

Understanding Why Ebola Deaths Occur at Home in Urban Montserrado County, Liberia

Report on the Findings from a Rapid Anthropological Assessment
December 22-31, 2014



Photo credit: Denise Roth Allen, CDC

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List of Acronyms and Abbreviations

CDC	Centers for Disease Control and Prevention
EOC	Emergency Operations Center
ETU	Ebola Treatment Unit
EVD	Ebola Virus Disease
FGD	Focus Group Discussion
IFRC	International Federation of Red Cross and Red Crescent Societies
IMS	Incident Management System
KII	Key Informant Interview
MOH	Liberian Ministry of Health

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Executive Summary

Ebola Virus Disease (EVD) home deaths occur as the result of infected persons not being detected early and sent to Ebola Treatment Units (ETU) where they can access care and have an improved chance of survival. From a public health standpoint, EVD deaths should not occur at home. Individuals suspected of being infected with EVD should be identified through case investigations or contact tracing efforts and then referred to an ETU, thus decreasing their risk of dying as well as minimizing the risk of exposing others to the disease.

This report presents results of a rapid anthropological assessment conducted in response to a request from the U.S. Centers for Disease Control and Prevention's (CDC) Epidemiology Team in Monrovia in December 2014 for qualitative data to better understand why EVD deaths were occurring at home in urban Montserrado County. Data from the International Federation of Red Cross and Red Crescent Societies (IFRC) had indicated that 30% of the 60-90 deceased persons collected weekly from ETUs and community settings in Monrovia by Liberian Red Cross burial teams between early November and early December had tested positive for EVD and nearly half of those had been collected in homes. This raised concerns that EVD case-finding and prevention efforts were not as effective as they could be.

The aim of this rapid anthropologic assessment was to identify areas where the Liberian government's strategies to reduce community-based EVD deaths could be improved. Qualitative data collection took place in the communities of New Kru Town, Sinkor, and West Point and was focused on describing community perspectives and experiences with EVD, documenting factors at the household-, community-, and EVD responder-levels that contribute to delayed care-seeking for EVD and deaths in the home, and eliciting participants' opinions on how to improve EVD response efforts in Liberia. Eleven community and contact tracer focus group discussions (FGD), two key informant interviews (KII) with contact tracing supervisors, and two days of burial team home visit observations were conducted.

This assessment found that several factors contributed to delayed care-seeking and home deaths among suspected or confirmed EVD cases in urban Montserrado County: concerns about the quality of care and lack of information from ETUs, widespread opposition to cremation, concerns about being subjected to Ebola-related stigma, concerns about the lack of food for quarantined households as well as limited access to health services for non-Ebola illnesses. Our findings also indicate that decisions about whether or not to seek health care or report a loved one's death take place in a context in which the circulation of community and first-person narratives about EVD fears and distrust of its medical/public health response efforts combined with the collapse of the non-Ebola related health infrastructure likely contributed to the occurrence of EVD-related home deaths in Montserrado County.

We presented preliminary findings from this assessment at Liberia's Ebola Incident Management System meeting in Monrovia on January 7, 2015. Results of subsequent and more detailed analyses were shared with persons working on Liberia's Safe Burial protocols in Monrovia in February 2015. We anticipate that findings presented in this final report will contribute to the evaluation of Liberia's EVD response efforts.

Introduction

When the World Health Organization (WHO) declared Liberia Ebola free on May 9, 2015,[1] a total of 10,898 suspected, probable, and confirmed cases of Ebola Virus Disease (EVD) and 4,852 deaths had been reported in Liberia.[2] Montserrado County (estimated population 1.5 million) accounted for more than half of those cases and deaths.ⁱ During the last week of June 2015, two new EVD cases were confirmed in Margibi County in a community on the outskirts of Monrovia.[3, 4]

This report presents results of a rapid anthropological assessment of factors contributing to home deaths that was conducted in Montserrado County from December 22-31, 2014. Although there had been a declining trend in the weekly number of new infections in Montserrado County since they peaked at 380 during Epi Week 38 (September 15-21, 2014),[5] at the time this assessment was conducted in late December 2014 there was still considerable concern that the trend could be easily reversed if vigilance surrounding Ebola response efforts waned.

In early December 2014, the U.S. Centers for Disease Control and Prevention's (CDC) Ebola Response Epidemiology Team in Monrovia requested a rapid assessment to better understand why EVD deaths were occurring in homes in urban Montserrado County. Data from the International Federation of Red Cross and Red Crescent Societies (IFRC) had indicated that 30% of the 60-90 deceased persons collected weekly by Liberian Red Cross burial teams from Ebola Treatment Units (ETU) and community settings in Monrovia from early November to early December had tested positive for EVD and nearly half of those had been collected in homes (IFRC unpublished data). This raised concerns that EVD case-finding and prevention efforts were not as effective as they could be. Successful case-finding is evidenced when EVD patients are detected early and sent to ETUs where they can access care, experience increased survival rates, and minimize community transmission. If effective prevention efforts coupled with early detection and contact tracing are in place, the transmission is likely to be much lower and thus home deaths also fewer.[6, 7]

To that end, this rapid anthropologic assessment was conducted to identify areas where the Liberian government's strategies to reduce community-based EVD deaths could be improved. Qualitative data collection took place in the communities of New Kru Town, Sinkor, and West Point and was focused on describing community perspectives and experiences with EVD, documenting factors at the household-, community-, and Ebola responder-levels that contribute to delayed healthcare-seeking for EVD and to home deaths, and eliciting participants' recommendations for improving EVD response efforts in Liberia

The design of this assessment was based on formative work conducted from November 24-December 13, 2014 by CDC's two-person team of medical anthropologists, Denise Roth Allen and Romel Lacson. Dr. Allen led the rapid assessment investigation in the field and compiled this report.

Some of the results from the formative work and rapid assessment were shared in real time or soon thereafter with members of CDC's Epidemiology Team and Liberia's National Task Force for Dead Body Management while Drs. Allen and Lacson were still on the ground in Monrovia.

ⁱ As of May 14, 2015 a total of 6,090 cases and 2,710 deaths have been reported in Montserrado County. Of the 6,090 total cases, 1,797 were laboratory-confirmed.

Denise Roth Allen presented preliminary results from the rapid assessment at Liberia's Ebola Incident Management System (IMS) meeting in Monrovia on January 7, 2015, a week after the assessment was concluded. Results of subsequent and more detailed analyses were shared with persons working on Liberia's Safe Burial protocols in Monrovia in February 2015.

Background: Burial Policies in Montserrado County during the EVD Crisis

The first EVD case in Montserrado County was detected in the borough of New Kru Town in June 2014.[7-9]. On August 4, 2014 the Liberian government imposed a policy of mandatory cremation in Montserrado County to contend with the large number of abandoned bodies on Monrovia's streets and increasing local opposition to mass burials in community settings.[7, 10, 11] With the exception of patients who died at the Eternal Love Winning Africa (ELWA)-3 ETU in Paynesville which operated its own crematorium, all persons who died in Montserrado County, including the capital city Monrovia, were to be taken to a crematorium located in Marshall that was donated by the Indian community.[5, 12, 13] Burial teams in Montserrado County initially operated under the auspices of the Liberian Ministry of Health (MOH) until early August when the Ministry of Internal Affairs assumed responsibility.ⁱⁱ[14] The Liberian Red Cross began deploying burial teams in Montserrado County on July 27, 2014 under the auspices of the IFRC.

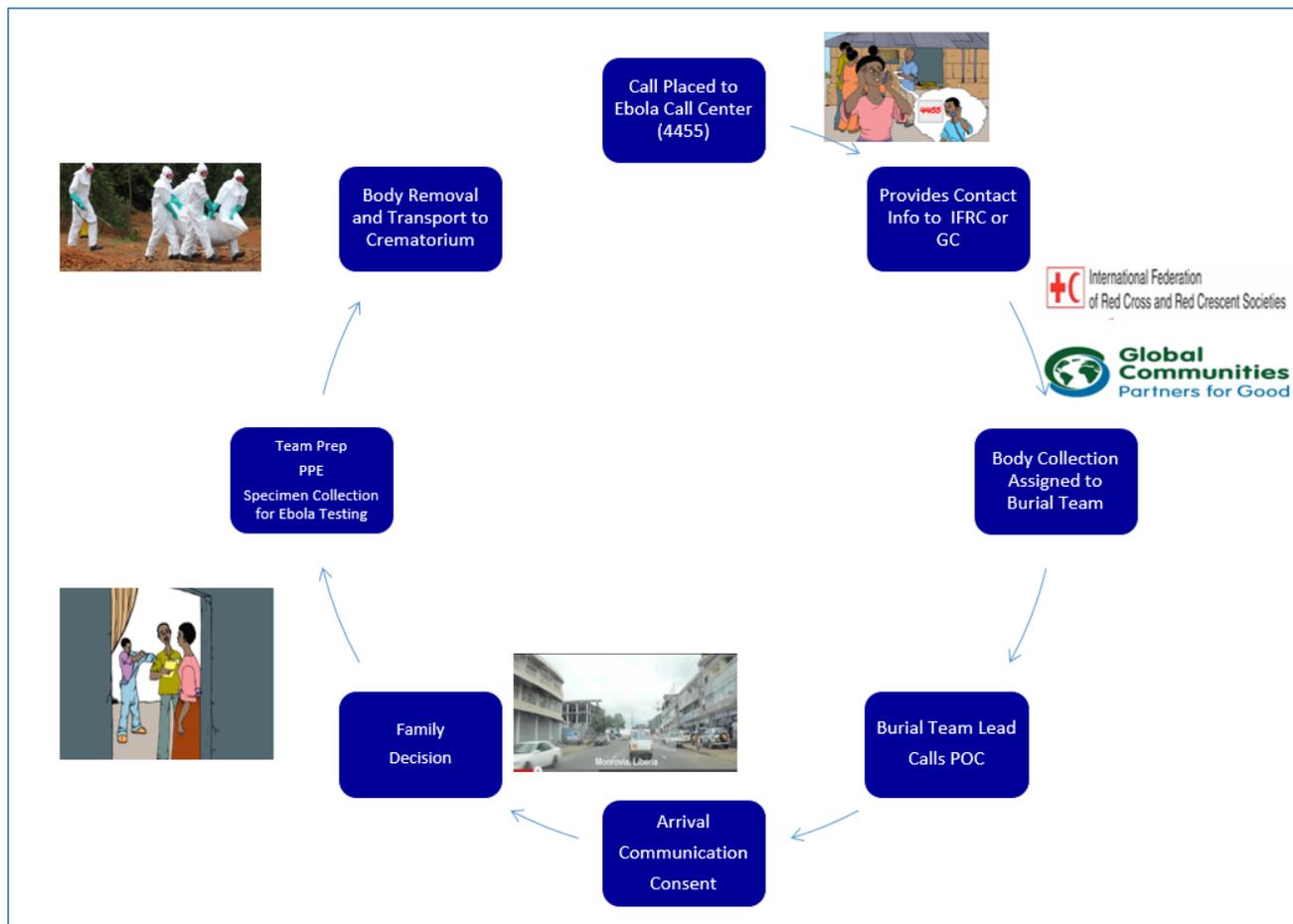
Government and Red Cross burial teams were responsible for collecting the deceased from ETUs (except ELWA-3) and community settings in Montserrado County and transporting them to the crematorium. In September 2014, Global Communities, an international non-profit organization, took over financial and logistical support for the government burial teams. Once Global Communities came on board, the responsibility for the collection of bodies in Montserrado County was split between Red Cross and Global Communities burial teams such that the Red Cross covered urban Montserrado County and Global Communities covered rural Montserrado County and the rest of the country.

Although the policy of mandatory cremation in Montserrado County was officially abolished on December 30, 2014, [15, 16] mandatory cremations effectively came to an end on December 24, 2014, a day after President Johnson Sirleaf officially opened the national cemetery. Located on 25 acres of land near Disco Hill on the outskirts of Monrovia in Margibi County, the cemetery is currently managed by Global Communities which also had primary responsibility for the development of the site.[17]

During the period of mandatory cremation (August 4-December 23, 2014), the process for reporting and removing the deceased from homes in Montserrado County was comprised of several steps (Figure 1). The first step consisted of a family or a community member calling the Ebola Call Center to report a death and provide information about the location of the corpse. Depending on whether the deceased had died in urban or rural Montserrado County, the call center would contact the Red Cross or Global Communities, who, in turn, would assign the body collection to one of their burial teams. As part of the formative work conducted in preparation for this assessment we conducted observations of Red Cross Burial Team in late November and early December while the cremation policy was still in place. Summary findings from those observations are presented in Appendix A.

ⁱⁱ At the time of the assessment, Liberia's Ministry of Health was known as the "Ministry of Health and Social Welfare". In keeping with the current nomenclature, we use "Ministry of Health" in this report.

Figure 1. Steps in the process for removing deceased persons from homes in Montserrado County during the period of mandatory cremation, August 4-December 23, 2014.



Assessment Objectives

Overall Objective

To describe the reasons behind home deaths in urban Montserrado County with the aim of contributing to government strategies to reduce community-based Ebola deaths.

