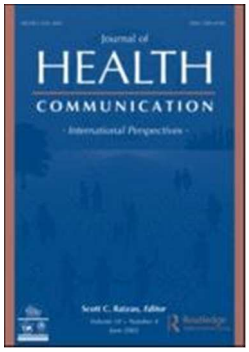

Securing exposed communities and fighting reluctances during Ebola outbreaks. Development of a community-based prevention, control and surveillance methodology: The case of Action Against Hunger in the Republic of Guinea

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Abstract

"In December 2013, a case of Ebola was recorded for the first time in the Republic of Guinea. By May 2015 the epidemic had accounted for 3,652 cases in the country, including 2,429 deaths. In 2014 Action Against Hunger (ACF) set to work on awareness and social mobilization, but two elements were identified by the team as major difficulties affecting the effectiveness of these activities. First, the spread of reluctances among the population with regards to the implementation of prevention and control measures in communities living in areas affected by the disease and second, the lack of appropriate targeting when choosing beneficiaries. Following a field study carried out by ACF, a methodology was developed, on the one hand, for identifying and working with the most exposed populations and, on the other, for working on a trust-building framework to help reduce reluctances by implementing community-based plans to prevent and control the disease."

Introduction

In December 2013, a case of Ebola appeared in the small village of Meliandou in the Republic of Guinea. From that moment on, the outbreak extended into three countries - Liberia and Sierra Leone, along with Guinea – and became an epidemic. In June 2015 nearly 30,000 people were affected with more than 11,000 deaths, 2,429 of them in Guinea itself[i].

By the end of 2014 two elements were identified by the Action Against Hunger (ACF) team as major difficulties affecting the effectiveness of the prevention and control mobilization strategy deployed by the NGO into endangered communities in the field.

These elements were:

- The spreading of forms of passive and active resistance by the population to the implementation of prevention and control measures in communities living in areas affected by the disease.
- A lack of appropriate criteria in determining the endangered communities targeted with awareness-raising and social mobilization activities.

The ACF team consequently identified the need to develop a methodology to identify the populations most exposed to the disease in order to work with them on social mobilization, with reluctances of all kinds contained or eliminated if possible.

Literature Review

Managing Ebola outbreaks is quite complex and goes well beyond strictly medical issues. Standard measures used to fight this kind of disease may enter into conflict with some of the fundamental rights of the people affected by these measures (WHO 2014)[ii]. It must also be remembered, "There is no vaccine or specific treatment against the virus, but drastic health measures that affect individual and collective freedoms" (Epelboin 2008).

To get an idea of what these measures entail in terms of human rights[iii] it is necessary to remember that the WHO recommends remaining vigilant, to ensure that implementing these measures do not come into conflict with the Syracuse Principles when in the field[iv].

Putting such measures into practice is complex. Apart from discussions regarding when the measures are necessary from a medical point of view, on the ground they are confronted with what is often called "reluctance". In other words, acts of resistance (whether active or passive) that involve non-observance of the measures and sometimes acts of violence against medical and humanitarian personnel and facilities. The reason behind such “reluctances” may come from their repressive character[v].

Although acts of reluctance had been recorded in almost all Ebola outbreaks (Epelboin, Hewlett BS, Hewlett BL.) Guinea is reported as having been especially affected by this problem[vi]. One reason for the higher presence of acts of reluctant in Guinea may be the nature of the response, which has been highly centralized. In other words, people simply do not trust the motives of the individuals and organizations responsible for prescribing said measures.

Building the necessary trust between the people affected by these measures and those responsible for their prescription and management therefore becomes a key element, with the decentralizing of managing the response to communities identified as a relevant factor

in the trust-building process. In fact, some experiments linking success in controlling the epidemic, decentralizing the response and community mobilization have been recorded[vii].

Anthropology's Role in the Fight against Ebola

Hewlett BS, Hewlett BL (2007) draft a list of 12 points anthropologists can contribute to multidisciplinary teams deployed on the ground in response to an Ebola outbreak. These 12 points are arranged in a 4-stage sequence (preparedness, early acute stage, duration of acute stage, final phases). If we look more closely, these points focus on documentation efforts (1-4), the building of trust at community level (5-8), supporting field teams in the interpretation of the local reality (9-10) and the study of the outbreak's impact on the affected communities (11-12).

In other words, "anthropology improves the knowledge of the transmission chains of the disease, to better understand the behavior of populations and find ways to humanize humanitarian intervention" (Epelboin 2014). Said humanization implies, above all, answering the question of "What can be done to build trust?" (Epelboin 2008).

