Humanisation and informed consent for people and populations during responses to VHF[1] in central Africa (2003-2008)

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Introduction

Whether from the point of view of the people directly concerned, the general public or health professionals, Ebola and Marburg viral haemorrhagic fever epidemics are particularly dramatic 'spectacular', and receive extensive media coverage, due to the following factors:

- Extraordinary mortality (30% to 90% of sufferers, depending on the type of virus);
- Extreme infectivity by direct contact with contaminated (animal or human) body fluids, with poorly estimated risk rates (many automatically assume it is 100%, though in reality the percentage of exposed subjects that develop the disease varies depending on the type of exposure:
  - Contact with infected animal body fluids: 30% to 100% of exposed subjects become infected,
  - Contact with infected human body fluids through dirty injections: up to 75% of exposed subjects can develop the disease,
  - Contact with infected human body fluids during funerals: 5% to 15%,
  - Contact with infected human body fluids during home care: 1% to 10% of exposed subjects become infected);
- Clinical severity, marked by multiple haemorrhagic signs, the intensity of fevers and aches and the speed of fatal evolution;
- The death of doctors, midwifes, nurses and healers, which paralyses health structures and dampens good will.

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[1] VHF = viral haemorrhagic fever.

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There is no vaccine or specific treatment against these viruses, just drastic sanitary measures that affect individual and collective freedoms:
- Identification of those infected ("suspect" cases and probable cases) and exposed subjects;
- Criminological-style epidemiological surveys designed to shed light on family secrets, as well as individual and collective unconscious beliefs and unspoken assumptions;
- Bans on the hunting and consumption of game, a key source of food, disrupting ordinary eating habits and local economies both materially and symbolically;
- Imposed isolation of the sick in controlled areas, perceived as places of death and/or contamination;
- Daily monitoring of the temperature and state of health of exposed subjects, who are immediately isolated if they fall sick and are considered "suspect" cases by clinicians;
- Supervision and/or banning of gatherings and travel;
- Disruption of funerary rituals, hindering the mourning process;
- Compulsory blood or tissue sampling for virological diagnosis, perceived as witchcraft; and so on.

The epidemic, a challenge of knowledge and power

Humanitarian mission, said the visa officer at the embassy in Paris (and therefore a priority, she thought), when told that the purpose of the trip was to participate in the fight against viral haemorrhagic fever.

Humanitarian, certainly, but from what point of view?

That of the indigenous populations in contact with epizootic outbreaks, which actually serve as sentinel observatories for viral haemorrhagic fevers and other diseases emerging from the depths of African forest ecosystems?

That of humanity, which (in reality or phantasmagorically) is threatened by a catastrophic spreading of viruses that it does not know how to treat, and which envisages various accidental, spontaneous or provoked epidemic scenarios at the urban and therefore the global level?

Providing protection and health cover for some also involves protecting others. However, the quality and resources of public medical and social structures in the remote, forgotten regions where these types of animal and human epidemics strike are often mediocre, indeed sometimes totally lacking.

Care for the health (and consequently the misfortune) of these populations is also provided by private medical structures (lay, denominational, charitable and/or profit-making, etc.) and local practitioners (traditional healers, religious leaders, neo-healers, traditional authorities, popular medicines). Numerous varied and often antagonistic divinatory techniques, phytopharmacopeia, incantations and prayers, amulets and rituals are accessible and hold great credibility. They help make sense of the misfortune of the epidemic, if not for the individual or society, at least in terms of the metaphysical order of the world. And in one way or another, they are constantly operating, for better or worse, at a psychological, economic, political or even epidemiological level.

Indeed, statistical and genetic explanations do not answer the fundamental questions of the individual and society: why now, why me and not someone else? What relationship is there between the various events that affect me, my friends and family, and my enemies?

Even with treatments and vaccines, let alone without, the biomedical model is just another explanatory model, leaving the field open to any psychological, social, economic or political interpretation of conscious or unconscious, spoken or unspoken misfortune.

During the Ebola and Marburg VHF epidemics that have been 'anthropologically' monitored since 2003, numerous explanatory models of the epidemics have co-existed. Each one has specific features that focus not on the type of supernatural explanation proposed but the social use it serves: paying for ancestral sins, settlements of account between old and young or with in-laws, between neighbourhoods or villages, between ethnic or religious groups, between natives and foreigners, between locals and the national authorities, between 'Westerners' and Africans, between political parties and economic groups…

The management of misfortune – whether biological or not – always boils down to a challenge of knowledge and power between the supporters of a world based on the existence of viruses, microbes and other molecules, and the supporters of worlds based on inherited or acquired mystical powers, supernatural beings, murderous sorcerers, divine interventions, etc. There is a conflict between "the science of scientists" and "indigenous sciences", against a backdrop of globalisation, shaken up by clashes between antagonistic interests.

