

## Medical Anthropology Study of the Ebola Virus Disease (EVD) Outbreak in Liberia/West Africa

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To: The World Health Organization Representative, Monrovia, Liberia, 24 August, 2014

## **Acknowledgments**

This study has been made possible by the actions and commitment of many individuals and organizations. The study team (Omidian, Tehoungue and Monger) want to thank the WHO Regional Office, Brazzaville, for the invitation and logistics in bringing Omidian to Liberia to conduct this study; the WHO Representative, Liberia, and the Liberia Country Office for help with travel logistics, coordination and field support. We want to also thank the Ministry of Health and Social Welfare, and their counterparts in Bong County, for their willingness to share information and allow us to sit in on key planning meetings. We offer also our immense gratitude is various community members and medical students who helped us organize gatherings in three counties. Without their help it would not have been possible to document the sociocultural and behavioral factors that promoted or hindered the outbreak of Ebola in Liberia.

## Table of Contents

ACKNOWLEDGMENTS .....	1
<b>INTRODUCTION .....</b>	<b>3</b>
BACKGROUND.....	3
<b>FINDINGS.....</b>	<b>3</b>
PERCEPTIONS OF EBOLA .....	3
CONCERNS NOTED BY WOMEN.....	6
PERCEPTIONS OF DISEASE TRANSMISSION .....	7
PERCEPTIONS OF HOSPITALS AND CLINICS .....	9
COMMUNICATION AND MESSAGING .....	10
<b>PSYCHOSOCIAL ISSUES .....</b>	<b>11</b>
CONTEXTUAL ISSUES FOR “DENIAL” .....	12
REACTIONS TO THE EBOLA RESPONSE .....	12
RISK BEHAVIORS.....	14
<b>CONCLUSIONS .....</b>	<b>15</b>
RECOMMENDATIONS .....	16
GIVE PEOPLE SOMETHING TO DO .....	17
<b>APPENDIX.....</b>	<b>18</b>
MAP OF COUNTIES .....	18
APPENDIX 2: RESEARCH QUESTIONS:.....	19

## **Introduction**

### **Background**

The current outbreak of Ebola Virus Disease (EVD) in West Africa (Guinea Conakry, Liberia and Sierra Leone) is causing anxiety, fear and panic for communities in these three countries, the deadliest in years with the majority of deaths occurring in Guinea and Sierra Leone. It is spreading faster than health services can cope, with many people hiding from services, refusing to turn bodies over to burial teams and government systems failing to respond when called upon. People flee to areas they deem safe, carrying the virus and its consequences with them. In addition, deeply rooted cultural practices, such as those around death and burial, can contribute to transmission. The WHO is leading the response to the outbreak, including addressing areas of social mobilization and risk communication. This study was carried out to better understand the local beliefs and practices likely to enhance or hinder efforts to respond to the outbreak in Liberia.

### **Methodology**

This ethnographic study was conducted in Montserrado, Margibi and Bong counties using the following methods:

- Key informant interviews
- Focus groups
- Observation and informal interviews.

Approximately 400 people participated in the study at various levels. Two research assistants were recruited to help with the survey, one a 2<sup>nd</sup> year medical student and the other a student graduating with a BA in Social Work. Both participated fully in the design and operationalization of the study and ensured its success.

It has been my intention to work closely with the Ministry of Health and Social Welfare, but with only two weeks to collect data it proved to work best to train two local students in qualitative methods and analysis. Instead, we conducted interviews in the counties of Montserrado and, Margibi from July 28 to August 17. Omidian collected data in Bong County on July 28, and August 14/15. Tehoungue, based on his contacts with medical students in Montserrado and Margibi counties, selected locations for focus groups.

### **Topics Explored**

1. Local knowledge and understand of Ebola, as a viral hemorrhagic disease
2. Understanding of current health messages
3. Community concerns regarding Ebola.

## **Findings**

### **Perceptions of Ebola**

In focus group discussions we elicited information on perceptions regarding Ebola, first by asking people to tell us rumors or stories they had heard and then to have people tell us what they knew from the messages broadcast through various media. This was followed by a discussion of what information was accurate and what was false. We also answered questions about Ebola, its symptoms, transmission and care. Over the 2

weeks of this study we witnessed people's perceptions shift toward greater acceptance of the reality of Ebola and deeper frustration with the lack of health services. At the beginning few would admit they even knew a person who had Ebola. Yet in each gathering, people began their discussions with the statement: we believe Ebola is real. It felt at first like that statement was for our benefit. In each group people complained that the messages from the government about the disease were hard to understand and were often in technical language. In many areas, English is not the primary language and needed information in one of the many languages and dialects used throughout the country. By the end of the second week we had many people talk openly about the Ebola patients they had seen. At that point, when they said "I know Ebola is real" one could tell they meant it.