It was shown above that lack of confidence may be at the root of the reluctance phenomenon. Among the actions undertaken by different actors in the field, there are some that can contribute to generating the appropriate conditions for fighting an outbreak, while some cannot and even contribute to an increase in reluctance. To identify these elements Fred Dunn (Dunn F 1985) developed a tool to incorporate anthropological research into the control of epidemics. This tool suggests there are four categories, each one consisting of cultural factors to be considered. They are:

1) factors within the community that help control the epidemic and improve the general health situation;

2) factors within the community that do not contribute to controlling the epidemic and improving the general health situation;

3) factors from outside a community that help control the epidemic and improve the general health situation; and

4) factors from outside a community that do not help control the epidemic and improve the general health situation.

This approach identifies a number of elements that can subsequently be integrated into the efforts on the ground to counter an epidemic. It also suggests that not all local specificities are in fact difficulties that need solving, with some specific cultural aspects possibly helping to fight the disease. There may also be cultural elements outside the community that may hinder or complicate the effectiveness of epidemic control measures. Among other things, this approach was used for the deployment of WHO response to Ebola outbreaks in Uganda (2000) and the Congo (2003) with some success (Hewlett BS, Hewlett BL 2007. Epelboin, Alain. Hewlett, B S. Hewlett, A B L. & Formenty 2005).

Methodology

The purpose of this article is to provide a response to the need for a methodology for working with the most endangered populations through social mobilization while also managing to reduce the reluctance of the population in both its active and passive forms. To do this, two key questions were asked.

- Who and where are the most exposed populations?

- Why is there resistance to or reluctance regarding the presence of local and international teams and the establishment of measures to prevent and control the disease?

To answer these questions, in-depth analysis was required of the nature of humanitarian intervention in an Ebola outbreak and the contribution of an organization like ACF. To do this, we used a 3-stage methodology:

Analysis of Transmission Chains

We performed the analysis of a set of data including all Ebola cases registered in the Boffa prefecture #from the end of 2014 to April 2015. This set included at least three chains and 37 cases[viii]. The analysis of these chains and the comparison of the results with those of similar research led us to identify the most exposed populations and extract a proposal of who should be the target of ACF's social mobilization strategy in order to have an impact on breaking the chains of transmission.

Participant Observation in the Response Team

The researcher became part of the ACF field team, participating in almost all decision-making spaces and field deployed teams. Using several different anthropological field tools, including an academic literature review, participant observation and semi-structured interviews, the goal was to accurately identify the most appropriate role that an organization like ACF should/could play in humanitarian deployment, bearing in mind ACF's areas of expertise.

Categorizing the Problem and Proposing an Intervention Methodology

All the data collected was placed in a suitable variation of the Dunn analysis scheme. From this diagram we developed an intervention methodology addressing all the identified issues and which takes into account the recommendations of the research teams in the field as well as other experiences identified during the literature review.

Findings

Analysis of Transmission Chains

By analyzing transmission chains in the Boffa prefecture, some interesting patterns can be identified. With the data available at the time of completion of the study, which covered 37 confirmed cases distributed in three different chains of transmission (or three cases not linked to any known chain)[ix], we find that:

- The vast majority of transmissions occurred through family ties (Figure 1). Thus, at least 70% of transmissions occur between people with family ties, compared to 16% between people who are not related. In 14% of cases there was no data on whether the cases were related or not. This finding was consistent with a study of 196 confirmed and probable cases from all of Guinea conducted between February and August 2014 (Faye, Ousmane 2015) where cases among relations amounted to 105 (72 %). This study concluded also that "82% (119 of 155) of transmission occurred in the community and 72% (105) between family members".

- Although community funerals and hospital care are privileged spaces of transmission to be taken into account, these are secondary spaces. The most dangerous area remains the

community and within the community, domestic spaces and, especially, family. In the aforementioned study (Faye, Ousmane 2015), 84% of cases had been exposed at least once within the community and at least 82% of cases had a reliable origin in the community. According to this study the proportion of cases from hospital contact is highly variable and could be due to poor hospital praxis, which is localized but has very serious consequences. From a simulation based on the testimony of 60 people who explained the way they contracted the disease, Hewlett BS, Hewlett BL (2007) presented percentages that go in the same direction. In their simulation, 60% of cases are related to intra-community transmission, 32% to funerals and 8% to hospital transmissions[x].

- The transmission channels are narrow. Thus, in Boffa's transmission chains each patient transmits the disease to 1.6 individuals. Faye (Faye, Ousmane 2015) states that for the areas analysed the overall transmission rate was 1.7 in March 2014. But what is more interesting is that, in their case at least, 1.0 of the overall rate of transmission corresponds to intra-community transmissions, 0.4 to hospital transmissions and 0.3 to transmissions through community funerals. Faye and her colleagues reported that since April 2014, cases of transmissions due to infected health workers fell to 0 and the same happens for the cases of patients admitted to hospital, whose possibilities of infecting someone else also fell to zero. What emerges from these data is that with intra-community transmission rates stable at 1.0, a transmission chain should be very responsive to awareness, as one success in not transmitting the disease could be enough to break the chain.

