

# PLANNING FOR POST-EBOLA

LESSONS LEARNED FROM DR CONGO'S 9<sup>TH</sup> EPIDEMIC

## PART III | RECOVERY



## The author

Lys Alcayna-Stevens is a medical anthropologist with over six years of experience conducting qualitative research and analysis in the Equateur region of the Democratic Republic of Congo. She received her PhD from the University of Cambridge and has conducted post-doctoral research with the Institut Pasteur, the London School of Hygiene and Tropical Medicine, and Harvard University. Her current research focuses on social and economic life in the wake of the 2014-18 Ebola epidemics in DR Congo.

## Acknowledgements

The author would like to thank Jonathan Shadid (UNICEF), Juliet Bedford (Anthrologica), Sharon Abramowitz (Rutgers), Romain Duda (Institut Pasteur/ALIMA), Ingrid Gercama (Anthrologica), Tamara Giles-Vernick (Institut Pasteur) and Silke Oldenburg (Universität Basel), for their valuable comments on the manuscript draft, as well as Dosithee Kazamba Nakahosa (UNICEF) and Carine Libango for their assistance and advice in Equateur Province.

## Disclaimer

The opinions expressed are those of the author, and do not necessarily reflect those of UNICEF. Responsibility for the opinions expressed in this report rests solely with the author. Publication of this document does not imply endorsement by UNICEF of the opinions expressed.

Lys Alcayna-Stevens, 2018

Planning for Post-Ebola: Lessons learned from DR Congo's 9<sup>th</sup> epidemic  
New York: Communication for Development, UNICEF

*Cover photo © L Alcayna-Stevens 2018*

# CONTENTS

---

|  |           |
|--|-----------|
| Acronyms and abbreviations.....                | 4         |
| <b>Executive summary.....</b>                  | <b>5</b>  |
| Planning for Post-Ebola.....                   | 6         |
| Planning for Post-Ebola: Recovery.....         | 7         |
| <b>3.1 Economic impacts.....</b>               | <b>8</b>  |
| 3.1.1 Cost of living.....                      | 8         |
| 3.1.2 Food crisis.....                         | 8         |
| 3.1.3 Lost property.....                       | 9         |
| 3.1.4 Debt & funerary costs.....               | 9         |
| 3.1.5 Embezzlement & unfulfilled promises..... | 10        |
| <b>3.2 Health impacts.....</b>                 | <b>11</b> |
| 3.2.1 Post-Ebola Syndrome.....                 | 11        |
| 3.2.2 Mental health.....                       | 11        |
| 3.2.3 Sexual transmission of Ebola.....        | 11        |
| 3.2.4 Unregistered patients.....               | 12        |
| <b>3.3 Social impacts.....</b>                 | <b>13</b> |
| 3.3.1 Stigma.....                              | 13        |
| 3.3.2 Torn social fabric.....                  | 13        |
| <b>Bibliography.....</b>                       | <b>14</b> |

# ACRONYMS AND ABBREVIATIONS

---

|               |  |
|---------------|--|
| <b>AC</b>     | Community Animators ( <i>Animateur Communautaire</i> ) <sup>1</sup>                              |
| <b>ALIMA</b>  | Alliance for International Medical Action  |
| <b>ANVE</b>   | National Association of Ebola Vanquishers ( <i>Association National des Vainqueurs d’Ebola</i> ) |
| <b>APS</b>    | Psycho-social assistant ( <i>Assistant Psycho-social</i> )                                       |
| <b>AT</b>     | Territorial Administrator ( <i>Administrateur du Territoire</i> )                                |
| <b>CAC</b>    | Community outreach units ( <i>Cellule d’Animation Communautaire</i> )                            |
| <b>CBO</b>    | Community-based organization   |
| <b>CE</b>     | Community engagement   |
| <b>CODESA</b> | Local health committees ( <i>Comité de Développement de l’aire de Santé</i> )                    |
| <b>DPS</b>    | Provisional health division ( <i>Division Provinciale de Santé</i> )                             |
| <b>EP</b>     | Protective equipment ( <i>équipement protective</i> )  |
| <b>ETC</b>    | Ebola Treatment Center   |
| <b>EVD</b>    | Ebola Virus Disease  |
| <b>FPIC</b>   | Free prior and informed consent  |
| <b>INRB</b>   | National Institute of Biomedical Research ( <i>Institut National de Recherche Biomédicale</i> )  |
| <b>MPH</b>    | Ministry of Public Health  |
| <b>MCZ</b>    | Medical Inspector of the Health Zone ( <i>Médecin Chef de Zone</i> )                             |
| <b>MSF</b>    | Doctors Without Borders ( <i>Médecins Sans Frontières</i> )                                      |
| <b>PA</b>     | Indigenous people ( <i>Peuple Autochtone</i> )   |
| <b>PBF</b>    | Performance-based financing  |
| <b>PPE</b>    | Personal protective equipment  |
| <b>RCCE</b>   | Risk communication and community engagement  |
| <b>RECO</b>   | Community health workers ( <i>relais communautaire</i> )   |
| <b>SANRU</b>  | Rural Health Program ( <i>Projet Santé Rurale</i> )  |
| <b>SDB</b>    | Safe and dignified burial  |
| <b>UNDP</b>   | United Nations Development Programme   |
| <b>UNICEF</b> | United Nations Children’s Fund   |
| <b>USAID</b>  | United States Agency for International Development   |
| <b>WHO</b>    | World Health Organization  |
| <b>WFP</b>    | World Food Programme   |

---

<sup>1</sup> The original French terms are written in italics and in parentheses.

