inevitably meant a good deal of improvisation'.[19] In the field, the hospital workers and doctors experienced high levels of fear. In Yambuku hospital, following wrong diagnoses and

[16] Georges, A-J *et al.*, 'Ebola Hemorrhagic Fever Outbreaks in Gabon, 1994-1997', *The Journal of Infectious Diseases*, 179 (supplement 1, 1999), p. S66.
[17] UN Integrated Regional Information Networks, 14 December 2001. Available Online: http://fr.allafrica.com/stories/printable/200112140453.
[18] *Gorilla Health*, Wildlife Conservation Society News, 18 July 2002. Available Online: http://wcs.org/7411/?art=64937.
[19] Brès, P. in Pattyn, S.R., *Ebola Virus Haemorrhagic Fever: Proceedings of an International Colloquium on Ebola Virus Infection and other Haemorrhagic Fevers*, held in Antwerp, Belgium, 6-8 December, 1977 (Amsterdam; New York, 1978), p. 237.

futile treatments, 13 of the 17 medical staff fell ill, and 11 died.[20] Accounts of first encounters with Ebola victims are often striking, and shall be examined in a later chapter.

A good way to establish both the questions posed by and the reactions of the medical community vis-à-vis the virus and the events in Africa, is to examine the contents of the first international colloquium on Ebola. The colloquium was held in Antwerp (Belgium), little more than a year following the end of the outbreaks. In the preface to the published version of the conference, Dr. Halter, then Secretary General of the Ministry of Public Health and Family Affairs in Brussels, asserted that the conference provided:

> a clear picture of the characteristics of the etiologic organism and its epidemic genius and also lift[ed] a side of the veil on the other mysterious and dangerous haemorrhagic diseases such as Lassa, Congo, Marburg or Ebola fevers. (my emphasis)[21]

Dr. Halter's preface highlights the enigmatic qualities of Ebola, and reflects an awe towards the organism and its effects that pervades the proceedings of the conference. Interestingly, the Ebola outbreaks acted as a catalyst to the study of other haemorrhagic fevers, which had before enjoyed the attention of only a few scientists. The scientists appear most astonished by the clinical manifestations of the Ebola virus. Piot *et al.* qualify the evolution of Ebola infection as 'inexorable'.[22] Murphy *et al.* call the cytopathic effects of Ebola on living tissue 'striking', and the progression from infection to cell death 'extreme' in its rapidity.[23] In the discussion, Dr. Francis

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[20] Initial diagnoses were: Malaria, Fulminating Typhoid, Yellow Fever and Lassa fever. See Close, W. *Ebola: Through the Eyes of the People* (Wyoming, 2002), p. 175, and Breman, J.G. *et al.* 'The Epidemiology of Ebola Haemorrhagic Fever in Zaire, 1976', in Pattyn, S.R. (see footnote 19)
[21] Halter, S., 'Preface', in Pattyn, S.R., p. 5.
[22] Piot, P. *et al.*, 'Clinical Aspects of Ebola Virus Infection in Yambuku Area, Zaire, 1976', in Pattyn, S.R., p. 20.
[23] Murphy, F. *et al.*, 'Ebola and Marburg Virus Morphology and Taxonomy', in Pattyn, S.R., p. 55.

mentions the 'tremendous amount of intratissular and diarrheal loss'.[24] Dr. El Tahir, upon arriving in the town of Maridi, Sudan, found 'a really grave situation', and concludes that the 76 Maridi hospital workers infected with Ebola makes this 'one of the most tragic hospital outbreaks that ever occurred in the recent history of medicine'.[25] The first encounters with Ebola, both in the laboratory and in the field, are marked by bewildered observations on the cellular and societal ravages of the virus.

In short, the conference presentations addressed a number of issues. They acknowledged the difficulty of diagnosing Ebola and the need for simple but rapid diagnostic tools. They called for more work on the virology of Ebola in order to develop a vaccine and improve treatment of the disease. On the epidemiological side, they raised the question of the outbreaks' origins and of the links between the two outbreaks. Speakers discussed the disseminating role of the hospitals and the consequent importance of publicizing the disease, they considered the containment and surveillance of Ebola during outbreaks, and reflected on the failed search for the reservoir. Finally, talks were devoted to the handling of highly infectious agents, and to the transport and care of infected patients.

The Ebola outbreaks, adding to the fear generated by Marburg, Lassa and Rift Valley Fever, provided a major stimulus for the establishment of high containment facilities at the Centers for Disease Control (CDC) in Atlanta.[26] For the first time, researchers

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[24] Francis, D., comment in discussion, in Pattyn, S.R., p. 34.
[25] El Tahir, B., 'The Haemorrhagic Fever Outbreak in Maridi, Western Equatoria, Southern Sudan', in Pattyn, S.R., p. 98.
[26] Peters, C.J., Personal Communication, 19 August 2002.
Lassa Fever is an acute viral disease. It was first isolated in 1969 following a hospital outbreak in Lassa, Nigeria. The high mortality, dramatic symptoms and the possibility of aerosol spread made

wore protective 'space suits' and passed through air-locked anterooms for decontamination. In May 1979, the CDC opened a new Maximum Containment Laboratory. The short delay between the end of the outbreaks and the holding of the conference, the sheer amount of information covered in the proceedings, and the 114 participants involved, reflect the considerable interest of the scientific community in Ebola. But this fascination did not translate into any kind of public excitement in Europe or the Americas. Unlike the 1995 Kikwit epidemic (DRC), where there were 84 journalists present, representing 13 countries, the 1976 Yambuku outbreak (DRC) did not benefit from any on-site coverage by foreign journalists.

In the affected Bumba zone (DRC), the after-shock of the 1976 outbreak among the inhabitants was evident. Karl Johnson, an M.D. involved in the control of the epidemic, described how even months after the official end of the quarantine:

> […] the commercial airlines still refused to fly, the people who ran the river boats between Kisangani and Kinshasa still wouldn't pull in to Bumba to take off cargo and the people of Zaire still retained a very great sense indeed of horror and anxiety about this whole happening.[27]

But horrors and tragedies abroad do not necessarily transfer into the pages of the national newspapers of Europe and North America. When did Ebola leave the limited realm of the scientific world to become entrenched in the psyche of the American and European populace, and what occurred in this transition?

Lassa Fever a major concern among the medical community in the 1970s. Rift Valley Fever (RVF), isolated in 1930, is a zoonotic disease affecting animals and humans. The discovery that RVF could develop into a haemorrhagic fever was spurred on by the 1975 Marburg outbreak in Johannesburg, South Africa.

[27] Johnson, K. M., comment in discussion, in Pattyn, S.R., p. 127.

The Spread of Ebola Out of Africa

In October 1989, a hundred monkeys (cynomolgus macaques) were sent from the Philippines to a quarantine facility in Reston, Virginia, USA. Alarmed by an uncommonly high death rate, scientists isolated an Ebola-like virus from the blood of the dead primates.[28] Although nonpathogenic to humans, this strain of the virus could be transmitted by aerosol. Journalists, focusing on this new mode of transmission, filled the newspapers with apocalyptic scenarios. In March 1992, Ebola Reston was found in monkeys in Sienna, Italy, sent from the same monkey facility in the Philippines. Ebola, even if nonpathogenic and originating from the Philippines, had emerged out of the 'dark continent' - popularly perceived as a hotbed of disease - and into the United States and Europe. A parallel can be drawn with Cholera in the 19th century, which to the shock of Europe and North America had spread from filth-ridden India to plague the great cities of 'civilized' countries.[29] Nations such as France, before the arrival of the epidemic, believed their 'civilized' state would protect them from such afflictions. In 1989, the United States - one of the world's wealthiest nations - did not anticipate the importation of this rare African disease into a suburb of Washington DC. The outbreak led Japan Airlines, All Nippon Airways, and Korean Airlines to stop importing certain monkey species into Japan. In addition, the United States introduced stricter disease control measures for the handling and importation of non-human primates.[30] Ebola, out of its protective African 'cage' and floating ominously in the North American air, was now newsworthy material.

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[28] A new subtype, Ebola Reston (REBOV), was identified.
[29] Delaporte, F., *Disease and Civilization* (Cambridge, MA, 1986), p. 16.
[30] DeMarcus, A., *et al.*, 'US Policy for Disease Control Among Imported Non-Human Primates', *The Journal of Infectious Diseases*, 179 (supplement 1, 1999), S281-2.

In October 1992, Richard Preston wrote a piece in the New Yorker magazine entitled 'Crisis in the Hot Zone', dramatically describing the events of the Reston episode.[31] Such was the popularity of the article that Preston was soon in talks with film producers, and expanded his New Yorker piece into a bestselling book, *The Hot Zone*, published in 1994. [32] In the same year, Newsday reporter Laurie Garrett complemented Preston with the publication of *The Coming Plague*.[33] The following year, in April 1995, Warner Brothers released the film *Outbreak*, which recounted the infiltration of an Ebola-like virus into a small North American town.[34] Indeed, Sheldon Ungar has argued that '1994 marks the "coming out" ceremony for infectious diseases in the popular media', explained possibly by a number of dramatic outbreaks in the early 1990s, such as the mysterious hantavirus pulmonary syndrome in the spring of 1993 in the United States and the Cholera epidemics in the Western Hemisphere and Asia.[35]

Whereas the 1976 Ebola outbreak in Yambuku (DRC) generated fewer than 10 newspaper articles, the 1995 Kikwit outbreak (DRC) was the topic of 2793 articles in English in the Lexis-Nexis search engine.[36] Ebola had emerged out of the tropical rainforests of deepest Africa, and leaped from the pages of specialist publications to those of newspapers and popular books. The transformation from scientific to popular could hardly have been more radical. The sociologist Renee Anspach has analyzed characteristic features of the language of written medical discourse.[37] The

[31] Preston, R. 'Crisis in the Hot Zone', *New Yorker*, 26 October 1992, 58-81.
[32] Preston, R. *The Hot Zone*, (London, 1994).
[33] Garrett, L. *The Coming Plague*, (New York, 1994).
[34] *Outbreak* [film], dir. W. Petersen, distr. Warner Bros, 1995.
[35] Ungar, S., 'Hot Crises and Media Reassurance', *British Journal of Sociology*, 49, 1 (1998), p. 41.
[36] Garrett, L. *The Betrayal of Trust*, p. 65 and p. 68.
[37] Anspach, R., 'Notes on the Sociology of Medical Discourse', *Journal of Health and Social Behavior*, 29 (1988), 357-375.

style of medical discourse uses a variety of linguistic features to stress objectivity. The following examples are taken from a scientific article describing the clinical manifestations of Ebola patients during the 1995 Kikwit epidemic.[38] One way is to make the medical procedure the agent of the sentence, thereby eliminating the human element. In the example below, this is reinforced by the use of a verb suggesting infallibility: 'Auscultation revealed clear lungs in several patients with terminal tachypnea.' (my emphasis)[39] The passive voice is frequently employed, and serves to obscure the agent: 'Different practices were used in the management of patients […] and resulted in various side effects.' (my emphasis).[40] In short, the rhetoric of medical discourse attempts to render observations and procedures free from human judgement or error. The person performing the auscultation or managing the patients is absent from the sentence. Furthermore, the conveying of detailed information in condensed form inevitably de-humanizes the object of the clinical description. This is evident in the following passage:

> Bleeding signs generally manifested as oozing from the punctured skin, the gums, and the nose. Prolonged bleeding at intravenous puncture sites was sometimes the first clue to the diagnosis of EHF. Overall the occurrence of visible bleeding signs indicated a poor prognosis, except from melena and bloody stools.[41]

Compare the above description with one found in Preston's *The Hot Zone*. I have underlined words and phrases which I deemed salient.

> Your mouth bleeds, and you bleed around your teeth, and you may have haemorrhages from the salivary glands – literally every opening in the body bleeds, no matter how small. The surface of the tongue turns brilliant red and then sloughs off, and is swallowed or spat out. It is said to be extraordinarily painful to lose the surface of one's tongue. […] Your heart bleeds onto itself. […] Ebola attacks the lining of the eyeball. You may go blind.

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[38] Bwaka, M. *et al.*, 'Ebola Haemorrhagic Fever in Kikwit, Democratic Republic of the Congo: Clinical Observations in 103 Patients', *Journal of Infectious Diseases,* 179 (supplement 1, 1999), S1-S7.
[39] Bwaka, M. *et al.*, p. S4.
[40] Bwaka, M. *et al.*, p. S4.
[41] Bwaka, M. *et al.*, p. S3.