- Transmissions taking place within the family predominantly involve brothers to/from sisters (31%), father-mother to/from son-daughter (39%) and husband to/from wife (12%) (Figure 2). In other words, between people with very close family ties. This may indicate that the location of transmission is the inner domestic space.

- Women are affected far more than men. In Boffa, 56% of those affected were women and 44% were men. This is understandable if we consider that we identified the home and domestic space as the most privileged transmission space and also bearing in mind that women are responsible for the bulk of activities related to caring for the sick. This is further confirmed if we analyse the age group ranging from 10 to 60 years (when women are active caregivers) and find that the percentage of women affected by the disease is 69% compared

to only 31% of men. In figure 3, which shows the Boffa data set grouped by sex and by age, it can be seen that the number of men affected by the disease does not vary significantly between any of the age groups, while the variability between females is very high and reaches its peak in the age groups ranging from 20 to 59 years, where the number of women are directly twice that of men.

From this analysis of transmission chains, we can extract the following elements:

- The main transmission space for the disease is within families and within the community. Transmission at funerals and through health system errors, although significant, may be classed as secondary, isolated and highly variable.

- Focusing awareness on these two communities (family and community) could have a real impact on transmission lines, especially if we consider that the rate of transmission between individuals is not very high. Just one "successful" awareness action that leads to a transmission not occurring can cause a chain extinction, if the intra-community transmission rate is 1.0 and if secondary channels do not intervene.

The key question raised in light of this is how we can identify the families and communities who will be affected by and are at risk of the disease.

As a result of the standard procedure applied by the WHO and national health systems in an Ebola outbreak (WHO 2014), many of the people who became sick were previously registered as “contacts” of other victims before developing the disease themselves[xi].

The contacts, if they contract the disease, start to become symptomatic and infectious within an average of 11 days after they have been exposed[xii]. This gives awareness teams a margin of time between the contacts being registered and the disease developing and this small but crucial time gap can be used to work on awareness with them and their families.

Given the vast majority of transmissions take place within the community, the families and communities of those who become symptomatic but who were never registered as contacts could be indirectly identified and targeted using awareness efforts. There is, therefore, a good chance that unidentified contacts live in communities where there are other contacts who themselves have been registered, which means the whole community should come into contact with any awareness efforts undertaken.

Participant Observation in the Response Team

The researcher was embedded with the ACF teams in the field for a period of seven weeks between March 16, 2015 and May 9, 2015. These teams covered two Guinean prefectures (Boffa and Forecariah) and two communes of the capital Conakry (Ratoma and Matoto), both affected by the disease. Observation work during this period included a mission to evaluate all health system centers in Boffa prefecture, a contact tracing mission conducted by WHO personnel in Boffa, some contact relief missions conducted by ACF personnel in Forecariah (2) and Conakry (1), a health worker training mission in control and prevention of infectious diseases, and some coordination meetings at every level of the humanitarian response system (national, regional, sectorial) at a rate of one meeting per day. At the same time, the researcher conducted a set of 5 workshop sessions with ACF awareness and community mobilization teams in Conakry (3) and Forécariah (2), where the participants were asked to explain their impressions of and experiences regarding the disease or the humanitarian response. Finally, we conducted a set of semi-structured interviews with a set of 5 contacts who were being assisted by WHO and ACF teams.

Some significant elements where observed and retained from the participant observation experience as a whole. If every element is put into the logical framework created by Dunn, it should appear as follows:

1) Factors within the community that contribute to controlling the epidemic and improving the general health situation.

- Community Agents (CA). The CAs are community health system auxiliaries that contribute as volunteers to controlling epidemics (not just during the Ebola outbreak). They are the basis of the contact monitoring system.
- Presence of community decision-making structures that are legitimized and respected. The communities are structured around a network of elders and community leaders. One of the pillars of this structure is usually the mosque.

2) Factors within the community that do not contribute to controlling the epidemic and improving the general health situation.

- Predisposition to breaching basic hygiene measures during care-giving activities. Ebola's transmission pattern reflects an enormous tension between what people are asked to do when taking care of a patient and what families feel they must do. Sometimes families choose to risk and expose themselves rather than exposing the family to stigmatization.
- General mistrust of all state actors. This lack of trust includes anything from outside the community and, particularly, anything coming from the state. This has its roots in a rather tragic ethnic and historical context following a colonial and post-colonial history in which the state has always been seen as an external and rather hostile or even dangerous element.
- Distrust of the health system. People have deserted health centers because they are perceived as death providers rather than health providers or as a focal point for disease transmission[xiii]. Some diseases usually treated at health centers are currently either treated at home or into the community by traditional healers.

3) Factors from outside the community that help control the epidemic and improve the general health situation.