Focus group discussions generally lasted three hours because our questions brought up for the group, many questions of their own. Most were requests either for clarification of the disease and how it is different from diseases they already know, or for information on what to do if someone becomes ill in their midst. For example, they asked when was it ok to touch someone and how would they know if the person had malaria or cholera, and not Ebola. They were afraid that someone would die of something that could be cured.

They knew that they were not to touch someone who showed any of the common signs of Ebola, but they wanted to know more. In every group someone would say that they heard on the radio that they were not to touch somebody who is infected. But some were afraid that touching anyone would cause them to get sick. Yet, hand washing was not commonly practiced and some looked forward to the time when they would be able to stop doing it all the time. Others noted that they didn't know the things they needed to do with patients in their homes.

They also asked what happened in the treatment centers, why they are so secretive, what kinds of treatment would their family member receive there. Some had stories about patients starving for want of food or attention.

#### ***Responses to Key Government Messages for Prevention***

##### **Always wash your hands with soap and clean water (or wash with chlorine solution)**

In all groups interviewed, hand washing was often listed as the most important way to prevent Ebola. We also were told by many that the government needs to supply chlorine, soap and buckets to poor families. Yet, when probed, most households have bleach for washing clothing.

- Always wash your hands.
- I have heard about ebola on the radio and I was told to wash my hands constantly with bleach and water and I have been doing that.

##### **Always cook your food properly**

Those who eat bush meat (often referred to as dried meat) said that this was the way to protect oneself. In discussions on cooking food properly, many seemed to confuse Ebola with cholera and this was also noted with their comments about keeping the environment clean.

- If you cook your food well it kills the virus.

##### **Report to the Health Facility anytime you have headache, pain, diarrhea, red eyes, rash or vomiting**

Although people could recite this message, they also told us stories that illustrated their fears of the centers or noted that they could not reach them (as in rural area) or that they were closed.

- Go to the hospital when you have headache, fever or running stomach.
- Ebola has no cure but can be prevented.
- Report sick persons in your community with signs any symptoms of Ebola.

**Don't touch people with Signs of or who have died of Ebola**

- Avoid visit to a family you have not seen for a long time.
- Don't shake hands.
- People get infected through sweat, urine, blood, vomit or feces of an infected person.
- The traditional practices of kissing, bathing/washing and/or hugging dead bodies spread the virus.
- The virus is spread if a person without ebola virus comes in contact with an infected person.
- Do not touch sick people or dead bodies.
- Avoid crowded areas.
- Close all businesses to help stop the spread of Ebola.

**Don't touch the clothing or bedding of someone who has died of Ebola**

- When a family member or friend has Ebola and you wear the clothes that the infected person has used, you will be infected.

**Don't play with monkeys or baboons**

- Don't play with monkeys and bats.

**Don't eat bush meat**

- Do not eat bush meat such as monkeys, baboons and bats. But can we eat dried bush meat?

**Don't eat plums eaten by bats**

- Because the government told people not to eat plums the fruit is rotting on the tree because everyone is afraid to eat it.

Group	Day (August 2014)	What are the top three ways to stay safe from Ebola?
1	4	Shake hands, avoid body contact, avoid bush meat
2	5	Avoid body contact, avoid body fluids, wash hands
3	6	Avoid body contact, wash hands, report sick people
4	7	Avoid body contact, wash hands, avoid bush meat
5	8	Avoid body contact, avoid body fluid, wash hands
6	9	Avoid body contact, wash hands, report sick people

7	10	Wash hands, clean environment, avoid bush meat
8	11	Wash hands, avoid sick person, avoid body contact
9	12	Wash hands, avoid body contacts, report all cases
10	13	N/A
11	14	Wash hands, awareness, cook food properly
12	14 (Bong)	Wash hands, avoid body contact, avoid bush meat
13	14 (Bong)	N/A
14	15 (Bong)	Wash hands, report sick people, awareness
15	15	Wash hands, avoid body contact, avoid bush meat
16	17	N/A

There were other ways that people assumed one could catch Ebola. For example, many thought that mosquitos and flies could spread the disease.

### **Concerns noted by women**

During the focus groups interviews with two groups in Monrovia that were exclusively women, issues of pregnancy and child-care were emphasized. With children out of school and bored, these women struggle to keep them safe by confining them to their houses but it is an impossible task. The children want to play with their friends outside, creating two problems for mothers: 1) the environment is unclean and children often become sick with diarrheal diseases, including cholera; and 2) the children socialize through physical contact, including touching, hugging, sharing of food and they rarely wash their hands.