The differences between the two passages are striking. First, Preston's description, through the constant repetition of 'you' and 'your', deeply involves the reader. He wishes the reader to imagine himself as suffering from the disease. The repetition of 'bleeds' and the inclusion of many parts of the anatomy, both external (mouth, teeth, tongue, eyes – note that these are all facial) and internal (salivary glands, heart) evoke a total disintegration of the self, a disintegration that is above all painful, and relentless, as alluded by the repeated use of the conjunction 'and'. Unlike medical discourse, Preston's writing does not necessarily prize lexical economy. Many of his clauses appear unnecessary, or rather serve only to emphasize information already given or otherwise obvious. There is, for instance, little doubt that losing the surface of one's tongue is excruciating. Joffe and Haarhoff, in their detailed examination of popular representations of Ebola in Britain, noted that a third of British tabloids, and next to half of the broadsheets referred to 'liquefying, disintegrating, combusting bodies'.[42] The vivid portrayal of Ebola's horrific symptoms, associated with speculations on the pandemic potential of the virus, evoke fear in the reader.

Medical historian Paul Slack suggests that knowledge of a disease's symptoms can affect the social and intellectual reactions to it, and plays a part in the representation of the disease in the public imagination.[43] In most societies, and throughout history, blood possesses powerful symbolic values, associated with life, vital energy and spirit. Ebola – a statistically insignificant disease – has acquired an almost mythical status among the media and the lay population, adorned with apocalyptic and science-fiction imagery. Inevitably, one commonly finds misinformation regarding transmissibility,

[42] Joffe, H. and Haarhoff, G., 'Representations of far-flung illnesses', *Social Science & Medicine*, 54 (2002), p. 962. The tabloids analyzed were *The Sun*, *The Daily Mail, The Daily Mirror*, and *The Daily Express*. The broadsheets were *The Daily Telegraph*, *The Guardian*, *The Independent* and *The Times*.
[43] Ranger, T. and Slack. P. (eds), *Epidemics and Ideas* (Cambridge, 1992), p. 8.

global threat, mortality rate and other characteristics in press articles.[44] Rebecca Weldon has summed up perhaps the main modification that occurred in the translation process from scientific discourse to popular discourse: the latter portrays the virus 'as a sentient being, stalking, invading, capable of hunting and capturing prey'.[45] But what were the consequences of Ebola's newfound notoriety?

Such a frightening image, coupled with the distortions of the media, engendered irrational decisions towards the afflicted communities, and occasionally, countries. Most recently, in December 2001, the Chinese government imposed a ban on apes imported from Gabon, and warned Gabonese citizens that they would be subject to extra scrutiny and possible isolation.[46] In November 2000, the Kenyan government deported over 100 Ugandans who were attending a conference in Nairobi, even after Kenyan doctors confirmed none of them carried the disease.[47] In January 2001, the Saudi Arabian government banned Ugandan Muslims from attending the annual Hajj, despite recommendations from the WHO that such measures were unnecessary.[48] During the outbreak in Kikwit, DRC (1995), four countries stopped all incoming flights from the DRC, and some European governments banned the importation of primates from the African continent.[49] Even the realm of sport was affected when players of the Zimbabwean football team refused to play against the DRC for the return leg of the African Nations' Cup.[50] Cathy Roth, of the Global Alert and Response Team at the WHO, asserted in an interview that such reactions arose

[44] Examples of misinformation may be found in Joffe and Haarhoff (2002).
[45] Weldon, R., 'An "Urban Legend" of Global Proportion', *Journal of Health Communication*, 6, 3 (2001), p. 285.
[46] 'China Fears Ebola Virus, Bans Some Gabon Animals', CARPE, 29 December 2001. Available Online: http://carpe.umd.edu/congo_basin_news/news_article.asp?article=90.
[47] Telewa, M., 'Ugandans Deported in Ebola Scare', BBC News Online, 24 November 2000.
[48] Borzello, A., 'Uganda "almost" Ebola Free', BBC News Online, 24 January 2001.
[49] Garrett, L., *The Betrayal of Trust*, p. 95.
[50] Campbell, H., 'Ebola and Biological Warfare', 1995. Available Online: http://syllabus.syr.edu/AAS/hgcampbe/aas312/pub.htm

'because the decisions are often made by people who are poorly informed on the disease'.[51] What determines these reactions is not so much the actual threat of Ebola, but rather the perceived threat. As the earlier comparison between a scientific and popular text demonstrated, the latter tends to inflate the statements of scientists during the translation process and, as a result, contributes to the creation of a perceived threat that eclipses the actual risk. The $900 or so million spent by the US government on smallpox vaccine this year is evidence that it is the perceived threat that drives decisions.[52]

The virus's notoriety also affects the actions taken to combat the disease. The Kikwit outbreak, for example, erupted in the DRC at a time when the budget for the Special Pathogens Branch at the Centers for Disease Control was decreasing. As one survey respondent wrote:

> Kikwit was an opportunity [for the CDC] to draw the attention of the US Congress on emerging diseases and to raise some budget. With CNN, CDC won an unexpectedly large budget.[53]

The media interest was directly responsible for the increased funding of the CDC. Dan Bausch, an epidemiologist working for the CDC, asserts that 'short-term financial commitments for a high-profile outbreak are relatively forthcoming' but points to the difficulty of obtaining the long-term support that would give researchers a greater understanding of the disease.[54] The situation appears worse in the United Kingdom. A leading British virologist who took part in the survey deplores the lack of government support for Ebola research:

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[51] Personal Communication, 8 April 2002.
[52] Burke, D., Personal Communication, 8 March 2002.
[53] Survey 27. Although not included in the Appendix, the author has numbered all the surveys from 1 to 33. These are available upon request.

[54] Bausch, D. 'The Ebola Virus', *United Nations Chronicle Online Edition*, 38, 2 (2001). Available Online: http://www.un.org/Pubs/chronicle/2001/issue2/0102p6.htm

> Since this disease is of no immediate epidemiological concern outside endemic areas, it is not considered a high priority by Government or Granting Authorities. It only becomes high on the political agenda when we identify an imported Viral Haemorrhage fever case in the Northern Hemisphere.[55]

Bioterrorism is another fear-induced source of attention and, for this reason, of income. Yet despite Ebola's notoriety, and the money generated from its reputation, most researchers lament the lack of funds. When the survey among laboratory researchers was conducted between March and August 2002, 29% of the respondents believed enough money was injected into Ebola research, as opposed to 71% calling for additional funding. Considering the direct involvement of the respondents in Ebola research, these results are unsurprising. Whether such an investment is a good use of limited resources is a question whose scope lies outside this thesis.

Extending the metaphor of Ebola as a stealthy assassin, the media exposes field epidemiologists as fearless 'hunters'. In fact, some epidemiologists have embraced this term, as indicated by the title of their books. It is interesting to note that the three scientists who chose to include the phrase 'virus hunter' or 'virus hunters' in their book title all worked with Ebola.[56] This popular portrayal highlights certain aspects of the epidemiologists' role, such as the search for cases and the inherent danger of infection, but obscures others, in particular the unsightly side of work in the field. The egos and rivalries among field workers, for instance, are not mentioned in the popular press. Scientists, after all, are eager to enhance their image to further their career and obtain funding. Unsurprisingly, press articles also fail to mention the negative effects of media presence on outbreak sites.

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[55] Survey 31.
[56] The authors are McCormick, J. and Fisher-Hoch, S. who co-authored *Virus Hunters of the CDC* (Atlanta, 1996), and Peters, C.J. who wrote *Virus Hunter* (New York, 1997).

Feeding on the popularity of the disease, press journalists have regularly been sent to investigate outbreaks on-site. The presence *en masse* of the media is a double-edged sword. As we have seen, media coverage of an outbreak can affect the distribution of funds to Ebola research. It can also accelerate the importation of much-needed equipment for control and management procedures. But in Kikwit, the dozens of rapacious journalists cared little for the privacy or safety of the scientists and afflicted populations. They attempted to infiltrate patient wards, filmed private funerals and the list of names of the dead or dying, and bribed airport officials to fly them to the quarantined town of Kikwit. In outrage, Pierre Rollin, a French scientist then working for the CDC, vowed never to give a press interview again. Cathy Roth called the Kikwit episode a 'circus'.[57] Reiter *et al*. end their article on the reservoir search in Kikwit with an appeal for unperturbed research:

> heavy media coverage […] has become a significant element in such field investigations and needs to be addressed if it is not to distort scientific research.[58]

With the flood of press journalists and camera crews, hotel rooms and accommodation soon became difficult to find for the newly arriving foreign scientists. As a consequence of the events in Kikwit, and the pleas of scientists such as Reiter, a closely regulated Press Centre was set up in the 2000/2001 Uganda outbreak, with specific times attributed to interviews and filming sessions.

Finally, it seems that media interest in Ebola is subsiding, despite the intense scrutiny it enjoyed after the terrorist attacks in September 2001 and the occasional brief mentions in articles on bioterrorism. The Ugandan outbreak attracted less press

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[57] Personal Communication, 8 April 2002.
[58] Reiter, P., *et al*., 'Field Investigations of an Outbreak of Ebola Haemorrhagic Fever, Kikwit, DRC, 1995: Arthropod Studies', *The Journal of Infectious Diseases*, 179 (supplement 1, 1999), p. S153.

attention than the outbreak in Kikwit, and the recent epidemics in Gabon and the DRC have gone largely unnoticed in the North American and European newspapers.

Perhaps more than any other disease, Ebola outbreaks reveal how popular representations of an affliction can have direct repercussions on the control and management of an epidemic. Print and media journalists, authors and film directors do not merely recount events or stories, they actively participate in the creation of an image. The case of Ebola demonstrates the far-reaching impact of this image.

CHAPTER 3

Face to Face (!) With Ebola

In the preceding chapter, we attempted to understand the initial reactions of the medical community and the construction of the disease in the public imagination. The effects of Ebola's notoriety on the actions taken to combat the disease were also discussed. This chapter will move away from the representations of Ebola in Western societies to focus on Africa, and the responses of medical staff and afflicted populations in what Preston terms the 'hot zone'.

The African Response to Ebola Outbreaks

The experience of frightening epidemics is not new to Africa. Perhaps the best documented cases of epidemics in Africa date from the colonial period, when colonial powers often controlled, prevented, and in some cases unwittingly started epidemics. The native inhabitants of early 20th century Belgian Congo (now DRC) were part of a complex disease environment, living amidst malaria, leprosy, river blindness, filariasis and a plethora of other infections. Sleeping sickness, which was to become a devastating epidemic upon the arrival and ensuing ecological disruption of the colonizers, was kept under check through a variety of preventive indigenous mechanisms. Faced with an outbreak of Ebola, villagers also possessed means to contain the disease. In 1976, when it dawned on the village chiefs that many were

dying of an unknown, highly lethal disease, they ordered the isolation of the village, arguably recalling the smallpox procedures learnt around the time of the WHO smallpox eradication programme in the late 1960s. A member of the international team involved in the Zaire epidemic wrote:

> When we arrived several villages had established road blocks to assure that no sick persons came to their village, to prevent sick ones from escaping and to find out what people and things were moving through their fiefdoms.[59]

Likewise, afflicted communities abandoned or modified certain local customs. As the epidemic progressed, people avoided the traditional physical contact with the corpse during a burial. But the social impact of Ebola went beyond the private sphere of funerals to the everyday, and paranoia escalated into stigma. In the town of Mbarara, during the Ugandan outbreak (2000/2001), inhabitants refused to shake hands or handle bills and coins, and wore latex gloves as a preventive measure.[60] In the same town, staff members of the local hospital, which cared for four Ebola cases, were victims of a stigma common to all the major Ebola outbreaks:

> Some members of staff were made to feel unwelcome in town and in some instances were refused entry to some establishments. A local radio station even advised the listeners to 'run away' from all staff members of MUTH [Mbarara University Teaching Hospital]. Following an occasion when the burial team was threatened with stones as they approached the burial ground with one of the bodies, subsequent visits were accompanied by armed military escort.[61]

Of the survivors of the 1995 Kikwit epidemic, 35% attempted to escape from their family or neighbourhood during their illness.[62] Alphonse Kuomissel, a survivor of the 1995-1997 Ebola outbreaks in Gabon, recounts his experience:

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[59] Survey 8.
[60] Locsin, R., and Matua, A., 'The Lived Experience of Waiting-to-know', *Journal of Advanced Nursing*, 37, 2 (2002), p. 174.
[61] Bitekyerezo, M. *et al*. 'The Outbreak and Control of Ebola Viral Haemorrhagic Fever in a Ugandan Medical School', *Tropical Doctor*, 32 (2002) p.13.
[62] De Roo, A. *et al*. 'Survey Among Survivors of the 1995 Ebola Epidemic in Kikwit, Democratic Republic of Congo: Their Feelings and Experiences', *Tropical Medicine and International Health*, 3, 11 (1998), p. 885.