- Mobilization of resources. Although at first the health system was overwhelmed it is now being trained and receiving supplies. This should result in an immediate improvement in its capabilities.
- Closeness of supervisors to communities. The physicians responsible for monitoring the CA have a direct relationship with communities. They have strong local knowledge and are a significant asset in negotiating with communities and building trust between response teams and communities.

4) Factors from outside the community that do not contribute to controlling the epidemic and improving the general health situation.

- Centralization and the authoritarian character of the response system. Community representatives (CA and supervisors) actually play a very limited role in what is happening on the ground. The actions are organized at a national level (patient mop-ups, awareness campaigns and social mobilization) and do not take into account the

specific needs of each community. This erodes their legitimacy as the representatives of local supervisors, with a limited role in any decision making.

- Excess resources. Monetization of health workers and the response system in general. The fact that tasks that until now were carried out on a volunteer basis have now become paid work risks jeopardizing their long-term sustainability and even their effectiveness on the ground. This is both the case of CAs and watch committees (CVCO). The latter, usually responsible for community vigilance and awareness, have become a common example of what has been called "Ebola Business". Their organizational model, based on a number of people chosen by the head of the village (7), who will be paid by international actors but with no monitoring of their activities or effectiveness, has been highly inefficient and discourages the emergence of unpaid forms of community involvement and engagement.

During the observation of ACF activities in the field, other significant factors were identified:

1. ACF does not systematically target the most exposed individuals during awareness actions. The beneficiaries of community awareness activities were selected either on criteria based on the fight against other diseases, for example cholera, or were chosen at random.

2. ACF closely followed the contacts registered by contact tracing efforts. These contacts were the target of a systematic distribution of food kits by ACF teams in the days following their registration. Furthermore, ACF provided financial support to maintain CA networks in communities where contacts were registered.

3. ACF would be able to deploy awareness actions targeting communities classified as "at risk" in the analysis of transmission chains. The presence of ACF food distribution teams on the ground in the days following the registration of contacts placed the organization in a privileged position with regards to deploying awareness actions to families and communities in which contacts had been registered in the 11 days following their exposure to the disease.

Categorizing the Problem and Proposing a Methodology

In view of the elements identified above and on the basis of the data obtained during ACF's team workshops, we began to develop an intervention methodology which, using the contacts tracing system, could lead to a set of awareness actions among the people at risk. These actions would take the specifics of Ebola outbreaks into account while helping with social mobilization to encourage the public to observe the coercive measures required to control the epidemic.

Some elements emerged from the academic literature review:

- Measures, especially coercive measures, must be prescribed and managed by actors legitimized by the community. These actors should be the communities themselves or local leaders. The introduction of such measures using the wrong approach, using actors the public does not trust, could be the root of reluctances or even violence.

- There are certain limitations in terms of the approaches that seek to involve communities in response management. These approaches, in some cases, could lead to an erosion of basic rights (see marginalization), especially among certain categories of the population, including women, and a militarization of communities (Alan Abramowitch 2014)[xiv].

It was therefore necessary to draw a methodology to:

1. Target at-risk populations (family and community contacts) for awareness actions,

2. Act within the required time, minimizing the risks of new transmissions (if possible within the first 10 days after a contact is registered within a community),

3. Use contact registration as a trigger, and

4. Consider the community as a key player that provides the required legitimacy for coercive measures to be implemented.

Based on these elements, we developed and proposed a two-stage methodology that would normally match all the required conditions[xv].

Through a set of four field actions, all those at risk and previously identified (contact-family-community) are progressively reached during the two stages. The stages are separate and self-sufficient and can be deployed separately if necessary. The internal logic of the methodology can be observed in Figure 4.

Stage 1: The Safety Belt

First, the proposed methodology affects the contacts and their families. As shown above, this intimate circle is most exposed to the disease, representing approximately 70% of total transmissions. Through the actions included in the safety belt, awareness teams would seek to (1) reduce the risk of transmission within the family during the first manifestations of the disease; (2) encourage the handover of care activities to health services by the patient and their family; (3) speed up the introduction of the infected individual into a health structure[xvi].

This phase is based on establishing a humanized relationship between awareness teams and targeted individuals[xvii]. The creation of such a climate of trust will then provide awareness teams with gradual access to a larger target group of households and families.

This methodology leads to awareness teams visiting the community at least twice, within 48 hours and within five days from when a contact is registered. The first of these visits should target the contact and should be focused on nutritional aspects relating to the nutrition kits delivered to every contact through the contact tracing system. The second visit would seek family contact and include the distribution of hygiene kits to all the domestic units that make up the family and related contacts.[xviii]

Specific techniques for the second meeting were developed by the field team in workshops. The techniques focused on making visible care connections through networks, so every person in every household was able to spot individuals at risk of getting sick if precautions weren't taken. Awareness teams employed these techniques in order to humanize the disease and narrow the gap between medical discourse and the everyday perception of the disease by the population.