Whether or not to believe in the virus

The existence of the virus, or its animal origin, is readily denied by "negationists", creationists, proponents of pan-African ideologies, challengers of the world order or xenophobes, both learned and ignorant.

They view support for the biomedical model of the response to epidemics as allegiance to the selfish interests of industrialised countries, which have crushed or are in the process of crushing (or turning into folklore) local cultures, scorning indigenous sciences and "beliefs", and imposing an atheistic, or even diabolical, ideological order. Those industrialised countries also quick to exploit anything that might make them some money, for example the pharmacologically active qualities of certain plants, or vaccine or drug trials on local populations.

Therefore, in the eyes of those same people, the teams implementing responses to epidemics (local and national personnel, international experts, NGO volunteers, etc.) in the name of global public health and Western science are no longer conscientious professionals or respectable humanitarian workers, but mercenaries, agents of a national and/or international health police, charged with imposing a despised political order. Moreover, they are accused of taking advantage of epidemics for personal financial gain. This last point sometimes proves to be true; rather than actual embezzlement, national and international funding, which is considerable at the source, melts like snow in the sun and, assuming it has not completely evaporated, seems pretty meagre by the time it reaches its destination: bereaved families and the ground staff of the epidemic response teams.

And so doubt reigns, over both the existence of the virus and the real intentions of the humanitarian workers, who locals confuse with the foreigners who are only interested in election campaigns, forest and mine prospecting, trade, war or religious proselytism.

On top of that, the safety protocols made necessary by the risk of transmission of the virus oblige humanitarian workers to keep a physical distance, which makes personal contact difficult. Normal spontaneous gestures such as shaking hands, touching the person spoken to, sharing drinks and food or transportation in the same vehicle are prohibited. Consequently, it is extremely difficult to convey empathy.

What can be done to build trust? How can the informed consent of individuals be obtained when the proposed measures are highly coercive and restrict individual and collective liberties?

What is the best way to manage people's beliefs, and their simultaneous support for the epidemiological model and other models for interpreting the disease and the misfortune of the epidemic? What measures can be taken to encourage the adoption of behaviours that help stop propagation of the virus, irrespective of any controversy about its existence?

Coercion and understanding

Historically, the approach to tackling epidemics of diseases for which there is no vaccine or effective treatment – whether attributed to miasmas, jinxes, curses or viruses – has consisted of a succession of infringements of people's liberties, and totalitarian measures. They are applied in the name of higher interests, are often confused with public health, and sacrifice individuals and groups. In any given situation, there is always confusion between knowledge and power, protection of some and exposure of others, stigmatisation and the search for scapegoats: witch doctors, immigrants, the sick, often the lower social classes or socially marginalised groups.

It was not until the second half of the 20th century, with the criticism of scientific triumphalism, the loss of hope in "health for all by the year 2000" and particularly the HIV epidemic, that we realised the limits of the coercive approach in public health and switched to an approach based on understanding.

The response to Ebola and Marburg VHF epidemics must involve coercion. It must be based on the application of coercive hygiene measures designed to break the chains of transmission, but only after a multi-disciplinary critical analysis of the proposed measures.

The response to Ebola and Marburg VHF epidemics must involve understanding and should:

- Ensure historic, cultural, linguistic and psychological understanding of the populations concerned;
- Be pragmatic and didactic, whether in dealings with opinion leaders or children, taking into account the specific characteristics of each region and working in line with local and national practices, know-how, customs, beliefs and religions;
- Involve the people concerned in all phases of operations that affect them;
- Combat – effectively and with full knowledge of the facts – those same "regional characteristics" when they contribute to the spread of the epidemic.

In a context in which urgency overshadows the individual and the measures imposed risk adding destitution to death, the prescribing doctor must constantly strive to ensure the validity, feasibility and implementation of his proposals: would they be acceptable if he were in the shoes of the patient, or if his nearest and dearest were under threat? An anthropologist or a clinical psychologist would recommend working on the social distance and ethnocentrism of both carers and patients.

The message must be conveyed that if individual and collective liberties are violated by the responses to Ebola and Marburg VHF epidemics, that is not an effect of exercising imperialistic medical power, but rather of carefully thought-out knowledge, which is constantly revalidated by critical and technical revisions, and adapted to each situation.

The informed consent of individuals and societies during such epidemics cannot be summarised as obtaining a hand-written signature at the bottom of a supposedly comprehensible, ethical and "legally sound" document. In fact, that is merely a bureaucratic act that arouses distrust, and is only carried out when taking biological samples. Moreover, in the societies in question, writing – like human fluid or tissue samples ante or post mortem – is often accused of being used for evil practices!