Specific Objectives

1. Describe community perspectives and experiences with Ebola
2. Document household-, community- and responder-level factors that contribute to delayed care-seeking or Ebola home deaths
3. Elicit community and responder opinions on how to improve Ebola response efforts in Liberia

Methods

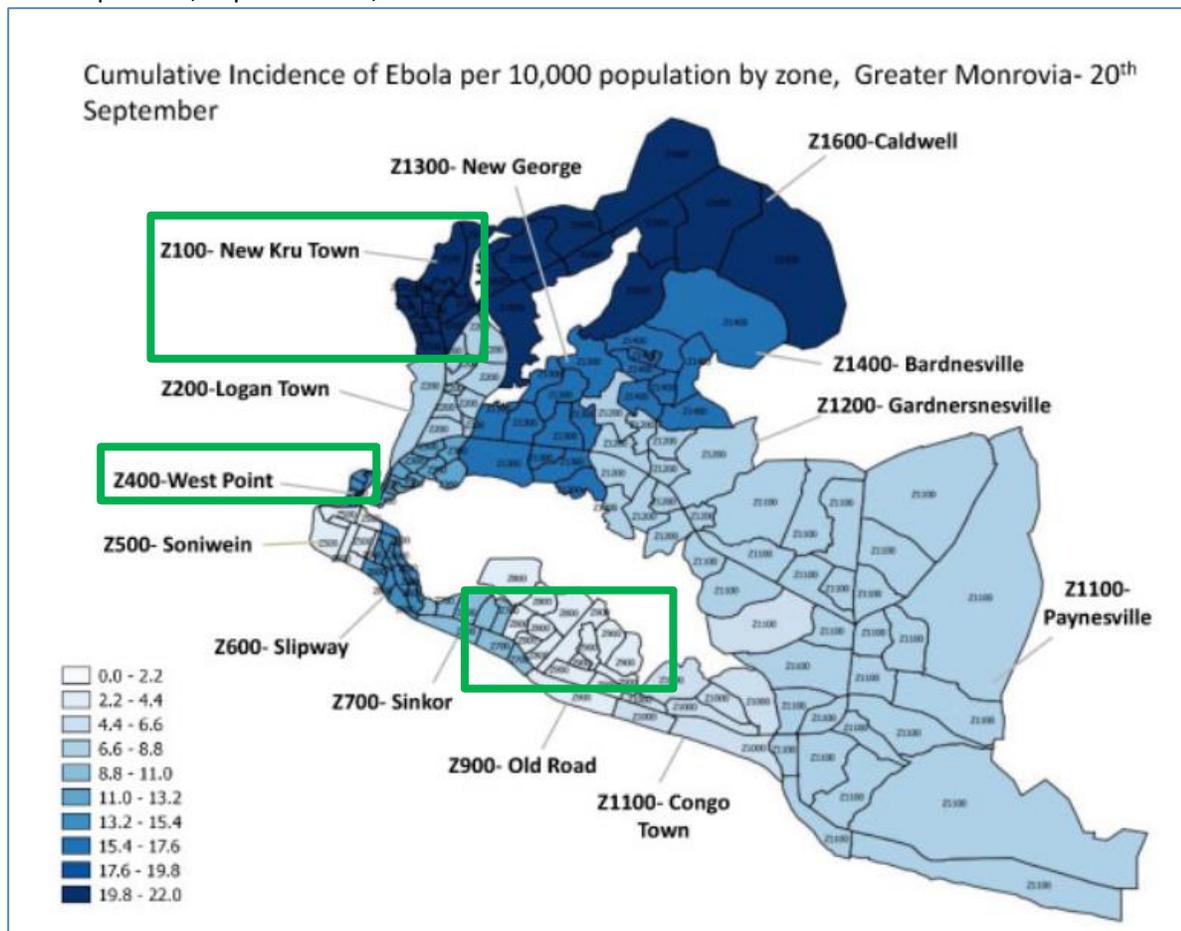
Ethical Review

This assessment received approval from the University of Liberia-Pacific Institute for Research & Evaluation (UL-PIRE) Institutional Review Board. In addition, it was determined to be non-research by CDC's Scientific Regulations Advisor for the Emergency Operations Center (EOC) Ebola Response under the category Public Health Practice: Public Health Emergency Response and Program Evaluation.

Site Selection

Qualitative data were collected in three communities in urban Montserrado County (Monrovia) over a ten day period from December 22-31, 2014. The borough of New Kru Town and the township of West Point were purposively selected based on both having experienced high numbers of EVD cases and home deaths. A neighborhood in Sinkor was purposively selected to document EVD experiences within a Muslim community. A map indicating the location of the assessment sites and their cumulative incidence of EVD cases at the height of the epidemic on September 20, 2014 in Monrovia (Epi Week 38) is shown in Figure 2.

Figure 2. Location of assessment sites in Monrovia in relation to cumulative incidence of EVD at the peak of the epidemic, September 20, 2014.



Map source: Mother Jones, Sept 24, 2014 citing Liberian MOH data.

Data Collection Methods

Three qualitative data collection methods were used in this assessment.

- *Focus Group Discussions (FGDs)* were conducted with community leaders, community members, and contact tracers. One community leader FGD and two community member FGDs were conducted at each of three assessment sites for a total of nine community FGDs. The community FGDs explored participants' knowledge and experiences with EVD and perspectives on the government's burial policies. A total of two contact tracer FGDs were conducted: one each in West Point and New Kru Town. The contact tracer FGDs examined participants' job responsibilities and experiences as Ebola responders in their communities. All FGDs were digitally recorded and the interviewers used a topic guide to guide the discussion. A copy of the community and contact tracer FGD topic guides are found in Appendices B-C.
- *Key Informant Interviews (KII)* were conducted with persons who supervised contact tracers in West Point and New Kru Town. KIIs examined aspects of contact tracing and the participants' experiences as contact tracing supervisors. Both KIIs were digitally recorded and topic guides were used to guide the discussion. A copy of the KII topic guide appears in Appendix D.
- *Observations* of Red Cross burial team visits were conducted to document aspects of burial team home visits with a focus on communication between burial team and family members.

The purpose of using several qualitative methods in combination is to triangulate and validate results across different methods and participant groups. In addition to providing checks on the accuracy of information collected, data triangulation can provide insight into particular issues from the perspectives of different types of participants.

The assessment field team was comprised of three members: Denise Roth Allen (principal investigator) and Soko Kamara and Kula Kiazolu (field interviewers).

Participant Selection

The selection of FGD and KII participants was purposive and differed by site and participant type.

New Kru Town:

The borough of New Kru Town is made up of 25 communities, each of which is headed by a chairperson. For the community leader FGD, the general chair was asked to recruit the chairpersons from ten communities hardest hit by EVD. These chairpersons were then asked to recruit one man and one woman from their communities to participate in the male and female FGDs. For the contact tracer FGD, six contact tracers who lived and worked in the borough were invited to participate. The supervisor KII was conducted with the contact tracing supervisor for that area.

The community leader FGD was a mixed gender FGD comprised of 8 male and 2 female chairpersons plus the chair of a women's group. Although the original plan for the community FGDs was to conduct separate FGDs with 10 men and 10 women, only six men and six women showed up on the day the FGD was scheduled so they were combined into one FGD. A second

community FGD comprised of four men and four women from a neighborhood near the government hospital in the center of New Kru Town was conducted a week later. Due to scheduling conflicts, only three of the six contact tracers were able to participate (2 male, 1 female).

West Point:

The township of West Point is divided into seven zones comprised of several blocks each. Participants for the West Point community leader FGD were recruited based on their being a zonal, block, religious, or other community group leader. The community leader FGD was comprised of 7 men and 4 women. Recruitment for the community member FGD was based on gender and zonal residence. The female FGD was comprised of seven participants and the male FGD of only six due to scheduling conflicts. The contact tracer FGD was comprised of six contact tracers (4 male and 2 female) who lived and worked in West Point. The supervisor KII was conducted with the contact tracing supervisor for that area.

Sinkor:

Muslim community leaders were approached by one of the field interviewers who lived in Sinkor to gauge their interest in participating in the assessment. They agreed and facilitated recruitment of male and female Muslim community members. The community leader FGD was comprised of one male religious leader and two male Muslim community leaders. The female community member FGD was comprised of six participants and the male community FGD was comprised of eight.

A summary of the specific assessment objectives by participant type and data collection method is presented in Table 1. A summary of interviews by assessment site, data collection method, and participant selection criteria is presented in Table 2.

Table 1. Specific assessment objectives by data collection method and participant type.

Specific Objective	Data Collection Methods	Participant Type
Describe community perspectives and experiences with EVD	FGD KII	Community leaders Community members Contact tracers Contact tracer supervisors
Document responder-, community- and household-level factors that contribute to delayed care of EVD home deaths	FGD KII Observations of burial team home visits	Community leaders Community members Burial team members
Elicit community and responder opinions on how to improve EVD response efforts in Liberia	FGD KII	Community members Community leaders Contact tracers Contact tracer supervisors

Interviewer Training

Field interviewers received a two-day refresher training in qualitative data collection methods to supplement an intensive two-week field interviewer training they received in January 2014. Prior to the start of data collection, the community FGD topic guides were piloted in a community located on the outskirts of Monrovia.

Consent and Interview Procedures

All participants were asked to provide consent prior to being interviewed and each consent process was witnessed by someone not affiliated with the assessment field team. The field team member responsible for conducting the interview read the consent form aloud to the participant(s). Persons who agreed to be interviewed provided their signature or thumbprint to indicate their consent. Upon completion of the consent process, each participant received a copy of their signed consent form. A copy of the FGD and KII consent forms appear in Appendix E-F.

One to two field team members were present at each interview. All interviews were conducted in either Liberian or Standard English and digitally recorded. With the exception of one of the community leader FGD, which was conducted by the principal investigator, community FGDs were conducted by a field interviewer. The principal investigator also led the contact tracer FGDs and supervisor KIIs and conducted the burial team observations.

To protect participant confidentiality, the names of participants are not included in this report. Similarly, to protect the confidentiality of the assessment communities wherever possible we use the pseudonyms “Site A”, “Site B” and “Site C” when presenting quotes from the different assessment sites.

Data Management and Analysis

Immediately upon completion of each interview, the interviewer filled out an interview summary form. The interview summary form summarized the interview’s main themes and documented characteristics of the interview such as the setting, the participant’s level of engagement, FGD dynamics, suggested topic guide revisions (where relevant), logistical challenges encountered, etc. The interviewer then reviewed the interview digital recording and completed an expanded note form based the content of the digital recording. The principal investigator created transcriptions from the digital recordings. Electronic copies of interview summary forms, expanded notes, and transcriptions were entered into NVivo 8 and content analysis was conducted by the principal investigator.

Table 2. Summary of interviews by assessment site, data collection method, and participant selection criteria.

Site Selection Criteria	Assessment Site	Data Collection Method	Participant Selection Criteria	# of Participants	Total # of Participants
High number of EVD cases and home deaths	New Kru Town	Community leader FGD	Male and female chairpersons from ten communities hardest hit by EVD	11	35
		Community member FGD	Men and women from ten communities hardest hit by EVD	12	
			Men and women from ethnic-specific neighborhood	8	
		Contact tracer FGD	Male and female contact tracers who live and work in assessment community	3	
		Contact tracer supervisor KII	Supervises contact tracers in assessment community	1	
High number of EVD cases and home deaths	West Point	Community leader FGD	Male and female community leaders (zonal or block leaders, religious leaders, community representatives)	11	31
		Community member FGD	Male community members (by zone)	6	
			Female community members (by zone)	7	
		Contact tracer FGD	Male and female contact tracers who live and work in assessment community	6	
		Contact tracer supervisor KII	Supervises contact tracers in assessment community	1	
Muslim community member	Sinkor	Community leader FGD	Religious or community leader	3	17
		Community member FGD	Male community member	8	
			Female community member	6	
Total Number of Participants					83

Results

We present the results in roughly the same order the questions appeared on the community FGD topic guide: from participants' general comments about EVD, to what happens when someone gets sick, to reasons why some people might decide to not seek treatment if they suspect they or a family member has EVD, to what happens when someone dies at home. We also present a summary of participants' recommendations with respect to government strategies to reduce EVD home deaths. Although this sometimes results in a repetition of themes, we think the repetition demonstrates their salience in the assessment communities.

General Comments about Ebola

Participants' responses to the initial question about what people in their communities were saying about Ebola fell under two overarching themes: 1) there was an initial disbelief that Ebola was real and 2) there was/is a high level of distrust and anger at the government's initial response efforts. Their responses also provide insight into how and why Ebola-related beliefs and behaviors changed over time.

Initial Disbelief Ebola Was Real

Many participants acknowledged there had been a lot of disbelief and misinformation about Ebola during the early months of Liberia's EVD epidemic in Montserrado County. Most attributed the source of that disbelief to three main factors: 1) to the symptoms of the disease itself, 2) to beliefs in supernatural causes, or 3) to beliefs in several conspiracy theories circulating via word of mouth, through local papers, or on the internet that Ebola was a man-made virus and/or a money-making scheme.

We never knew, you know, how it would treat us. So we all were just making fun out of it...And the only thing about it now, it has the symptom almost like the normal sicknesses that we have. So mainly this is what we overlooked. It has the very symptoms like malaria, the symptom like diarrhea, the symptom like vomiting, the same malaria also. So we were just playing with it, playing with it, playing with it until it got rid of us. (Community member FGD, Site C)

And we said "Ok, the running stomach issue have been going on in Liberia, especially Montserrado. Cholera came here." And we was in doubt whether it is Ebola or it is this cholera that came again. (Community member FGD, Site A)

This deadly disease called Ebola within the boroughs, started from my community, in the whole borough it started from my community. And quite frankly, there was all sort of information about those who passed on. Some said the family members got involved with some ritual and as a result of that it started hunting the family. The parents died in Lofa. One of the daughters came to my community with the rest of the family there and made contact and people started dying. So all along in our community we just thought that that had been the case. So the issue of Ebola was not really considered, but rather something ritual. (Community leader FGD, Site C)

At first we had problem convincing people that Ebola is real and that Ebola is a disease. And many people thought Ebola was something that had to do with some African sign, like witchcraft or something was connected with Ebola. That was one of the main thing. And secondly, many people

also, people in the community also thought that Ebola was something that was kind of artificial and it was manufactured...(Community member FGD, Site C)

After certain time, we start getting some information too from the internet, I think one of our brother have it here [referring to a video clip on his phone]. And some people came here...they displayed it...People went to watch it...And this fellow who stress that this Ebola is a biological weapon that brought in Liberia, Guinea, and Sierra Leone. Other country refuse it. But it was Liberia, Sierra Leone, and Guinea accepted for this biological weapon to be tried for \$144 million US dollar. (Contact tracer FGD)

Although participants noted that some in their communities continued to doubt that Ebola was a real illness, they acknowledged that most had eventually accepted it as truth and began taking active measures to prevent it. Having experienced the death of a loved one, friend, or neighbor emerged as the key factor in those changes.

What I got to say about Ebola, those that say Ebola not real, maybe someone not die from them. But some of us, people died from us, and we saw many thing about Ebola. Because every day we see our friend human being in the car, the whole truck full Ebola [bodies] came out to carry, to go burning [cremate]. Up to today, our hearts burning. Some of us get [high blood] pressure up to today. We can't come to ourself. We suffer, we suffer, up to now we still suffering...Ebola is real. (Community member FGD, Site A)

Firstly when the virus enter the country, few people, uh more people I mean, they tried to doubt the information that the virus "That lie, the government want to eat money." But as time go by, the people start dying in July, the massive death in July, in August, late, lately September, massive try to believe that Ebola exist, they try to believe that Ebola exist...(Contact tracer FGD)

For my community, actually, Ebola was a strange disease, so they found it difficult to believe it...But now as we speak currently, if I would say on a percentage, we can say 65% of the people are now convinced there is something called Ebola, while 35 of them, out of the 35, 20% believe that this virus exist but it's man-made virus and 15% does not believe anything of the kind. (Community leader FGD, Site C)

Anger and Distrust

Responses to our initial general question about Ebola also revealed a lot of anger and distrust of authorities. These sometimes included general comments about the government or specific comments about government-related services. Some participants cited the initial failure to close the borders or the inadequacy of initial Ebola health education efforts as proof authorities did not have their best interests at heart. Others cited the closure of health facilities, especially the lack of health services for pregnant women, with some noting that even during Liberia's civil war, health facilities had remained open.