Phase 2: The Community Plan (CP)

The implementation of a Community Plan within communities seeks to create Ebola management systems in all communities that live in a "hot zone" and/or have contacts that are being monitored. The aim of the CP methodology is to allow each community to implement WHO-recommended standard protection and control measures internally. The Community Plan works under the principle of decentralizing the prescription and management of control and prevention measures in order to gain legitimacy.

The result of implementing a Community Plan (CP) in exposed communities should be to minimize the possibility of transmissions within the community during the first phase of the disease, when patients have yet to be taken by health workers. The deployment of a CP is expected to extend the measures initiated with the safety belt to the whole community - where data shows 82-83% of transmissions take place - and complement these measures, which are focused on hygiene in the household, along with other measures concerning community security, patient transport, temporary isolation, destigmatization and community surveillance, among others.

The methodology of the community plan is based on a Community-Led Total Sanitation (CLTS)[xix] approach but with some new elements.

On the one hand, CLTS is based on a behavioral approach. Beyond ethical considerations on the rather coercive nature of CLTS techniques[xx], Ebola scenarios could be judged to be inappropriate or even dangerous, if such shock-based techniques were applied to communities already experiencing a situation of emotional shock.

While CLTS triggering techniques are designed to produce a shock within communities, CP triggering is done without using techniques which appeal to such behavioral or emotional aspects. The methodology is based exclusively on the visualization of the most common ways Ebola is transmitted, in order to get the community to discuss and rethink what can be done to prevent transmissions from occurring. The aim is to build a community response based on reflection and community consensus rather than individual emotions.

This would require specific visualization tools. Once the objective of the triggering session has been precisely laid out (to visualize ways in which Ebola is transmitted, leading to the community's commitment to implementing specific measures), we require an alternative

technique for triggering said target to the techniques used by CLTS, which is designed to visualize the way water-related diseases are transmitted by exploiting the emotional aspects of the notion of dirt and equalizing “dirt” to “contamination”.

From workshops carried out with the team, we managed to propose a visualization technique focusing on the community's daily reports of the disease. This technique requires the awareness team to carry out three specific situations (touching potentially ill individuals, caring for a potentially ill individual and transporting a potentially ill individual). These situations are dramatized by using a net full of coal in the sick person's place. As none of these actions can be done without the team getting dirty from coal dust, the awareness team connects coal dust to the Ebola virus and getting dirt from coal dust to Ebola transmission. During the dramatization, members of the community are involved by managing a roulette showing the three previously announced situations. This implies community is not just listening in a passive way but is also involved and leading the awareness team's action.

During the dramatization, the awareness team introduces the community to some commitments to be made. Everything is based on a table of commitments that links the three situations with a list of 11 commitments that correspond the measures that, in an ideal situation, the community should implement based on standard practices in Ebola control and prevention. Each community should be able to choose some of the commitments on their own and by taking into account their own situation[xxi].

Once the community has accepted a number of commitments, the people in charge of implementing these commitments emerges from the community. In a second working session, these people should be trained on successfully implementing and managing the commitments engaged by the community. A follow-up framework is established with the community with at least three more visits on the seventh, fourteenth and thirtieth days after triggering (Figure 5).

Discussion of Results

At the end of the field work, the degree of deployment of the proposed methodology was still very limited. In all, Safety Belt activities had been deployed in one prefecture (Forecariah) and two communes of Conakry (Ratoma and Matoto). Meanwhile, the team

had just launched the first Community Plans in Forecariah prefecture as part of a pilot project which was to last four months and was to include a set of 24 communities. In the meantime, three interesting elements emerged from the initial experiences.

Coordination of Awareness Activities with Overall Outbreak Response Activities

The proposed methodology assumes that the NGO carrying out awareness activities has a mandate to conduct awareness activities in the communities affected by the disease from the national health authorities and that their activities are closely coordinated with the rest of the actors on the field. In our case the NGO was also in charge of some other key tasks, including:

Managing the network of community agents (CA) responsible for monitoring the contacts tracing system at an economic and organizational level.

A mandate to distribute food kits to every contact registered in the contact tracing system or at least to monitor the distribution of food kits by other organizations.

If these two elements were not acquired by the NGO, deploying the methodology would require strong coordination with the organizations responsible for implementing these tasks.

Impact of the Methodology: Indicators

It is likely that the most useful figure to examine would be the decrease in the patient transmission rate in each community. As we have seen, the average disease transmission rate stands at around 1.6 and 1.4 transmissions per patient and 1.0 related to intra-community transmissions. Taking into account that the target of this methodology is to reduce intra-community transmissions, if average rates fell significantly below the observed rates in targeted communities, some awareness success could be established. This is applicable only in communities with confirmed Ebola cases.