Even though mothers say they explain the prevention messages to their children (such as not touching and avoiding body fluids like saliva) they worry that their children cannot follow this, either because they are too young or because they forget. Most mothers said they try to wash the children's hands themselves but they cannot stop them from playing with their friends. And because the children are not in school, they are more boisterous than usual. They say the children are innocent and full of curiosity. If they see something dead they will touch it. And, if their mother, friend or family member is showing signs of illness they will hug that person and try to comfort them. Sometimes, we were told, a mother continues to care for her children, even when she is sick and suspects she has Ebola. And this caring involves body contact. People said they could not isolate their children from the ill in the family. If a child gets infected from his or her mother then that child is likely to infect others, including their friends in other families in the community.

Women related stories of when an infected Ebola patient died in a house and the children were left there. Instead of removing the children to protect them from infection, other community members would refuse to take the children into care for fear that those children would infect their own. In one case, the Ebola Response Team came and collected a specimen but left the body and the children in the house. One woman said

that the government needed to set up a facility to care for these children, whose parents were either sick or dead from the disease.

The other concern women expressed was the need for clinics to open and care for maternity cases.

Pregnant women lives are at risk. They are losing their lives and their unborn babies are dying in their stomach.

And:

Pregnant women are dying because health workers are afraid to touch them because they (health workers) are not protected.

Women were afraid that they would die in childbirth as there were no facilities open to care for their needs. Because “everything is Ebola” even a woman coming into a center to deliver a baby could be rejected by the doctors for fear of the virus. A woman in her first trimester of pregnancy and was suffering from morning sickness was shunned by her husband’s family for fear of Ebola. Those who are not suffering still carry the fear of rejection.

The next point of fear is at the time of delivery. One woman described what happened to her niece:

I am thankful to God for the WHO to gather us here to talk. Those who work in the hospital, pray for them. I am pleading for the babies and pregnant women who cannot control what they do and they get all those symptoms. No hospital is open and 2 days ago my niece was ready to deliver so we took her to the Tower Hill clinic as she needed an operation but the doctor sent her back to Monrovia. And we got back to here and went to JFK but the doctor was afraid to touch her. And we tried to go to another clinic or hospital but she got sick in taxi and vomited. The taxi driver ran away. She was fighting and she died in the car and the Ebola Response team came and sprayed her body but we could see the baby still alive in her stomach and then the baby also died. I appeal to help all the pregnant women in the country. My niece is gone but there are others who need help. Where do we run? Afraid of blood and vomit but these illnesses are normal here.

We tried to get my niece help and her body would not give the baby so she died and the doctor said it was from ‘Ebola’ so he would not give us her body and we had to fight. We pleaded for hours for her body. We have plenty of pregnant women and no one stops women from getting pregnant or helps them to delivery.

In Bong county, where all health facilities are closed a woman asked me:

What am I supposed to do? My time is almost here and I have had three babies by operation (C-section) and there are no doctors or hospitals to help me. What can I do? What can any woman do?

The Ebola outbreak is also leaving children orphaned and abandoned. Some children’s parents have died of the disease and even when the child is healthy his or her family are afraid to take them home. There are stories from many health workers of children whose needs are not being met.

### **Perceptions of Disease Transmission**

Ebola is now infecting people across 10 of the 15 counties, including in Monrovia, the capital. We had many variations on the concepts of disease transmission. Some



concepts were accurate interpretations of the Ebola messages received, such as when one person said:

When a family member or friend has ebola and you wear clothe that the infected person has used, you will be infected.

Or:

When people who have the virus are treated with needles by health workers and persons who do not have the virus use those same needles, they will get infected.

A few spoke from a disbelief in the disease, saying “I don’t believe the virus”, because they felt that symptoms were indicators of other, familiar, illnesses.

### **Community Issues of Ebola**

- Everything is Ebola
- Denial issues
- Information needed on what to do (education issues on care, etc)
- Community concerns (like concerns about children)
- Community leaders involvement
- Rumors
- Fear

Many of the people from each sector have stated a denial of EVD in the country so they have refused to take sick family members for care and treatment. Because the summer rainy season is the time of year when both malaria and cholera are common, and both illnesses have similar symptoms as EVD, people have trouble accepting a disease that is so deadly that taking care of one’s loved ones can put one at risk. Even Lassa Fever, another hemorrhagic illness, with similar symptoms, can be cured when treated. We were often told that clinicians and doctors would wrongly diagnose a disease as Ebola. Over and over we heard people say: Everything is now Ebola.

Many people in our Focus groups knew how Ebola entered into Liberia. Some participants told us that health workers in Lofa became infected because they took care of patients with the disease who had come from Guinea. These health workers did not know the danger and took no special precautions and caught Ebola. Then they spread the disease to other health care workers and their own families.