> People would walk backward away from you, to make sure you wouldn't touch them. Taxis were afraid to stop. Even the police at the roadblocks just waved you through because they didn't want to touch your identity card. [63]

Although no substantial articles have yet been written on the recent outbreaks in Gabon and the DRC, Dr. Bernard Morinière, an epidemiologist who visited the affected sites in February 2002, told me that survivors returning to their villages were also heavily stigmatized.[64]

One aspect that has received virtually no attention is the role of traditional medicine during Ebola outbreaks. More than mere anthropological curiosity, knowledge of traditional healing practices during severe epidemics could prevent unnecessary spread of the virus. Medical historians have shown that ignoring these belief systems often leads to conflict. Maryinez Lyons has described how the colonizers neglected African customs during the sleeping sickness epidemic that ravaged the Belgian Congo in the early 20th century, and the hazardous effects of this cultural disdain.[65] From the perspective of the afflicted Africans, the invasive colonizers prevented their movement, touched and inspected their bodies in unfamiliar ways, forced them to take certain drugs whose efficacy they doubted, and sent their loved ones to lazarettos from which they would seldom return. As a result, many villagers hid during the much-feared doctors' visits, patients in the lazarettos regularly fled, and in two cases, revolts occurred.

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[63] Salopek, P., 'An Ill Wind in Gabon Blows a Warning to the World', *The Seattle Times*, 21 January 2000. Available Online: http://seattletimes.nwsource.com/news/nation-world/html98/afri_20000121.html

[64] Personal Communication, 11 March 2002.

[65] Lyons, M., *The Colonial Disease* (Cambridge, 1992).

Similar acts of resistance have occurred during Ebola outbreaks. David Simpson, on site during the Yambuku outbreak in 1976, spoke of the difficulty of tracing sick patients. The international team would ask children for information on the whereabouts of the afflicted, as adults were not always reliable.[66] In D.H. Smith's article on the clinical manifestations of Ebola in the Sudan outbreak (1976), one reads the following, isolated statement: 'Patients both resisted and resented physical examination'.[67] Nothing more is said. In the recent outbreak in Gabon (2001/2), where local hostility towards medical teams has been particularly fierce, some villagers hid contacts and suspects from the surveillance teams, refused to send cases to isolation wards, and did not adhere to the instructions given by the health workers for burials.[68] In Kikwit, the epidemic was rekindled when the corpse of a woman was forcibly snatched away from the Red Cross burial team by family members. She was then buried according to local customs.[69] In that outbreak, volunteers of the Red Cross - composed almost entirely of trained Africans - temporarily went on strike, tired of the poor pay and intense stigma. In January 2002, the international team of experts was forced to flee the village of Mekambo, Gabon, when hostile villagers threatened them with violence. One survey respondent was not surprised by such reactions, and highlighted the social implications of many of the restrictions:

> Locals are asked not to give nursing care to diseased family members but to hand them over to strangers in space-suits […] Locals are asked not to prepare bodies for eternal rest, and not to perform burial rites that allow social life to continue normally after the death of a beloved one. In the recent outbreaks in Gabon/Congo, some experts even advised the locals not to hunt – that of course must be unacceptable in a gatherer/hunter society – people there live on bushmeat.[70]

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[66] Simpson, D. in *Virus*, BBC Radio 4, 9 March 1999.
[67] D.H. Smith *et al.* 'African Haemorrhagic Fever in the Southern Sudan, 1976: The Clinical Manifestations', in Pattyn S. R., p. 28.
[68] Survey 7.
[69] Guimard, Y., *et al*., 'Organization of Patient Care During the Ebola Hemorrhagic Fever Epidemic in Kikwit, DRC, 1995.', *Journal of Infectious Diseases,* 179 (supplement 1, 1999), p. S272.
[70] Survey 16.

The significance of traditional healing practices varies from outbreak to outbreak. Small, isolated villages are more likely to depend on traditional healers than large towns, such as Kikwit, which has approximately 400 000 inhabitants and where biomedicine is firmly established. In countries such as Uganda, the high cost of healthcare means that villagers turn to more affordable traditional healers for treatment.[71] Joel Breman noted the scarifications found on the bodies of eight cases in the Yambuku outbreak (1976), and described a potentially hazardous purgative practice among women:

> […] it was done with a thin bamboo reet put into the rectum and then the others would blow material through this reet. The same reet was used for all women. Of course this could have incised the intestinal mucosa and certainly implicated blood products or stool as a vector. [72]

Traditional healers in another village also regularly cut patients' skin with unsterilized knives. During the 1996/7 Ebola outbreak in Gabon, a traditional healer and his assistant got infected with the virus after treating a patient suffering from the disease.[73] No study has yet focused on the role of traditional medicine in Ebola outbreaks. In light of the evidence above, the tendency of outbreaks to affect isolated populations, and the increasing frequency of epidemics, such a study is urgently needed.

The irony lies in that, historically, a person has a higher risk of Ebola infection by going to a hospital than to a traditional healer. The public health infrastructure of Ebola-endemic countries is, at best, inadequate, and, at worst, nonexistent. A report on the DRC, published by Médecins Sans Frontières in 1999, revealed that only two

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[71] Leggett, I., *Uganda* (Oxford, 2001), p. 63.
[72] Breman, J., comment in discussion, in Pattyn, S.R., p. 115.
[73] Kunii, O *et al*., 'Epidemics and Related Cultural Factors for Ebola Hemorrhagic Fever in Gabon', *Nippon Koshu Eisei Zasshi*, 48, 10 (2001), 853-859.

of the 11 provincial health inspectors possessed vehicles, that health personnel risked kidnapping by soldiers and rebels, and that medical equipment, buildings and supplies were deteriorating. The report concluded that 'the [Ministry of Health's] budget is inadequate and really only exists on paper'. [74] In sub-Saharan Africa as a whole, with the possible exception of South Africa, access to healthcare in rural areas is limited.[75] Indeed, in many outbreaks, Ebola only became epidemic through nosocomial spread in grossly underresourced hospitals. The lack of medical equipment and protective gear favoured person-person transmission of the virus.

Throughout Ebola's recorded history, the hospital has played an important role as an amplifier of epidemics. In Yambuku (1976), the mission hospital, which admitted between 6000 and 12 000 outpatients a month, used five needles and syringes a day. Eleven of the 17 hospital staff contracted the disease and died. The report of the International Commission affirms that the closure of the Yambuku hospital was 'the single event of greatest importance in the eventual termination of the outbreak'.[76] In the teaching hospital of Maridi, Sudan (1976), a third of all hospital staff fell ill with the disease (76 cases out of 230 employees). In the 1979 outbreak in Nzara, Sudan, the outbreak started when an infected person was admitted to Nzara hospital, and started a chain of infection. In Kikwit, 25% of the Ebola cases were healthcare workers. In addition to working in a facility lacking electricity, running water or a waste disposal system, many staff members had not been paid for months.[77] In October 1996, a Gabonese doctor contracted the disease and later died following an

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[74] *Survival in the Democratic Republic of Congo*, Médecins Sans Frontières Research Centre, Brussels, December 1999. Available Online: http://www.aerzte-ohne-grenzen.de/.
[75] Sanne, I., 'Conference Report: Developing an HIV/AIDS Therapeutic Agenda for Resource-Limited Countries', *Medscape HIV/AIDS ejournal*, 7, 6 (2001). Available Online: http://www.medscape.com/viewpublication/124_index.
[76] 'Ebola Haemorrhagic Fever in Zaire, 1976', *Bulletin of the WHO*, 56, 2 (1978), p. 280.
[77] Guimard, Y. *et al*., p. S272.

endoscopy on an Ebola-infected patient. The South African nurse who cared for him in Johannesburg, where he was admitted for treatment, also died. In the Ugandan outbreak (2000/1), 14 of 22 health staff in the Gulu district were infected after nursing patients. With this in mind, it is understandable that hospital personnel and afflicted persons have reacted strongly to working or staying in the hospital. Like the sleeping sickness lazarettos of early 20th century DRC, hospitals became associated with death for many of the inhabitants.

Flight or avoidance from the hospital, by both patients and hospital staff, is recurrent in Ebola outbreaks. Attendance at Yambuku hospital dwindled as the epidemic progressed and medical staff died, until it closed completely on the 3rd October 1976. In the town of Maridi, Sudan, most nurses fled from the hospital, and some patients refused to be sent to the isolation wards at the hospital.[78] When P. Lolik, sent by the Regional Ministry of Health in Juba, arrived in Maridi hospital on the 23rd October, he found only three nurses working in an establishment entirely lacking in hospital supplies, and discovered that two suspected cases had earlier escaped.[79] A similar, if more extreme, scenario occurred in Kikwit General Hospital (1995). There the vast majority of patients and health workers deserted the premises, and only moribund patients and voluntary workers remained. Tom Ksiazek, of the CDC's Special Pathogens Branch, visited the abandoned hospital and found 30 expiring patients, left to care for themselves amid rotting corpses, sometimes in the same bed.[80] Even in one of Uganda's major hospitals, Mbarara Teaching Hospital, the patient's experience during the Ugandan outbreak was traumatic. Bitekyerezo *et al*. write:

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[78] 'Ebola Haemorrhagic Fever in Sudan, 1976', *Bulletin of the WHO,* 56, 2 (1978), p. 250.
[79] Lolik, P., 'Containment and Surveillance of the Ebola Virus Epidemic in Southern Sudan', in Pattyn, S. R., p. 128.
[80] *Virus*, BBC Radio 4, 9 March 1999.

> Our patients all died in isolation without contact with family or friends, cared for by people wearing masks and goggles. The psychological and spiritual needs of such patients should not be overlooked.[81]

But the staff were also experiencing distress. Eleven of the 18 staff members caring for the patients developed Ebola-like symptoms and suffered from such extreme anxiety that they required counselling.[82] In 1976, the four doctors looking after an Ebola patient at the Coppetts Wood Hospital in London developed similar so-called 'phantom' symptoms. They experienced a 'flu-like' illness with stomach pains, which disappeared several days later. Antibody studies revealed no infection.[83]

In St. Mary's Hospital, another leading hospital in northern Uganda, the 400 health-care workers mutinied and assembled in protest, calling for the closure of the hospital. Dr. Matthew Lukwiya, the hospital's medical superintendent and later victim of the disease, persuaded them to stay.[84] Yet he too was aware of the perils of working in such an environment, and his hospital colleague, junior doctor Yoti Zabulon, recalled a proleptic conversation with Dr. Lukwiya: 'One time he told me "my God, Dr. Yoti, we're going to die on duty one of these days!"'. He pursued his narrative with a recollection of the conditions in the isolation ward of the hospital:

> […] so you can imagine 69 people, seriously sick, some running up and down, bleeding, vomiting, having diarrhoea with high fever, crying with aches, and you are two doctors on duty, with less than ten nurses. It was so dramatic![85]

In such chaotic and exhausting conditions, precautions are sometimes overlooked by medical personnel. Dr. Lukwiya's death is believed to have occurred through an

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[81] Bitekyerezo, M. *et al*., p. 14.
[82] Bitekyerezo, M. *et al*., p. 13.
[83] Emond, R., p. 33.
[84] For a detailed and fascinating account of what occurred in St. Mary's Hospital, and in particular Dr. Lukwiya's involvement in the outbreak, see Harden, B., 'Dr. Matthew's Passion', *The New York Times Magazine*, 18 February 2001.
[85] Zabulon, Y., in *On the Ebola Frontline*, BBC Radio 4, 26 May 2002.

uncharacteristic lapse: on the night of November 20, he wore no protective goggles when caring for a heavily bleeding patient. The role of the African doctors is often overlooked in Western press articles, who prefer to focus on the life-saving acts of the international medical teams, but one scientist wrote in a personal communication:

> During any of the Ebola/Marburg manifestations the job of the African physicians has been tremendous, courageous, unique sometimes at the early stage of the epidemics before anyone from the civilized occident intervened and took the floor.[86]

The most comprehensive study to date on indigenous responses to an Ebola outbreak was conducted by Barry Hewlett, a cultural anthropologist from Washington State University.[87] Hewlett spent 16 days among the hard-hit Acholi tribe during the Ugandan outbreak. His findings enlighten us on native treatments and interpretations of fulminating epidemic diseases, but also lay out the positive and negative health effects of both the international team and the local community. The study clearly reveals the importance of cultural understanding to avoid conflict. In colonial times, the medical staff involved in the control of epidemics would have been based *in situ* and, as a result of longer stays, arguably more aware of indigenous beliefs and practices. Today, such medical bases are fewer, and help generally comes from abroad. Scientists from the CDC, for instance, are often sent on assignment at very short notice, and with no knowledge of the cultural context of the epidemics.[88] The closure of the training bases has also affected the number of suitably trained scientists. There is at present - in the words of Dan Bausch - a 'vacuum of young researchers truly versed in the study of tropical pathogens'.[89]

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[86] Personal Communication.
[87] Hewlett, B., 'The Cultural Contexts of Ebola in Northern Uganda; A Preliminary Report', 15 March 2001. Available Online: http://www.vancouver.wsu.edu/fac/hewlett/ebola.html
[88] Personal Communication.
[89] Bausch, D., 'The Ebola Virus', *United Nations Chronicle*, 38, 2 (2001), p. 4.