The Use of the Proposed Methodology in Post-outbreak and Pre-outbreak Contexts

The proposed methodology was designed on the assumption that it will be deployed in the context of an Ebola outbreak. With regards to working in other contexts, we observed that:

- Until now the emergence of outbreaks seems to follow a fairly random pattern. Maintaining some of the proposed measures just "in case" could have the opposite effect to our aims. Some of the proposed measures cannot go on forever because they are coercive measures which need exceptional and emergency situations in order to be activated. In this context, awareness should probably be raised by means other than the CP and the methodology as explained above.

- Once an outbreak is over certain effects remain within communities, as in the case of the stigmatization of survivors, families and other communities, such as local Red Cross volunteers or health workers[xxii]. Some of these people may fall into a situation of chronic stigma with very serious consequences on their living conditions, aggravating the loss of loved ones and/or the traumatic experience of the crisis.

These two factors lead us to consider that applying the methodology preventively would not be appropriate and anti-stigmatization elements should most likely be the focus for a community's awareness and social mobilization in a post-epidemic context.

Conclusions

The results observed lead us to extract the following conclusions and recommendations:

- During an outbreak the most exposed populations to the disease are contacts registered by contact tracing systems, their domestic units, their families (with particular attention to sisters/brothers, fathers/mothers, sons/daughters) and their communities. These people represent more than 80% of transmissions and need to be placed at the center of awareness activities. One "success" in the form of a transmission that has not taken place could be enough to cut a transmission chain.

- These actions must, above all, aim to build confidence between the most exposed populations and the health system teams and facilities. This implies that these actions must not be a one-off but medium-term and progressive, always going from the smallest groups (contacts and those closest to the patient) to the biggest groups (the entire community).

- The intensity and number of reluctances can be reduced by implementing a community-based approach that gives the communities the role as subject and not object of the proposed control measures.

- The legitimacy of the people who have the responsibility for prescription and management of coercive prevention, control and surveillance measures is critical to the success of such measures. A community-based approach should focus on the commitment of natural community leaders in prescribing and managing such measures. The proper identification of these leaders and the fact that they rally the measures can be decisive.

- The proposed methodology combines all these considerations and can be an effective tool for raising awareness and social mobilization in the fight against Ebola.

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Organisation Mondiale de la Santé (OMS) Key Messages for Social Mobilization and Community Engagement in Intense Transmission Areas Septembre 2014

Organisation Mondiale de la Santé (OMS) Recherche des contacts pendant une flambée de maladie à virus ébola Septembre 2014

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i Ebola Situation Report – 3 June 2015 – World Health Organisation

ii WHO 2014 « Epidémies de fièvres hémorragiques à virus Ebola et Marburg : préparation, alerte, lutte et évaluation » pag 24 et WHO 2014 « Ethical considerations in developing a public health response to pandemic influenza »

iii A list of these measures is available on Epelboin 2008 pag 26. Other considerations on the measures to be undertaken are available at WHO 2014 "Epidemics of haemorrhagic fever Ebola and Marburg: preparation, warning, control and measurement" pag 24

iv The Siracusa Principles are the result of an international high-level conference on the provisions of the International Covenant on Civil and Political Rights authorizing restrictions or exemptions. The Conference was held in Syracuse (Italy) from 30 April to 4 May 1984. The Conference concluded with the adoption of a set of principles entitled "Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights"

v Cheikh Ibrahima Niang said that during his visit to the villages most affected by the disease in Sierra Leone "It became clear that resistance was a way people affirmed their position when their dignity felt threatened." - Ebola diaries: Lessons in listening - Cheikh Ibrahima Niang, professor of social and medical anthropology at the University Cheikh Anta Diop of Dakar (Senegal) in 2015 - http://www.who.int/features/2015/ebola-diaries-niang/en/ Julienne Anoko (J Anoko 2014) reports that reluctance "represent the frustration of the population in epidemics of Ebola and Marburg virus face the authorities, described as corrupt and disengaged or unable to provide a response to problems." The study *"*ACAPS 2015 Ebola in West Africa , Guinea: Resistance to the Ebola Response" reported that reluctances were rooted in "(1) Social tensions and existing policies, (2) The general cultural mistrust of foreigners and refusal to accept them into the community, (3) distrust of authorities, security forces and international actors (4) Exclusion of key groups from response system, such as women and youth, (5) Politicization of the epidemic, the government and the opposition (6) Fear and rumors "

vi ACAPS 2015 Ebola in West Africa , Guinea: Resistance to the Ebola Response - pag 1 « Resistance to the Ebola response has been more widespread and more severe in Guinea, than in Liberia and Sierra Leone, with sometimes violent incidents. This is due to a complex interaction of many factors, including underlying causes and the nature of the response. »