And me, I vex [angry] with Liberian government, because Liberian government not take it to be serious thing. (Interviewer[!]:Ebola?) To take Ebola to be serious thing sooner. And the time that Ebola come, our people were dying, and some of them, they not die for Ebola...[E]ven when your child skin hot, they will say "Oh, don't touch your child. Put glove in your hand." And you carry the child to the hospital, they will not touch him. Even when the war come in the country, even the war

come, the fighting go all over, the hospital can be open. But the Ebola come, they close it...the hospital. Even when pregnant woman in pain, when you go to the clinic, they will say "You get Ebola." We saw it on TV, one woman she delivered twins on the street. Twins! It not supposed to be like that...[W]e hear news that only Liberia was not even serious about Ebola business. Because they take human being just like animal. Animal!...Of course, the one that made Ebola serious, we used to bathe body. It made the Ebola serious. But of course when the child sick, our hospital have to be open! To get medicine! ...[If] you not take medicine, how you will get better? You want to get better! So that one, I vex with the Liberian government. (Community member FGD, Site A)

Although we have heard other people say now Ebola is not real, other people saying Ebola is real, but other people have feeling, especially me, if education for Ebola have come sooner, properly, and if it had gone widespread like now, people wouldn't have died more like how it happened. Because the preventative measure now is sooo accurate. If people educated from the beginning like that, people were not gonna die like that. So for me, and from what I've heard from people, that's where my bad feeling come. If Ebola—Ebola is real for me, I know that Ebola is real—but if the education was done early on, doctors were not gonna be refusing people. But because even the doctors and nurses were not educated fully, so they were afraid because they too would have died, so they abandoned people, things happened. That's it. (Community leader FGD, Site B)

What Happens When an Ebola Case is Suspected

In order to get a sense of what happens if a household or community member is suspected of having Ebola, we asked three broad but related questions: 1) What do people usually do if they think they or a family member has Ebola, 2) What happens to people who live in the same house? 3) What happens to the friends and neighbors they know? When we specifically asked if there was a difference in how sick children, adults, or the elderly were treated if Ebola was suspected, nearly all noted there was no difference. The response below is typical.

The same thing you do to the child is the same thing you do to adult, because it is a virus. It can affect you at the same time as the baby now. (Community member FGD, Site B)

As indicated below, participants mentioned a range of actions that household and community members take if Ebola is the suspected cause of illness, from calling the Ebola hotline immediately, to concealing one's illness, to leaving the household or community altogether. Some also noted the various response efforts that are set in motion once a suspected case is identified. Some participants alluded to the stigma that individuals, households, and communities are sometimes subjected to when Ebola is suspected, while others mentioned stigma outright.

Immediately Call the Ebola Hotline

Some participants said people usually called the Ebola hotline at the first sign of a fever or other suspicious symptom. This was also sometimes referred to as calling "the Ebola center," "the Ebola team," "the Ebola people," or simply "4455" which is the number for the Ebola hotline. In some cases, community leaders—including members of the local Ebola task force if one existed—were also contacted. Some participants also mentioned the protective measures that household members take either before or after Ebola responders were called, such as isolating the sick person or using items from the home protection kits that some reported receiving.

But sometimes you don't know what is Ebola. Immediately you get fevers and you start calling 4455. (Community member FGD, Site C)

If somebody have Ebola in your environment or like in your house, like the advice the people give, if you can't get to the Ebola center to call them, you should keep the person in the house...somewhere where no person will enter there. (Community member FGD, Site A)

Once that person is showing sign and symptom we are being taught to carry on protective measure, to protect ourselves...advise the person to go to the nearby ETU center, call the hotline, call the hotline. They come and you know take the person...[W]e protect ourself, we wear our protective something that they give us from the Ministry of Health. Every household has a kit, and then they went and carried on the training and tell us how to use that kit. (Community leader FGD, Site C)

The first thing you do before even taking preventive measures, you have to call the Ebola center. You call the Ebola center there, then you take the preventive measures...You have to spray around the Ebola patient, you don't touch, okay? You don't go near the patient, okay, you wear your long dress. Maybe sometimes you can be vomiting this and that, you have to spray around the vomiting area. (!: What do you use to spray?) Chlorine! All the chemical that was supplied by the Ministry of Health that was here. (Community leader FGD, Site B)

It was also noted that some community members contact the Ebola responders or local authorities unbeknownst to the sick person or the affected household. Sometimes those cases turned out to be Ebola but sometimes they did not.

[I]t happened to one of our brothers here, he died...He was not well for just 2 days. They were giving him treatment in Caldwell. In the community, somebody within the community, not known, called the next day. When the people came and said "Oh"—at that time he was sitting down, just how you and I sitting down talking—the people came and said "Oh, we learned that Ebola patient is in here. They called us...to come for the person." They give the name and everything. Then he said, "Okay, it is my name...If they say that I have Ebola [I will go]." He himself walked and got in the car, in the ambulance. (Community member FGD, Site C)

There was a guy who almost like he was not well but he just say to his friend, "I have a headache, my head is hurting." So what happened is that he never knew that this guy had the contact number of this task force. The guy just went behind the house and just called "There's a guy sick here." He never expected this. Right away he just see ambulance at the house...[W]hen they saw the guy they had to pick the guy straight to the ETU. So that kind of stigmatization. Later they could realize that it was not Ebola...It was typhoid they were treating the guy. (Community member FGD, Site A)

Others mentioned the Ebola response efforts that kick into gear as soon as a suspected case is identified, such as the mandatory 21-day quarantine period for the sick person's contacts or various community policing activities:

I noticed if a person in my community has Ebola they quarantine the person for 21 days. If after 21 days no signs or symptoms then the person is release. (Community leader FGD, Site C)

That's where the neighbor come in, making sure to call the 4455, to make sure that that particular area is quarantined. (Community member FGD, Site B)

In some quarter, in some area, they blow alarm...“We have a sick person here-o. They vomiting-o.” So people do that. But not all communities did that. Those that concealed the information, you know, precipitated the spreading of Ebola. (Community leader FGD, Site A)

Adopt a Wait-And-See Approach

Another option is to adopt a wait-and-see approach while giving the sick person “first aid drugs” in the hope they will get better. “Malaria tablets,” antibiotics, Flagyl, and paracetamol were the common drugs mentioned. And in contrast to what was noted above, some participants’ comments about buying chlorox or gloves in local shops indicate that not every household had received a home protection kit.

But first of all, you don't even know that you got Ebola. So, the only thing you do, when you having to get the symptoms that has to do with headache, running stomach, other diseases, normally you try to apply those standards that we used to take first...You take your malaria tablet, you take your, how you call it, for the stomach to stop, you take that tablet. Sometime you observe yourself or your family members. If you see it is continuing then of course, you try to bring them right here at the ETU, you bring them here. (Community member FGD, Site C)

Ebola is very complicated disease to admit, because everything we pass through in Africa it is measured in Ebola. Malaria is Ebola. Diarrhea, dehydration...Typhoid, typhoid grab you almost like Ebola also. You don't know whether that Ebola so that why it sometime good to have some first aid medication at home. That's why if you get the symptom of Ebola, what you do, you start the first aid...You got typhoid, you got cipro [ciprofloxin]. You can use cipro. You can, if it explain weaknesses in your body, you can use cipro. You can use brofin [ibuprofen]. If that headache, paracetamont [paracetamol]. You can try doxycylun [doxycycline], it is one of the best drugs for dehydration, that's the antibiotics, if you start with that. If it can't work, then you have to report yourself, as an elder, you have to report yourself to Ebola center, because earlier is better. (Community member FGD, Site A).

We said “Let's make sure that the vomit don't touch us.” So we got ourself and then hurriedly we went [to a shop] to get chlorox. “Make sure, look just make sure that the thing don't touch you. Find a glove, clean [the child's] mouth, clean her.” And then we hurried, went and get a chlorox and put it in the water and then we started using it to clean her up. So the next thing we thought to do, to get some Flagyl to see, because that one thing we can get easily. Since the issue of the Ebola started, there are few drugs that are prescribed. So we try our best to get them in our house. (Community leader FGD, Site B)

Conceal the Illness from Others

Participants also reported that people sometimes hid their own or a family member’s illness, often out of fear. While many participants specifically mentioned the fear of being taken to an ETU, some spoke about the fear they felt if they suspected they might be experiencing an Ebola symptom themselves.

So even if you have somebody that is, that got the symptom of Ebola, let it be by the stomach running, diarrhea, vomit and all that stuff, you want to conceal the information to treat the person by buying medicine secretly and come and treat the person. So that also degenerated until many of

our family member died. Concealing Ebola patient. (Community leader FGD, Site A)

When I saw the Ebola car passing...I bring [the child] back into the house because I was afraid. Your person going in the hospital, they don't come [back]. (Community member FGD, Site A)

Like for example, I can use myself as an example. Once upon a time, I was having cold. And you know this chronic cold, where I have to bleed from my nose. And then I was so afraid and I did not allow anybody to know...[T]he way people disseminated the info at the time, people were afraid. And you know, by the time you say "Look, I'm having running stomach: '5544' [meaning "4455"]. They come to pick you up and carry you [to the ETU]. (Community member FGD, Site B)

Avoid the Suspected House

Participants also noted that sometimes people avoided particular houses in the community, either because someone who lived there had died of Ebola or because a current occupant was sick. Although some community members might help the members of the suspected household out by hauling water for them or bringing them food, this was not always the case.

Their reaction to that house, the first thing...whether that Ebola, not Ebola, when they hear somebody sick in that house, completely they have concluded that Ebola. So right there it's stigmatization. You have been stigmatized in that house. (Community member FGD, Site A)

There's a man who got sick and died in the ETU and some of his children got sick and started dying. Then the people in the area got afraid, they stopped going around the house, they came to me by telling me that I should stop the people from drawing water from the pump, the children that remained in the house with their ma. So I the chairperson now, I the one use to haul the water and carry it...I just put it right to the door's mouth and tell them come get the water...Even down to food, I myself used to carry food for the rest of the family that live in the house. I was doing that for 2 to 3 weeks before I saw other people come in to help me, you see? So when those things happen people in the area they be afraid of the people that sick in the house, they can go away from them. (Community leader FGD, Site C)

Leave the Home or Community

There were also reports of people moving out of their homes or communities completely. Participants offered a variety of explanations as to why such movements occurred, such as wanting to avoid being associated with an Ebola-affected area, to avoid conflict from informing on sick neighbors, or to avoid becoming infected themselves. Sometimes these movements out of a home or a community resulted in the sick being left to fend for themselves.

[S]ome people when another community be affected, they will be trying to avoid [being] stigmatize. So they will migrate from another community to go to a community where no one know nothing about what happened to their families or their loved ones. (Community leader FGD, Site C)

If you are to take a phone and call the 4455 number people start to feel bad about you. So what people normally do...just decide to leave the community and go to another place. So there was an exodus of people leaving from one community to another community because they didn't want to call the number to have any, to create, to create animosity. So they left, and it just remained that way. (Community member FGD, Site C)

I: So do you know what happens if they isolate the person and the person is by themselves? How do they get food?

P1: So that cause the death of the person. No food.

P2: No food, nothing.

P3: They have nobody talking to them, everybody afraid to come to you. Nobody bring you food, no water. You stay there for a couple of days...

I: And that's it? (Yeah)...

P1: Everybody will hear you screaming, but everybody afraid...

P2: If the person dies, then that's the time they call the people.

I: So you've heard that has happened before?

P3: It happening!

P1: We have an uncle that died through that...People left the area.

I: Wow, completely? Even his wife left?

P1: No, my uncle was not married, but he had family around but they all ran away from there.

(Community leader FGD, Site A)

Others noted that sometimes it was the sick who left either out of fear they would be taken away if they stayed or as the result of pressure from community members. One participant mentioned the case of a man who fled the community after his girlfriend, who had been experiencing Ebola-like symptoms during a recent visit, died three days after she had left his home. Another cited the case of a sick visitor who was pressured to leave.

We also had the experience, the guy who came from Cape Mount, he was sick. But the problem here is that the family were afraid to spread the news over to the community here. They hide him in their place. And so, the next morning when we got the information, we said "But what happened? And he came all the way from Cape Mount with this thing?" So the mother decided to take him out of the community. (Community leader FGD, Site B)

Nevertheless, some participants acknowledged that as a result of increased Ebola awareness, these types of movements or "Ebola migrations" (as one participant characterized them) had declined over time. Those who left (or were forced to leave) were now being tracked down and sent back.

[T]hat was then. But when people started getting to know the facts about Ebola, the issue of Ebola migration, so to speak, it also become difficult. Because if someone find out that, maybe someone was staying in a particular house, or maybe someone had died there, another person sick there and you left that house or that community for...another place, and if they get to know they will send you back. (Community member FGD, Site C)

Reasons for Not Seeking Treatment When Ebola is Suspected

In order to help understand why Ebola deaths were occurring at home, we asked participants why people might decide not to seek treatment if they thought they or a family member had Ebola. Fear of being subjected to the various actions that follow an Ebola diagnosis emerged as a key factor in people's reluctance to seek treatment: fear of being sent to an ETU, fear of cremation if a loved one died, as well as the fear of being placed under household quarantine. And similar to what has been noted above, stigma was also an overarching concern.

Fear of ETUs

Many of the fears about ETUs that participants mentioned were either based on what they had personally experienced when a family member was sent to an ETU or what they heard others had experienced. Participants spoke about loved ones or friends who never returned, who were not well-cared for or encouraged while there, or about whom they had received no information at all. Although many participants acknowledged that the quality of care at some ETUs had improved over time, in other ETUs it had not.

People believed that when they go there, they just kill them. A lot people conclude that when you go to that center they will kill you, they will finish you. So people get sick they say, "Let me just stay home and die." (Community leader FGD, Site A)

At the beginning now, there was no care, there was no food, they would dash you [abandon you]. And you know, at the end you yourself would die...So more people prefer to sit at home and [use] our traditional health medicine. (Community member FGD, Site C)

And when they carry you, there is no information is coming back, and at that time it was so crucial to the extent that when people leave and go to ETU, they don't come back. No information, no communication as compared to now...Whether they are dead, you don't know, what happened about them we don't even know, you understand? So because of this, people were so much afraid, even to the point where they would rather die by themselves then to go to hospitals. (Community member FGD, Site B)

The lack of information about ETU patients also posed problems for contact tracing efforts in that sometimes family members refused to cooperate in the absence of information about their relative's status.

You see, for each time we take the patient to the ETU, we don't have redress. They carry our contact number as a tracer, they come for the patient, carry our contact number as the tracer or maybe somebody from the family. But they never one day call to give us the status...And for each time we went to the house to monitor, the people will begin, in fact they will get vex [angry]. They don't want to see us...So that's the major problem. It can really embarrass us. (Contact tracer FGD)

Others mentioned concerns about the chemicals that were sprayed on people either before or after arriving at an ETU as well the stigma people were subjected to after returning home.