Rather than instruction manuals and guidelines (each of the institutions involved has its own "guide" or endeavours to draft one), measures adapted to each context must be devised for each situation to thoroughly manage coercive needs and mesological constraints relating to the specific indigenous, ecological, economic, political, cultural, psychological, historic and religious characteristics of the region.

In other words, the treatment of the living and the dead must be "humanised", with social mobilisation and awareness raising, i.e. treating people and not only bodies or infected cohorts. This is what must be done if we want to start obtaining real informed consent, from both individuals and entire populations, even if only by ad hoc and informal means.

Recommendations to promote understanding

To clarify these proposals for humanisation, we have prepared a few specific recommendations, both from the field and from multi-disciplinary workshops with those implementing the responses to epidemics (Brazzaville 2004, Paris 2004, Versoix 2005, Winnipeg 2006, Libreville 2008). They combine simple

recommendations based on plain good sense and functional medicine and other more sophisticated recommendations based on applied anthropology. Obviously, they are not exhaustive and must be used in conjunction with the recommendations of the current instruction manuals. Like these guidelines, they must not be applied dogmatically, but assessed in light of the specificities of the field and new scientific discoveries, then revalidated, supplemented, revised and updated in an ongoing process.

Recommendations concerning travel by response teams

- Drive slowly in vehicles with the windows open;
- Smile and greet people confidently, do not show your fear;
- Use local forms of greeting from a distance, a wave of the hand and/or bow of the head or upper body, with the thumbs raised, the hands together, clicking the fingers, etc.;
- Systematically take time to explain your actions at every step, encouraging those concerned to ask questions and express their thoughts;
- Try, as often as possible, to establish a direct dialogue with people expressing hostility;
- Discourage anonymous personnel dressed in personal protective clothing from driving in cars, as this may unnecessarily alarm the population and prompt reactions of fear or violence.

Recommendations concerning home treatment and aftercare of patients

- Encourage the putting on and taking off of personal protective clothing on the site where the action is carried out;
- Use field activities as an awareness-raising opportunity, with the handing out of illustrated documents and, where possible, the generous distribution of gloves;
- Systematically explain the actions to be carried out to the persons concerned, before commencing;
- Invite a member of the family to oversee the action, providing him or her with personal protective clothing;
- Obtain the consent of families before taking biological samples (blood, saliva, urine, or organs in the event of an autopsy);
- Use saliva or urine samples when blood samples create problems;
- Ensure that there is always a “monitor” for staff in personal protective clothing, positioned at the edge of the infected area, wearing civilian clothing, equipped

with gloves and a hand spray, to help staff get dressed, point out and rectify any hygiene mistakes and act as an intermediary between the team in uniform and any third parties (family, neighbours);
- Try to limit the number of contact persons for families;
- Constantly strive to prevent the accumulation of excessive protective layers or symbolic over-protection, obscuring the real health risks;
- Provide scrapers to thoroughly clean boots, and avoid merely rinsing soles superficially;
- Allow the treatment at home of suspects and/or sick patients who refuse hospitalisation, with the provision of personal protective materials and medicines, as a second resort to build trust with the patient and/or the patient's family;
- During disinfection, take into account local use of the habitat, such as the wiping of nasal discharge on posts, places that are often touched by dirty hands, etc.;
- Systematically advise exposed subjects to avoid attending gatherings (school, sports events, etc.), when such events are not forbidden;
- Give the patient or representative lab results in the form of a printed and signed document.

Recommendations concerning the isolation centre

- Remove opaque barriers and put up thorough, clear signs, demarcating areas reserved for staff and those potentially contaminated;
- Provide permanent night-time lighting in patient accommodation;
- Inform families of the condition of sick family members and the treatments carried out, on a very regular basis;
- Organise secure visits of relatives to sick family members;
- Authorise, under medical supervision, deliveries of food prepared at home;
- Include local flavours and foods in the meals and drinks given to patients;
- On a case-by-case basis, consider allowing the secure access of priests or traditional healers to hospitalised patients, at the express request of patients, but prohibiting intrarectal injections, scarification and the prescription of emetic and purgative products.

When treating patients suffering from VHF, the medical team must comply with the *Patient Care Charter*, namely:
- Quality of care must be a priority for care staff,
- Hospital staff must give patients and their families psychological support,
- The information given to patients and their families must be honest,

- Informed consent must be the rule for any intervention,
- Consent forms written in the national language must be the rule for specific research,
- Patients' beliefs and religions must be respected,
- Patient privacy must be protected,
- The medical team must give patients the chance to express their views on the way their cases are managed.