## EXECUTIVE SUMMARY

---

This report is for supervisors managing ongoing Ebola outbreaks, or working on preparedness and recovery activities in regions at risk of, or affected by, Ebola epidemics. It is based on rapid and intensive ethnographic field research in Equateur Province, Democratic Republic of Congo, undertaken less than a month after the epidemic was declared over in July 2018. The research comprised 60 separate open-ended, semi-structured interviews with local health workers, government officials and administrators, Ebola survivors and their families, community leaders, and national and international responders.

The overall finding of the report is that an Ebola epidemic, along with the way the response itself is conducted, can have significant social, psychological, economic, and health impacts for the communities involved. By providing a close, qualitative reportage on perceptions of the epidemic and the response in Equateur Province, the report aims to render tangible the social, political and economic dimensions of an Ebola epidemic and to offer recommendations for the response which prepare communities for life ‘post-Ebola’ at each stage of an intervention.

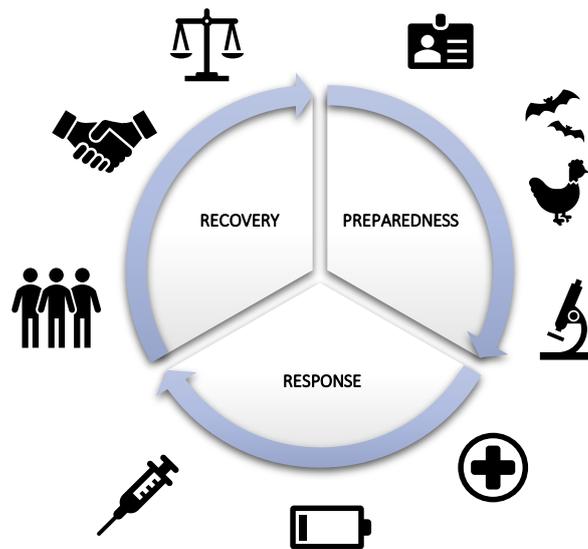
Epidemic management focuses on what needs to be done before, during and after an epidemic in order to minimize the health, social and economic impacts of the epidemic. This report, **Part Three: Recovery**, which provides information and recommendations on the economic, health (including mental health), and social repercussions of the epidemic and response. It is part of a series which examines each one of the temporal stages of an epidemic from the report ‘Planning for Post-Ebola’ (Alcayna-Stevens 2018). The other reports in the series are: **Part One: Preparedness**, provides information and recommendations on emergence, surveillance and health system capacity, vulnerable and marginalized populations, and the political and economic context of the 2018 Equateur outbreak; and **Part Two: Response**, which provides information and recommendations on transmission, risk communication, contact tracing, vaccine deployment, case management, and burials. An index can be found at the end of the report to locate cross-cutting themes covered in multiple sections.

The report provides recommendations relevant for supervisors working on risk communication, coordination, surveillance and contact tracing, infection prevention and control, case management, and safe & dignified burials (SDBs). Recommendations are divided into those that are operational (i.e. immediately applicable in the event of an outbreak) and those that are orientated toward long-term capacity building. Key recommendations are presented at the beginning of each section and are brought together in the overall conclusion.

The series proposes a **Grassroots Model for Epidemic Response**, based on four key principles: (1) **A ‘whole society’ approach** that attends not only to those individuals directly affected by the outbreak, but also to their broader communities; (2) **a commitment to inclusivity** appreciates that ‘communities’ are not homogenous, and prioritizes the engagement of marginalized and vulnerable populations; (3) **an attention to local stakes** that can help responders appreciate why Ebola epidemics are understood through the lens of broader issues such as politics, economics and religion; and finally, (4) **a commitment to utilizing pre-existing epidemic response capacity** in order to coordinate an effective response and ensures that interventions build on the social and cultural resources of the communities they seek to support.

# PLANNING FOR POST-EBOLA

Epidemic management focuses on what needs to be done before, during and after an epidemic. Each of the reports in this series examines one of these temporal stages. During 'preparedness', the focus is on reducing vulnerability to disaster and strengthening capacity, surveillance and early detection. 'Response' begins with a coordinated and rapid investigation, and then the implementation of appropriate control and case management, which is supported at each step and in every aspect by robust, clear and two-way communication. Finally, 'recovery' focuses on evaluation and accompanies affected communities in their lives 'post-Ebola.' Each stage should seek to minimise the health, social and economic impacts of the epidemic.