You want to wonder whether it is the chemical that is causing these people to go off [die] and what have you. So people have been saying when they spray you, you will die before you even get to the hospital. So for this reason, people will get frightened, people will get frightened to go to the clinic. (Community leader FGD, Site B)

[E]ven if it is not Ebola...when you come back, when the health team bring you back in your community...everybody will start avoiding you, everybody [will say] you had Ebola, nobody will go around you again. So it is stigma. (Community member FGD, Site C)

Opposition to Cremation

Nearly all participants expressed their strong opposition to the government's cremation policy

which mandated that the bodies of persons who died in Monrovia be cremated, a practice many participants also referred to as “burning bodies” or “crimination.” Most who voiced their objections to the policy did so on cultural or religious grounds. Others objected to cremation on the grounds that the sick person had not died of Ebola. As discussed later in this report, the opposition to cremation was also cited as a major factor in people’s decisions to conceal a loved one’s death.

Crimination [cremation] has never been our culture. We hate it, we dislike it. In any way we cannot appreciate it, we cannot welcome it. We are denouncing it in the strongest terms that it be abolished. (Community leader FGD, Site C)

[T]he people used to be afraid when somebody died that they would burn the body. Crimination of the body...In our religion, we don't allow that. (Community leader FGD, Site A)

The people feeling bad. Because Liberia have a different culture. Liberia have a different system. That only the Hindus and Buddhists, India can burn body, but never in our days to burn someone body. So it's not part of our culture. (Contact tracer FGD)

P1: Some people believe that their people did not die from Ebola and they don't want to see their people burn...Like maybe before the Ebola come you were already sick, something like that. And then, they don't want the people to carry the body and just burn it like that. They said that it is not our style to burn somebody.

P2: Even if they even know that the person died from Ebola, even they don't want that person to be burn. Because in our, in our country, our religion we feel it is too wicked, it's barbaric to burn somebody. (Community leader FGD, Site B)

While participants were nearly unanimous in their opposition to the government’s cremation policy, a few expressed some qualified support. One noted he was in favor of the policy as long as everyone was treated equally, while another supported it as long as family members were shown their loved ones’ ashes. Another expressed her full support of the government’s cremation policy noting the potential risk of ground water becoming polluted if the graves were not dug deep enough.

Experiences of Being Turned Away from Health Facilities

Some participants referenced past failed attempts at accessing treatment in government health facilities as the reason they decided not to seek care. This often resulted in decisions to self-treat at home instead. Comments about being turned away by health workers or the general lack of health services for non-Ebola illnesses were common, as were complaints about the lack delivery services for pregnant women.

People refuse to go to the hospital because when they go to the hospital, they can't find [anyone] to turn to. Everybody afraid...The nurses are refusing you, even the pregnant women up to this time. Pregnant women have been denied whenever they been delivered. So people afraid. (Community leader FGD, Site C)

[I]f someone got sick with headache, you go to the hospital, no hospital open, no doctor... Everybody afraid because nobody know who is who...The doctors who are supposed to treat the woman that is

in pain is not there. Now the woman go to give birth, she die...So people were just dying like that. (Contact tracer FGD)

Concerns about Being Quarantined

The policy of quarantining people who had been identified as a contact of someone who had been diagnosed or died of Ebola was another reason cited for some people's reluctance to seek treatment if someone in their household became ill. Sometimes the concern was that the household would be erroneously quarantined for a non-Ebola illness.

[T]his whole thing quarantine, the group quarantine, because you don't even know that maybe you will have some old sickness that have to do with [high blood] pressure, with diabetes or what have you, you know that what you got. (Community member FGD, Site C)

Others mentioned concerns about accessing food and other essentials while quarantined. The lack of food for quarantined households was also a common theme in our interviews with contact tracing staff. All noted that many people were refusing to comply with the quarantine because they needed to search for food to feed their families. This meant that contact tracers had to wake up early in order to "catch" the quarantined in their homes before they left for the day.

They need the food to quarantine the family. But if that person not get food, when you go to them they will say "Me, I won't be here-o. I want to go look for food." (Contact tracer FGD)

P: There are some contacts who say "You will not see me today because you just got me here and no food so I'm not going to talk to you"...

I: Does that happen often that people are complaining about food?

P: Yes, almost every day the contact complain "No food." (Supervisor KII)

So now, they are compelling us now to wake up early in the morning to go catch the people [before they leave their homes]. Why they are compelling us now because they are not able to feed these people, the people have to go early to look for food and we now have to meet the challenge but getting early in the morning to go there. So you see there? (Contact tracer FGD)

What Happens When Someone Dies at Home

Many of the issues participants raised in response to our questions about home deaths were similar to the issues they had raised when we asked about suspected Ebola cases. As with the latter, most said there was no difference in how the deaths of children and adults were treated.

Some Report Home Deaths to Authorities

Most participants said that the relevant authorities (i.e. the "Ebola team", "the Ebola people," "4455," the burial team, community leaders) were usually contacted soon after a home death occurred. In some cases, family members reported the death to authorities; in other cases, community members contacted the authorities with or without the bereaved household's knowledge.

[W]hen someone die in the place, the first thing, family gather because the government have said that any death must be reported, Ebola or no Ebola. Now the Ebola team will come and verify. (Community leader FGD, Site B)

Right now when a family member dies at home, the first thing they do now is they call the community chairperson...Because right now you don't just take a body from the house to carry anywhere because the community as a whole or the neighbor they are all on their light [meaning they are watching]. So if somebody die, even if that family did not call the community chairperson, someone next door will call and say "Oh, there's a dead person here." And so immediately the community chairperson ensure that the tracer, active case finder move onto that house and then they will call all the field supervisor of the district task force or also connect [to the organization responsible for contact tracing] to send another tracer and they will go and do another investigation, to investigate what led to the death of that person. (Community leader FGD, Site C)

In fact, the whole house will be closely watched what will happen next. (Community member FGD, Site B)

Several noted that although there used to be long delays before the dead were removed from homes, “currently” burial teams usually arrived within 24 hours of a death being reported.

Participants’ accounts of what happened once a burial team arrived at a home varied. While some mentioned specific aspects of the visit such as what the burial team members wore or recounted the various activities they conducted while the team was at the home, others described the visit in more general terms.

Their accounts of what happened to the deceased’s body after it was removed from the home also varied. Some participants described a process similar to the government’s policy for Monrovia prior to official opening of the national cemetery in that the burial team immediately carried the body away to be cremated. But others noted that in some cases the burial team buried the deceased or let the family take the body to a funeral home. Several participants noted that the burial team’s decisions to carry the body away or allow it to be safely buried depended on their assessment of whether it was an “Ebola body” or not.

They test the body and if the body is not an Ebola body, they give the family the go-ahead, they will work along with the team that will come. They will identify the area where you want the corpse to be buried. (Community member FGD, Site C)

They not forcing people anymore like before. Like before, whether that Ebola or not Ebola they will carry it. But this time, they giving people's bodies to them. I've seen 3, 4, 5. If they check that not Ebola they turn it to you...But if you want them to carry it, they carry it too. That's why I saw about 3, 4 in my community. (Community leader FGD, Site B)

P1: If [the burial team] suspect that not Ebola, they will actually tell you it's not Ebola and you can have your body.

I: So [the burial team] can turn over the body to do a safe burial?

P1: Yeah, they can turn over the body to do a safe burial. That's how you see sometimes Saturday, you see people come from the funeral to bury. Other people go and bury, but it have to be

confirmed.

P2: That one happened lastly, lastly. When the crisis of Ebola was going on, there was no, you know, anybody they come they see, whether that Ebola, they not Ebola, everybody going. Only just recently when they come they will say, yeah this one that not Ebola. All bodies used to go. (Community member, Site A)

Although some made references to the body being “tested” or “checked” to determine whether or not it was an “Ebola body,” their descriptions of what the “test” or “check” entailed varied. As indicated below, sometimes their references to a “test” appeared to coincide with the official policy of laboratory testing oral specimens that were collected from corpses, while other comments suggest that the “test” the burial team conducted did not involve a laboratory assessment at all.

Assessing Whether a Body is an Ebola Body or Not

Laboratory Assessments

Some participants described a testing process similar to the official Ebola testing policy in that the burial team took a specimen from the body, removed the body from the home, and then returned the results to the family between 2-21 days later. Some noted the reassuring aspects of receiving a negative test result in that it meant the family would not be placed under quarantine and no longer stigmatized because they had been “cleared” of having Ebola.

The burial team they always can tell you between 2-21 days the result will come, then they tell you it. (Community member FGD, Site B)

They will carry the body and take the specimen and then run the test. If you negative, they will send it to your family and say no your body or the person, you will clear that, you know, stigmatization, you will say your person has not die of Ebola. But if at you die of Ebola, they try to quarantine your family. (Community member FGD, Site C)

Others expressed dissatisfaction with the testing, either due to concerns that it was not objective, that the deceased’s body was not returned to the family when the test result was negative, or because of the length of time it took to get the results back.

[T]he burial team wants to carry the person, the body to be examined to see whether it is Ebola or not, but if it is not Ebola, the fear of the people is that if it is not Ebola, it is the prerogative of the people who examine it to say if it is Ebola or not. But [the burial team] have the right to carry...and do whatever they want to do with it. So this has been the problem. Usually they do not come back and say “It is not, so take your body.” They say once it's transferred from the family “We will not come back again.” (Community leader FGD, Site C)

But it was also noted that some may ask the burial team to take the body even before the test results are known due to their lack of financial resources to pay for burial-related expenses.

Sometimes the family member will just conclude, you know, because they know that to embalm that body it takes, you know, time and it costs a whole lot of money and resources so...whether that Ebola or that not Ebola...Some family...call the Ebola team, they say while they waiting for [test] results they say “My people, you all come and take the body because nobody want to be wasting time with

body now.” (Community leader FGD, Site C)

When they know that no way to go bury at that time, they will try to call the burial team to come. (Community leader FGD, Site B)

Non-Laboratory Assessments

In other cases, participants’ descriptions of the “tests” or “checks” the burial team conducted to determine if it was an “Ebola body” or not were harder to decipher. In one such example, the participant described a test that measured the body’s temperature. Apparently, a high temperature meant the body was an Ebola body which the burial team would then immediately carry away.

[W]hen they come and do the body test, they will tell you say, your body is not Ebola, immediately they will leave the body with you. But if they do the test, and they say if the temperature go higher, then they say “We carrying this body here.” But all of these bodies that we bury was given to us. (Community member FGD, Site A)

Other comments indicate that the burial team’s assessment was sometimes based on the deceased’s illness history or death certificate indicating that Ebola had not been the cause of death.

[I]f the person from the investigation [learns] that maybe that the person have been sick for long...and the people can attest, they interview next door and they attest that that person yes had been sick for good while and you know and then with that they can give go ahead for them to either carry the body to the funeral home or burial. But when that person come down with symptom like I said, then the burial team take over. (Community leader FGD, Site C)

P1: Because the news now is that even when you call the Ebola people before they carry the body, they want to see whether you have a death certificate or not. So, if we want the body to be buried in the proper form, we try to get a death certificate. When we have the death certificate, the Ebola people are called in to see how they can help us to get the body to the funeral home. If we want to take it to the funeral home.

I: That is if the body is not an Ebola body. But what if it is found out that it is an Ebola body?

P2: The Ebola can carry!

P1: The Ebola people carry. (Community leader FGD, Site B)

Participants also mentioned financial ability or social connections as factors that influenced whether the body of their loved one would be cremated or buried. These included having money to pay someone off, purchase a fake death certificate, or knowing someone high up in the government who could intervene on the family’s behalf.

P1: You know, I experienced something, it happened. When someone die in the home, sometime not Ebola, sometime that Ebola. When the ETU, when the people come, they can bribe them. Sometime they will bribe them, if that Ebola, they will bribe them, give them token say "Oh leave you all our body, we go and bury our body."

I: How much can they pay?

P1: Sometime 150, 200. One friend one time told me 300 U.S. cash they give them.

I: So they can leave the body?

P1: Yeah, leave the body for them to...have a, they say wake. They have program, they bury the body, so they left the body. And someone told me that body was Ebola patient, because all the symptom came out. And they pay another group to go bury the body. (Community member FGD, Site A)

P1: The people want to fake their own document.

P2: People are giving order. Sometime from the high up! From the high up!

P1: We have one area off Broad St. [located in the heart of Monrovia] they call the World Trade Center. They call the place World Trade Center off Broad St...Any document you want in Liberia, you go, they will give you it...

P2. And even when those documents are fixed, are falsified, still there is someone from the up there who is behind it. They don't just do it just like that. Someone from up there can be behind it. (I: Up there, up there being where?) Up high. (I: Up high where?) In the government. Maybe from the executive, or the judiciary, of the legislature. (I: Any big big person.) Yeah, the big big person. (Contact tracer FGD)

Some participants expressed their frustration with the inconsistent way in which the government's burial policy was being applied in that that some families were being allowed to give their relative a "befitting burial" while others' deceased relatives were taken away and cremated. As suggested below, this type of differential treatment was sometimes spoken about as a likely source of tension between community members and Ebola responders.

[W]e see people coming, carrying their people, I don't know they say 'decent burial' eh? (All: Decent burial), with casket coming, putting their body, people marching behind the car, they going to bury it. These people, are they quite different from other people who we go to and say "Don't carry it. Ebola people will carry your body"? So now, what is happening now, tomorrow somebody die, we go for that body, they will call Ebola people, you know. You don't think it will bring big fighting there? (Contact tracer FGD)

What we see is that there are certain bodies they can carry and certain bodies that can be compromised. And for us we think that's problem. You can't carry other people body and go and burn it and then other people you go and say you can go and bury it. (Community member FGD, Site C)

Some Conceal Home Deaths and Bury in Secret

When we asked participants why some people might be reluctant to report a home death, they reiterated their previous comments regarding people's fears about Ebola-related stigma, about cremation, and about being quarantined.

That some of the thing we explained before. Because people used to be afraid when you are stigmatize by Ebola, the whole family is in problem. Somebody die from you, whether that Ebola, not Ebola, that trouble in that house now. Everybody afraid. (Community member FGD, Site A)

P1: [T]here have been this uproar that oh yeah, when the Ebola people carry the body, people don't know where the body is being buried.

P2: They can burn it.

P1: So they demand here in the community that if we're going to have the body being taken, there should be information about the site, the burial site where the body is going to be buried. (Community leader FGD, Site B)

[S]ome people, they wouldn't allow them to carry the body because they hear that big word "I going to burn." So that is one of the main thing why people can resist for the body. (Contact tracer FGD)

The above reference to people refusing to let bodies be carried away speaks to another theme that emerged in response to our questions about home deaths: rather than report a home death to local authorities, some chose to bury their deceased relative on their own, a practice commonly referred to as a “secret burial”.

Although nearly all of the participants reported having heard of secret burials and most offered explanations as to why they were conducted, some nevertheless denied secret burials occurred in their communities. Overall, participants from West Point were more likely than those from New Kru Town or Sinkor to say that secret burials were commonly practiced in their community. Some of the New Kru Town and Sinkor participants were adamant that secret burials were not being conducted in their communities at all.