We probed into notions of infection. Some participants said that if you come in contact with needles that were used on Ebola patients by health workers you would become infected. They explained that the virus lived outside its natural hose for three days. So if you come in physical contact with the needles within that time you would be infected. These individuals urged mothers and caretakers to make sure their children don’t play in the garbage near a hospital or clinic because no one would know which ones were used on Ebola patients.

Other ways people said one could become infected was by:

- Eating with the same spoon as someone who is infected
- Having someone sweaty lean against you or shake your hand and getting their sweat on you
- Having droplets of infected saliva land on your skin when they talk
- Getting warm and sweaty so that your pores are open and then the virus could enter your body through the pores

- Kissing or having sex with an infected person or someone who has recovered and not waited 3 months
- Handling dead bodies of Ebola victims because the virus is on their skin and in their body fluids
- Eating bush meat

### **Perceptions of Hospitals and Clinics**

Unlike Yellow Fever, Lassa Fever, cholera and HIV/AIDS, Ebola patients have a very low survival rate and are said to disappear when they are taken to a treatment unit. We were often told that in the ETU, patients would disappear never to be seen again and their bodies would be “thrown away.” After death, families would not get the bodies back for burial. That was probably the hardest news to accept.

- Closures
- Everything is Ebola
- Pregnant women/ need to address other health issues
- Health worker safety
- Perceptions of the ETU / Patients disappear
- Burial issues / such as no respect for the dead

Most comments about treatments centers came from stories people had heard from friends or health workers, rather than first hand accounts of family members placed in the centers. We were often told that people are kept in the centers but not treated or fed. Some claimed that people who have tested positive receive no care in the centers. Their families are not allowed to see them or talk to them or even find out how they are doing. Those who believe this told us that if the patients would receive treatment and proper food, they would survive and the recovery rate would be higher. They blame the government for not providing enough to the centers. For this reason many said they would not want their family member to be taken to a center. It's a place to be isolated, and left to die. One mother related that her 10 year old daughter told her: if I get diarrhea, don't take me to the clinic or they will put me in an Ebola center and I will die.

There is a general fear of clinics and how people are treated once they arrive. For example, we were told that the health staff sprays the patients until they die. Many of those interviewed added that those who go to treatment centers are forced to die, that the health workers give them pills that kill them more quickly. Some of these stories are also connected to the rumor that the patients are being killed for their body parts, mostly kidneys.

There is no Ebola. Health workers are using this as a means to extract body parts from people who they claimed to have Ebola as a ritual or business. The people who are taken to the treatment centers do not have Ebola. The health workers are killing them and selling their kidneys and sending it overseas to sell. It's a complete business strategy for the health workers.

Others, who also talked about the sale of body parts, attributed the increase in this to the up-coming elections—saying they needed the parts to do rituals so that they could stay in power.

The other reason given is that health workers are killing people because the wards are over-crowded. One health worker (currently out of work either because of the closure of health services or because he left his job because of the fear of being infected) said:

It takes 21 days for a person to die of Ebola, but when your relative is showing signs like fever and headache and you take them to the center, you are told within hours that the person died. Or sometimes you are told the next day. This shows that the health workers are killing our relatives and the government is not doing anything about it. Its even in the government's favor because the money that is supposed to be used on treatment will be used for their personal use.

People assume that both suspected cases and those who have tested positive are kept in the same room and that those who are not infected become infected in the ward. Others elaborated that those who are testing negative are allowed to go home but, because they become infected in the ward, they take the disease back to their families. Family members and friends assume they are safe to hug and become infected.

On the other hand, health workers are afraid to enter the centers in many areas because they don't have protective gear. They often know of colleagues who died because they treated someone in a hospital or clinic. Their fear keeps them away, particularly from county facilities. Any patient coming to the clinic puts the unprotected health worker at risk, since many don't have gloves or have to reuse the ones they are given. At the same time, by treating each person as an Ebola patient increases the public distrust of the health care setting. Finally, there are reports, particularly in poor or rural areas of nurses and other health workers treating family, friends and community members in their homes—after hours. This practice increases the risk to the health care provider.

Because of the high mortality rate and the government messages that Ebola has no cure, fear is intense. Those families with an Ebola patient will be shunned. Survivors may not be allowed to return home. Children who lost their parents to Ebola or who themselves have recovered from the disease may be abandoned. These attitudes contribute to the hiding of patients and the flight of family members to other areas of the country to avoid contact tracers.