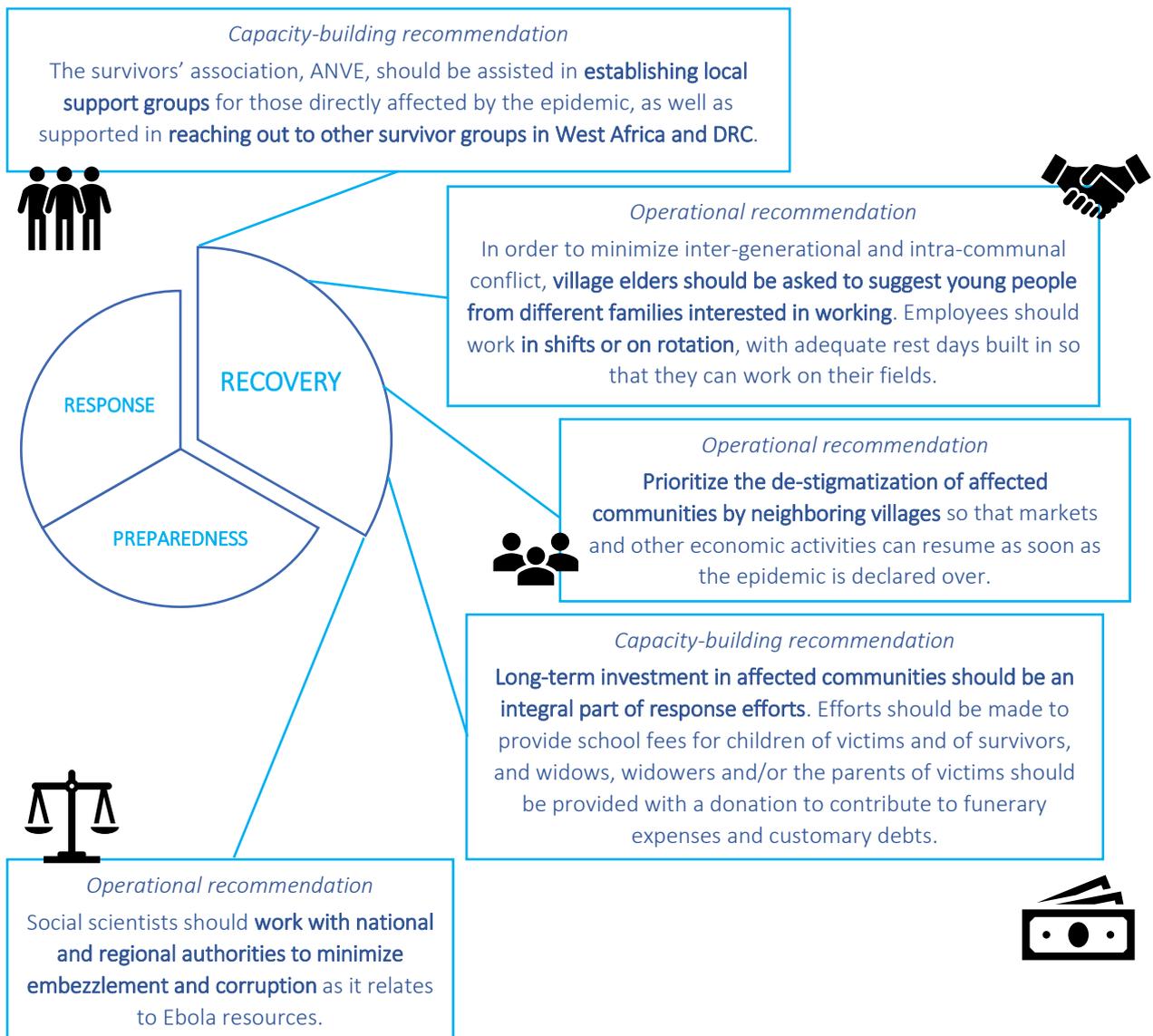


## GRASSROOTS MODEL FOR EPIDEMIC RESPONSE

-  (1) A **'WHOLE SOCIETY' APPROACH** attends not only to those individuals directly affected by the outbreak, but also to their broader communities.
-  (2) A **COMMITMENT TO INCLUSIVITY** appreciates that 'communities' are not homogenous and prioritizes the engagement of marginalized and vulnerable populations.
-  (3) **ATTENDING TO LOCAL PERSPECTIVES** can help responders appreciate why Ebola epidemics are understood through alternative lenses and broader issues, such as politics, economics and religion.
-  (4) **UTILIZING PRE-EXISTING EPIDEMIC RESPONSE CAPACITY** ensures that interventions build on the social and cultural resources of the communities they seek to support.

# PLANNING FOR POST-EBOLA: RECOVERY

For an Ebola outbreak to be officially declared over, two incubation periods (a total of 42 days) must pass without any confirmed cases. Traditionally, recovery efforts focus on governments driving the safe reactivation of essential health services and tackling pre-existing health system constraints that contributed to delayed detection and early spread of the virus. Immediate recovery efforts should lay the foundations for a stronger, more resilient health system, and thus feed back into preparedness. However, the research conducted in preparation for this report has suggested that recovery should be conceptualized beyond the improvement of health services and should encompass the broader psychosocial and economic impacts of the epidemic. This section of the report provides detail on the challenges with which communities and individuals affected by the 2018 Equateur outbreak continue to struggle, and to suggest an approach to Ebola epidemics which would plan for life 'post-Ebola' at each stage of the response.



## 3. RECOVERY

### 3.1 ECONOMIC IMPACTS

Response teams must consider from the outset the kinds of enduring impacts their presence could have on local economies. This section outlines the significant economic impacts that an Ebola epidemic has on survivors, their families, the families of victims, and broader communities. It also examines the unintended economic impacts that the Ebola response teams have on local economies and on the economic conditions of individual families.