P1 It happen in the borough here but not in our community.

P2: It never happen in our community.

P3: In our community, no way. Eyes on eyes. Security on security.

I: But in other community you hear about people doing secret burials there?

P3: Yes.

P2: In Caldwell. (Community member FGD)

P1: We heard it, but not in the community

P2: I heard that from Gardnersville area, Jacob town. (Community member FGD)

No secret burial. Even when you carry the body to the gravesite, the people in the neighborhood near that gravesite will not allow you to bury that body. Before they will see that [death] certificate they will not allow you. So no secret burial. (Community member FGD)

Several of the participants from West Point acknowledged that secret burials had been a common practice in their community even before the Ebola epidemic due to the lack of available land for burial plots in that densely populated setting. When secret burials were conducted, the deceased were often transported by canoe at night to a nearby location known locally as “Dead Island” or “Bad Mouth.”

*I: Have you ever heard that sometimes people bury bodies secretly? Do you hear about secret burials?
P. Yes. (Others: Yes). What I have now, I have photographs where they do, how they call it, secret burials. Right across the river there's a place they call "Dead Island." (Community member FGD, Site B)*

There's a place they call "Bad Mouth" between Freeport and West Point, there's an island between Freeport and West Point. There they have the secret burial...The reason why they call it Bad Mouth, because the water is very rough. That's the intersection between the river and the sea, so it is very

rough. (Supervisor KII)

Why Bury Secretly

Fears of stigma, cremation, and quarantine

Participants from all three communities offered a variety of explanations for secret burials. Not surprisingly, and as already mentioned above, people's decisions to conceal a loved one's death and bury the body secretly were motivated by some of the same factors that contributed to their decisions to conceal their own or a loved one's illness: concerns about cremation, about being stigmatized and placed under quarantine. Others attributed people's decisions to conduct secret burials to denials that Ebola had been the cause of a loved one's death.

P1: Some people do the secret burial because if one person die in their house and another person die, they afraid.

P2: That stigma there.

P3: That Ebola house there. (Community leader FGD, Site B)

*P1: Some people will even bury that body at night to avoid crimination [cremation]. (Others: Oh yes!)
I: So they have secret burials.*

P1: They know that if you give the body to the government, they will go and criminate the body.

I: Does that happen a lot? Do you think that happens a lot, the secret burials?

P1: Yes, that happen! It happen in secrecy. (Community leader FGD, Site A)

Actually secret burials came about if you actually understand the condition of the person who died and you get to understand this person has a problem. That somebody got TB before and it happened that this person died. So secret burial can come because people afraid. Now if you say I got a body here, for sure if they come your whole house will be quarantined. (Community member FGD, Site A)

P1: I think another thing too is denial. Denial is one of the main reason why people conduct secret burial.

I: Denial of what?

P2: Denial of Ebola virus. So people believe that it is not Ebola, it is malaria and [the burial team] will carry their loved one to bury the person in the despicable manner that they don't like. So for that reason, they will always want to hide that body and bury it secretly. So I think denial is one of the main reason. (Community member FGD, Site C)

Religious or cultural values

Other participants cited the importance of religiously-mandated burial rituals, such as the "righteous bathing" of the deceased practiced by Muslims, as the reason people preferred to secretly bury. Some also noted the critical role their religious leaders played in eventually convincing them to abandon such practices.

You know, being a Muslim, we have some values that we never compromise for anything but because of this Ebola, we have compromised those values...When somebody dies, we feel that before you go into your grave you must be pure and that purity has to be done with water. And this water is exclusive from ordinary water in the sense, in the sense the water, we make it half warm, not too hot, not too cold. That the living body, you choose whether to bathe with cold water or to bathe with whatsoever degree of hot water you want, but for the body we feel that it needs to be treated with

patience, it needs to be treated with honesty, it is supposed to be treated honorably so the water will not be so cold, it will not be so warm, it will be half way. Then we bathe the body with that water...So they used to be adamant [not] to give that person out to the Ebola people...[T]hey would start to do the righteous bathing, to wash the body. So with that, most of them got affected. (Community member FGD, Site A)

[O]ur Iman go on air [the radio] and accepted and gave us the warning don't touch body because the body is a more, is a danger if the person die. So we are truly, the Muslim we go by that. And we accepted the advice not to wash body, not to make secret burial, and we go by that. (Community leader FGD, Site B)

Some participants made general references to the importance of cultural rituals or traditions that honor the dead as the reason some decided to conduct secret burials.

The family, you know, this is Africa, [in] Africa we respect our culture. Whether you are a child or adult, we respect you when it relate to the body. When you die, the people want to give you the last respect that they have to give you. The people don't want to see their body being taken away to be crimated. So you will find that the only thing the people have to do as the last honor to give that body is to do secret burial. And that body will be carried over at night. It will be buried by the family. (Contact tracer FGD)

Others specifically mentioned “Decoration Day,” an annual national holiday that occurs on the second Wednesday in March. It is a day that Liberians visit the graves of their loved ones to clean and decorate them. Cremation meant that there would be no grave for a family to visit.

That's one of the major factor for which people hid their loved ones. I mean this is one of the major factor people will even hide their dead...[T]heir fear is that they won't have no, during Decoration Day there will be no recognition, no remembrance of their lost one. But rather they crimate the body, and that has been a bad practice, they have never done that before, you see. They have never done that in this country before. (Community leader FGD, Site C)

Who is Buried Secretly

Children more likely than adults

Although nearly all participants stated that there was no difference in how the deaths of children and adults were treated, when we asked who was most likely to be buried in secret, “a child” was by far the most common response in all three communities. Most noted this was because the burials of small children were easier to conceal than the burials of adults.

The rightful procedure is that you contact the community chairperson, or the contact tracers, or the 4455. But since it is a child, they want to use, to bury a child is more easier than to bury an adult. (I: Why?) What makes it easier, to bury an adult you have to dig certain feet, and you can't do it secretly. But a child can fit in this carton and secretly you can carry it somewhere without people knowing. (Community leader, Site C)

You know a child, you don't have to go to graveyard. There's possibility you can even bury the child in the backyard. You understand? The older person you have to go to the graveyard. Everybody have to

be involved. (Community member FGD, Site A)

P1: Like a small child, a small child is very easy to carry. Very small, so very simple to handle.

P2: One person can just wrap it..(Community leader FGD, Site B)

One participant recounted the case of an attempted secret burial of a two-year old child in New Kru Town who was later determined to have had Ebola. He noted that before the child died, the mother had kept him hidden inside a room while she attempted to treat him herself.

Let me give you a case, like my community. This two year old child died from the virus. But I did not know that even the child was sick because the child was always kept in the home by the mother. She was keeping the child inside the room while buying paracetamol from hospital, buying flagyls and other thing. It was after the death of the child, thinking how to bury the child, before trying to get two, three persons to do a burial and then I was contacted. And when I was contacted, I investigated the case. [Before dying] the child came down with some symptom and immediately I called the burial team and they came for it. So if not that information, that person was not going to give it to me. They were going to bury the child, most expected on the beach in the night.

According to him, the child's parents become ill shortly thereafter and were taken to an ETU where both died two weeks later.

Although most participants noted that children were more likely than adults to be buried secretly, some of the West Point participants said there were no age distinctions when it came to secret burials.

P: The secret burial they are doing here, they bury both old and young.

I: So you wouldn't say that children are more likely to be buried secretly?

P: No, No. Because they bury all. Whether children, whether adult, they just want to have a place where they will go tomorrow and say "Oh, when my relative died, this is where." (Supervisor KII)

One of the community leaders from New Kru Town who had been adamant that secret burials were not conducted in her community nevertheless recounted the case of an adult in her community who had been secretly buried. Once discovered, the body was exhumed and taken away for cremation.

P1. If there had been secret burial in this borough, uh with me, not to my knowledge but what I want to say here is once upon a time somebody died and they buried the person in the yard. And the authority of this borough mandated the people to dig the body.

P2: Exhume the body.

P1: They dug the body, the burial team came and dug the body and they disposed the body.

I: Where did they take the body?

P1: They, the burial team, the burial people came.

I: Did they bury it someplace else?

P1: They carried the body.

I: So they did cremation?

P3: Yes, to do cremation.

Respected Muslim elders more likely than Muslim children

Some of the Muslim participants reported that respected elders were more likely than children to be buried in secret. As indicated below, this was due partly due to their opposition to cremation, but also likely related to the religiously-mandated burial rituals that are conducted to honor the deceased. As already noted above and again below, some specifically noted that these rituals had been put on hold due to the risk of Ebola transmission.

P: Well, you know, they decide to hide a body due to the importance of that person in the community. But like a child, they will say "Let them take the child." But some responsible representative within the community that will have position died, they don't want to pass this person's body. Or family member, very, very respectable, then they will say "But to go criminate this our father?" Then they will either prefer to bury the body in secret or whatsoever...

I: But right now you said you guys aren't, you've stopped doing that?

P: No we've stopped it, until Liberia can be considered Ebola-free. (Community leader FGD, Site A)

West Point: The poor more likely than the less poor or rich

West Pointers were more likely than other participants to mention financial hardship as the reason for secret burials.

P: There are many people in our locality who do not have the financial power to hold, how they call it, decent burial. So when their loved one dies, they do something we call "first flight." First flight.

I: First flight. So that's [how] a secret burial is being referred to?

P: Yes. (Community member FGD, Site B)

Because people do not have the hand [money] to call a funeral car and other things there...[and] it's terrible the person's body will be cremated. The people prefer carrying it across the river. On the beach across there and bury the person there. (Contact tracer FGD)

But some family member don't have the money to find quick spot. So because of that, they just want to carry the body somewhere and place it there, bury there, so tomorrow they will remember that "Oh I buried my relative in so so place. (Supervisor KII)

Participant Recommendations

In this section we present a sampling of participants' recommendations with respect to government strategies to improve people's willingness to report suspected EVD symptoms or deaths.

Stop "Burning Bodies" and Provide a Burial Site

Participants had a lot to say with respect to the government's burial policy as applied in Monrovia. Although the national cemetery was officially opened on December 24, 2014 and its cremation policy unofficially put on hold, most participants were not yet aware of those policy changes. As a result, recommendations that the government stop "burning bodies" and instead provide land where the deceased could be properly buried were common, as were recommendations that bereaved be allowed to visit their loved ones' graves.

P1: For burning human being, we tired with it in Liberia...

P2: An additional we want to recommend, that the government provide a burial site for us, a burial site. Not only that, that government also provide means that the bereaved family can have access to the site where their loved ones will be buried. (Community leader FGD, Site B)

The government has more lands. Let the government allocate land when somebody die from Ebola, you can take that body, put that body in casket, you carry that body...Let the burial [team] carry it there and bury it instead of burning it. (Community member FGD, Site C)

For them, crimination is what they don't want to hear about. They are totally against crimination. So if a family member dies and arrangement can be made, the burial team can safely bury at a site as identified by the family, that would be even better...The family wants to make sure that their relative, their love one receives a befitting burial. When they are buried properly to their satisfaction, they can cooperate [with] us fully. (Supervisor KII)

Improve the Health Sector

Recommendations targeting the health sector were also common, including the critical need to re-open health facilities for illnesses other than Ebola and improve the quality of their services, including those for pregnant women.

But what I want all you to do, you NGO people, the same way you all sending people around to come in the homes to check the sick people and to know how we're coming on, I want you all to go right back to...the government hospital there, and carry examiner. Let the people see how really they taking care of the sick people then you all will know what making us afraid to go to the hospital. (Community member FGD, Site C)

One thing I would like government to do is to re-activate the entire health system. Because right now the concentration is on Ebola, Ebola, Ebola, Ebola. But there are a lot of people who are not dying from Ebola because they are not getting care from other health facilities. Take for example, pregnant woman who does not have Ebola and needs to deliver. Now we are running out of the OPD here, outpatient department, there are a lot of pregnant women in antenatal care. Where are they delivering? (Supervisor KII)

I want the government to actually pay serious attention because Ebola has a bit subside, but we still have Ebola in Liberia. So what we want them to do is that all the health centers in the country should be adequately equipped. Emphasis should be placed on medical practitioner. If you look, most of those that were victim of Ebola were medical people. This is why this people have refused to treat people that have the signs and symptoms of Ebola. (Community member FGD, Site B)

Some pointed out the irony of ETU Ebola-negative patients being sent home while still sick because there was no functioning health facility where they could be transferred for treatment. When those patients subsequently died from the non-Ebola illness, the Ebola response effort was started all over again: the burial team was sent to the home to collect the body for testing and removal, and household members were once again placed under quarantine until the test results were known.

Like most of the time when we carry the patient to the ETU when that patient is negative, they can send that patient back at home. And he's still sick. But they will send that patient back at home. Now when that patient died, that Ebola team will come for that patient. So at least I think, they could when they check the patient negative not to send the patient at home. You know, they should transfer that patient to another hospital where they would be treating that person until that person get better. (Community leader FGD, Site B)

[T]here are many we taking now to the Ebola treatment unit and they saying "No case, no case, no case" and those people are being sent back home and they are sick!...So if those people have places, health facility to go to be treated, even if they die in the hospital, the hospital will know, because they also will be doing tests to know whether this person is positive or negative. If it is negative, they will be able to give the body to the family member. Wouldn't have the crisis that we having, fighting over dead body, the family member say no, tracer say yes. (Supervisor KII)

Some participants suggested that improving health workers' pay was an important aspect of improving health services in that health workers would be more satisfied with their jobs and thus treat their patients better.

The government must pay the health workers on time. On time. Usually when they pay them on time, the work will be done properly, but for now [shakes head]...They haven't paid the people on time, so their heart is not satisfied with the job. (Contact tracer FGD)

Improve Testing Procedures and Provide Timely Results

Participants also had several recommendations with respect to Ebola testing. They wanted timelier testing of the sick and the deceased and a timelier return of test results. Some noted that delays hampered contact tracing efforts in that persons suspected of being an Ebola contact sometimes refused to provide information to case investigators, cooperate with contact tracers, or be quarantined in the absence of test results. Others specifically called for the development of an Ebola rapid diagnostic test, with one participant noting that it could help ensure that bodies turned over to family members for burial were truly safe for unsupervised burials.

Sometime when the contact tracers go to those people to do their work, to do the follow-up, they will tell them "No result, we will not agree to be followed up." So now, we don't know if this person is positive. If this person is positive, he might be in, let me say, contact [with] other people. So that person, the person who is in contact with this dead body or this patient, will carry to another place. (Community leader FGD, Site B)

I suggest that the government improve the system. People will die at home. That will always happen. But let us say, if in 2 or 3 hours' time, if government able to tell you that this is Ebola body or not Ebola bod that will be very fine. (Community member FGD, Site B)

[T]he government really need to see how best they can do the rapid test because if we now say government should turn the body over to the family, what happen if that person is a Ebola case? And we have not done the test, and maybe we just sit down reluctantly and say "Oh yes, let the government turn the body over to the people" and after maybe few days you see people dying in their house. But if the government can make things available, or material available to be able to do

*rapid test it will be alright for us. They can do the rapid test, right after the result they can give.
(Supervisor KII)*

Ensure the Quarantined Have Access to Food

The lack of a regular supply of food to quarantined households and its negative impact on Ebola response efforts was another common area for improvement participants mentioned.