### Communication and Messaging

- Gov't information too scientific
- Information needed in local dialects
- Information limited to urban areas
- No information on what to do

In the focus groups we asked people to rank the messages they heard from the government, giving us their top three choices for how to stay safe from Ebola. They listed the following:

Topic:	1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>
Avoid body contact	6	4	1
Wash hands often	7	3	2
Report Ebola cases		2	3
Don't eat bush meat			5
Avoid body fluids		2	
Clean Environment		1	
Awareness		1	1
Cook food properly			1

We explored with each group what was meant when they said that it is important to wash hands frequently and to use chlorine solution in the water to kill the virus. We also asked what they meant by when they said to avoid body contact. Respondents said they were including handshakes, touching someone when in the markets or in a taxi, and even avoiding contact with dead bodies. They listed the avoidance of bodily fluids, such as vomit, feces, urine and saliva, separately.

### ***Rumors on Ebola***

Based on interviews with over 350 community members and 50 health and community leaders, we found that most people were able to report to us on basic information about the Ebola virus and the Ebola Viral Disease. We found consistent and similar responses across ethnic and socio-economic groups.

Many Christians believe that the outbreak of EVD is a curse from God due to the various evil practices by the leadership of the country. They attribute the outbreak on the visit to the country by the Queen of Sheba, a woman they claim is from the “dark world and who is the devil incarnate.” (\*\*Add in news article source <http://www.nairaland.com/312423/queen-sheba-took-off-arrival> and <http://legendsrumors.blogspot.com/2014/08/ebola-and-queen-of-sheba.html>) Those who speak of this believe that she visited Liberia because she wanted blood to increase her powers in the dark world.

Many of the traditionalist said that EVD was brought here by the White people from the West. They also believe that Docgtors and nurses were extracting the body parts of their loved ones who were taken to the hospital. They also noted that the government wanted them to stop hunting because this is what the White people told them to stop eating bush meat. A common rumor that was found in every interview conducted, regardless of county was that people were getting Ebola because the wells have been poisoned with formaldehyde. People are afraid to drink the water and spend their money buying mineral water whenever possible.

Among the urban educated, some said they did not believe that Ebola is real. Their argument was that the government created the situation in order to generate income for themselves. In fact some said that the reason we have had two waves of the outbreak is that the government got 1 million US dollars during the first wave and decided they wanted more money. By making a much larger outbreak they have managed to get promises for US \$5 million. A few said that this was to be used to pay the striking health workers. Some noted that EVD is viral terrorism by the West.

We were asked to tell the government to develop a cadre of community health volunteers to translate the messages into local languages and to help spread the message so that everyone can understand it and have their most pressing questions answered.

## **Psychosocial issues**

### **Contextual issues for “Denial”**

- Hiding complex paradigm
- Few people we surveyed denied Ebola
- They are denying the consequences of ebola for them because it is too frightening.
  - a. Act in “Survival” mode based on patterns developed during war
- Listen to what people have to say
  - a. Deepen psychosocial strategies
  - b. Help people meet emotional needs

### **Reactions to the Ebola Response**

- Identification of care and protection issues of burials (To few burial teams)
- Actions taken or not
- No adequate response for getting patients from the communities
- Limited treatment centers
- Limited trained HW
- Limited supplies of Ebola equipment

Most, if not all, of the communities we interviewed blamed the government and the Ebola Response Team for inadequate responses to community needs in this crisis. People stated that the government had done little to help prevent the disease. Although people could state the various prevention activities and avoidances, most did not understand transmission. Many showed confusion between these messages, the symptoms being displayed and other illnesses with which they were familiar—such as malaria, cholera and yellow fever. This misunderstanding of the nature of the disease, with the message that the disease has no cure, while the other illnesses do, added to community perceptions that the government and health workers must be either renegeing on their obligations or collecting money through corrupt practices.

Unfortunately, numbers provided by the government for people to call if they were sick or had a death from Ebola rarely worked during the time of this study. The system was poorly managed, with calls rarely answered. If someone did answer the phone it might be days before a team would be sent to deal with the patient or body. On one trip to the office from the hotel in a WHO car, Omidian (with other WHO staff members) found the main road blocked by a crowd who had put boxes and rocks across the intersection. They had done this in protest of the lack of response. Almost 24 hours before they had identified a possible Ebola patient and called the hotline. No one sent an ambulance, even after repeated calls for help. The community isolated the person by locking him in a room and then, in desperation, closed off the street. The crowd was not violent but they were determined. One man stood in the road with a sign that read:

*Please help us. We have an Ebola patient and no one will help us.*

The local WHO staff person let the crowd know that she was calling for help and that she would listen to their concerns. She was able to diffuse the situation and shortly after police and other help arrived.