#### 3.1.1 COST OF LIVING

Itipo village became one of the epicenters of the epidemic, and had, at one point, teams of over 200 national and international personnel. While much of their food and equipment was brought in by helicopter, the response teams nonetheless consumed some local goods, including domestic livestock, water (for washing) and products for sale at the market.

One of the most common complaints we heard against these response teams, was that they had increased the cost of living for ordinary people. As one man explained, with reference to the PA who Nkundo people employ to work in their fields:

*“We used to pay 1,000FC for a field, now we have to pay 2,000FC or more!”*

This increase in the cost of labor was due to the fact that workers were being paid up to 8,000FC for a day’s work (such as digging latrines or building fences) and had therefore begun to refuse the exploitatively low pay that they had received in the past for hard agricultural labor.

Others found work for the response washing clothes, fetching water, acting as security guards or building structures. All of these activities had an impact on local labor economies, just as the sale of domestic livestock at ‘foreigner prices’ (*ntalo ya mindele* in Lingala), impacted the market price of livestock.

The relatively sudden imbalances in wealth between those who had worked for the response and those who had not, also created a lot of resentment and bad feeling (*motema mabe* in Lingala) between neighbors and friends, and

within families. In some cases, the employment of young men, and their rapid acquisition of wealth, led to intergenerational conflict.

#### *Operational recommendations*

» **Social scientists should be deployed to conduct research with communities to determine potential impacts and conduct a rapid assessment based on a study of local economies and the labor and resources the response team will require**

» **Social scientists should also assess the impacts of privileging one generation over another in terms of employment. It may be beneficial to ask all village elders to suggest several young people from their own family who would be interested in working, so that certain families do not benefit more than others.**

#### 3.1.2 FOOD CRISIS

Several nurses, particularly in the smallest villages, who were very concerned about a looming food crisis. They spoke of an alarming rise in the number of malnourished children they were seeing. They attributed this to the following 6 factors:

(1) While working for the response, people had neglected work in their fields; (2) Survivors suffering from post-Ebola syndrome, and families decimated by the epidemic no longer had the labor-power necessary to work on their fields; (3) Contacts – as well as others in the community – had stayed away from their fields out of necessity (to stay isolated and not to travel), or fear, during the active outbreak; (4) Due to the effects of the response on the local economy, people were now unable to afford the (PA) agricultural labor they had previously relied upon; (5) Fear and stigma during and immediately after the epidemic meant

that, on the one hand, people were prevented from selling their agricultural or forest products in other villages, and on the other hand, traders no longer came to sell goods in their villages; (6) Fear surrounding bushmeat meant that children were no longer receiving an important source of protein, and were increasingly presenting to health centers with kwashiorkor.

Several members of the community expressed frustration and resentment that only directly-affected families had received food aid, and yet the food crisis would affect almost everyone.

#### *Operational recommendations*

» During the outbreak, labor should be divided in a predictable, rather than haphazard fashion, so that people do not waste the morning hours (when much agricultural labor is undertaken) waiting at the coordination office to see if they will be offered work. All employees and laborers should work in shifts or on rotation, with adequate rest days built in so that they can work on their fields.

» Communications teams should prioritize the de-stigmatization of affected communities in the surrounding region, so that markets and other economic activities can resume as soon as the epidemic is declared over.

» Response teams and their local partners should consider providing victims, survivors and contacts who were unable to undertake subsistence activities during the active phase of the epidemic with pest-resistant seeds of manioc, rice, soy, legumes and vegetables to kick-start their subsistence activities.

#### **3.1.3 LOST PROPERTY**

The first complaint of every affected family which participated in the research, was that response teams (Croix Rouge RDC) had burned items belonging to the patient or the deceased and had not replaced those items nor offered compensation. This has also been reported for previous epidemics.<sup>2</sup>

For the families involved, these were often valuable items, which were difficult to replace, or required monetary resources which they did not possess, such as beds and mattresses. One man explained to us that his mobile phone had been

destroyed when decontamination teams sprayed him and his possessions with chlorine.

Some people acknowledged that they had received small tokens of compensation, but the majority assured us that they had received no replacement or compensation for their loss. The experience was often a traumatic one which people felt augmented stigmatization.

The issue was even more complex in cases where families had, in fear and panic, destroyed or threw away other items, such as pots and pans, without instruction from response teams.

#### *Operational recommendation*

» It is important that communications teams address clearly which personal possessions run the risk of contaminating others (e.g. soiled mattresses), and which do not (e.g. metal pots and pans).

#### **3.1.4 DEBT AND FUNERARY COSTS**

When a man dies, his widow becomes responsible for the debts he had accrued while alive. These debts are often connected to the family's home (building a house out of durable materials such as bricks or a tin roof, adding doors, building beds or tables). Sometimes they are for purchases such as a radio or bicycle. In any case, they were always incurred by a family with the anticipation that the couple's combined labor would eventually result in the debt being paid off. When one person dies – and especially when this is the husband – the widow(er) finds themselves in a very difficult situation, often unable to pay off the debt.

Widow(er)s often have many children (sometimes up to 12). Not all of these are biological children, but they remain children for whom the couple was responsible. Caring for these children without the help of their spouse also becomes incredibly difficult, especially as older children's school fees become increasingly expensive. Several widows lamented that they no longer had the money to pay for children who were in their final year of school and who had been progressing well and had been hoping to pass their secondary school certificate that year.