If someone die of Ebola at their home, automatically that area will have to be quarantined. Therefore government should create all measures so there will be food and what have you for the people to be eating in that quarantined area. (Community leader FGD, Site C)

[I]t's difficult for us to do effective contact tracing when the family members are scattered because they have to go to find food. If food was available, the moment the information gets to us that this person was confirmed, if food was readily made available to the contacts, it would make the work easy for us. (Supervisor KII)

Remain Vigilant and Plan for the Future

Some participants cautioned that the government should not be complacent as the number of Ebola cases decline. In order to remain vigilant, they recommended the government continue its support of Ebola awareness and prevention activities. Others suggested the formation of a ready response team comprised of former EVD responders who could deal with future health emergencies, whether Ebola or not.

And one thing too I want the government to be doing, government should not feel complacent. Because what we understand that Ebola in countries that have Ebola, it come there more than 2 or 3 times. So in order for us to protect future occurrence, let the sensitization, awareness, prevention measures of Ebola should continue. (Community leader FGD, Site A)

[T]hose social workers that are on the field, contact tracers, monitors, active case finder, the government should incorporate them into the health system and train them and work with them and not leave them in case of any other case. They should be put into various various areas so they can work effectively to attack any other thing that will come up in Liberia. God bless Liberia, God bless the government. (Community leader FGD, Site C).

Expressions of Appreciation

Several participants expressed their gratitude to the various governments, agencies and international and local organizations that provided assistance during the epidemic. Some directed their words of thanks to partners in general, while others mentioned specific partners by name. A sampling of their comments appears below.

I want to say thank you to the government, to NGOs, to the national partners who have really helped us. I want to strongly believe that the government of Liberia was caught unaware, and government needs to prepare herself. (Community member FGD, Site C)

But we tell God thank you for some NGOs, like the MSF, the UNDP, the World Health Organization, they have come to help us in the process and people are understanding the need for ETUs. (Community leader FGD, Site C)

[W]e are thankful to US Government who the other day announced some 6 billion dollar to help improve the medical sectors of the 3 neighboring countries. We hope that that money can be used wisely...(Community leader FGD, Site C).

P: We want to be thankful to God, thankful to our partners.

I: I'll be sure and say that in the report. (Community leader FGD, Site A)

Observations of Red Cross Burial Team Visits

Two different Red Cross burial teams were observed on different days: Team A on December 29 and Team B on December 31. Each of the teams was comprised of several members: a burial team lead who served as the main point of contact for the team, one case investigator who documented the deceased's recent illness history, and an additional 6-7 persons tasked with either collecting the oral specimen, removing the deceased from the home, or disinfection duties. Although the burial teams usually included a person specifically tasked with communicating the various aspects of the burial team's visit to family members, on both observation days the burial team lead served as the primary communicator with the case investigator sometimes chiming in.

The Red Cross supervisor assigned each team four locations to visit and gave each burial team lead a list of names and phone numbers to call and confirm that someone had died at that location and that the corpse was still there. Team A was assigned collections in Doe Town, New Kru Town, St. Paul's Bridge, and Stockton Clinic near Caldwell and was able to confirm there was a corpse at each of those locations. Team B was assigned collections in New Georgia Estate, Johnsonville, Jacob Town, and Weh Town but was only able to confirm a corpse at the Johnsonville location; the New Georgia contact hung-up when the burial team lead identified himself as from the Red Cross, the Weh Town contact never answered the phone, and the contact from Jacob Town reported the corpse had already been removed from the home because it had started to decompose.

Of the four collections assigned to Team A, two of the deceased were buried in private cemeteries and one was transported to the national cemetery where it was buried in the Muslim section by Global Communities' on-site burial team. Due to concerns about time constraints (the national cemetery does not accept bodies for burial after 4 pm), Team A's fourth collection was re-assigned to a different Red Cross burial team. In order to meet the national cemetery's deadline, Team A then split up: one Red Cross vehicle with staff was assigned to assist with the two private cemetery burials while the remaining staff and vehicles transported the body collected from Doe Town to the national cemetery. Team B transported the body collected at the Johnsonville location to the national cemetery where it was buried in the Christian section by the on-site burial team. A summary of the burial team visit observations is presented in Table 3

Table 3. Summary observations from Red Cross burial team community visits in urban Montserrado County, December 29 and 31, 2014

Location (# of relatives, neighbors, or others present)	Deceased's Demographics	Who Called	Cause of Death (Per Family or Health Provider Diagnosis)	Burial Location
Doe Town (10-15)	Adult male (Muslim, 67 years)	Family member	Not an EVD case. Complications resulting from an infected cut on leg.	Buried at the national cemetery in a body bag provided by the Red Cross burial team. The family requested to have their relative buried at a private Muslim cemetery but were told the government did not allow burials there because those graves were not dug to the regulation 6 ft. The family agreed to let the burial team take the body to the national cemetery instead, noting that their only concern had been about cremation. Family members asked if they could accompany the body to the national cemetery but were told it was not yet prepared to accept visitors.
New Kru Town (10-15)	Adult male (65 years)	Family member	Not an EVD case. High blood pressure.	Buried at a private cemetery in a casket provided by the family. There was some initial tension between the burial team lead and family because the family had already begun to dig the grave at a cemetery in Caldwell. After much back-and-forth discussion, the team agreed to assist the family with the burial as long as the grave was dug to the required 6 feet. The team returned several hours later and removed the body from the home.
Stockton Clinic (Difficult to assess but at least 3)	Adult male (Muslim, age unknown)	Clinic staff	Clinic said cause of death was malaria (3+) but also took blood specimen for EVD testing. The deceased's wife had died in West Point 3 weeks earlier from high blood pressure and he had been listed as one of her contacts.	Burial at a private cemetery in a casket provided by the family. There was some initial tension between the burial team lead and the family representative over accusations that Muslims do not dig their graves deep enough. After assurances that the grave had already been dug six feet, the team agreed to accompany the family to the cemetery and conduct the burial.
Johnsonville (25-35)	Male child (14 years)	Family member	Not an EVD case. Boy had been ill off and on since March 2010 with debilitating headaches. No recent history of fever, diarrhea, or vomiting but white foam came out his mouth when he died.	Buried at the national cemetery in a body bag provided by the Red Cross burial team. Burial in a private cemetery was not mentioned as an option. The father insisted on being present at the burial and two family members accompanied him to the national cemetery on a rented motorcycle.

Communication between Burial Teams and Family Members

With the exception of Team A's visit to the Stockton Clinic location, communication between the burial team lead, the case investigator s and family members took place in front of the deceased's home within earshot of all present. The number of relatives and other community members present during the visits fluctuated between 10-15 at the homes in Doe Town and New Kru Town and between 25-35 at the Johnsonville home. At the Stockton Clinic, it was difficult to discern who was a relative or community member because the interaction between the burial team and family took place on the public street in front of the clinic and there were many passersby. The burial team lead and case investigator directly interacted with just two persons there: the son of the deceased and a family representative.

At the start of their respective home visits, both burial team leads explained the purpose of their visit and briefly described the activities that would take place (e.g. the deceased's illness history would be taken, a sample of saliva from the deceased's mouth would be collected to test for Ebola, the body disinfected and removed, and the deceased's room sprayed). Both burial team leads also mentioned the recent changes to the government's burial policy, e.g. that the government was no longer "burning bodies" and instead was providing burials free of charge at the newly opened national cemetery near Disco Hill. All families were also informed that the Ebola test results would be returned to the family between 2-21 days although the information regarding how they would get the results was inconsistent. The three families visited by Team A were told that someone from the Ministry of Health would call them to give them the results, while the burial team lead from Team B told the Johnsonville family someone from the family would need to go to the Ministry of Health to pick-up the results themselves.

Upon Team A's arrival at the New Kru Town home, the family informed the team they wanted to bury their relative at a private cemetery in Caldwell and had already begun to dig the grave. After some arguing back-and-forth between the burial team lead and deceased's relatives about where the body should be buried and a phone call to the Red Cross supervisor, the burial team lead agreed to let the family transport the deceased to the private cemetery under the condition that the burial team place the body in the casket and conduct the burial. Discussion about where the body at the Stockton Clinic would be buried began over the phone prior to Team A's arrival. The family was Muslim and wanted their relative buried at a Muslim cemetery in Caldwell. By the time the team arrived, the family was there with a truck and a casket. There was some initial argument between the burial team lead and family representative about the proposed burial site, with the burial team noting that noted that Muslims "were known" for not digging their graves deep enough. After assurances from the obviously irritated family representative that the grave had already been dug to the required six feet, it was agreed that the burial team would accompany the family to the Muslim cemetery and conduct the burial.

Neither of the two families whose relatives were buried at the national cemetery were offered the option of a private cemetery burial. Although the Doe Town family asked if their relative could be buried at the Muslim cemetery in Sinkor, the burial team lead said it was not allowed because the graves at that cemetery were too shallow; the Johnsonville family did not ask about alternatives to burial at the national cemetery.

Although the Doe Town and Johnsonville families both asked if they could accompany their

relative's body to the national cemetery, the former's request was denied on the grounds the cemetery was not yet ready to receive family members. After some lengthy back-and-forth discussion between the burial team lead and the Johnsonville family, it was finally agreed that a few family members could go to the national cemetery provided they found their own transportation there. When the father expressed some initial concerns about the cost of transportation, the case investigator asked the small crowd that had gathered in front of the home whether anyone would be willing to contribute. Although it was not clear at the time whether or not the case investigator's request was heeded, the father and two others arrived at the cemetery on a motorcycle just as the child was being buried.

Family Members' Questions and Concerns: The Johnsonville Family

Of the three homes visited, family members at the Johnsonville location asked the most questions, including how and when they would be informed of the Ebola test results, whether the body would be returned to them if the test was negative, and whether the family would be allowed to visit the child's grave thereafter.

The Johnsonville family was also the only family to outwardly express concerns about Ebola-related stigma. These concerns were alluded to early on in the visit as soon as the case investigator began asking questions about the child's illness history. The father prefaced his initial responses with a statement that he welcomed the opportunity to answer the questions in front of everyone present in order to clear up any suspicions that his child had died from Ebola. When the burial team lead told them that it could take between 2-21 days before they would know the test results, some relatives complained about the delay, noting "the whole time, the stigma on you." Their concerns about being stigmatized appear to have been well-founded: one of the neighbors asked the case investigator if they should be avoiding the house until the test results were known, to which the case investigator responded that if people took the "proper procedures" such as washing their hands and maintaining a safe distance it would be fine for them to visit the family to sympathize.

It took eleven days for the Johnsonville family to get results from the oral specimen back, although it was not for a lack of trying on their part. On the afternoon of January 5, five days after the child was buried, the principal investigator encountered the child's uncle at the Liberia's Emergency Operations Center (EOC) in Monrovia as he was walking up the stairs in search of his nephew's test results. He recounted that based on what the burial team lead had told him during the burial team's visit to Johnsonville, he had gone to the MOH that morning to look for the test results but was told he was in the wrong place. Someone there sent him to the old MOH building which was about a 30-35 minutes' drive away (depending on traffic). Upon his arrival at the old MOH building, he was again informed he was in the wrong place. He was subsequently sent to the EOC (about a 20-25 minutes' drive away). He had just arrived when the principal investigator met him walking up the stairs. She offered to find out where the results were. After asking an official she knew at the EOC where the uncle needed to go to get the results, she was told to check with her CDC epidemiology colleagues at the MOH. She took the uncle's phone number and the specimen number and promised to call as soon as she found something out. After several days of phone calls and discussions between CDC, MOH, and Red Cross personnel about the procedures for returning results, the family was informed of the results on January 11, 2015. The test was negative.

Subsequent follow-up regarding the cause of the delay indicated that although the child's test results had been verified several days earlier, the standard operating procedures for returning EVD test results were still under development and there was some concern about returning results before those procedures were finalized. Decisions with respect to several key issues were still pending, including how best to return the results (By phone? By official letter? In person, and if so, by whom?); how best to ensure the family's confidentiality throughout; and how best to return negative test results to families whose relatives had already been cremated.

Discussion

EVD home deaths occur as the result of infected persons not being detected early and sent to ETUs where they can access care and have an improved chance of survival. From a public health standpoint, EVD deaths should not occur at home. Individuals suspected of being infected with EVD should have been identified through case investigations or contact tracing efforts and then referred to an ETU, thus decreasing their risk of dying as well as minimizing the risk of exposing others to the disease. While many of the participants in this assessment noted that family or community members usually reported suspected Ebola cases to the relevant authorities, our focus was on understanding the reasons why some EVD cases do not get reported and thus result in a home death.

Findings from this assessment indicate that delays in seeking care at an ETU were generally the result of one of two decisions: either to treat the patient at home or to abandon the patient to fend for him or herself. Decisions to either keep the patient at home or abandon the sick, in turn, were largely influenced by people's experiences with and concerns about EVD or the related response efforts. As summarized below, these included individual and collective concerns about the quality of care in ETUs, about the cremation policy as applied in Montserrado County, about being stigmatized, about the lack of food for quarantined households, and the lack of health services for non-Ebola illnesses and conditions. Our findings indicate that similar concerns also contributed to people's decisions to conceal a loved one's death and conduct their burials in secret. Our analysis is driven by a social constructivist approach to understanding health-related decisions. In other words, our concern here is on how different persons/communities make meaning and use knowledge from their experiences with EVD and response efforts to make decisions and then act and in the ways these experiences may have contributed to home deaths.

Ebola-Related Experiences and Concerns that Contribute to Home Deaths

Hewlett and Hewlett [18] and Minor [19] provide theoretical and ethnographic insights into how pre-EVD and EVD related response activities, systems and structural policies negatively and disproportionately affect the health of the most vulnerable persons/communities. Nevertheless, it would be incorrect to view these individuals/communities as passively accepting EVD policies. On the contrary, we found that individual and community reactions and resulting actions contesting some of the EVD response efforts were not difficult for us to imagine taking part in ourselves were we confronted with a similar situation, i.e. someone showing up at our homes unannounced to take an ill child or spouse away with the knowledge that we might never see them again. Indeed, people's concerns that they or a loved one might be transported to an ETU never to be heard from again emerged as a key reason for decisions to conceal their own or a loved one's illness. Many of the concerns people expressed were based on their own or a family members' negative experiences with ETUs, experiences that ran the gamut from being

mistakenly taken to an ETU, to being poorly treated by ETU staff while there, to family members not receiving information about the status of loved ones who had been taken away. Although some participants acknowledged that the quality of care at ETUs had greatly improved over time, several specifically stated they would rather die at home than be sent to an ETU. Other qualitative studies conducted in Liberia roughly during the same time period reiterated this fear of ETUs, even describing such places as “death traps”[20, 21]. Over time, a host of factors may have contributed to changing perceptions of ETUs including but not limited to improvements in the quality of care, providing the means for families to communicate with their sick relatives, the decline in EVD cases (and the increasing numbers of persons surviving Ebola)[7], and acceptance of ETUs as places of healing.[20] Still, the question remains, to what extent can trust and acceptance of ETUs be initiated from the onset, sustained and reiterated over time?