The Acholi initially considered Ebola a regular illness and, accordingly, treated the disease with a mixture of indigenous (herbs and consultations with traditional healers) and biomedical (chloroquine and antibiotics) remedies. Following a string of deaths, some families hired traditional healers to perform animal sacrifices and remove the disease-causing 'yat', or poisons, from their household. The financial cost of such a procedure was debilitating to many families.[90] In the stricken village of Mekambo, Gabon (2001/2), the prohibitions on hunting and selling bushmeat also took a heavy financial toll on the inhabitants, causing general discontent towards the control measures. When deaths continued to occur among the Acholi, the disease changed classification from 'yat' to the more severe 'gemo' and triggered a protocol to prevent and contain the outbreak. The explanation for 'gemo' is unclear. Hewlett writes:

> Gemo is said to be rather mysterious in that it just comes on its own, but several people indicated that it comes because of lack of respect and honor for jok ['spirits' or 'gods']. People talk about gemo catching you, so if someone is close to a person with gemo it is easier for gemo to catch you.[91]

The exact mechanisms of the 'gemo' protocol are too numerous to describe in detail but they emphasized the isolation of the patient and the restriction of the community's movements. The ban on eating rotten or smoked meat, the prohibition of sexual intercourse, the caring for patients by survivors, and the quarantine requirements would all have contributed to the termination of the outbreak. The lessons of past epidemics are reflected in some of the methods, such as the prohibition of sex and the refusal of food offered by outsiders, no doubt reflecting experiences with previously encountered sexually-transmitted or food-borne diseases.

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[90] Families paid 150 000 Ugandan shillings (roughly $88), 4 or 5 goats or sheep, and one chicken. Hewlett, B. p. 4.
[91] Hewlett, B., p. 5.

Hewlett's classification of Acholi belief systems regarding disease into a neat bi-partite explanatory model is, although informative, rather simplistic. It fails to acknowledge the plurality and diversity of interpretations within the community. Indeed, upon discovering the futility of traditional treatments, some Acholi looked elsewhere for alternative therapies. One such example was the use of the powerful bleach 'Jik'. Believing that Jik could kill Ebola inside as well as outside the body, people literally imbibed or bathed in the disinfectant. A member of the Ugandan parliament had to openly discourage these practices.[92]

Survivors and their relatives, as discussed earlier in the chapter, were commonly stigmatized. Hewlett affirms that along with rejection at the village market or water hole, some were not allowed back in their homes, their clothes were burned and some spouses abandoned their partners. Survivors were often unable to find work. One man, whose wife had died of Ebola, committed suicide. To counter this, teams of volunteers, trained by the Ugandan Red Cross, visited villages to dispel any myths and persuade the communities to accept the return of survivors. A recent letter published in the journal *Tropical Doctor*, which refers to the continuing stigmatization of survivors as a 'second epidemic', suggests that these efforts have not been entirely successful.[93] The only beneficiaries of this intense stigmatization were the 40 prisoners held by the Lord's Resistance Army, a brutal anti-government rebel group, who were released when the Army leaders feared they might contract the disease.[94]

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[92] Buwembo, J. 'With Our Burning Blankets, We Shall Save Africa', *The East African*, 12 November 2001.
[93] Jeppson, A., 'Defend the Human Rights of Ebola Victims!', *Tropical Doctor*, 32 (2002), p.182.
[94] Maurice, J., 'The Ugandan Ebola Outbreak – Not All Negative', *Bulletin of the WHO*, 78, 12 (2000), p. 1477.

The ‘gemo’ protocol was largely effective in controlling the disease, but certain practices served as amplifiers. Fifty-seven percent of survey respondents found that locals prevented or slowed down the implementation of control procedures. Hewlett’s study provides several examples of this. As in many Ebola outbreaks, funeral practices played a considerable role in the early dissemination of the virus. The washing, dressing and regular contact with the body, as well as the ritual washing of hands in a bowl, presented opportunities for disease transmission among the attendants. The transportation of the sick or deceased by bicycle or cart, and the ensuing proximity between the ill and the healthy, was another possible amplifier. Finally, although the practice was in decline after the experience with HIV/AIDS, certain traditional healers inserted medicines through cuts on the body, encouraging the interchange of contaminated blood.

Members of the international community, although in many ways helpful in controlling the outbreak, contributed to the social havoc in the villages. The WHO produced an educational video which they sent to hospitals in Uganda, describing the principal characteristics of Ebola and the management procedures to be followed. Although it alleviated certain fears, some individuals developed an obsessive attention to hygiene which drove them to burn the beds, clothes and houses of survivors. Burial teams occasionally buried bodies before the verification of the corpse by family members. As a consequence, families hid their sick, refused to send them to hospital, and rumours of Europeans selling body parts for profit proliferated. The lack of feedback between researchers and families, in particular when blood samples were collected, led to some distrust of health care workers.[95] In Kikwit (1995), the

[95] Hewlett, B., p. 11.

association between the hospital and Ebola deaths generated a popular rumour: doctors were suspected of murdering workers who had smuggled diamonds out from the mines. The workers ingested the diamonds to avoid the strip-search, and visited surgeons to retrieve them from their gut.[96] These rumours are reminiscent of the 1832 Cholera epidemic in Paris, when the working class victims accused the ruling class of poisoning their food and water.[97]

Such rumours are not to be dismissed as meaningless superstition. The historian Luise White argues that rumours are products of an African 'voice', and as such can provide insights into African interpretations of Western practices.[98] Professor N'sanga Kibari, of the University of Bandundu (DRC), claims that most of the Catholic inhabitants of Kikwit did not attribute the 1995 Ebola epidemic to a virus, but to God's punishment. Others blamed an American missionary doctor who was rumoured to transform himself into a hippopotamus and cast evil spells as he swam down the river.[99] This apparently bizarre explanation might be partly explained by the hippopotamus' reputation. Hippopotamuses, although prized for their meat, destroy agricultural crops, overturn boats and are generally feared by native Africans for their aggressive behaviour.[100] These examples show that the Africans and Europeans differed in their interpretation of the outbreaks, and that the former did not unanimously accept the aetiological explanations of biomedicine. With the inability of biomedicine to treat the disease, and the flight of medical personnel from the

[96] Garrett, L. *The Betrayal of Trust* (New York, 2002), p. 68.
[97] Delaporte, F., *Disease and Civilization* (Cambridge, MA, 1986), 48-50.
[98] White, L. 'They Could Make Their Victims Dull', *The American Historical Review*, 100, 5 (1995), 1379-1402.
[99] Quoted in Garrett, L. *The Betrayal of Trust*, 106-107.
[100] Shefferly, N., 'Hippopotamus Amphibius', *Animal Diversity Web* (May 2000). Available Online: http://animaldiversity.ummz.umich.edu/

hospitals, the afflicted Africans adopted alternative theories of causation based on indigenous beliefs.

In answer to the survey question 'did you sense that the locals were suspicious of you and the international teams?', 38% of respondents replied 'yes', 38% 'no', and 19% circled 'depends' as their answer.

So far, we have attempted to reconstruct the African responses to Ebola outbreaks from the perspective of both the medical staff and the affected communities. Although there are common behavioural responses from outbreak to outbreak, such as local resistance, fear, flight, and stigmatization, it would be wrong to establish an unchanging anatomy of Ebola outbreaks. The all-encompassing terms above provide little more than a skeletal sketch of Ebola epidemics; the rest is particular to individual outbreaks. Local resistance, for example, was encountered in every major outbreak, yet there is considerable variation in the degree and extent of resistance, from a single person to entire villages, from verbal discontent to physical violence. With this caveat in mind, we now turn our attention to the initial reactions of members of the international teams.

Western Health Workers' Reaction to Ebola

The difficulty in diagnosing Ebola, combined with poor health infrastructure, defective communication systems, and occasionally governmental reluctance, explain the significant delay between the appearance of the index case and the arrival of foreign assistance. In Yambuku (DRC, 1976), the International Commission was

formed at least seven weeks after the start of the epidemic. In Maridi (Sudan, 1976), the WHO team arrived four months after the first identifiable case was admitted to hospital. In Kikwit (DRC, 1995), it was three months before the district health officer even notified the national health authorities. As a consequence, international teams usually arrived at the middle or tail end of the epidemics, and immediately witnessed the impact of the outbreak on the communities involved.

The report of the WHO International Commission on the Yambuku asserts that 'no more dramatic or potentially explosive epidemic of a new acute viral disease has occurred in the world in the past 30 years'.[101] Sixteen days before the formation of the International Commission, two Western doctors, Jean-François Ruppol (from the Fonds Médical Tropical) and Gilbert Raffier (from the Mission Médicale Française) were sent from the capital Kinshasa to investigate the situation in Yambuku. Dr. Ruppol recounted to me: 'We went there with almost no support, we only knew the language, their customs and history. We had some operating coats and a little bit of good sense'.[102] A few years after the end of the epidemic, Dr. Raffier gave an oral account of the visit to his friend, Dr. Dutertre, at the time chief epidemiologist of the French Army Health Service. Dr. Dutertre in turn transcribed it as a narrative. Extracts of the text are worth quoting, for they provide a unique insight into the fear and helplessness felt by all involved.

> All those who could flee had already gone, foreign doctors (let's not dwell on this), first-aid workers, nurses. The sheer scale of the disaster, the obvious futility of all treatment, the horrible, unfading contagiousness of this fever had caused everyone to flee, except the Belgian colleague Van Wollenbeck [a pseudonym referring to Dr. Ruppol] and myself.

[101] 'Ebola Haemorrhagic Fever in Zaire, 1976', *Bulletin of the WHO*, 56, 2 (1978), p. 288.
[102] Personal Communication, 1 March 2002.

In the face of such desolation, the two doctors dug up a pit and dumped the blood-drenched corpses into it. The makeshift grave was set alight.

> It's at this very moment – I don't know who initiated it, nor why, as it served no purpose – that we undressed, threw everything in the fire, shirt, trousers, sandals, everything, and we stood there, in front of this purifying fire, naked and pitiful […][103]

Clearly, the dramatic symptoms of Ebola contribute significantly to medical workers' reaction to the disease, however experienced they might me. Dan Bausch, who has worked with many viral haemorrhagic fevers (VHFs), said in a telephone interview:

> For a scientist or clinician, seeing Ebola is a very impressive thing. As a clinician, I've never seen another disease that will kill so reliably and rapidly. Marburg is not pretty either, but even other VHFs (Lassa, Rift Valley) are not as impressive in their brusqueness. Unfortunately, the victims suffer. They suffer a lot.[104]

David Simpson, a microbiologist from the London School of Hygiene and Tropical Medicine, was sent to handle the outbreak in Sudan (1976). In the radio program *Virus*, he recalled that the situation when he arrived was 'very worrying indeed'. The postmortems, performed on grossly disfigured corpses and on the ground, were 'horrific', the heat was unbearable and aggravated by clouds of buzzing flies. 'I bloody nearly collapsed afterwards because it was so hot!' he added.[105]

The scientists involved in the 1976 epidemics were faced with the difficult task of handling a disease about which virtually nothing was known. As these were the first outbreaks of an unknown disease, epidemiological and clinical features had to be established from scratch. How did epidemiologists deal with a disease with so many unknown variables? In an address given to the University of Southern California's

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[103] Dutertre, J., *Une Fièvre en Brousse*, Available Online: http://perso.wanadoo.fr/jdtr/Fievre.htm. Translated from the original French by the author.
[104] Personal Communication, 8 March 2002.
[105] Simpson, D. in *Virus*, BBC Radio 4, 9 March 1999.

medical students on 28 May 1995, Joel Breman remembered the CDC's briefing on the situation in the DRC:

> I was told only the following: first, an outbreak of a severe unknown disease was spreading rapidly into all of the villages in a remote area of northern Zaire. Second, all of the people in the epidemic area had died. This information was frightening, but it really didn't make sense. At that time I knew of only one disease that caused such high mortality, Rabies, and this didn't sound like Rabies.