In an interview with a woman from Logan Town (the day after riots in West Point), Monrovia, a woman related the following story:

A few weeks ago in Grant Cape Mount County a man died of Ebola and the health worker came and tested the body. When they found out that the man was positive, they locked his wife and his daughter in the house with no food or water.

The son was able to escape and he hid in the forest, living off of cassava. The woman and her daughter cried for help but no one came to their aid for fear of Ebola. After three days in the house the woman died of starvation. When the team came back they took the woman's body and her daughter to Monrovia.

Such responses add to people's negative opinions of Ebola teams and the Ebola response, deepening the sense of distrust and causing some to wonder if the whole process was a hoax to gain money from foreigners.

In addition, many of the communities we interviewed believe that if the government would build more treatment centers around the country and train the staff, bring more equipment for the health workers, it would enable them to fight the outbreak. In every group we had health workers or family members of health workers who were afraid for their lives and that of their families. They felt that the lack of equipment and training increases the death rate of health workers.

### ***Cremation***

We were taken by surprise when we asked focus groups their opinions about cremation. Most of the conversations started with a comment by someone who said, unequivocally, that this is against African culture and values. Then the group as a whole would begin to debate the issue, weighing cultural values and religion against their understanding of disease and transmission. As this is the rainy season, most moved toward a discussion of ground water and whether the burial of Ebola infected bodies might contaminate their water supply.

The government should cremate Ebola dead bodies because when the bodies are buried, it will create health problems for people when they drink well water that has been polluted by the bodies. This cremating of bodies will make our water save.

Many times someone noted that, because people often do not take care of where they defecate, rains wash fecal matter into the wells, increasing the chances for outbreaks of cholera and other intestinal diseases. So they reasoned that, with the high water table and the ability of the virus to survive a dead host, the group persuaded others that it is better to burn bodies than to bury them; "once the body is burned the virus is dead." The other argument used was that no one wanted to have Ebola victims buried near their villages, again because of contamination, or because there would be too many bodies to bury, leaving less room for the living. In the end each group voted. Of the 12 groups that were asked this question, only 1 group voted against cremation, one of the all female groups.

Those against cremation felt that the government could allocate a special field for the burials and this would allow families a place to go to mourn the victims. One articulate man said that he wanted cremation and a park set aside as a memorial for all those who died from the 2014 Ebola Outbreak.

Some people suggested that the government should allocate site for mass grave to enable people to remember the dead on National Memorial Day.

### ***Law Enforcement***

This was a much more complex question that brought out concerns directly related to the trust of the government and its motivations. Most of the groups agreed that law

enforcement had a role in protecting health workers and clinics, but few felt they should be used to quarantine communities that refused to give up bodies or patients to burial or health teams. Many noted that they did not trust the police not to steal from people if they were to enter homes. Participants expressed the need to educate communities on why the dead must be buried in special ways and to allow community leaders (whether chiefs or zonal leaders) to convince people to take their sick to clinics. Also, it would be the community leaders and members who would be best at preventing outsiders from entering the community if that person were fleeing another area to escape treatment and thus spreading the disease.

### **Risk Behaviors**

Culture of touch  
Care for the sick

#### ***Burial practices that contribute to the spread of the disease***

People have not accepted the key messages of isolation and avoidance of contact with people who are sick and instructions not to touch dead bodies. Death rituals are particularly dangerous. In all groups, the body would be washed, with women washing other women, men washing men's bodies. Depending on the religion and or economic level, families might be more or less involved.

Some Muslims interviewed stated that EVD is not real and was a strategy of stopping them from performing their normal rituals of worship, particularly those that relate to the burial of their dead. As soon as the person dies, their body is carried to the mosque for ritual washing, then the body will be wrapped in white cloth, according to ritual standards and buried within 24 hours of death. Several people will wash the body, cleanse the mouth and other orifices, shave the head (for a man) or braid a woman's hair.

As with other groups, traditional families care for their dead within their circle. Family members care for their dead, with men shaving a man's head or women braiding the woman's. The body would be placed on a mat or bed in the house. It is common to even sleep with the body, lying next to it, kissing and touching it. There are rituals that include putting alcohol in the mouth of the dead and then drinking it as a symbol of love and respect.

Burial practices for the urban families vary by ethnicity and economics. Most Christians take their dead to funeral homes for embalming, after which they bring the body back home until the actual funeral and interment a day or two later. They will also dress the body, shave the head or dress the hair of the person. During this time they will hug and kiss the body as people come to pay their respects.

The tragedy is that most of these actions put people at risk during an Ebola outbreak. The virus is most contagious at the time of death and after, right at the time when people are interacting most intimately with the body of their loved one.