These economic difficulties are compounded by the fact that funerals and funerary rituals are themselves very expensive. Families must pay for

---

<sup>2</sup> Epelboin et al (2008).

the coffin and burial, but they must also provide food, drink and housing for all of the extended family and friends who arrive to mourn the deceased. Often, the mourning period does not end until one final day of celebration and feasting is organized, meaning that bereaved families who cannot afford to organize a large feast, must continue feeding guests while they try to gather the resources necessary for the feast.

Other families explained that when they travelled to the ETC for treatment, or to be close to a sick relative, or during the extended mourning period, household items and domestic livestock had been destroyed, consumed or stolen by neighbors, in-laws and guests. On top of these costs, widow(er)s must typically pay a customary fine (called *nongo* in Lingala) to their in-laws when their spouse dies.

#### *Operational recommendations*

- » **Provide school fees for children of victims (orphans) and of survivors, often unable to work because of post-Ebola syndrome, for one year.**
- » **Provide widows, widowers and/or the parents of victims with a donation to contribute to funerary expenses and customary debts.**

### 3.1.5 EMBEZZLEMENT & UNFULFILLED PROMISES

Dozens of stories circulate in Equateur about the embezzlement of Ebola funds. Communities which were not directly affected by the outbreak say that the epidemic was fabricated in order to attract the funding of big international donors. Those who were directly affected lament the fact that they 'have not benefitted' while national and regional elites and international respondents have made thousands of dollars through their participation in the response.

Stories also circulated among both affected communities and international response teams that local administrative leaders have embezzled not only Ebola funds, but the material and equipment, such as motorbikes and electric generators, which (it is said) were intended for affected communities or rural hospitals and health centers.

Several of the RECO who participated in the research expressed anger that their names had not appeared on the lists of RECO who received a

'bonus' directly from the Minister of Health. Many pointed to corruption and nepotism on the part of their superiors.

While the finger of blame is sometimes pointed at specific individuals in positions of power, other people are not as sure about who is to blame for the fact that the most affected communities feel dispossessed. For many people, the differences between different international actors and NGOs are not clear. Oftentimes, they were grouped together, and (as perceived representatives of UNICEF) so were we, with many people asking us (*botiki bisu kaka boye?* In Lingala):

*“So, you are just going to leave us like this?”*

When people spoke of seeing 'no visible impact', they were referring to the vast displays of wealth they had witnessed with the logistics (cars, motorbikes, helicopters, airplanes, electric generators) of the response, and the fact that, despite still being in need (many thousands more people will die from malaria than Ebola in Equateur this year), they would no longer benefit from this when the response teams left. This led to protests when NGOs began to pull out their personnel and equipment to assist in Beni.

Part of the reason for this disappointment was a conviction that various actors – politicians, national and international responders, and local administrators – had promised to leave this equipment for affected communities, or build hospitals, health centers and maternity clinics.

Response teams should never make promises about the support which will follow an Ebola outbreak, unless they will be part of a program funded to undertake this – differences between humanitarian assistant and development work should be emphasized.

#### *Operational recommendations*

- » **Response teams should work with national and regional authorities to minimize embezzlement and corruption as it relates to Ebola resources.**

#### *Capacity-building recommendation*

- » **Long-term investment in affected communities should be an integral part of response efforts, at least for a one-year recovery period.**

## 3.2 HEALTH IMPACTS

This section outlines the impacts that EVD has on survivors' health, including their mental health and the psycho-social impacts of monitoring Ebola survivors for a lingering infection which could lead them to be contagious to others. It also considers the mental and physical health of EVD survivors who were never registered and feelings of exclusion and resentment towards the response.

### 3.2.1 POST-EBOLA SYNDROME

Until the West Africa crisis, post-Ebola syndrome was a rumored but little-studied after-effect of EVD. Symptoms include joint and muscle pain, eye problems, including blindness, various neurological problems, and other ailments.

Most of the survivors who participated in the research alluded to continuous ill health, physical pain and in some cases, neurological conditions such as confusion and forgetfulness, and mental health problems connected to trauma. Several people spoke of conditions (pain and weakness) so severe that they were still unable to work.

ALIMA is currently following all survivors in order to monitor this syndrome, and is also treating certain conditions, such as the eye problems. While an earlier report suggested that, towards the end of the epidemic (early July 2018), this monitoring was burdensome on survivors because it was extensive and almost daily,<sup>3</sup> during our interviews (September 2018), survivors had undergone some time without surveillance, and were eager for the check-ups and treatment to begin again. They were particularly concerned with finding treatment for their joint pain. Where these visits had caused them to feel some shame before, they were now welcomed as a continuation of care.

It is important to follow EVD survivors in order to determine the varied symptoms following EVD infection and to determine the best care. However, a delicate balance must be struck between continuing the care of EVD survivors and burdening their time with too many tests and check-ups.

### 3.2.2 MENTAL HEALTH

Mental health is a very important issue in rural Congo, even as it is almost completely neglected by national biomedical structures. Following an Ebola epidemic, mental health issues arise from

the trauma of the disease, from the trauma of losing family members, and from the social stigmatization experienced by many EVD survivors.