For the physicians on-site, the indefinite means of transmission of the virus was the most worrying question mark. Bill Close, head of logistics for the international team, commented in an interview:

> If you have a bad disease, and you don't know how it's spread, that means that every time a fly lands on you, or every time you eat something, or every time there's a puff of dust that comes from the road, you wonder whether it's carrying whatever's causing these deaths![106]

The African heat, coupled with multiple layers of protective gear, made any prolonged activity uncomfortable, and unsafe. Dan Bausch remembers the anxieties experienced by the fully-suited medical personnel in Uganda: 'we wondered if it was just particularly hot that day or maybe we were especially tired, or was this the first day of a fever?'.[107] One scientist of the international team in Kikwit (1995) found the stress of dealing with Ebola patients and the interminable working hours so unbearable that he collapsed with a nervous breakdown six days after his arrival.[108] Similarly, two team members resigned from the assignment after reading the first official report of the situation in Yambuku (1976).[109] Some accounts stress the surreal aspect of the situation, such as David Heymann's recollections of his visit to Kikwit General Hospital, in 1995. Heymann had witnessed the Yambuku epidemic in 1976,

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[106] Interview with William T. Close, *Ebola*, Wyoming Public Radio Network,17 April 2002.
[107] Bausch, D. 'The Ebola Virus, *United Nations Chronicle Online Edition*, 38, 2 (2001).
[108] Garrett, L. *The Betrayal of Trust*, p. 76.
[109] Garrett, L. *The Coming Plague*, p. 130.

and possessed extensive experience working as a medical epidemiologist for the CDC in sub-Saharan Africa. He commented:

> There was blood everywhere. Blood on the mattresses, on the floors, on the walls. Vomit, diarrhoea…When we got here it was really awful. Apocalyptic. There were people dying everywhere. And the women were wailing. It was surreal.[110]

Heymann's account, although brief, is deeply evocative. Strangely, it is the blood, not the patients, that he notices first. He shifts from the general ('blood everywhere') to the particular: beds, floors, walls. To this purely visual scene of red, he adds another image and, with it, another sense: the stench of the vomit and faeces. Amid this malodorous squalor, he finally reveals human elements, and the sound of the wailing women joins the visual and the olfactory to heighten the poignancy of the narrative.

Western medical workers have arrived at the site of outbreaks *in media res*, and immediately faced the full horror of the epidemic. First-hand accounts, such as David Heymann's, reveal astonishment of the awful conditions in hospitals, their mass desertion by patients and hospital staff, the lack of even basic equipment, the spectacular nature of the disease, and of course the physicians' fear of contracting the disease themselves, sometimes translated into 'phantom' symptoms. Answers to the survey, in particular to the question regarding the uniqueness of Ebola epidemics, support these observations. One respondent comments on the 'great fear of infection by many team members', another on the difficulty of 'protecting myself and other workers from Ebola and other diseases endemic in the same area', and yet another on 'the stress of entire families and hospital wards being wiped-out'.[111]

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[110] Garrett, L. *The Betrayal of Trust*, p. 69.
[111] Surveys 4, 8 and 7, respectively.

One type of reaction by Western medical workers on ground zero has been totally ignored in media articles, and barely touched upon in more scholarly publications: rivalry. One reference to the problem, however, appeared in the 2002 Institute of Medicine Report on emerging zoonoses. Alluding to recent zoonotic outbreaks, Frederick Murphy wrote that 'scientists became competitive and insular, seeming to worry more about their publications than about the public's health'.[112] One scientist I interviewed cautiously said of the Ugandan episode (2000/1): 'a few groups and individuals for short periods may not have worked for the overall good!'.[113] Two respondents of the 'field' survey mentioned poor cooperation among scientists in the field. One scientist involved in the 1976 outbreak in the DRC affirmed that locals were not suspicious of the medical personnel but that 'the only suspicions may have been from other international scientists with a similar agenda'.[114] The other scientist, who formed part of the international team in the Ugandan outbreak, stated that 'even among the professional, there was a lot of competition and mistrust, which sometimes affected the control interventions'.[115] The competition for limited funds and status-enhancing publications has led to rivalry among scientists in the field, but also laboratories dealing with biosafety-level 4 pathogens. The refusal of some laboratories to share reagents, specimens and other necessities inevitably slows down the pace of research. But scientists are conscious of the financial importance of a positive image, and this unsightly aspect of scientific research remains strictly within the recondite sphere of the epidemiologists and virologists involved.

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[112] *The Emergence of Zoonotic Diseases*, Institute of Medicine Report, 2002, p. 7.
[113] Personal Communication.
[114] Survey 8.
[115] Survey 9.

The media hype and sensationalism surrounding Ebola in Western countries has made the disease a household name, but by constantly associating the virus with science-fiction elements (e.g. space suits, liquefying bodies, 'apocalypse' bugs), it has also erected a conceptual barrier that distances the layperson from the reality of the disease.[116] The layperson experiences a fear similar to that which he might experience in front of a frightening movie. It vanishes as soon as the movie ends, when rational thought once again prevails over fantasy. This last chapter attempted to reconstruct and interpret the experiences of the afflicted communities and the mobilized medical personnel, both African and Western. During all Ebola outbreaks, public health specialists underwent their own reconstruction, seeking to assemble pieces of what remains an epidemiological puzzle.

[116] See Joffe, H. and Haarhoff, G.

CHAPTER 4

An Epi(demi)c Mystery: In Search of Answers.

In the last 30 years, newly emerging infectious diseases have been reported with increasing frequency. The complacent optimism of the second half of the 20th century, supported by the quasi-eradication in industrialized countries of polio, typhoid, tetanus and many childhood diseases, is no longer justified. HIV/AIDS alone has killed over 19 million people worldwide, making it the second largest epidemic of the 20th century after the 1918/1919 influenza pandemic.[117] The unanticipated emergence of diseases such as Hantavirus Pulmonary Syndrome, new variant Creutzfeldt-Jakob disease, H5N1 avian influenza, and Nipah virus continue to cause great concern in the public health community. As Professor Richard Levins, of the Harvard School of Public Health, asserted in a lecture: 'Public Health as a whole was caught by surprise'.[118] The Ebola outbreaks of 1976 signalled the start of a new epidemiological era, when novel diseases gave rise to a heightened appreciation of epidemic and environmental complexity.

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[117] Bartlett, J., 'Global Impact of the HIV Pandemic', Lecture Presented at the 4th Annual Brazil-Johns Hopkins Conference on HIV/AIDS, October 2000.
[118] Levins, Richard, 'The Challenge of New Diseases', *Annals of the New York Academy of Sciences*, 740 (1994), p. xvii.

Ebola and Scientific Uncertainty

An epidemiological investigation, by its very nature, always possesses some unknowns. In the face of these, epidemiologists use prior knowledge of a disease as a starting point. So, for instance, an outbreak of Crimean-Congo haemorrhagic fever (CCHF) would immediately suggest the presence of *Hyalomma* ticks and human contact with infected livestock. Application of pesticides to control the tick vector, the use of protective clothing and insect repellent, or simply the avoidance of tick-infested areas would constitute an effective arsenal against further spread of the disease. Many elements in the epidemiological equation are already known variables, and these greatly facilitate the choice of control measures. A very recent example of a thorny epidemiological problem is the epidemic of the previously unknown Nipah virus in Malaysia in 1998. The case of Nipah clearly illustrates the sheer complexity of disease emergence, and the difficult task epidemiologists face in deciphering it.

Between September 1998 and April 1999, an outbreak of a mysterious disease caused the death of 105 persons and the preventive destruction of 1.1 million pigs in the Malay Peninsula. Most of the victims were pig farmers. The new virus was named Nipah, after the pig-farming village of Sungei Nipah. In an example of the way similarities between diseases can provide epidemiological information, the genetic link between Nipah virus and the bat-transmitted Hendra virus enabled researchers to identify the fruit bat as the reservoir. A number of events combined to drive the emergence and the dissemination of Nipah virus: the human encroachment into fruit bat habitat, the slight decrease in forested cover, the establishment of high-density pig farms, the dramatic drop in oil palm production caused by the climatic disturbances of

El Niño, the ensuing lack of fruiting trees for the bats, and finally the mass transport of pigs for commerce.

As the epidemiology of Nipah virus and most other newly emerging infections - including Ebola - demonstrates, the human/animal divide has become increasingly blurred in the eyes of the public health community. This realization culminated in the 2002 Institute of Medicine report on the 'Emergence of Zoonotic Diseases', which made clear that a better understanding of emerging diseases in wildlife could aid investigators in understanding those in humans.[119] The recent calls for inter-disciplinary cooperation to solve complex epidemiological puzzles also bear witness to the new facets of the problem. The parasitologist Dr Peter Dazsak, in the 2002 International Conference on Emerging Infections in Atlanta, spoke of the need to 'look far beyond the standard outbreak investigation'.[120] Today, the epidemiologist can no longer deal with epidemics on his own, but requires a team which would ideally involve veterinarians, entomologists, ecologists, social and behavioural scientists, physicians and public health officials.

The 1977 Ebola conference in Belgium lifted - in the words of Dr. Halter - 'a side of the veil' on Ebola and other haemorrhagic fevers.[121] Yet despite some insights, there remained a deep sense of scientific uncertainty. Where did Ebola come from? Why did it arise? How did it kill its victims? How was it transmitted? How could it be treated? These questions gave rise to broader concerns among the public health community in industrialized countries: how can we prevent Ebola epidemics? How could we stop international dissemination of the virus? How would we handle

[119] Burroughs, T., *et al*. (eds), *The Emergence of Zoonotic Diseases* (Washington DC, 2002).
[120] Daszak, P. See footnote 9.
[121] Halter, S., Preface, in Pattyn, S.R., p.5.

imported cases of Ebola? Could Ebola be used as a biological weapon by nations in conflict or by bioterrorist groups? Could we cope with such an attack? The micro-level questions, related to on-the-ground epidemiological issues (reservoir, spread, vaccine, treatment) gave rise to macro-level questions, concerned with more general matters (public health infrastructure, socio-political situations, introduction of virus in Western country, use of Ebola as biological weapon). Finally, there were questions stemming from an even broader perspective, that of global public health. These pertained to the justification of Ebola research and surveillance in the face of statistically larger burdens of health. The three-tiered distinction - micro, macro, and global - is convenient for illustrative purposes, but in order to get a sense of the interconnectedness of the layers, we shall treat the issues collectively.

As one survey respondent stated, Ebola is a 'real challenge for field epidemiology' and the only virus whose natural history is unknown 30 years after the discovery of the disease's etiology.[122] Yet the hunt for the reservoir began as early as November 1976, when a survey team from the International Commission searched the environs of Yambuku. The team caught mosquitoes in glass tubes, collected bedbugs from beds and soil, trapped bats in nets, got hunters to shoot monkeys, villagers to capture rodents, and finally extracted the organs of two cows and the blood of ten pigs for testing. No trace of the Ebola virus was found. The low mosquito activity during the outbreak, and the rarity of *A. aegypti* suggested that arthropod transmission was unlikely. The high mortality of monkeys infected with Marburg relegated non-human primates low in the list of potential suspects.

[122] Survey 27.

