Pandemics of fear in an interconnected world
A paradigmatic story about emerging infections

‘........begins with the identification of an emerging infection, includes discussion of the global networks throughout which it travels, and chronicles the epidemiological work that end with its containment. As epidemiologists trace the routes of the microbes, they catalogue the spaces and interactions of global modernity. Microbes, spaces, and interactions blend together as they animate the landscape and motivate the plot of the outbreak narrative: a contradictory but compelling story of the perils of human interdependence and the triumph of human connection and cooperation, scientific authority and the evolutionary advantages of the microbe, ecological balance and impending disaster’ (Priscilla Wald, *Contagious*, 2008: 2).
Why stories?

• Challenge of responding to outbreaks of infectious disease – including (re) emergent zoonoses – is upon us

• Practical and moral dilemmas:
  – Short-term, emergency measures may fail to address the underlying drivers of outbreaks;
  – Privileging acute outbreaks may neglect more endemic manifestations;
  – Eradication may be attempted when control and management would be more appropriate;
  – Protecting some populations may infringe on the rights of others

• Given the complexity of both disease and political dynamics, how can policy-makers, health practitioners, and citizens contribute to generating sustainable responses to epidemic diseases that benefit the health and well-being of all?

• Stories help reveal the implicit assumptions that shape policies, and (valuable) alternative perspectives that are often left out – and hence clarify choices.
Epidemics – a pathways approach

• Disease emergence and dynamics involve complex interlocking of ecological, social, technological and human-animal interaction processes.

• Case studies - how do different policy-makers, scientists, and local populations construct narratives—accounts of causes and appropriate responses — about epidemics at global, national and local levels?

• What pathways of response result? With what effects? Who gains and loses?

• Dominant and alternative narratives/pathways – scope for combination, complementarity, deliberation?
Why viral haemorrhagic fevers?

- Ebola and Lassa Fevers as part of larger group of viral haemorrhagic fevers, and the two epidemiologically most significant in the African context.
- A personal history…
- Ebola as archetype for ‘outbreak narrative’ in policy and popular discourse (and WHO history)
- Some intriguing alternative stories:
  - Local cultural logics and ‘outbreak anthropology’ – Barry Hewlett and others
  - Ebola and Lassa – epidemic vs. endemic contrasts
- Some broader insights and lessons?
Some background
Ebola

- Fierce, ‘rapid killing’ filo-viral disease, causing death in 50-90% of clinically diagnosed cases.
- US government lists as potential biological weapon in highest-risk group (biosafety level 4).
- Passed via blood and bodily fluids; rapid onset of symptoms (high temperature, shivering and aches, gastric problems, rashes and throat lesions, spontaneous bleeding and renal failure, extreme lethargy and hallucinations); usually death within two weeks.
- Zoonotic disease with natural reservoir in rats or bats in forest environments (but uncertainty and unresolved debate). Transmission via apes touched or consumed as bushmeat thought to be a major infection route.
- Five varieties: Zaire (80-90% case mortality rate, tropical forest areas), Sudan (40-50% mortality rate, mixed savanna-forest environments), Bundibugyo (25% mortality rate, mountain forest environments), Reston and Ivory Coast.
- No available antiviral or vaccine
Primary African outbreaks of filovirus (Ebola-Zaire, Ebola-Sudan and Marburg)

<table>
<thead>
<tr>
<th>Year</th>
<th>Gabon</th>
<th>Congo</th>
<th>DR Congo</th>
<th>Angola</th>
<th>Uganda</th>
<th>Sudan</th>
</tr>
</thead>
<tbody>
<tr>
<td>1976</td>
<td></td>
<td></td>
<td>318</td>
<td></td>
<td>284</td>
<td></td>
</tr>
<tr>
<td>1979</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>34</td>
</tr>
<tr>
<td>1994</td>
<td>52</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1995</td>
<td></td>
<td></td>
<td>315</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>37, 61</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1999</td>
<td></td>
<td></td>
<td></td>
<td>73</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>425</td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>65</td>
<td></td>
<td>57</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td></td>
<td></td>
<td>13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>143; 35</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>12</td>
<td></td>
<td>351</td>
<td></td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>2007-2008</td>
<td></td>
<td>264</td>
<td></td>
<td>149</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: adapted from Hewlett and Hewlett, 2008, p5 and CDC (cdc.gov/ncidod/dvrd/spb/mnpages/dispages/ebola/ebolatable.htm)