Recommendations concerning funeral rites

- Systematically offer your condolences to the family of the deceased;
- Inform the family in advance of the different phases of the operation;
- Do not prevent local forms of expression of grief, such as weeping and wailing, however loud and upsetting they may be;
- Supervise the putting on and taking off of personal protective clothing of the team on the site of the operation;
- Organise the presence, in personal protective clothing, of a member of the family, when placing the corpse in a (opaque) body bag and coffin;
- Handle corpses gently and without knocking them, showing due respect;
- If possible, avoid burials without a coffin and make provision to organise or pay for them;
- Systematically invite the families to place any personal belongings that the deceased "may need on the other side" in the body bag or coffin;
- At the home of the deceased, only burn contaminated objects that cannot be salvaged and have no value for close family: do this in a remote place of the plot designated by the family;
- Thoroughly disinfect contaminated objects that the family wishes to keep, even if they seem worthless to the response team;
- Ensure that the operation is performed by a single team, on a single occasion, including removal of the body, placing in the body bag and coffin and disinfection of the areas of the home (bedroom, toilet) likely to have been contaminated;
- Organise the carrying of the disinfected coffin, and burial by members of the family equipped with gloves, under the supervision of the sanitary teams in civilian clothing;
- Transport coffins to the cemetery in convoys, driving very slowly, with the hazard warning lights on and observing other local signs of mourning (such as bunches of palm leaves);
- Systematically ensure that members of the family are present during the burial;
- Provide the family with a vehicle with enough room to transport the coffin and

accompanying relatives to the cemetery;
- Take care with the positioning of the head of the corpse in the coffin, the transportation vehicle and the grave; where no coffin is used, arrange for the body bag to be carefully lowered into the grave, without dropping it, and ensuring that the corpse is positioned appropriately;
- Systematically arrange nameplates for graves;
- Systematically suggest that the participants wash their hands and feet using a spray containing appropriately diluted bleach after the different stages of the funeral (collection of the body, burial);
- If families express the wish to keep a photograph of the deceased or the ceremony to show absent friends or family that the funeral was carried out properly, offer to take a photo with a digital camera and give it to them promptly;
- Provide a death certificate, signed by a local authority.

Recommendations concerning social awareness-raising and mobilisation

- Compile relevant scientific articles and articles accessible to lay readers, guidelines and documents (pamphlets, photos, drawings, posters, video, audio) used during earlier epidemics on copiable CDs or DVDs (that can be read on a computer and/or DVD player);
- Make this "collection" available to the teams implementing responses to epidemics to assist with their (re)training and allow them to choose the materials that will be useful for their own social mobilisation and awareness-raising actions;
- Add to this collection, throughout the epidemic, with new media specific to the situation in question;
- Clearly identify the target groups and social actors (opinion leaders), taking care not to overlook women, marginal groups or illegal groups (medicine hawkers, poachers, gold washers, illegal aliens, etc.);
- Anticipate risks related to scapegoating, stigmatisation of survivors, people exposed to the disease and the families of the deceased;
- Rather than totally banning the consumption of game, which would be unrealistic, focus messages on the danger of touching and consuming animals found dead or sick: stress the need to be able to trace the origin of meat, from the forest to the village;
- Raise the awareness of hunters, particularly to the danger of animals found dead, which should not be perceived as "a divine gift", and the need to avoid animals that are sick and/or behaving strangely;
- Avoid blurring messages specific to VHF (contact with body fluids) by combining them with general public health messages (environmental health,

vector control);
- Stress the need to avoid contact with body fluids, especially in cases of fever, as the absence of airborne contamination;
- Systematically provide the families of the sick, exposed subjects and biomedical and traditional practitioners exposed to the sick with gloves;
- Where gloves and chlorinated water are not available, recommend the use of detergent, soap and plastic bags;
- Provide information about the risks of domestic accidents related to the presence of chlorinated water in the home;
- Raise the awareness of professionals and the population about the risks of infection linked to using old injection equipment and shared rectal bulb syringes;
- Produce and widely circulate health messages in the form of songs sung in local languages by popular local musicians, in addition to wide use of the usual media (leaflets, posters, meetings, radio discussions, TV adverts, etc.);
- Show ethnographic videos to health personnel and the general public, explaining the various actions of the response teams (treatment of the sick, funerals, testimonies, etc.).

Recommendations concerning awareness-raising among opinion leaders

- Carry out individual and collective awareness-raising and mobilisation actions by providing them with educational materials (paper, audio, video) and, where possible, gloves and bleach;
- Counter the often xenophobic ambivalence that aims to implicate “outsiders” in the introduction and spread of the epidemic;
- Skilfully manage or fight negationists and creationists on the issue of the existence of the virus, and promoters of “miracle cures” related to indigenous religions and sciences.

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