#### **Burial Risk due to confusing information**

Finally, in discussions with one community in Bong, Omidian was asked for information on how the burial teams do the burials. They knew that the community was required to dig the grave but their question was on who would fill in the grave afterwards. I took the question first to the WHO doctor in Bong. He said that he was not sure but that it made

sense to have the community fill in the grave after the body is placed there. He said that if the burial team did the work then the community's tools would be contaminated. Then I asked the staff at the Bong health center. They also told me that it would have to be the community because they only have one burial team for the whole county and they are too busy to do it. When I arrived back in Monrovia I asked one of the Ebola experts in the WHO office and she said that it had to be the burial team to prevent spread of the illness. She and others in the Monrovia office consider this to be a critical issue because of the high risk of transmission.

## **Conclusions**

It is important to consider this outbreak as a larger humanitarian crisis than just being about a disease. The health system, already weak and poorly functioning was completely closed for most of the time of this study, meaning no one was able to receive health care. Also, as numbers of infected have grown and borders/ports have closed, the economy of Liberia has weakened further. Each day that markets are closed (and there have been many of these days) poor women who work there lose the opportunity to provide for their families. This is a country of deep poverty and this outbreak is adding to their deprivation.

People are stressed and even re-traumatized because of memories of their lives during the war that ended only 11 years ago. The war experiences affect how people react to government messages. One person told me that there is no trust in the government and their messaging reminded him of the war when there would be a message over the radio of troops taking over an area when it was not true. When the president of Liberia declared a national emergency shops people queued in long lines to stock up on food staples like rice and oil. Most telling of the way people respond is in how people flee an area to go to another part of the country when they perceive danger. When someone dies of Ebola, it is common for survivors to pack up and move to another area. Those who are rural may go to family members living in an urban area, or they might move to another county where they cannot be easily traced. This practice, appropriate in wartime, has contributed to the spread of the disease. Also, everyone is told that if their loved one, including their own child, who exhibits such common symptoms as fever with headaches, diarrhea and vomiting must not be touched. At least in a war, one can care for one's loved ones. Its no wonder that people are not able to believe what they hear from their government.

This is a humanitarian crisis that need to have a multi-sectorial response. The critical need for health services is obvious to all, but, like in a warzone when people are traumatized or displaced, other services need to be included. It is important that basic needs of food, shelter and livelihood are protected or provided. Also important, but more difficult to address are the emotional needs and social needs within communities. This is particularly important for the mental well-being of people in high context cultures like those in Liberia. A disease that can only be stopped when people stop touching each other and caring for their sick loved ones has a horrendous impact on the emotional wellbeing of those very family members. Schools and colleges are closed, disrupting routines for children, increasing stressors for them and their care-givers and impacting the social needs of children.



## Recommendations

- Need for a 2-tiered strategy with the continuing effort to open health facilities and treatment centers)]
- Community leaders and civil society must be mobilized from household level upward
- Give people something to do
- Response is needed to address this humanitarian crisis through a multi-sectorial approach

## Community Issues

- Involve religious and community leaders in all aspects of the Ebola response, from education on prevention, transfer to treatment centers, to contact tracing and burials.
- Increase involvement by civil society
- There should be at least one trained person in every community to educate people on key Ebola signs and what to do if someone is sick. This could be a village health worker who is already trusted.
  - This person can educate community members on what to do for a person who exhibits symptoms, while they are waiting for services or want to transport someone to an ETU.
  - If there is a person suspected to be an Ebola patient and they have children, the community leader or someone designated by the community should take care of the children so that they do not get infected.
  - Each community should receive items for washing hands (buckets, chlorine, etc).
  - It is important to involve families in the care of their loved ones as much as possible so that they can give moral and emotional support. This would also reduce the distrust families have of the ETUs.
  - Give information to families on all aspects of the process so that they can understand what is happening. This is also important regarding burial procedures.

## Communication

- There is clearly miscommunication around the issue of burial and whether or not the community fills in the grave after the burial team has put the body there. This much be sorted and information shared.
  - Keep the messages simple and few in number and train local spokespersons to answer questions that may arise.
- Representatives from each county (at least 5) should be trained to on the ebola awareness message and to work with a designated person in each village in their area.
  - People should be educated on how the virus is transmitted. Its important to address their fears. Information on what to do and why you should do it is needed. If people are not told why, they are less likely to follow instructions.

## Ebola Response

- There should be at least one health and burial team in each district.
- There must be more than one ambulance per county.
- Family members should be informed about the burial process of their dead relatives. If possible, a family member could accompany the burial team to the cemetery.

- In cases of cremation, the ashes can be returned to the family so that memorial activities can be conducted.

#### Ebola

- It is important to describe disease transmission in terms that people can understand—such as local examples like “the chicken sickness”. Also the concept of a disease reservoir can be explained so that people understand why they are told to avoid fresh bush meat.