A reservoir search was also performed in Nzara, Sudan, but eight months after the initial outbreak, between January and February 1977. By that time, the seasonal fluctuations, cyclical life patterns and short life-span of many organisms had inevitably altered the forest environment. The authors of this early study dwell on bats as possible reservoirs, although serological evidence for this suspicion was not yet available. They noted:

> […] the known range of *Tadarida (Mops) trevori* […] closely paralleled the distribution in Sudan and Zaire, the area of the epidemic. This bat species was collected from a large roof colony in the cotton factory directly over the storeroom where the primary cases worked and which was laden with faeces and urine. Several bats were collected in the room on the desk of the unfortunate primary case. Although conjecture only, it is interesting.[123]

The authors also devote a paragraph on the effect of anthropogenic ecological disturbances on human health. This was to become a topos in the discourse on emerging infectious diseases.[124]

In 1989, a new strain of Ebola was imported in the United States via infected primates from the Philippines. Prior to this event, Ebola was believed to be confined to Africa, so the question was: how did Ebola get there? There were two distinct hypotheses: some unknown migratory host could have transported the virus from Africa to Asia. A recent example of this trans-oceanic expansion of disease range is the epidemic of West Nile Virus in New York City in the fall of 1999. This was the first recorded appearance of the disease in North America. Infected birds, along with mosquitoes and humans, are suspected culprits. Alternatively, the Ebola virus could have been introduced artificially, possibly through the illegal importation of live African monkeys. The discovery of Ebola Reston (REBOV) in the Philippines, one of the

[123] Arata, A., and Johnson, B., 'Approaches Towards Studies on Potential Reservoirs of Viral Haemorrhagic Fever in Southern Sudan (1977)', in Pattyn, S.R., p. 137.
[124] Arata, A. and Johnson, B., p. 138.

world's primary suppliers of monkeys for biomedical research, is a cause for concern. Although REBOV is considered nonpathogenic to humans, the direct infection of Ebola Côte d'Ivoire (CIEBOV) from a dead monkey to a Swiss researcher in 1994 bears testimony to the perils of the illegal - and indeed legal - monkey trade. Furthermore, the feasibility of manipulating Ebola to enhance, or trigger, lethality makes even a nonpathogenic strain a potential danger to humans.

In June 1995, another survey team attempted to solve the 'reservoir' mystery. The team painstakingly reconstructed the activities of the index case and collected specimens in accordance with his previous whereabouts. By the end of the five week investigation, the team had gathered 34 985 arthropods, including more than 15 000 mosquitoes, and over 12 000 ticks and bedbugs.[125] Again, no virus was found. The authors adopted what Arata and Johnson, the two biologists who first hunted the reservoir in 1977, called the 'catch all and analyze all' philosophy.[126] Although not directly related to the topic at hand, two comments from the article are worth quoting. At the outset of the article, the authors remind the reader that past studies have revealed no evidence of arthropod transmission. They continue

> However, since many of the diseases that the public associate with the tropics are vector borne, there was strong pressure to include arthropods in the work of the international teams. (my emphasis)

At the end of the article, the authors express their regret on the poor timing of the study, but confess that 'the urgency of making a visible response to the widely publicized human tragedy was an important factor in the decision-making process'.[127] These comments reflect the lasting association of the tropics with vector-borne diseases, and reveal the practical consequences of such preconceptions. Scientists

[125] Reiter, P., *et al*., p. S151.
[126] Arata, A., and Johnson, B., p. 138.
[127] Reiter, P., *et al*., p. S148 and p. S153.

must respond to the expectations of the public, and Reiter's remark on the need for an immediate 'visible response' confirms this.

Also in June 1995, the WHO and CDC sponsored another survey to elucidate the identity of the reservoir. On this occasion, researchers only tested vertebrates but the results were no different: no trace of Ebola. Unlike the other reports however, the review highlights in some detail the logistical difficulties encountered in the field, namely the

> […] transport and power supply problems, the cold-chain maintenance of biologic materials, lack of up-to-date maps of the area to help select sample collection sites, recruitment of specialist staff members, and biosafety concerns.[128]

These comments are reminders that investigations, even ecological studies, did not occur in a vacuum, but within social contexts that at times hindered research efforts. This will be discussed later.

The quest for the reservoir, in spite of the extensive surveys, remains unfulfilled. Most survey respondents agree that finding the reservoir would substantially affect control efforts, allowing more focused control measures, preventing initial infection of the index case and dispelling deleterious rumours and myths on the disease.[129] On the other hand, some doubt the impact of unmasking the reservoir on disease prevention. Professor Susan Fisher-Hoch, formerly of the CDC and now based at the University of Texas, explained in an e-mail:

> Normally it is essential not just to know but to understand the reservoir. However, with Ebola, things are different. Primary infections with Ebola are extraordinarily rare. Sure, it would be useful to be able to predict or prevent

[128] Leirs, H., *et al*., 'Search for the Ebola Virus Reservoir in Kikwit, DRC', *The Journal of Infectious Diseases*, 179 (supplement 1, 1999), p. S159.
[129] 56% of respondents believed that identifying the reservoir would have an 'important effect', while 38% deemed the finding of 'modest' importance.

> them, but given that they probably occur in very remote locations under conditions we cannot hope to control without destroying all tropical rainforests, we have to live with the fact that occasionally primary infections will occur, unpredictably.[130]

However useful the identification of the reservoir turns out to be, the mysterious origins of Ebola, coupled with the lack of treatment and prophylaxis, have contributed to the disease's notoriety. The disease's enigmatic provenance has fuelled the metaphors representing the virus as an indiscernible 'stalker', and field epidemiologists as intrepid 'hunters'.

Beyond the Reach of Science

On a more general level, the emergence of Ebola and other new infectious diseases out of the African rainforests caused some disquiet in the public health community. Ebola became an oft-cited example of the dangers of anthropogenic environmental disturbances on human health. Yet the articles in the media usually construed deforestation and other man-induced disturbances as invariably nefarious. They failed to acknowledge the paradox inherent to the problem. It is economically nonsensical to stop roadbuilding and logging in many African countries since these are essential for their financial development. As Wilkie *et al*. write of the Congo Basin:

> The development of roads and road networks is strongly correlated with economic growth and national wealth and linked to the scale of ecological disturbance and natural resource degradation.[131]

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[130] Personal Communication, 28 March 2002.
[131] Wilkie, D., *et al*., 'Roads, Development, and Conservation in the Congo Basin', *Conservation Biology*, 14, 6 (2000), 1614-15.

The construction of roads, by reducing or destroying habitats, leads to the loss of species and very occasionally unleashes pathogens that affect humans. But roads also lower expensive transport costs, reduce insect damage common to floating timber logs, and provide more bushmeat to local hunters. Press articles rarely mention the economic necessity of deforestation to impoverished countries such as the DRC. The issue is not whether deforestation should be practiced, but, as Wilkie *et al*. assert, how to 'maximize[s] the social and economic benefits [of deforestation] and minimize[s] environmental damage'.[132] In short, media and, in some cases, scientific articles have presented an oversimplified and one-sided exposition of the problem, focusing on ecology but ignoring economy, both of which have an impact on human health. Economic, and thus political, considerations cannot be divorced from discussions on environmental change.

Ebola epidemics have erupted in countries with adverse political conditions. In Gabon, Uganda and the DRC, central governments have struggled to stave off rebel groups, and experienced corruption among their ranks. Political issues have repeatedly affected the control and management procedures of Ebola epidemics. In the most recent outbreak in Gabon (2001/2002), the rebels occupying the eastern half of the country were asked to allow the free movement of doctors and sufferers. Rebels apart, ongoing elections also affected the deployment of assistance. In a telephone interview, Bernard Morinière said:

> The government was right in the middle of an election period so there was a delay in providing assistance. The Prime Minister also resigned which didn't help things. In fact, the region had the legislative elections postponed due to the outbreak and the two competing candidates claimed the government used Ebola to ruin their chances. So it was all very complicated.[133]

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[132] Wilkie, D., *et al*., p. 1620.
[133] Personal Communication, 11 March 2002.

In Uganda (2000/1), epidemiologists faced the threat of violent rebel groups. Dan Bausch, Acting Chief of the Special Pathogens Branch of the CDC, recounted: 'one problem […] was the Resistance Army. There were no incidents but we needed military escorts to go from one place to the other'.[134] This threat prevented the tracing of suspected cases living in rural areas, increasing the risk of virus spread.

Faced with myriad domestic problems and fearful of Ebola's impact on trade and tourism, governments have at times reacted half-heartedly to Ebola alerts. Anecdotal but pertinent is the story of Bonzali Katanga, district health officer of Watsa-Durba in the DRC. In late 1998, Dr. Bonzali witnessed a string of unusual deaths among gold miners and, suspecting Ebola or Marburg, alerted his superiors by radio. Despite repeated pleas for urgent assistance, it was six months before any help arrived. Once on site, the investigators found Dr. Bonzali dead, and a sample of his blood carefully preserved in the refrigerator so that the disease could be identified.[135] Scientists isolated Marburg virus from the sample. Cathy Roth asserts that such attempts to alert the outside world were also made in Kikwit (1995), DRC. This is confirmed by one of the survey respondents**,** who claims that 'information was not reported to the central government quickly and precisely' and that the 'government was reluctant to accept the fact [the existence of an Ebola outbreak], […] wanted to hide its epidemic, and delayed its alarm'.[136] Referring to the 1994 and 1996 Ebola outbreaks in Gabon, and based on internal documents from non-governmental organizations, Borchert *et al*. reveal that 'the central level has occasionally played down the seriousness of the

[134] Personal Communication, 8 March 2002.
[135] Roth, C., Personal Communication, 8 April 2002. Also, Vick, K., 'Where Disease and War Intersect', *washingtonpost.com*, 17 October 2000. Available Online: http://www.washingtonpost.com/ac2/wp-dyn?pagename=article&node=&contentId=A19573-2000Oct16
[136] Survey 10.

situation or discouraged the disclosure of outbreak information to the international community'.[137] When asked if such reactions were common, Cathy Roth replied:

> It depends on the country. In some cases, it might be beneficial to call for help as it would give international attention to their desperate situation. In others, the governments are worried about trade, tourism, and the reaction of other countries.[138]

The Ebola outbreak in Uganda, for example, considerably affected the country's tourism industry, even though the epidemic was geographically limited.[139] An outbreak of, say, Measles would not have produced such an effect. The reluctance of governments to openly acknowledge Ebola outbreaks is thus linked to the popular perception of the disease. An Ebola epidemic, through the ink and lens of hundreds of foreign journalists and reporters, reflects negatively on the afflicted country. With no coverage, however, an epidemic is harmless to the international reputation of a nation.

Despite the best efforts of scientists to solve Ebola's many puzzles, economic and political factors in epidemic countries leave the complete resolution of problems beyond the reach of science alone. Much like Russian dolls, the immediate problems are embedded within larger ones, but the publicized drama of Ebola outbreaks often obscure the fundamental issues to be addressed. Both the media and the scientific literature fail to mention the larger biosocial contexts in which epidemics occur. Even after 30 years, the epidemiological puzzle of Ebola epidemics remains unresolved, but the underlying causes of the epidemics are far from inscrutable: civil

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[137] Borchert, M., *et al*. 'Viewpoint: Filovirus Haemorrhagic Fever Outbreaks', *Tropical Medicine and International Health*, 5, 5 (2000), p. 321, and Personal Communication, 12 May 2002.
[138] Personal Communication, 8 April 2002.
[139] Busharizi, P., 'Ebola Hits Uganda's Tourism Revival Effort', *Reuters News Service*, 27 December 2000.

conflict, rash environmental disturbances, poor public health infrastructures and irresponsible governments both cause and exacerbate epidemics.

CHAPTER 5

Conclusion

With the regular identification of newly emerging infections, the close study of Ebola's turbulent history becomes increasingly important. For although statistically minor, the lessons learnt from Ebola might well prove useful in the handling of other fulminating diseases. This short thesis examined what can be termed the 'Ebola phenomenon', the sudden rise of a hitherto trivial disease to a 'Hollywood' virus, and analyzed the many changes that accompanied this transformation. More than the fact itself, the consequences of this notoriety reveal the extent to which the social construction of a disease influences its control and management.

The far-reaching tentacles of the media impeded control measures by their invasiveness, and exasperated scientists in the field. The terrifying image of the virus projected by the media proliferated outwards to distant countries and continents, and unwittingly stigmatized Ebola-struck nations. The metaphorical mutation of the virus into a disfiguring and, above all, mobile killer engendered irrational fears of pandemic spread. These fears, made worse by the threat of bioterrorism, spurred governments to inject additional funds into Ebola research, and sparked off a competitive struggle for attention among the relevant laboratories and scientists.