Note:
• Increasing frequency of outbreaks
• Overall numbers of deaths relatively small
Lassa Fever

- Lassa haemorrhagic fever caused by a single-stranded RNA virus (of family Arenaviridae).
- Endemic in Guinea-Conakry, Sierra Leone, Liberia and parts of Nigeria, and possibly also in other countries in the West African region. Highest incidence in ‘hyperendemic’ Kenema District, Sierra Leone.
- Zoonotic disease, whose animal reservoir is a rat of the genus Mastomys. Infection through direct exposure to excreta of infected rats, or – more rarely - by transmission from person to person via body fluids.
- Asymptomatic in c.80% of cases, but causes acute illness in others (fever, headache, chest pain, vomiting, diarrhoea, cough, fluid in the lung cavity, bleeding from orifices, disorientation and coma). Deafness occurs in 25%.
- Case fatality rate only around 1%, rising to 15% of hospitalised cases. But estimated 300,000 infections and 5,000 deaths per year.
• Ebola as ‘much ado about nothing’ – locally devastating, but of marginal international importance? (Borchert et al, 2000).

• Lassa fever as ‘an unheralded problem’ demanding more international attention? (Birmingham and Kenyon, 2001).

• Number of people affected by each disease is out of proportion with their international profile and scale of western media attention.

• Reasons for and consequences of Ebola sensationalisation and exceptionalism?
Four narratives

• *A global threat*: tackling an emerging plague out-of-Africa

• *Deadly local disease events*: the building of universal rapid response

• *Culture and context*: Building positively on local knowledge

• *Mysteries and mobility*: taking long-term ecological and social dynamics seriously
  – *Temporal sequence – mid 90s – present*
  – *Overlap, interact….***
A global threat

An emerging, fierce predatory virus threatens to spread rapidly in a mobile and interconnected world to affect global populations, so outbreaks require rapid international notification and response.

Early – mid 1990s – linking popular fiction and media with some perspectives amongst virologists, epidemiologists, international organisations (WHO, CDC)
Key elements of narrative and response....

- Originates primarily from Euro-American sources - popular and sensationalized fiction and non-fiction newspaper reports, books and films about Ebola or Ebola-like outbreaks
- Global system, global security, global (northern) populations
- Viral agency (human exploitation in bioterrorism....)
  "the infamous Ebola virus …punches holes in capillaries and blood teeming with viruses oozes into tissues and body fluids. So while the patient is prostrate with high fever, severe pain, generalized bleeding and catastrophic vomiting and diarrhoea, the viruses in body fluids take the opportunity to pass to unsuspecting family members and hospital staff (Crawford 2007: 17)… ‘exploiting international travel routes to infect naïve populations worldwide. (2007: 138)
- Scientific heroism – discovery, identification
## Popular Euro-American haemorrhagic fever cultural model

<table>
<thead>
<tr>
<th>Common signs and symptoms</th>
<th>Flu-like, fever, vomiting, bleeding from orifices, skin rash or lesions, difficulty breathing, rapid death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common causes - global threat</td>
<td>Mutant virus from foreign land (Africa, China), secret government labs, foreign terrorists</td>
</tr>
<tr>
<td>Common ways disease is transmitted</td>
<td>Airborne, touch</td>
</tr>
<tr>
<td>Treatment</td>
<td>None until high tech scientist discovers vaccine or other cure, otherwise everyone dies</td>
</tr>
<tr>
<td>Prevention and containment</td>
<td>Flee area of outbreak, isolate self and family, close schools and churches, wear masks</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Not good until science discovers cure</td>
</tr>
<tr>
<td>Risk groups</td>
<td>Health workers and general public</td>
</tr>
<tr>
<td>Common human responses to outbreak</td>
<td>Panic, violence, competition</td>
</tr>
</tbody>
</table>
Implications