This assessment also highlighted the impact that the government’s cremation policy for Montserrado County had on people’s willingness to report suspected EVD cases and deaths. The policy, which was implemented in August 2014, two months after the first EVD case was diagnosed in Monrovia, mandated that all corpses in Montserrado County be cremated irrespective of cause of death.[10] Our results indicate that opposition to the policy was widespread and often couched in terms of cremation being an assault on cultural or religious values. Deciding to treat a sick loved one at home rather than send them to an ETU was an effort to ensure they were buried with honor and dignity were they to die as a result of their illness. Interestingly, earlier reports suggested that although the general public had some reservations about cremation there was no overt opposition to it.[22] Why the difference? Perhaps these contradictory results could be explained by what others have referred to as the “particular circumstances of the fieldwork,”[23] that is, gathering community perceptions about cremation at different time periods of the epidemic. We posit that as the epidemic and cremation policy prolonged for months, the public’s willingness to comply—that is, to adapt or suspend pre-Ebola cultural practices surrounding death—began to weaken as the number of EVD cases began to fall below the number of deaths by other causes. Perhaps the increasing opposition to the policy reflected both a weariness of EVD response efforts as well as a longing for a return to normality. For example, being able to visit a loved one’s gravesite on Decoration Day, Liberia’s national day of remembrance set aside to honor the dead and decorate their graves; cremation meant there would be no grave to visit.[24] Findings from our observations of burial team home visits seven weeks apart indicate that tensions between burial teams and family members had substantially decreased after the government officially opened the national cemetery in late December 2014, lending additional support to participants’ claims that cremation was a key factor in people’s decisions to conceal a loved one’s illness or death.

Our findings also indicate that sometimes people’s decisions to treat their own or a loved one’s illness at home was not the result of EVD-related concerns at all. Instead, sometimes such decisions were the result of lack of health services for non-Ebola-related illnesses or conditions. As has been noted elsewhere, basic medical services were shut down during the EVD crisis in Liberia,[25]. Several participants noted that even after the government began opening health facilities, health workers often refused to treat patients out of fear that they might be infected with EVD. Some participants specifically noted that their decision to treat a sick family member at home was based on their previous experience of being turned away by a health worker

reflecting a much larger issue about trust and reliance on the health system.

Household-, Community-, and Responder-Level Factors that Contribute to Home Deaths

Reports of people leaving their homes or communities provide another possible explanation for home deaths. Participants offered a variety of explanations as to why such movements or “Ebola migrations” occurred, including wanting to avoid being associated with an “Ebola area,” to avoid becoming infected themselves, or to avoid being stigmatized for having lived in a house where an Ebola patient had lived or died. In some cases, these movements out of a home or a community resulted in the sick being left to fend for themselves. Others attributed people’s decisions to leave their communities as a strategy to avoid “creating animosity” or conflict as a result of reporting a community member’s suspicious symptoms to authorities, a behavior that some of the early Ebola prevention messaging campaigns promoted.[26] One of the unintended consequences of these types of reporting practices is that it creates an environment of suspicion, both on the part of the patient (suspicious that others will report on them) and the people who are recruited to conduct Ebola suspect ‘surveillance’ in the community (suspicious that people in their community are concealing their illness). The success of public health interventions like case investigations and contact tracing depends on being sensitive to clients’ needs and developing trust with the community and those directly affected by Ebola. Trust that the public and individuals at risk will do their part to seek care and treatment and prevent further transmission. Trust that the responders will treat the public and suspects with respect while ensuring, to the extent possible, privacy and confidentiality. Where there is lack of privacy and confidentiality, there may well be a lack of success of public health interventions.[27]

Other situations where trust is challenged involved community members reporting suspected Ebola cases or home deaths to authorities unbeknownst to the affected household or neighbor. When ambulances or burial teams arrive at homes unannounced to take the sick or dead away, it is a situation fraught with complications. To the responder, it is an indication that attempts to hide the sick or the dead were not always successful. On the flip side, the Ebola response activities performed in the public arena were a preview of what community members who were witnessing the events could expect if their own family members became ill or died at home. It is not so far-fetched to conclude that if onlookers perceived the interaction between the burial team and family as contentious and/or traumatic, this might affect their willingness to report suspected cases and deaths in the future.

Assessment participants also highlighted other factors that were no less important in people’s experiences and perceptions of EVD response efforts, such as the chronic lack of food and other essentials for those placed under quarantine, a factor that other anthropologists working in Liberia around the same time have also noted.[28]. Some participants spoke of people’s reluctance to report suspect cases out of fear they too would be quarantined and subject to daily monitoring. Others complained that the long delays in reporting Ebola test results unnecessarily lengthened the period in which contacts were under suspicion. As noted by relatives during one of the Red Cross burial team home visit observations, “the whole time, the stigma on you.” It is likely that these and similar concerns are additional reasons people decide to hide a loved one’s illness and/or resist, reject and/or avoid the cascade of public health interventions (case investigation/ contract tracing). A public health ethical framework is necessary to discuss issues surrounding individual rights to lab results and mandatory public health actions. The tensions

between individual liberties versus what is best for the public good is well documented. At the same time, the West African EVD Epidemic, because of its magnitude and scale, should add new insight into how best to balance the rights of the individual and what is best for the public good.

Participants' Recommendations for Improving Ebola Response Efforts

Participants suggested a variety of strategies to improve Liberia's EVD response efforts and prevent or at least significantly reduce EVD home deaths. These included the government putting an end to its policy of mandatory cremation and instead providing a burial site where the bereaved could visit their loved ones' graves. Additional recommendations centered around the need for improvements in EVD testing procedures, including shortening the time that people had to wait before knowing if they were to be quarantined or not. Recommendations about improving the supply of food and other essentials to the quarantined were also common, as were participants' comments about the critical need to re-open health facilities for non-Ebola illnesses and the importance of improving the quality of health services in general. Many participants also advised that the Liberian government remain vigilant and plan for the future, including the formation of a rapid response team comprised of former EVD responders who could deal with future public health emergencies, whether they be related to EVD or not.

Some of the participants' recommendations for improving Liberia's EVD response efforts have already been implemented. As noted earlier in the report, the first burial at the newly-opened national cemetery took place December 24, 2014 which effectively ended the government's cremation policy. By the end of February 2015, the SOPs for returning Ebola tests results to families had been finalized and most families were receiving their relatives' test results within 24 hours or soon thereafter. Once the test results are known, someone from the MOH informs the database clerk who calls the contact tracing monitor who informs the family during a home visit. Policies that cover the removal of the deceased from homes or other community settings have also been revised. Reports from colleagues working on the response in Monrovia in March 2015 indicated that "currently" burial teams charged with removing bodies from homes "now" take the body of the deceased to a cold storage facility until the results of the Ebola test are known. Corpses that test negative are returned to families to either bury at private cemeteries or the national cemetery with support from the safe burial teams or through a funeral home. Corpses that test positive for Ebola are buried in the national cemetery by the on-site safe burial teams. Although families whose relatives test negative for Ebola are not required to be buried in the national cemetery, many families still choose that option to avoid funeral costs (Personal communication with an EVD contact tracer monitor).

Limitations

In this report we have attempted to highlight potential contributions to EVD-related home deaths in urban Montserrado County, Liberia. This assessment has a number of limitations. There are documented limitations on the use of rapid anthropological assessments in public health which will not be repeated here.[29, 30] We would like to highlight specific limitations that related to the time and place of our assessment. As in most anthropological and qualitative studies, our sample size was small, and to that end, our findings may be unique to those taking part in our assessment. Though the design of this assessment included various groups and communities affected by Ebola, these groups may not be representative of the entire urban area in Monrovia. At the same time, our intent in conducting this assessment was to describe and to interpret the

context surrounding the occurrence of EVD home deaths; therefore, it was necessarily feasible to obtain more in-depth descriptions with fewer participants while at the same time try to interview those persons most closely associated with relevant activities. Other challenges in the assessment include the difficulty we encountered in distinguishing between first and second person accounts. Importantly, we were intrigued by the frequency by which similar stories were being retold and circulating in the public. Conditions in our assessment setting significantly changed from the time we conducted our formative work (early November 2014) to the time the IRB approved protocol was implemented (late December 2014) which was approximately 7 weeks. During this span of time, the number of overall Ebola cases and deaths declined,[31] the Liberian National Cemetery officially opened [17] and the emergency public health order for cremation was lifted.[16] These were significant events in Liberia's EVD epidemic and these changes may have influenced how participants responded to relevant topics. This limitation may also account for why some of our results differed from other anthropologists'/qualitative researchers' findings, most notably community perspectives on cremation.

Summary

While this rapid anthropological assessment produced a wealth of information on a variety of EVD-related topics, the focus of this report has been on the factors that contribute to suspected or confirmed EVD deaths in the home. Our findings also provide insight into the context in which decisions about whether or not to report a loved one's illness or death were made during the first seven months of the epidemic in Montserrado County. It is a context in which the circulation of community and first-person narratives about EVD fears and distrust of its medical/public health response combined with a weak health infrastructure unable to provide treatment for non-Ebola illnesses. It is likely this combination contributed to the occurrence of EVD-related home deaths. What is unique about this assessment is that it illustrates why these contributing factors should not be thought of as unidimensional or static but as ever-changing and dependent on past experiences (with EVD and EVD response efforts) and the current concretizations/refutations of those experiences[32]. These experiences at the community level are combined in very powerful ways to create community driven narratives that sometimes countered the official government statements about EVD and EVD response efforts. These stories, which were repeated and circulated in the public and sometimes took on new meanings, perhaps contributing to the public's less than full cooperation with EVD responders.[33]

Stepping back from individual stories and culminating a meta-narrative, we would also like to pose another theory indirectly contributing to Ebola deaths occurring at home: public health emergency order fatigue[34]. Many of the stories and responses to our questions were repeated not only in the formal data gathering but were also initially touched upon during in our formative assessment activities conducted one month prior to the formal rapid anthropological assessment. The prolonged public health emergency order of mandatory cremation regardless of cause of death challenged the public's initial acceptance of mandatory cremation [26] as more stories of public outcries critical of the policy circulated in the media.[35, 36] In addition, our assessment supported reports that the cremation policy was differentially applied depending on the family's social connection or the ability of the family to pay for a funeral. Claims of inconsistent implementation of public health emergency orders created an environment in which the trustworthiness of the EVD responders and the associated authorities were compromised. Other contextual factors noted by participants were stories circulating about the low quality of 1) care

received at ETUs (patient abandonment) and 2) public health interventions (complaints of no food or insufficient food stuffs for those quarantined) possibly signaling a breakdown in the management of the response and contributing to the public's lack of confidence in the Ebola response. Although these factors were present at different points in time during the emergency response [26] public outcries and other manifestations of resistance seemed to intensify the longer the duration of the emergency order even in the midst of dramatic decreases in Ebola cases and deaths[34]. While other anthropologists have noted that we cannot necessarily infer resistance from a failure to comply[37], the impact of a prolonged state of emergency as well as the differential implementation of medical/public health interventions (ETUs, dead body management, contact tracing) in sub-optimal conditions contributed to an environment in which the public was left to devise alternate modes of protection and survival not always in their best interest.

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Appendices

Appendix A. Summary Findings from Formative Assessment Observations of Burial Team Visits

As part of our formative assessment activities we conducted observations of Red Cross burial team visits in Monrovia on November 28 and December 3, 2014. We conducted for a total of eight observations in eight different locations. These observations were undertaken while the policy of mandatory cremation in Montserrado County was still in effect.

Each burial team observed was comprised of several members: the burial team lead who had overall responsibility for the home visits; a team communicator whose primary role was to explain the burial team's activities to family members, take the deceased's illness history and answer any questions the family might have; and 5-6 additional team members tasked with various activities including collection of the oral specimen, removing the body from the home, disinfecting the room or area where the deceased had died, and disinfecting burial team members before they left the premises. Although each burial team usually travelled in a convoy of three vehicles (two to carry team members and a truck to transport the deceased), on both observation days an additional vehicle was added to each convoy to transport the CDC observers.

Prior to arriving at the home, the burial team lead called a family member or community point of contact to confirm the location of the corpse. Upon arriving at the home, a member of the burial team would explain the purpose their visit and the activities they would conduct to family members (i.e. documentation of the deceased's illness history, specimen collection, removal of the body from the home, disinfection with chlorine spray). The collection of oral swab specimens for EVD testing was instituted the third week of October (Epi Week 43). If the family agreed for the corpse to be removed, designated burial team members would then don personal protection equipment (PPE), collect the oral specimen, place the corpse in a body bag and remove it from the home, and disinfect the room or area where the deceased had stayed. Upon completion of these activities, the team would then transport the corpse to the crematorium. If the team had been assigned additional corpses to collect that day, depending on their location the team might collect those bodies first and then transport all bodies to the crematorium at the same time. Within 24-48 hours, a separate government team returned to the home to conduct a more thorough disinfection.³

Seven of the eight burial team visits took place at homes, while another took place in a hospital setting where the deceased, a young pregnant woman, had recently died. Those present during the home visits included the burial team, the deceased's relatives, a CDC observer, as well as a small crowd of spectators comprised of neighbors or other community members. At a few of the homes, community leaders such as the Town Commissioner were also present. At the hospital location, the father of the deceased, a young pregnant woman, was the only family member

³ As discussed elsewhere in this report, after the national cemetery was opened in late December 2014, burial teams began transporting bodies directly to the national cemetery where they were buried by Global Communities' on-site burial team or the team accompanied the deceased's family to a private cemetery and conducted a safe burial there. By early March 2015 the body retrieval process was subsequently revised such that after removal from the home, bodies of the deceased were taken to a cold storage facility until the Ebola test results were known. Bodies that tested positive were transported to the national cemetery for burial. Bodies that tested negative were returned to the family for burial.

present. This latter “visit” continued a few hours later at a home in a different part of Monrovia where the father had gone to consult with family members about his daughter’s death.