Away from the hypothetical, the very real social impact of Ebola outbreaks was obscured by the sobriety of scientific articles and the sensationalism of the mass media. The behaviour of affected African communities, especially before the arrival of the international teams, was largely overlooked by the literature. Although common to many outbreaks, foreign scientists did not anticipate local resistance to the control measures. They acted in ignorance of the belief systems underlying the actions of the indigenous populations. The many rumours that circulated during epidemics show that indigenous theories of disease causation are plentiful, and some quite dissimilar to biomedical aetiology. A historical glance at past Ebola outbreaks makes clear the importance of cultural sensitivity in limiting confrontations.

Neither did the scientists imagine the horror and panic they would find on arrival at the epidemic sites. The fear they experienced was heightened by the nature of the virus itself, in particular the untreatability of the disease, the unknown reservoir, and the near certainty of its clinical course. This work has shown to what extent Ebola outbreaks turn affected communities topsy-turvy, and examined the roles of the various actors - African and Western - in this drama.

Finally, the observations of the scientists in the field exposed broader issues, such as the effects of political instability, and the barely existing public health infrastructures. These problems, intrinsically associated with epidemics of Ebola and other diseases, are simply beyond the reach of science. What emerges from the thesis is an idea of the intricate web of events and issues that surround what is essentially a core of sub-microscopic virions. The complexity of the pathogen itself is, as it were, translated into a broader conceptual density.

APPENDIX

SUMMARY OF SURVEYS SENT TO 16 FIELD SCIENTISTS

• Question 1: '**Do you think we are better able to deal with Ebola epidemics today than in 1976?**'

a) yes, definitely
b) yes, but not much
c) no

Results: [140]

	a	b	c	TOTAL
Number of replies	9	6	1	16
Percentage of total (%)	56	38	6	100

Comments:

- Better understanding of epidemiology, although reservoir unknown.
- Better knowledge of clinical course of disease, although no treatment or vaccine.
- Higher on index of suspicion.
- Better knowledge of transmission.
- More international partners to control epidemics.
- Standards for surveillance and clinical care established.
- Prevention is, however, difficult. Human behaviour and environmental change not easy to modify. Need to enhance acceptability of control measures.
- Problem is getting simple equipment for barrier nursing to isolated, impoverished communities. Also, early recognition and notification of outbreaks is vital.

• Question 2: '**Ebola has appeared with increasing frequency in the last few years. Can you see this trend continuing? Any reasons**?

[140] Percentages are rounded to the nearest whole number. Consequently, the total may not equal 100.

	Yes	No	Don't know	TOTAL
Number of replies	15	0	1	16
Percentage of total (%)	94	0	6	100

Comments:

- Better awareness and detection.
- Better communication to signal outbreak.
- Unknown reservoir host makes spillage from reservoir to human population difficult to prevent.
- Ill-defined epidemiological belt.
- Increase in trade, population movement, and civil unrest, facilitating dissemination of virus.
- Environmental degradation.
- Poor infrastructure and hospitals.
- Increased population densities, more movement into forest, and closer contact with monkeys.

• Question 3: '**Past outbreaks of Ebola have shown that there is often a considerable delay between the appearance of the index case and the triggering of the alarm. What kind of things, from your experience, cause this delay? And what do you think can realistically be done to reduce them.**'

Comments:

Causes:

- Poor accessibility to health care, due to weak public health system caused by economic breakdown, war or negligence.
- Consultation of traditional healers, delaying response.
- Lack of concern at community, regional and central levels until health workers affected. Low transmission levels until amplification event.
- Non-specific clinical symptoms. Lack of familiarity with disease, so late physician recognition.
- Lack of trained staff, and diagnostic capability.
- Poor international collaboration and coordination of laboratory, epidemiologic and public health support.
- Desire of some researchers to control all specimens and data. Reluctance of central government to acknowledge problem.

Solutions:

- Better surveillance and response systems.
- Heightened awareness of disease in risk areas.
- Reduce isolation of most communities, which means dealing with political and military impasses causing poverty and isolation.
- More political commitment of governments to improve public health.

- Promotion of training and sensitization of health professionals to disease.
- Focus on hospitals (health workers at highest risk), then peripheral health units.
- Improving mechanism for collection and shipment of samples from suspected cases to appropriate lab for confirmation.
- Wide availability of simple diagnostic tests.

• Question 4: '**Ebola, like the Sabia virus, still has an unknown reservoir, to what extent do you think this unknown element affects the control and management of the disease.**'

	Important effect	Modest effect	Hard to tell	TOTAL
Number of replies	9	6	1	16
Percentage of total (%)	56	38	6	100

Comments:

Important effect:

- Greatly affects detection, hence control.
- Fear of unknown, fuels rumours and irrational attitudes.
- More focused prevention (especially in high-risk areas) and control once natural cycle elucidated.
- Ability to cut transmission cycle, preventing occurrence of index case.

Modest effect:

- Depends on outbreak. In Gabon (2001/2002), important effect, as multiple introductions probably involved. In most cases, usually single person infected and then person-person transmission.
- Reservoir probably bat – ecological niche known and can already advise people not to handle dead animals.
- Contact between reservoir and humans is rare, so knowledge of exact species unlikely to reduce frequency of contact. We also know areas where primary cases are likely to arise. Main problem is poor hospital conditions.
- Better understanding of ecological circumstances leading to Ebola outbreaks may help to make predictions.

Hard to tell:

- Hard to tell until reservoir and chain of transmission are known.

• Question 5: '**Did you sense that the locals were suspicious of you and the international teams?**'

	Yes	No	Depends	No answer	TOTAL
Number of replies	6	6	3	1	16
Percentage of total (%)	38	38	19	6	101

Comments:

Yes:

- In latest Gabonese and DRC outbreak: no support from local and national authorities due to elections.
- In some areas where disease is new, refusal or denial of disease by people.
- Little understanding among some populations of transmissible infectious agents – belief that 'white man' is responsible for introducing the virus. Information for local population vital. But resistance understandable, as sometimes enormous adaptations are asked of locals, such as breaking burial traditions and telling hunter/gatherer societies to cease hunting.
- In Uganda: little help at national level/ managerial level, especially when figures not tallying and discrepancies arose. Competition and mistrust among internationals occasionally affected control interventions. Some locals refused to go into isolation.

No:

- Affected local communities cooperative in Uganda (with one exception when population refused to offer a burial ground and to have an isolation unit created in a district hospital for fear of spread). In most outbreaks, local people very involved and cooperative.
- In 1976 Zaire outbreak, people leading control efforts had thorough knowledge of country, language and customs. Great deal of time spent with village chiefs to educate and facilitate cooperation.

• Question 6: '**Did the locals do anything, willingly or unwillingly, that prevented or slowed down the implementation of control procedures? If so, can you list some?**'

	Yes	No	No answer	TOTAL
Number of replies	9	5	2	16
Percentage of total (%)	57	31	13	101

Comments:

- Hiding cases and not providing names and whereabouts of contacts.
- Refusing contacts to be seen or ill family members to enter isolation units.
- Continuing burial rites despite recommendations not to do so.
- Stigmatization of cases, contacts and survivors.
- Overt acts of hostility (road blocks, threatening gestures with weapons)

- Continuing to eat chimpanzee meat and consulting traditional healers.
- Not keeping distance to other family members and not using barrier nursing during care giving.
- Spreading vicious rumours about experts bringing disease.
- Good cooperation early in outbreak, but not in middle of control effort because of perceived danger. Return to previous practices once emergency over.
- Zaire, 1976: good cooperation because of time spent with villagers explaining and enlisting help. Local custom to isolate village when threatened from outside.

• Question 7: '**Did you find local health authorities cooperative?**'

	Yes	No	Reasonably	Varies	No answer	TOTAL
Replies	8	1	2	4	1	16
%	50	5	13	25	6	99

Comments:

- Yambuku outbreak: Local health workers helped as best they could, especially as many locals and internationals refused to because of fear. Local health workers did fear working on isolation ward.
- Uganda outbreak: strong national support to control disease. Heads of hospitals and district health officers dealt almost uniquely with Ebola for four months.
- Varies with country. Sometimes very cooperative, other times only when pressured.
- Gabon (2001/2): cooperative locally, less so at central level.
- Depends on local health authority. Degree of politics always involved, some attempt to make political capital from outbreak, attempt to impress. Unhappy when negative statements about epidemic announced ('the same thing would happen in the USA.')

• Question 8: '**Had international teams not arrived at all, do you think the evolution of the epidemic would have been radically different?**'

	Yes	No	Depends on outbreak	Don't know	No answer	TOTAL
Replies	10	3	1	1	1	16
%	63	19	6	6	6	100

Comments:

Yes:

- Uganda: more experience with disease, extra resources for outbreak control in terms of manpower, mobilization of required resources and logistics, CDC lab for on-site case confirmation. Getting people into isolation. Estimate: in Uganda outbreak, instead of approximately 400 cases, probably 700 or 800. More intense human-human transmission and nosocomial transmission.
- As local capacity increases, evolution might be less affected by arrival of international teams.

No:

- Yambuku, arrival of team as epidemic was waning so negligible impact on evolution (but led to documentation of the disease!).
- Most epidemics more or less over by the time team arrives. Local people isolate spontaneously, flee hospitals (epicenters of disease) and impose simple form of quarantine. Allusion to 1976, when local chiefs put up own *cordons sanitaires* (remembering smallpox procedures).

• Question 9: '"**Research in filoviruses is an investment into an uncertain future: nobody knows how useful it will be in the end." (Borchert et al., 2000)[141] Do you consider money spent on the development of an Ebola vaccine or other Ebola-related projects (surveillance, reservoir seeking) a good use of limited resources?'**

	Yes	No	No opinion	No answer given	TOTAL
Replies	10	4	0	2	16
%	63	25	0	13	101

Comments**:**

Yes:

- Value of possessing antiviral drug and vaccine for healthcare workers, laboratory workers, and selected communities during outbreaks.
- Importance of antiviral drug for 'nasty eventualities'. Problem is that affected countries are not spending their limited resources.
- Ebola and related disease 'turn endemic areas, countries, WHO and the world topsy turvy when outbreaks occur'.
- Important to know reservoir to predict future outbreaks.
- Strengthening surveillance and outbreak preparedness on national and international level is the most important approach.

No:

- Definite overemphasis. Money better spent on 'well managed, transparent development programs, and AIDS'.

[141] Borchert, M. *et al.* 'Viewpoint: Filovirus Haemorrhagic Fever Outbreaks: Much Ado About Nothing?', *Tropical Medicine and International Health*, 5, 5 (2000), p. 322.

- Other infectious diseases need more urgent work in terms of vaccine development. Vaccine not really needed at present time.
- Ebola surveillance, on its own, would not be a good investment. Frequency and scale of epidemics, combined with limited resources, do not justify spending.
- 'Not cost-effective at a spectacular level'. Some funds, however, needed for reservoir seeking, surveillance, and training of health personnel.

• Question 10: '**From your experience on the field with Ebola and other diseases, what problems did you encounter with Ebola that were not found when dealing with other microbes?**'

Comments:

- Yambuku: Starting from scratch in defining clinical and epidemiological features.
- Obtaining volunteers to help in the field due to high infection and fatality rate.
- Protecting oneself and others from Ebola and other endemic diseases.
- Limited information on disease.
- Risk of nosocomial spread.
- Spectacular nature of disease.
- More institutions/organizations involved.
- Strong competition among implementers of control strategies. Use of outbreaks for personal growth among researchers.
- Potential for contact infection during field and clinical investigations.
- Fear of infection by many team members because of lack of vaccine and treatment.
- Need to achieve very high standard of hospital hygiene to avoid nosocomial transmission.
- Stigmatization of survivors by community. Their possessions and homes were burned in Uganda.
- Stress of seeing entire families and hospital wards wiped out by the disease.
- International fear for local disease: negative impact of media coverage (comparison of Ugandan outbreak with simultaneous yellow fever outbreak in Guinea with very little international aid).
- Sensitiveness of central government on the issue.
- Hype and importance of dealing with media.

• Question 11: '**Some experts have suggested downgrading EHF to a BSL-3 status. What is your stance on this?**'

	Agree	Disagree	Depends	No opinion	No answer	TOTAL
Number of replies	2	7	1	5	1	16
Percentage of total (%)	13	44	6	31	6	100

Comments:

Agree:

- No BSL grade when dealing with patients.
- Would accelerate research.