• Dramatic fear and perception of global spread has motivated national and international health and government officials to develop policy based on this vision, with media popularisation increasing public interest and support. Ebola in this respect as ‘exceptional’ or ‘master status’ disease.
  – 1995 outbreak in Zaire, and the ‘perception that the Kikwit outbreak was going to spread to the rest of the world’ ‘key to building political momentum’ in the processes leading to the WHO’s creation of a revised set of International Health Regulations (IHR) in 2005 (interview, WHO, July 8 2008)
• Interest in knowledge of scientists, epidemiologists, doctors, but not of the public. African forest dwellers portrayed as backward and primitive – cave dwellers, monkey eaters, tribal rituals
  – *People who have contracted the disease, my impression is that they have done so in this, sort of, cave area, where the monkeys hang out*’ (broadsheet reader, cited in Joffe and Haarhoff, 2002, p9)
Deadly local disease events

HF outbreaks cause high local mortality, and can and should be contained by rapid-response teams using standard isolation and public health measures

WHO/CDC outbreak alert and response programmes; GOARN ‘Ebola control peppers its history’
Key elements of narrative and response….

• Short-term outbreaks, mortality impact on local populations
• Biomedical cultural model of disease
• Responsive networks emphasise resilience in face of uncertain occurrence of ebola shocks
• Lassa fever presents a contrast, requiring more sustained engagement of health teams and measures to deal with its more endemic character. Yet ‘we prefer to deal with these outbreak-like HF, like ebola’ (interview, WHO 2008)
• Authority of epidemiological and medical knowledge; standardised technical response package (isolation, contact-tracing, barrier nursing)
Local people seen as ignorant, mired in misguided tradition and dangerous cultural practices

- Beliefs in traditional remedies, and misunderstandings of miscarriage as attributable to witchcraft, associated with delays to timely presentation of Lassa cases for treatment (Merlin, 2002).

- Medical staff in Sierra Leone lament community traditions that encourage the eating of rats, and identify dry season festivals where this happens at scale as a major cause of Lassa outbreaks (interview, Kenema, April 2009).

- Research in Gabon into Ebola outbreaks identified ‘problematic’ cultural practices including family members remaining close to the patient to nurse him/her; hugging and touching the dead at funerals, and traditional healers’ treatments such as cutting a patient’s skin with unsterilised knives and applying blood to the skin (Kunii et al, 2001).
Implications

• Top-down, standardised responses and control measures

• Have provoked local fears

• Injustice (restrictions on movement, rights to bury dead)

• Have sometimes proved unsustainable, facing resistance from local populations (e.g. Gabon 2001 - US and French teams expelled)
Culture and context

HF{s have been long-present amongst local populations whose knowledge, cultural logics and practices should be integrated into responses

Local populations, anthropologists, enlightened field scientists

...the eerie silence in a village with all its house doors boarded up. Entering a house where an old woman lay dying, her profound terror was matched by my own terror; in my white isolation suit I was either God or the devil (recollec{on of Gabon, 1996; interview, Geneva, July 2008).
Key elements of narrative and response....

• Short-term outbreaks, local populations
• Local cultural models of disease taken seriously
• Acknowledgement of uncertainties and ambiguities about local disease dynamics and contexts – role for interdisciplinary and local knowledge
• Incorporation of cultural logics and social protocols into response strategies
• Tuning of technologies to local contexts
• Social justice, rights and emotional support balanced with disease control aims
Local cultural model for epidemic illness (*gemo*) amongst Acholi people, Uganda (Hewlett and Hewlett 2008)

<table>
<thead>
<tr>
<th>Description</th>
<th>Bad spirit that comes suddenly like the wind and rapidly affects many people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signs and Symptoms</td>
<td>Mental confusion, high fever, rapid death</td>
</tr>
<tr>
<td>Cause</td>
<td>Lack of respect for <em>jok</em> (spirit), sometimes no reason</td>
</tr>
<tr>
<td>Transmission</td>
<td>Physical proximity, wind</td>
</tr>
<tr>
<td>Treatment</td>
<td>Talk to spirits via traditional healer</td>
</tr>
</tbody>
</table>