vii This is the case of Liberia, where social mobilization have been a key element in stopping the epidemic. Just in the city of Loffa "behavioral change resulting from a successful social mobilization campaign may have averted hundreds, if not thousands, of EVD cases in Lofa County" (Fast SM, Mekaru S, Brownstein JS, Postlethwaite TA, Markuzon N. 2015). For UNICEF, the role of community mobilization is one of the reasons for the success of efforts in the country « Towards the end of the year, the country had clearly turned a corner, as communities increasingly took it upon themselves to battle the crisis, adopting safe behaviours » UNICEF News - UNICEF hails Liberia's victory over Ebola, but warns against complacency as cases remain in neighbouring countries - http://www.unicef.org/childsurvival/media_81855.html In Guinea we found that UNMEER reported that In Dubreka sustained community engagement resulted in a decrease in reticence – unmeersitreps – UN Mission for Ebola Emergency Response (UNMEER) – 13 March 2015

viii Data source was the WHO epidemic control team for the Boffa prefecture, who managed contact tracing efforts and epidemic control at the time.

ix In this study we used the WHO definitions of suspect, probable and confirmed (WHO 2014).

x The data used by (2007) were extracted from the opinion of a sample of survivors about the way they contracted the disease. On the contrary we analysed data which included a sample of sick persons, not just survivors. The fact that the results of the analysis of Boffa data are consistent with the results of Faye, Ousmane and others, 2015, who analyses a great sample of sick persons in the same area, gave us some confidence. But we cannot know if the difference between the percentages found by the Hewletts and ours is the result of just some kind of local specificity or if it is just a perception of the survivors who had oversized the importance of funerals in the transmission of the disease, or even if we are facing something else. In fact the organisation of funerals is a cultural element, and it's impact on disease transmission could be highly variable. For example the fact that Guinée is basically a Muslim country where the people must be buried as soon as possible, preferably within hours, may make a very big difference in comparison with other African countries where funeral practices involve a body to wait even weeks before being buried.

xi This percentage may be highly variable. For the month of May 2015, the latest report from epidemiological situation noted that this percentage was of 78% but the average for the months of April, March and May was 40%. This figure is important because a low percentage would be proof that "there is a High number of unregistered contacts while not known chains of transmission persist" WHO - Sitrep - March 11, 2015

xii WHO. Ebola Response Team. Ebola virus disease in west Africa — the first 9 months of the epidemic and forward projections. N Engl J Med 2014; 371: 1481–95.

xiii During a tour to the set of health centers of Boffa's prefecture all center's managers reported, with one exception, highly significative reductions in users attending the centers during the first quarter of 2015. These reductions goes until 75% in the case of some centers (kobba). When asked what was happening in the answer always referred to the "fear".

xiv Alan Abramowitch warns that one of the unwanted results of community-based approachs could be the development of some vulnerable communities, including women. The establishment of a community based monitoring system in order to enforce quarantine zones and control the movement of people within the community also entail risks. The fact that social control tasks are delegated to a task force which is made on the basis of differentiation of roles already in place within the community can lead to a militarization of life within the community that would increase the vulnerability of women or other marginalised or vulnerable groups.

xv For more details on the methodology a detailed manual was elaborated and can be consulted « Sécurisation des contacts et mise en place de Plans Communautaires de prévention et de riposte, Guide Méthodologique », ACF, 2015

xvi Faye, Ousmane and others, 2015, suggests that accelerating for a few days the admission of sick people into health facilities would have a very significant impact on the number of transmissions. Specifically their simulations show a reduction of 26% in the number of

transmissions if we managed to increase the number of hospital admissions 10%. In any case it seems clear that we must minimize the length of the stay of symptomatic patients within their communities, since it is in this period that would occur most of transmissions.

xvii We understand humanization in the direction indicated by Alain Epelboin Pierre Formenty, Julienne and Anoko Yokouid Allarangar in "Humanisation and informed consent for people and populations during responses to VHF 1 in central Africa (2003-2008)." This concept can be summarized in treating each household visited in a personalized way to escape the bureaucratic procedures and to give time to the ACF team to start a dialogue with the household that enables us to start trust building so we can make use of the personal links established in the sessions that follow.

xviii Homes or properties in the communities visited tended to include more than one household. These households tended to be closely related to each other by family ties.

xix Community Led Total Sanitation (CLTS) - is an approach that aims to achieve a sustainable behavior change in people through a process of "triggering" leading to the drop out of open defecation practices on a spontaneous and long-term basis. It was first applied in India in 2000 and since this technique had have some success in several countries. ACF explored applying a CLTS approach with few modifications to Ebola outbreak management in Sierra Leone in 2014. It is from this approach that some key elements have been taken to develop community plan methodology as exposed here.