Disagree:

- Ebola fits the criteria established for p4 agents. No antiviral, no vaccine. ▪Politically, hard to justify lab accident if reduced to p3. Estimate: if lowered to p3, death of lab worker every 1 or 2 years.

Depends:

- PCR after sterilisation with GIT-buffer should not require BSL-4 facilities. Isolating/cultivating virus should. PCR could therefore play role of early diagnostic technique while virus isolation/cultivation should remain limited to BSL-4 labs.

• Question 12: '**Moren contrasts the $7.5 million dollars spent on the 1995 Kikwit outbreak with the measles epidemics in Niger in 1991 and 1995, which led to 100 000 cases with a CFR of 10% but little national or international attention. Why do you think Ebola enjoys such attention?**'[142]

Comments:

- Rare. Exotic. Novel. Frightening.
- Dramatic clinical course and high fatality rate.
- Lack of vaccine or drugs.
- Weapon weaponized by Soviets so direct interest by US military.
- Affects all age groups and otherwise healthy people.
- Publicity. Media interest for stories of gruesome diseases, fuelled by mysterious nature of disease (e.g. unknown reservoir). Focus of writers on Ebola (articles, books, films and, in Zaire, songs).

[142] Moren, A., 'Co-ordination of International Responses to Epidemics', in Greenwood, B., and De Cock, K., *New and Resurgent Infections: Prediction, Detection and Management of Tomorrow's Epidemics* (Chichester, 1998), p. 149.

SUMMARY OF SURVEYS SENT TO 17 LABORATORY SCIENTISTS

• Question 1: '**Since 1976, our knowledge of the virology of Ebola has increased quite considerably, yet do you think we are better able to deal with Ebola epidemics today than in 1976?**'

a) yes, definitely
b) yes, but not much
c) no

Results:

	a	b	C	TOTAL
Number of replies	8	8	1	17
Percentage of total (%)	47	47	6	100

Comments:

Positive:

- Improved diagnostics and faster identification.
- Precautions to be taken for management of patient clearly defined, as well as organisation of isolation unit in rural setting.
- Possession of specific immunoglobulins for emergency preventive maintenance. Knowledge of the efficiency of plasmopheresis, coagulation therapy, etc.

- Depends on how rapidly the disease is detected. Political sensitivities with various countries also involved in quality and usefulness of response.

Negative:

- 'On the surface, the 2000-2001 outbreak in Uganda with 400+ cases doesn't look much different to the outbreaks in the late 1970s.'
- Lack of knowledge and interest of Ebola natural history and human population at risk (habits, behaviour), as demonstrated by hostile attitude of local population in the current epidemic in Gabon.
- Response too late after appearance of index case (generally 3+ months).
- Reservoir unknown.
- Barrier nursing still key to controlling outbreak. 'Science has not yet kicked in', simply adherence to good hygiene.
- Still much to understand on pathogenesis of virus.

• Question 2: '**Some experts have suggested downgrading Ebola to BSL-3 status. What is your stance on this? Do you think it would accelerate research?**'

	Agree	Disagree	No opinion	TOTAL
Number of replies	3	14	0	17
Percentage of total (%)	18	82	0	100

Comments:

Agree:

- Highly virulent but infection easily prevented by barrier nursing.
- Controllable. No aerosol. Only contaminated blood is infected – 'most common thing in virology'.

Disagree:

- No possible prophylaxis. Too many unknowns. Excessive risk involved for laboratory personnel.
- If downgraded, laboratory acquired infections and unnecessary deaths likely. Knock-on effects for research in case of infections (huge clamp-down, recriminations, etc.).
- Biosecurity issues to consider. Research 'moving forward pretty well now'.

• Question 3: '**Do you believe enough money is injected into Ebola laboratory research?**'

	Yes	No	TOTAL
Number of replies	5	12	17
Percentage of total (%)	29	71	100

Comments:

Yes:

- Ebola doesn't represent public health issue; main issue is bioterrorism and enough money is injected in research for that purpose.
- Relative to the public health need and the risk, enough money is attributed to Ebola research.
- Enough money, but improper distribution of funds. More money given for very visible projects than real science (e.g. long term studies or surveys).

No:

- Adhere to highest safety standards and maintenance of facilities naturally expensive. Staff have to retain their scientific skills at this level.

- Ebola is of no immediate epidemiological concern outside endemic areas, so Government and Granting Authorities only generous when imported case of Viral Haemorrhagic Fever case is identified in Northern Hemisphere.
- No long term international or national strategies in place to address the research or skill acquisition deficiencies. Those that exist are disjointed.
- In UK, very little spent on exotic pathogens. Globally, situation more satisfactory.
- Potential of bioterrorism justifies more research on antivirals and perhaps a vaccine.
- Recent plus in bioterrorism dollars, but key is getting the funds to the researchers actually working on Ebola.

• Question 4: '**Is there enough cooperation between laboratories and researchers working on Ebola? If not, why is this and what consequences does this have?**'

	Yes	No	Depends	No opinion	TOTAL
Number of Replies	8	6	2	1	17
Percentage %	47	35	12	6	100

Comments:

Yes:

- Majority of labs work collaborate.
- USAMRIID mentioned twice: try very hard to help but overwhelmed.
- Lack of collaboration more likely to stem from funding deficiencies.
- More collaboration possible.

No:

- All labs and researchers following own scientific and political agendas; they ensure any advances made feed their own research funding requirements.
- Few labs work on Ebola, so lack of international cooperation means all labs try to cover wide range of interests (anti-virals, diagnostic and reagent development, molecular epidemiology, understanding pathogenesis). This approach is not cost-effective way of using scarce resources. Ideally, facilities should support 1) exchange of scientists 2) receive visiting scientists 3) non infectious programmes.
- Research scientists competitive by nature. Some get along, others don't. Ego and lack of trust (founded or unfounded) are main reasons for poor cooperation.
- Laboratories that have access to critical material, such as primary human materials from outbreaks, tend to be very protective of those materials and are extremely reluctant to share with others in the field.
- Small trust of politicians towards scientists, which restricts cooperation between labs. Note: security issues can pose logistical barriers between international labs and researchers who might otherwise wish to cooperate.

- CDC mentioned twice as possessive of BSL-4 agents and uncooperative. Consequence: slower pace of research.

Other:

- How is cooperation defined? Two labs working together, not just one side providing means and support. Lab wishing to get into field must 'bring something to the table' and not simply provide whatever is requested.

• Question 5: '**Do you think Ebola research should be directly relevant to what is occurring on the field?**'

	Yes	No	No answer	TOTAL
Number of Replies	6	7	4	17
Percentage %	35	41	24	100

Comments:

Yes:

- Vital need for constant surveillance systems in proven endemic areas. Need to transfer diagnostic technologies and reagents to local areas, and educate local population on these and other infections. This requires providing supportive infrastructure. (WHO attempts at outbreak response support is dependent on countries allowing and supporting the redeployment of experienced staff to affected areas. This can be very slow and bureaucratic.)

No:

- Need for basic research, as well as goal-oriented work. Contributions in an unrelated area can have unforeseen benefits later.
- Research should cover significant spectrum of fundamental problems.
- 'Research should be unfettered'
- Ebola research should focus on understanding fundamental mechanisms of disease pathogenesis – this is vital for the development of candidate vaccines and identify targets for chemotherapeutic interventions. Volchkov's reverse genetics system 'should be instrumental in studying key regulatory elements in the viral life cycle, and will likely result in the development of new vaccines, e.g. replication-deficient viruses'.

• Question 6: '**The literature has often criticized the sensitivity of certain diagnostic tests, leading to false alarms and, likewise, missed cases. Do you consider this a major problem?**'

	Yes	No	TOTAL
Number of replies	4	13	17
Percentage (%)	24	76	100

Comments:

Yes:

- Some groups don't question their results.
- RT-PCR inherently prone to cross-contamination. The more widespread use of this technique may cause new filoviruses to go unnoticed, 'would RT-PCR pick up a new Ebola virus?'.
- No substitute for viral isolation and/or direct visualization of virions, but logistical issues concerning utilization of these techniques in affected countries.

No:

- Several tests can be combined for diagnosis of acute cases.
- Most important thing until diagnosis is revealed is isolation of patient.
- One problem is occasional overreaction of popular press.
- False positive doesn't lead to missed cases.
- Ebola diagnosis is easy to do, but labs don't want to give the appropriate inactivated antigen to ones that don't have p4 facilities.
- Population-based serosurveys problematic in past, but newer tests should provide more reliable results. Many 'cross-reactive' tests were serological, but contemporary ones are molecular based.

• Question 7: '**A new, faster diagnostic test has very recently been developed. Do you think this will have a significant impact on case identification?**'

a) yes, definitely
b) yes, but not much
c) no
d) no answer selected

	a	B	c	D	TOTAL
Number of Replies	2	8	2	5	17
Percentage %	12	47	12	29	101

Comments:

Yes, definitely:

- Allows diagnosis at early phase of disease and requires minimum safety precautions to be performed.

Yes, but not much & No:

- Not much of an impact now, but should in 5-10 years time.
- Test needs to be available in remote places in Africa.
- Test essentially a new sample preparation procedure, based on existing RT-PCR methods, so probably not a big impact.
- Possible impact of case identification, but not detection of epidemics, especially sporadic cases.
- Key to detection is clinical observations by clinicians, without that even the best diagnostic assays are not useful.

Other:

- Test yet to be validated with clinical cases and outbreak situations.
- System should be validated by all laboratories working on Ebola to establish reliable quality assurance and control system.
- Too early to say. Most important thing is availability of test to physician in endemic/enzootic areas.

• Question 8: '**From your experience with Ebola and with other microbes, in what way would you consider Ebola unique or unusual?'**

Comments:

- Very high mortality rate and no treatment.
- Spectacular symptoms, dramatic course of disease.
- More frightening.
- Inability to determine natural history after knowing infective agent for 25 years.
- Easy spread in family and hospital setting if isolation and necessary precautions not implemented.
- Scientific questions based on virus evolution and understanding of pathogenic processes during disease stages (transmission, infection, disease, death and recovery) that are intriguing areas requiring answers.
- Ability to completely shut down normal anti-viral mechanisms.
- Extent of spread of virus throughout body.
- Celebrity status. Voraciousness of popular press.
- Social hysteria engendered by outbreak.
- Significant threat of bioterrorism.
- 'Do not consider Ebola more unique or unusual than other agents'.
- 'It is not very unique – the mortality rate in the case of Rabies is much higher.'

• Question 9: '**Moren contrasts the $7.5 million dollars spent on the 1995 Kikwit outbreak with the measles epidemics in Niger in 1991 and 1995, which led to 100 000 cases with a case fatality rate of 10% but little national or international attention. Why do you think Ebola enjoys such attention?**'

Comments:

- Mediatisation of virus by movies, press, etc.
- Fear of spread of disease out of endemic countries.
- Fear of bioterrorism.
- Exoticism of Ebola.
- Mysterious nature of Ebola.
- Explosive and unpredictable outbreaks with high mortality.
- Lack of understanding of natural history.
- No proven anti-virals available.
- Bleeding more mediatic than encephalitis.
- One mention of Kikwit outbreak providing the CDC with opportunity to draw the attention of the US Congress on emerging diseases and to boost a hitherto decreasing Special Pathogens Branch budget.
- Vaccine available for Measles (although coverage level is low in developing countries).
- Measles is 'common place' – people in developed countries don't understand fatality of Measles outbreaks in poorly nourished countries. 'Measles, not Ebola, is an embarrassing failure of science, medicine, and politics. Ebola is simply a scientific curiosity.'

• Question 10: '**Do you consider the fear of Ebola being used as a biological weapon unfounded or exaggerated?**'

	Yes	No	No Answer	TOTAL
Number of replies	6	10	1	17
Percentage (%)	35	59	6	100

Comments:

Yes:

- Real threat but exaggerated.
- Difficult to use as biological weapon, but might be good weapon of bioterrorism.

No:

- High fatality rate, no treatment, no vaccine, easy spread.
- Synthesizing Ebola 'WILL happen sooner or later'. Synthesizing the virus will get easier with time.
- Probability nevertheless quite low; disease unlikely to spread widely. Impact would still be significant due to notoriety of Ebola. Mass hysteria even in the absence of a large-scale epidemic.
- References to September 11th, anthrax incidents, Tokyo cult.

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