Mental health requires a 'whole of society' approach, and psychological support should be accompanied by communication which reduce stigma in the broader community.<sup>4</sup> Families of victims, especially widows and orphaned children, are also in need of continued psycho-social support. If resources permit, women should have the possibility of talking to female psychologists.

#### *Capacity-building recommendation*

» **After the epidemic, survivors should be supported by the creation of community support groups, which can be established in collaboration with ANVE.**

### 3.2.3 SEXUAL TRANSMISSION OF EBOLA

Viral traces of Ebola have been found to persist in semen, vaginal secretions and breastmilk after a patient recovers and no longer has any detectable virus in other bodily fluids.<sup>5</sup> In West Africa, there have been cases of the sexual transmission of Ebola, and of the transmission from mother to breastfeeding infant.

One important part of ALIMA's post-Ebola check-ups, is to monitor the virus in the body fluids of survivors. However, the possibility of remaining contagious is one of the sources of stigmatization against which survivors must struggle, and so the ALIMA teams must make sure that these investigations do not jeopardize the social standing of their patients.

There are also challenges in getting survivors to use condoms during sexual intercourse, as condoms are often associated with disease or with a socially unacceptable level of sexual promiscuity.

---

<sup>3</sup> Duda (2018).

<sup>4</sup> IASC (2008; 2015).

<sup>5</sup> Sissoko et al (2017).

EVD survivors have emphasized the need for those conducting tests on body fluids to be non-local staff, to assure that their confidentiality is protected. In order to minimize the stigma which could be attached to such tests, they should be conducted as part of a comprehensive check-up. Efforts should be made to minimize alarm in the community, while providing survivors with the information necessary to protect themselves and others.

#### *Operational recommendation*

**» In order to destigmatize the use of condoms and encourage EVD survivors to use them, village-wide regional campaigns should be undertaken to encourage their use.**

### 3.2.4 UNREGISTERED PATIENTS

Following the epidemic, some health actors have felt overwhelmed and frustrated by the number of unregistered patients who have subsequently claimed to have had Ebola.

Many of the health actors who participated in the research attributed this to the support EVD survivors and families of victims have received during and following the epidemic. They claim that those who may have had Ebola, but who fled

the response out of fear (and perhaps even some people who were sick but did not have Ebola) are now making claims so that they too may benefit from this support.

This is a challenging ethical question with no easy answer: What to do with those people who were sick, but were too afraid to collaborate with the Ebola response teams during the outbreak? Do they deserve the same level of care as other patients who passed through the ETCs? Or should they receive no care in order to encourage people to collaborate with the system if they wish to benefit from it?

This question becomes all the more pressing when one considers the EVD survivors and families of victims who were affected at the onset of the epidemic when the response had not yet arrived. As a family member of the first confirmed case of Ebola, in Ikoko Impenge village, told us, referring to international response team personnel:

*“We were the first to fall sick,  
and yet we have not benefitted  
from your presence.”*

## 3.3 SOCIAL IMPACTS

This section outlines the enduring social repercussions of the Ebola epidemic, and draws attention to organizations, such as the National Association of Ebola Vanquishers (ANVE), which can be collaborated with and supported in order to aid both survivors and their broader communities.

### 3.3.1 STIGMA

Stigma is multifaceted and has had an impact on many different people; from local healers or Batwa who were thought to be at the origin of the Ebola ‘curse’, to survivors, families of victims, and local health actors, who, in some cases, continue to be referred to as ‘contaminated.’

For the latter, this is often expressed through avoidance and rejection, with several health workers and survivors telling us that they have been unable to visit family members, who refuse to offer them food and housing. It is also experienced in the form of mockery and jeering.

People often fear direct contact, although they may also refuse to eat food cooked by a survivor, or to touch goods or money handled by a survivor. This fear may be particularly acute because of the ongoing follow-up exams, which seek to monitor the presence of the virus in survivors’ body fluids.

Many RECO and doctors have experienced a rejection by some members of society, initially because they were rumored to be collaborating with a project to infect people with Ebola for financial gain, and subsequently because of the large amounts of money they are said to have made by participating in the coordination.

On the other hand, some rural health actors have found themselves mocked for having lost so much money during the epidemic, and for being unable to afford their children’s school fees. *See also, 2.3.4: Free health care.*

Discrimination of survivors and the families of victims is ongoing and should continuously be addressed by the response, including in the months following the end of the epidemic.<sup>6</sup>

Celebrations organized when survivors leave ETCs, in which broader communities can participate, and are reassured that it is safe to interact with survivors, are an excellent way of reintegrating survivors.

#### *Capacity-building recommendations*

» Stigmatization of survivors can be minimized by donating sewing machines, bicycle repair kits to ANVE, so that survivors can play a more important role in the community.

» ANVE should be supported in the establishment of support groups for those directly affected by the epidemic, so that it can reach out to more isolated families and survivors, who do not live in proximity to its base in Itipo.

» ANVE should also be supported in reaching out to other survivor groups in West Africa, in creating a national network in DRC and in applying for funds for its own projects.

### 3.3.2 TORN SOCIAL FABRIC

Fear of contagion led many people to stop shaking hands, to distance themselves physically from others, to stop visiting others and to limit their attendance at funerals. This fear and lack of trust continues to erode relationships and to make people feel afraid and isolated.