#### Hospitals

- It is important to open health care facilities across the country to deal with other illnesses, diseases and accidental injuries.
- Open more ETUs and Holding Centers across the country, particularly in counties with the greatest number of cases.
- Children have special needs, which could be managed best with special Ebola treatment centers designated for them. These centers could be affiliated with existing centers but would be child-friendly spaces.
- Every health care worker must know that every patient is a potential Ebola patient.
- Health workers should have training and use of PPEs, with a strengthening on universal precautions.

#### Burials and Death ceremonies

- It is possible to re-enact ceremonies that were used during the war years when family members died but there might not have been a body to mourn. During that time there were a variety of rituals to commemorate the dead: warrior dances, planting of trees, or night-long candlelight vigils in front of a picture of the deceased. Communities could be encouraged to bring some of these back.
- The government could consider creating a memorial park or gathering place so that families would have somewhere to go to remember their dead.

#### Give people something to do

- People have the basic messages. Its time for the next level of information
- The messages also need to shift so that people have something they can DO.
- Without something to do, people react
- People need to be able to take positive action

#### **An Example of “Something to do...”**

- If someone in your house is sick and you cannot get them to a center (or while you wait for help to arrive)
  - Have only one family member be the designated care provider
  - Isolate person from all other family members, and especially the children
  - Remember the rules—i.e., no contact with body or body fluids
  - Stock the following items (chlorine, ORS, etc.)

# Appendix

## Map of Counties



## Appendix 2: Research Questions:

Interview Date: \_\_\_\_\_

### A. Basic Information

Name of Interviewer

Date

Number of people being interviewed

Gender of person(s) interviewed

Age(s)

### B. Location

County/District

City/town/village

Neighborhood

### C. Brief Description of setting

#### D. Understanding of Reservoir /host source

Local images, stories and rumors of Ebola

Please tell me what you and your community knew about Ebola before you heard the recent messages from the government.

Official and or government messages about Ebola

What people have learned from health messages

Based on the message you have listed, please tell us what you feel are the most important things you and your family can do to stay safe from Ebola.

#### E. Perceptions of 2 Government actions

Please tell us what you think about the government order to cremate the bodies of Ebola victims.

Please tell us your reactions to the government's use of law enforcement in this emergency.

#### F. Stories to prompt thinking about Ebola and reactions to Ebola, including psychosocial support

##### Story # 1

##### **This is a little story about two (2) very close girl friends and their families.**

The girls were called Kebbeh and Musu and they lived with families in the township of Johnsonville. These two families were so very close that people couldn't tell whether these were separate families. Kebbeh and Musu attended the same school, one day while they were at school Kebbeh's uncle Joe felt ill with the following signs and symptoms: fever, running stomach and vomiting. People in the community who knew a little of Ebola called an ambulance to take him to the hospital. When was taken to the hospital, he was tested and diagnosed of Ebola. The hospital authorities sent him to the isolation center for supportive treatments. When the girls returned from school, Kebbeh was informed that her uncle was diagnosed of ebola, she burst into tears.

Q 1: What would make it less painful or stressful for the family/friends/ others?

Q 2: What moral or emotional support would you recommend they give to help the patient to recover?

## **Story # 2**

**This is a story about a nurse who works at the JFK medical center.**

Tenneh Flomo work in the emergency department of the hospital. She has been very courageous, instrumental and very diligent to her work. Tenneh lived in the Lakpazee community; because of her concern for humanity she had a lot of friends. One Monday morning she went to work where she got to know that a nurse working in the pediatrics ward got ill and was suspected of been infected with the Ebola virus.

Three days later there was news about the doctor from surgical ward been suspected of Ebola. When she went home that evening a neighbor got ill and was rush to the hospital. News later from the hospital was that her neighbor was suspected of been Ebola positive. Since Tenneh got to know about these few issues, she got afraid and abandoned her job.

Q 1: Did she do the right thing?

Q 2: Why or why not?

## **Story # 3**

Joseph, David and Emmanuel were three friends who lived and schooled in the township of Congo town. These friends were so very close that many persons considered them brothers. Their families admired the friendship so much that anyone of these guys could eat, sleep or do many other things at each of these homes and their parents didn't considered it a problem. One fair Saturday evening, these guys went to play football, while on the field David received a call from home that his mother felt ill and was rushed to the hospital. David left the field with no delay rush to the hospital to check his mother health status. In a few hours she was diagnosed of Ebola. She was taken to the isolation center for supportive treatment; there after a few days she died of Ebola.

Q 0: Explain a safe burial.

Q 1: How could a safe burial be made less stressful or painful for the family?

Q 2: What kind of emotional support would help the family?