xx CLTS has raised some critics because of the level of violence and coercion that this methodology can happen to generate at intra-Community level. Liz Chatterjee, PhD student at the University of Oxford, summarized this in a report prepared on behalf of UNICEF in 2011 while noting that CLTS, in some cases, "was founded on community-led coercion" This coercion adopted several forms of intra-community violence where the most vulnerable groups would be particularly exposed, including women or children belonging to low income families. http://www.theguardian.com/global-development/poverty-matters/2011/jun/09/dirty-truth-behind-community-sanitation

xxi In one of the pilot communities the inhabitants decided to set fines on households without a functional hand washing device at the door of their concession. This measure was not originally included in the package proposed by ACF.

xxii Several authors report that the consequences of stigma are long-term. A.Epelboin in the documentary "Ebola is not a laughing matter," said the stigma from Congo Ebola outbreak wich took place in 2003, is yet present in the daily lives of people in the community in 2007, four years later. Hewlett & Hewlett (2008) also explain several effects of stigma, which may include the inability to go to the market, rent a house or bring the kids to school, among others. In their work they also indicate that one of the group that feels most affected by stigma is that of health workers.

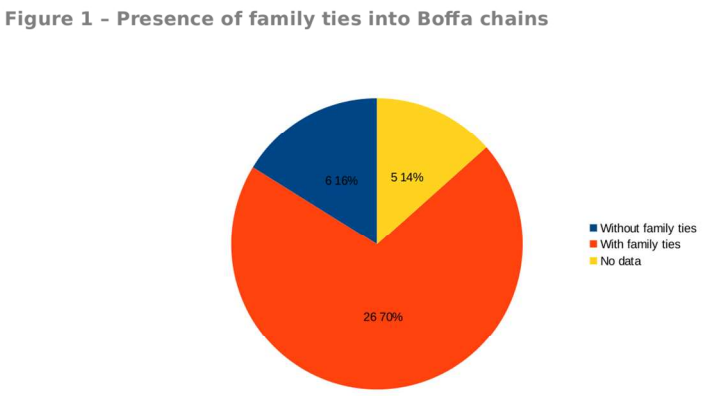

Figure 1 – Presence of family ties into Boffa chains

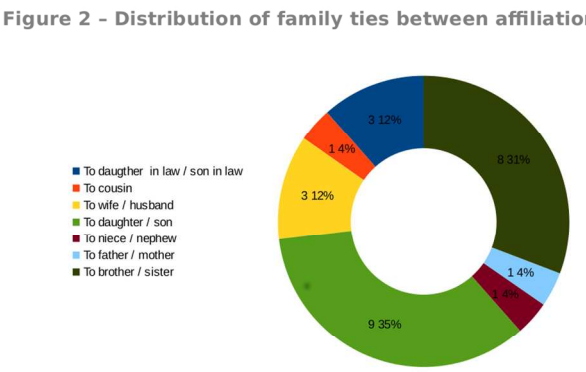

Figure 2 – Distribution of family ties between affiliation categories

Figure 3 – Boffa data set grouped by sex and by age

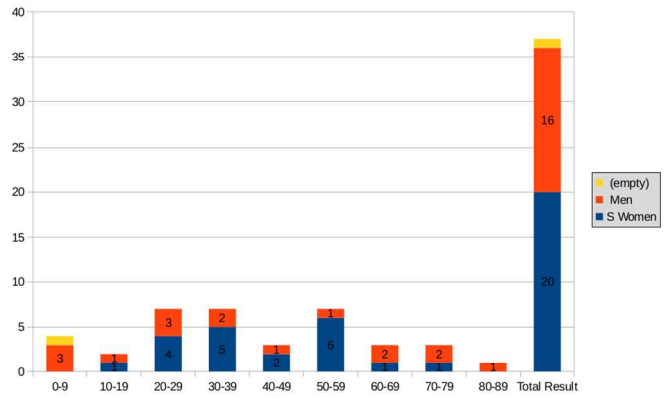

Figure 3 – Boffa data set grouped by sex and by age

Figure 4 - The proposed methodology

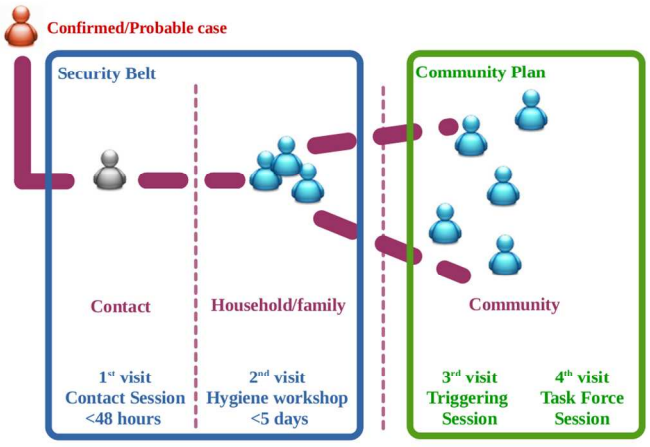

Figure 4 – The proposed methodology

Figure 5 – The Community Plan