Many people describe the epidemic as akin to ‘war’. They are referring to the chaos, the fear, the ways in which they had to mobilize all their resources in the fight to stop the disease, and in the losses they suffered.

Several people told us that their pain would be ease if a hospital, a maternity ward, a school, or another symbolic building could be constructed or refurbished in order to mark this momentous event and honor those whose lives were lost.

#### *Capacity-building recommendation*

» A ‘whole society’ approach should be used to develop plans with affected communities for appropriate memorialization of the epidemic, its victims and the sacrifices and losses of affected communities.

---

<sup>6</sup> ERAP (2014); Arwady et al (2014).

## BIBLIOGRAPHY

---

- Abramowitz, S., McKune, M., Fallah, J., Monger, K., Tehoungue and P. A. Omidian (2017). 'The Opposite of Denial: Social Learning at the Onset of the Ebola Emergency in Liberia.' *Journal of Health Communication* 22(sup1): 59-65.
- Abramowitz, S. A., K. E., McLean, S., L. McKune., Bardosh, K. L., M. Fallah, J., Monger, Tehoungue, K. and P. A. Omidian (2015). 'Community-Centered Responses to Ebola in Urban Liberia: The View from Below.' *Plos Neglected Tropical Diseases*, 9(4): e0003706.
- Alcayna-Stevens, L. (forthcoming) 'Epidemic economies'
- Alcayna-Stevens, L. & Giles-Vernick, T. (forthcoming) 'African epidemics and ecologies of blame'
- Alcayna-Stevens, L. & Bedford, J. (2018) 'Key Considerations: Burial, Funeral and Mourning Practices in Équateur Province, DRC' June 2018. Brighton and Oxford: Social Science for Humanitarian Action Platform.
- Anoko, J & Falero, F. (2018). Anthropologie de l'intervention : défis d'une riposte équitable pendant l'épidémie de la MVE en RDC. Brief note for EVD Response in Mbandaka-Bikoro.
- Arwady, M. A., E. L., Garcia, B., Wollor, L. G., Mabande, E. J., Reaves, J. M., Montgomery, C. (2014). Reintegration of Ebola Survivors into their Communities – Firestone District, Liberia, 2014. *Centers for Disease and Prevention MMWR. Morbidity and mortality weekly report* 63(50): 1207-1209.
- Bebell, L.M., Oduyebo, T. and Riley, L.E., (2017). Ebola virus disease and pregnancy: A review of the current knowledge of Ebola virus pathogenesis, maternal, and neonatal outcomes. *Birth defects research*, 109(5), pp.353-362.
- Bedford, J. (2018a). Key Considerations: The Context of North Kivu Province, DRC. Brighton and Oxford: Social Science for Humanitarian Action Platform.
- Bedford, J. (2018b). WhatsApp and Local Media (Grand Nord) – 9-18 September 2018. Brighton and Oxford: Social Science for Humanitarian Action Platform.
- Bedford, J. (2018c). Key Considerations: Health-Seeking Behaviours in Équateur Province, DRC. Brighton and Oxford: Social Science for Humanitarian Action Platform.
- Bedford, J. (2018d). Key Considerations: Burial, Funeral and Mourning Practices in Équateur Province, DRC June 2018. Brighton and Oxford: Social Science for Humanitarian Action Platform.
- Bonwitt, J. M., Dawson, M., Kandeh, R., Ansumana, F., Sahr, H., Brown and Kelly, A. H. (2018). 'Unintended Consequences of the "bushmeat ban" in West Africa during the 2013–2016 Ebola virus disease epidemic.' *Social Science & Medicine* 200: 166-173.
- Duda, R. (2018) 'Approche anthropologique de l'épidémie d'Ebola à Itipo, Province de l'Équateur, RDC : Rapport de mission.' Paris : ALIMA.
- Duda, R., L. Alcayna-Stevens and Bedford, J. (2018). Key Considerations: Engaging Twa Communities in Équateur Province. Brighton and Oxford: Social Science in Humanitarian Action Platform.
- Epelboin, A. and Formenty, P. (2011). Anthropologie sociale et culturelle et lutte contre les épidémies de fièvre Ebola et Marburg. *Les maladies infectieuses émergentes: état de la situation et perspectives*. Haut Conseil de la santé publique. Paris, LaDocumentation française.
- Epelboin A, Formenty P, Anoko J & Allarangar Y. 2008. Humanisations et consentements éclairés des personnes et des populations lors des réponses aux épidémies de FHV en Afrique centrale (2003-2008). In *Mesures de contrôle des infections et droits individuels : un dilemme éthique pour le personnel médical*. In *Humanitarian Stakes* N°1. September 2008. pp 25-37 [28-40]
- Epelboin, A., A. Odugleh-Kolev and Formenty, P. (2014). 'Contribution de l'anthropologie médicale à la lutte contre les épidémies de fièvres hémorragiques à virus Ebola et Marburg.' *Flambées épidémiques de maladie à virus Ebola et Marburg: préparation, alerte, lutte et évaluation*. OMS octobre.
- ERAP (2014). Stigma And Ebola: An Anthropological Approach to Understanding and Addressing Stigma Operationally in the Ebola Response. ERAP Policy briefing note 11/12/2014. Brighton: Ebola Response Anthropology Platform.