Protocol for *gemo* prevention and control: isolating the patient in a house at least 100m from others; having a survivor of the epidemic feed and care for the patient; identifying houses with ill patients with two long poles of elephant grass; limiting general movement and advising people to stay in their household and not move between villages; and, finally, keeping patients who no longer have symptoms in isolation for one full lunar cycle before moving about freely in the village.
Implications

• Integrating cultural logics and local social protocols into outbreak response strategies

• Blending local and scientific knowledge in pathways of response
  – Complementarity - *gemo* protocol constitutes a broad-spectrum approach to epidemic control which also makes sense in relation to the biomedical cultural model employed by international teams.

• Ebola as a pioneer disease, offering broader lessons?
  – ‘*anthropological integration is now a key pillar of our response strategy – as important as isolation*’ (Interview, WHO 2008)

• Lassa Fever – pioneering participatory theatre in 1980s, but research into local cultural models only just starting
Mysteries and mobility - long-term dynamics

HF outbreaks are a manifestation of long-term drivers in social, environmental, land use and health systems that must be addressed to reduce frequency, vulnerability and impact.

Departments and programmes in international health agencies – climate change and health, health systems
Environmental and development policy actors
Social science and environmental researchers
New interdisciplinary programmes (e.g. UK MRC/NERC 'Environmental and Social Ecology of Infectious Disease, ESEI)

Numerous partial storylines and fields of response….. But many uncertainties
Key elements of narrative and response….

• Long-term disease drivers and amplifiers
  – Deforestation and human-vector contact (logging, farming, mining)
  – Bushmeat dependence and trade
  – Poverty and social dynamics
  – Migration – to forests, cities
  – Climate change, shrinking forest frontier, fleeing environmental refugees
  – Urban expansion, overcrowding
  – Structural violence
  – Weak health systems
  – Conflict

• Local-national-global dynamics; political disease-ecologies; ‘regions at risk’
• Dominant views construct dynamics as linear, and knowable
  – E.g. progressive deforestation on forest frontier
• But environmental-social-animal-disease-ecological systems are complex and often non-linear, and incorporate uncertainties
  – Uncertain vector population and transmission dynamics
  – Non-linear forest-savanna-land use dynamics
  – Sudden shocks, whether political (conflict) or economic (bushmeat markets)
• Need for scenarios (future stories), foresight, agility in response
• Dominant policy responses emphasise control-oriented, top-down interventions
  • protected areas, re-organising trade, livelihood bans
  • But more flexible, adaptive strategies might be needed to build resilience in the face of dynamics and uncertainties
    – Adaptive forest management?
    – Integrated vector management?
• Emphasis on formal science – environmental, medical
• But roles for alternative knowledge combinations – ecological anthropology, historical and political ecology, local knowledge, participatory eco-epidemiology
Combining narratives – and challenges

• Narratives 1-4 differ along many axes:
  – Who are the actors telling the story
  – Who/what is blamed
  – How is ‘the system’ framed, at what scale
  – What is the problem, fear, goal
  – What, and whose, knowledge is valued
  – What strategies should be used in response

• Roles for elements of each; in practice they co-exist, interact and co-evolve (e.g. Uganda 2008)

• Challenge to understand the political economy and policy processes amongst narratives and pathways, and related institutional and cognitive pressures
• Integrating ‘outbreak narratives’ and responses (narratives 1 and 2) with attention to longer-term dynamics and endemic situations (narratives 3 and 4, and Lassa Fever in general)

• Integrating the global (narratives 1 and 4) and the local (narratives 2 and 3)

• Sustaining the integration of culture and context (narrative 3) amidst new attention to the environmental dynamics of disease

• Amidst inevitable incertitude and ongoing dynamics, building inclusive, participatory approaches that combine diverse knowledges, enable resilience and robustness, and social justice?
Thank you for your attention

Looking forward to discussion