- Gillespie, A. M., Obregon, R., El Asawi, R., Richey, C., Manoncourt, E., Joshi, K., Naqvi, S., Pouye, A., Safi, N., Chitnis, K. and Quereshi, S. (2016). 'Social Mobilization and Community Engagement Central to the Ebola Response in West Africa: Lessons for Future Public Health Emergencies.' *Global Health: Science and Practice* 4.4: 626-646.
- Hewlett, B. S. (2016). 'Evolutionary Cultural Anthropology: Containing Ebola Outbreaks and Explaining Hunter-Gatherer Childhoods.' *Current Anthropology*, 57(S13): S27-S37.
- Hewlett, B. S. and Amola, R. P. (2003). 'Cultural Contexts of Ebola in Northern Uganda.' *Emerging Infectious Diseases* 9.10: 1242-1248.
- Hewlett, B. S. and Hewlett, B. L. (2008). *Ebola, Culture, And Politics : The Anthropology Of An Emerging Disease*. Belmont, Calif: Thomson.
- Hulstaert, G. 1961. *Les Mongo: aperçu général*. Tervuren: Musée royal de l'Afrique Centrale. *Archives d'ethnographie*, 5. P.66.
- IASC (2008). *Guidelines on Mental Health and Psychosocial Support in Emergency settings*.  
[https://interagencystandingcommittee.org/system/files/legacy\\_files/Checklist%20for%20field%20use%20IASC%20MHPSS.pdf](https://interagencystandingcommittee.org/system/files/legacy_files/Checklist%20for%20field%20use%20IASC%20MHPSS.pdf)
- IASC (2015). *Mental Health and Psychosocial Support in Ebola Virus Disease Outbreaks. A Guide for Public Health Programme Planners*.  
[http://www.who.int/mental\\_health/emergencies/ebola\\_programme\\_planners/en/](http://www.who.int/mental_health/emergencies/ebola_programme_planners/en/)
- Kemba, B. (2018). *Implication de l'Association de Taximotos de Mbandaka, « ATAMBA »/Equateur-RDC. Dans la riposte contre Ebola : Sensibilisation (Note de Briefing)*
- Leroy, E.M., Epelboin, A., Mondonge, V., Pourrut, X., Gonzalez, J.P., Muyembe-Tamfum, J.J. and Formenty, P., (2009.) *Human Ebola outbreak resulting from direct exposure to fruit bats in Luebo, Democratic Republic of Congo, 2007. Vector-borne and zoonotic diseases*, 9(6), pp.723-728.
- Menéndez, C., Lucas, A., Munguambe, K., and Langer, A. (2015). 'Ebola Crisis: The Unequal Impact on Women and Children's Health.' *The Lancet Global Health*, 3.3: e130.
- Oldenburg, S. (2018). *Engagement de la jeunesse dans la riposte d'Ebola. Nord Kivu. UNICEF*.
- Pagezy, H. 1975. *Les interrelations homme-faune de la forêt du Zaïre*. In *L'Homme et l'Animal*, 1er colloque d'Ethnozoologie, juin 1975. Paris, Inst. Int. Ethnoscience : 63-88.
- Richards, P. (2016). 'Ebola: How A People's Science Helped End An Epidemic.'
- Richards, P., Amara, J., Ferme, M. C., Kamara, P., Mokuwa, E., Sheriff, A. I., Suluku, R. and Voors, M. (2015). 'Social Pathways for Ebola Virus Disease in Rural Sierra Leone, and Some Implications for Containment.' *PLoS Neglected Tropical Diseases* 9.4: e0003567.
- Ripoll, S. Gercama, I. Jones, T. Wilkinson, A. (2018). *Social Science in Epidemics: Ebola Virus Disease lessons learned*. Brighton and Oxford: Social Science for Humanitarian Action Platform.
- Samndong, R. A. (2016). 'Institutional Choice and Fragmented Citizenship in Forestry and Development Interventions in Bikoro Territory of the Democratic Republic of Congo.' *Forum for Development Studies* 43.2: 251-279.
- Sulzmann, E. 1986. *Batwa und Baoto, die Symbiose von Wildbeutern und Pflanzern bei den Ekonda und Bolia (Zaïre)*. *Sprache und Geschichte in Afrika* 7(1): 369-389.
- Unicef (2015). *UNICEF Annual Report 2015: Democratic Republic of Congo*
- Vansina, J. (1965). *Introduction à l'ethnographie du Congo, Bruxelles/Kinsangani. Kinshasa. Lubumbashi*
- WHO (2015). *Maternal mortality in 1990-2015: Democratic Republic of the Congo*. WHO, UNICEF, UNFPA, World Bank Group, and United Nations Population Division Maternal Mortality Estimation Inter-Agency Group
- World Bank (2017). *Mortality rate, infant (per 1,000 live births): Estimates developed by the UN Inter-agency Group for Child Mortality Estimation ( UNICEF, WHO, World Bank, UN DESA Population Division )*
- Yong, E. (2018) 'Most maps of the new Ebola outbreak are wrong.' Retrieved 1/31/18:  
<https://www.theatlantic.com/health/archive/2018/05/most-maps-of-the-new-ebola-outbreak-are-wrong/560777/>