The burial team visits were intense, emotionally-charged encounters. At least two of the families appeared to have had no prior warning that a burial team had been contacted until the team showed up “unannounced” at the home. In the majority of visits observed there was a lot of tense back-and-forth discussions between the burial team lead, the team communicator, relatives of the deceased and, sometimes, neighbors and other community members. Much of the discussion centered on whether or not the deceased had died of EVD and what would happen to the body after it was removed from the home. During several of the visits, these “discussions” would be more aptly described as “heated arguments.” One such exchange, which consisted of multiple raised voices and shouting, ended with the burial leaving after 15 minutes without the deceased. Of the eight burial team visits observed, six families denied that EVD had been the cause of their relative’s death. Two families produced medical records or x-rays as proof, while the third, the father who had accompanied his pregnant daughter to the hospital, produced a death certificate indicating she had died of eclampsia. During an encounter at another home, some of relatives and neighbors who were present cited remarked to the team that they also valued their lives so if they thought that the deceased had really died from EVD, they would be standing much further away from the house as well insisting that the body be removed from the home, neither of which they were doing.

While the burial team’s task was to remove the corpse from the home, the burial team lead or team communicator usually informed the family that they were not there to “force” and that the ultimate decision of whether the burial team could remove it was the family’s to make. Although most of the families initially expressed outward opposition to their relative’s corpse being taken away, some were more insistent in their opposition than others. Two families refused to allow the burial team to take the body, while three other families relented after initially saying no. During one of those latter visits, a relative of the deceased called a high-level MOH official to ask for permission to bury their relative which the official granted over the phone. When the relative tried to hand the phone over to the Red Cross burial team lead to hear the health official’s pronouncement, the burial team lead refused to take the phone, insisting that the official call the Red Cross supervisor instead. After some additional back-and-forth discussion between the burial team, the family, and the Town Commissioner that the family would need to produce a death certificate certifying that EVD was not the cause of their relative’s death before they would be allowed to bury their relative, the family finally agreed the burial team could take the body. A key factor in their change of heart appeared to be the burial team lead’s argument, supported by the Town Commissioner, that their relative’s body would continue to decompose in the heat during the several days’ time it would take the family to get an official death certificate. In some of the other visits observed, burial team members used a similar line of argument in terms of the impact on the corpse if the family insisted it not be removed until results of EVD testing of the oral specimens were known, which could be anywhere from 2-21 days. Upon hearing this, most family members eventually, albeit reluctantly, agreed that the burial team could take the body. Summary results from the burial team observations appear in Table 2 and 3.

Table A-1. Formative assessment summary observations of three out of eight burial team home visits whereby the family refused to allow the burial team to remove the corpse, November 29, 2014 and December 3, 2014, Monrovia, Liberia.

Location of observation	Deceased's demographics	Who informed authorities	Cause of death (Per family or health provider diagnosis)	Was the corpse released to the burial team?
Johnsonville	No body seen	Contact Tracer (CT)	Family denied there had been a death. The "deceased" in question had been transported by ambulance to an ETU the day before.	No. Although the Town Commissioner had contacted the CT about a home death, the CT had not actually seen a body.
Mamba Point	Adult female (68 years)	Family member (Daughter)	Not an EVD case. The mother had been bedridden for the past year. The left side of her brain and the left side of her heart "were not operating correctly."	No. The family agreed to oral specimen collection but refused to let the team take the body because they were opposed to cremation. Although family members were quite distressed, there were no heated arguments. The daughter said she had only called the Ebola hotline number because she thought that was the process for getting a paper certifying her mother could be taken to the funeral home. When the burial team lead informed her the team did not issue death certificates, she left to try and get a death certificate from her mother's doctor.
Sinkor	Adult male (Age unknown but he had adult children)	Chairman of the Community Ebola Task Force	Not an EVD case. Broken spine resulting from fall from a house roof.	No. The burial team left after intense arguments between family members, chairman, and the burial team. A lot of raised voices and shouting. The team left after 15 minutes.

Table A-2. Formative assessment summary observations of five out of eight burial team home visits whereby the family allowed the burial team to remove the corpse, November 29, 2014 and December 3, 2014, Monrovia, Liberia.

Location of observation	Deceased's demographics	Who informed authorities	Cause of death (Per family or health provider diagnosis)	Was the corpse released to the burial team?
Barnersville	Adult male (71 years)	Unknown community member	Not an EVD case. Bedridden since suffering a stroke in 2006. He has been paralyzed since that time. A local health home aide visits the home daily to change pampers, bathe and feed him. He had a fever that started 4 days previously but no other symptoms.	Yes, but only after strong initial resistance and a lot of back-and-forth discussion. Someone called a government official at the MOH and received approval over the phone to bury. The burial team lead refused to take the call, stating that the official would need to call his Red Cross supervisor. After some convincing by the Town Commissioner, who echoed the burial team's warning that the body would decompose in the time it would take them to obtain a proper death certificate, they allowed the burial team to take the body.
Morris Town	Female child (12 years)	Community Ebola Task Force Chairman	Not an EVD case. Female child had been sick for 3 months. X-ray revealed an enlarged heart. Suffering from anemia and Hepatitis B.	Yes. The family appeared resigned to the fact that their child would be taken away but did not resist.
Spriggs Airfield	Adult female (57 years)	Family Member (Brother)	Not an EVD case. Sister had been suffering from cancer since January 2014. Provided hospital documentation.	Yes. Although the deceased's brother allowed the burial team to take his sister's body, he repeatedly corrected the burial team member who was incorrectly documenting her illness history by listing EVD-like symptoms she had not actually experienced.
St. Joseph Hospital	Young adult female (Age unknown)	Hospital	Cause of death on death certificate was eclampsia but the hospital could not rule out EVD because no EVD test conducted.	Yes, but strong initial resistance from the father at the hospital and later with family members after negotiations with the burial team were taken up again in West Point where the father and the deceased resided. Negotiations between the West Point Commissioner, family members, and the burial team resulted in an agreement that the body could be transported to Buchanan in Grand Bassa County for safe burial.
West Point	Adult male (62 years)	Commissioner	Family's "diagnosis" of cause of death was not clear.	Yes, but only after strong initial resistance and intense arguments between the family and burial team. The family had questions about being able to get the body back if EVD test results were negative.

Appendix B. Topic Guide for Community Leader and Community Member Focus Group Discussion

Form Approved
OMB No. 0920-1011
Exp. Date 03/31/2017

Public reporting burden of this collection of information is estimated to average 90 minute per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74 Atlanta, Georgia 30333; ATTN: PRA (0920-1011)

Community Knowledge about Ebola and Care-Seeking Behaviors

1. What are people in this community saying about Ebola? What are some of their concerns?
2. What do people do to prevent themselves or family members from getting Ebola?
3. What do people usually do if they think they or a family member has Ebola?
4. If a family member becomes sick with Ebola, what happens to people who live in the same house?
 - 4.1 What happens to the friends and neighbors they know?
5. What are some of the reasons people might not want to seek treatment if they think they or a family member has Ebola?
6. Does this community have an Ebola Task Force? If yes, what is its role?
 - 6.1 Which groups of people are on the Task Force?

Ebola-Related Services in the Community

7. What is the government doing to help people who get sick from Ebola?
8. What are other organizations doing to help?
9. What are the names of the ETUs that you know? What are people saying about the different ETUs?

Community-Based Deaths

10. What happens if someone in the community dies at home? What do family members do?
 - 10.1 What do community members do?
11. What do family members do if a child dies from Ebola at home? An adult? An elderly person?
 - 11.1 Do family members use a funeral home for the death of a child? For an adult?
12. If someone dies at home, how long do people usually keep the body at home?
 - 12.1 Is there any stigma to keeping the body at home?
13. Since this Ebola business started, has anyone died in this community? If yes, did they die at home or somewhere else?
 - 13.1 What happened to the body?
14. Have you ever heard that sometimes people bury the body secretly? If yes, ask:
 - 14.1 Why do they do bury secretly and who conducts the secret burial?
 - 14.2 How much do secret burials cost?
 - 14.3 Have there been any secret burials in this community?
15. Which bodies are people more likely to bury in secret? Why?
16. What does the government say people should do if someone dies at home? Are people supposed to call anyone? If so, who?
 - 16.1 Do people follow the government's advice? Why or why not? [If not mentioned, probe about cremation policy]

Final Comments or Suggestions

17. What do you think the government should do about Ebola?
18. What do you think the government should do when people die at home?
19. Is there anything else about Ebola in this community or in Liberia that you would like to mention or think we should know? Is there anything you think the government should know?

FOR COMMUNITY LEADER FGD ONLY, ASK Q. 20-23***Community Demographics***

- 20.** How many people live in this community?
- 21.** How is this community organized in terms of leadership? What are the different leadership positions and responsibilities? (E.g. Community chairperson, governor, other community group leader, community members, etc.)
- 22.** How are community leaders selected?
- 23.** What different types of social groups or organizations are there in the community (e.g. women's groups, youth groups, etc.)?

Appendix C. Topic Guide for Contact Tracer Focus Group Discussion

Form Approved
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Public reporting burden of this collection of information is estimated to average 60 minute per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74 Atlanta, Georgia 30333; ATTN: PRA (0920-1011)

Community Knowledge about Ebola and Care-Seeking Behaviors

1. What are people in the communities you visit saying about Ebola? What are some of their concerns?

Job Responsibilities

2. What are the job responsibilities of a contact tracer?
3. How do you know which people are contacts?
4. How do you know which homes to visit?
5. What do you do once you arrive at a home?
6. What kind of information do you collect?
7. Which forms do you fill out?
8. What do you do if the people refuse to provide the information?
9. What do you do if the contacts you are supposed to see are not at home?
10. What happens with the information you collect from the contacts you visit?
11. What Ebola safety precautions do you take while you are working?

Challenges of the Job, Job Recruitment and Training

12. What are the biggest challenges of your job?
13. What was the reason you decided to work as a contact tracer?
14. How were you recruited?
15. How long have you had this job?
16. What type of training have you received for this job?
17. Who provided the training and how long did the training last?
18. What kinds of things did you learn?
19. Have you received any refresher training? If so, how many times?
20. What kinds of things did you learn at the refresher training?

Final Comments or Suggestions

21. What do you think the government should do about Ebola?
22. What do you think the government should do when people die at home?
23. Is there anything else about your job or Ebola that you would like to mention or think we should know? Is there anything you think the government should know?

Appendix D. Topic Guide for Contact Tracer Supervisor Key Informant Interview

Form Approved
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Public reporting burden of this collection of information is estimated to average 40 minute per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74 Atlanta, Georgia 30333; ATTN: PRA (0920-1011)

Community Knowledge about Ebola

1. What are people in the communities you visit saying about Ebola? What are some of their concerns?

Job Responsibilities and Contact Tracing Activities

2. What are your job responsibilities of a contact tracer supervisor?
3. How is your team notified about which contacts to follow?
4. How do they know which homes to visit?
5. What are contact tracers supposed to do once they arrive at a home?
6. What kind of information do they collect?
7. What are they supposed to do if the people they are supposed to see are not at home?
8. What do you do with the information the contact tracers collect?

Challenges of the Job, Recruitment, and Training

9. What are the biggest challenges of your job?
10. What was the reason you decided to work as contact tracer supervisor?
11. How long have you been a supervisor?
12. How were you recruited?
13. What type of training did you receive?
14. Who provided the training and how long did the training last?
15. Have you received any refresher training? If yes, when?
16. What kinds of things did you learn?

Final Comments or Suggestions

17. What do you think the government should do about Ebola?
18. What do you think the government should do when people die at home?
19. Is there anything else about Ebola in this community that you think I should know? Is there anything you think the government should know?

Demographics

20. How old are you?
21. What is the last grade you completed in school?
22. Which languages do you speak?

Appendix E. Consent Script for Focus Group Discussion

INTRODUCTION AND PURPOSE

The Ministry of Health and Social Welfare (Republic of Liberia) and the Centers for Disease Control and Prevention (USA) are conducting an assessment to learn about people's knowledge and experiences with Ebola in their communities.

This assessment will help us understand how people's access to Ebola-related resources can be improved. To do this, we will be talking with people in [insert Liberia community]. We would like you to take part in [a group discussion with other people from your [neighborhood/organization]].

PROCEDURES

Being part of this assessment is up to you. If you do not want to take part in this [group discussion] [interview], it will not affect any health care or treatment you receive. It will not cost you or your family anything. If you agree, we will ask you some questions about people's access to Ebola resources in this community. You can choose not to answer any questions that you wish for any reason. The group discussion will take about 45-60 minutes to complete.

We will write what you say in a notebook and use a tape recorder so we don't forget what you say. We will keep the notebooks and tapes in locked files and only assessment staff will be allowed to read and listen to them.

This assessment has little risk. We may ask you some questions about persons you know who may have had Ebola. However, if any questions we ask you make you uneasy, you can choose not to answer any of them, for any reason.

BENEFITS

The information we collect during our interview will not help you directly, but it could benefit many other people in the future because it will help the Ministry of Health and Social Welfare to improve its Ebola programs.

CONFIDENTIALITY

What we talk about will be kept private to the extent allowed by law. To keep your privacy, we will keep the records under a number and will not record your name. We might use your exact words when we report the findings of this assessment, but your name or other facts that might point to you will not appear in the report. We will keep the records and tape recordings in locked files and only staff from this assessment will be allowed to look at them. Your name or other facts that might point to you will not appear when we report the findings of this assessment. Complete privacy cannot be guaranteed. There is the potential risk that information shared during the focus group could be discussed by another participant outside of the group.

I observed the process of consent. The form was read to the study participant and the participant was given the chance to ask questions, appeared to accept the answers, and signed to take part in the study with his/her signature or thumbprint.

Witness _____ Signature/Thumbprint _____ Date: ____/____/____

DD MM YYYY

Appendix F. Consent Script for Individual Interview

INTRODUCTION AND PURPOSE

The Ministry of Health and Social Welfare (Republic of Liberia) and the Centers for Disease Control and Prevention (USA) are conducting an assessment to learn about people's knowledge and experiences with Ebola in their communities.

This assessment will help us understand how people's access to Ebola-related resources can be improved. To do this, we will be talking with people in [insert Liberia community]. We would like you to take part in an individual interview.

PROCEDURES

Being part of this assessment is up to you. If you do not want to take part in this [group discussion] [interview], it will not affect any health care or treatment you receive. It will not cost you or your family anything. If you agree, we will ask you some questions about people's access to Ebola resources in this community. You can choose not to answer any questions that you wish for any reason. The interview will take about 45-60 minutes to complete.

We will write what you say in a notebook and use a tape recorder so we don't forget what you say. We will keep the notebooks and tapes in locked files and only assessment staff will be allowed to read and listen to them.

This assessment has little risk. We may ask you some questions about persons you know who may have had Ebola. However, if any questions we ask you make you uneasy, you can choose not to answer any of them, for any reason.

BENEFITS

The information we collect during our interview will not help you directly, but it could benefit many other people in the future because it will help the Ministry of Health and Social Welfare to improve its Ebola programs.

CONFIDENTIALITY

What we talk about will be kept private to the extent allowed by law. To keep your privacy, we will keep the records under a number and will not record your name. We might use your exact words when we report the findings of this assessment, but your name or other facts that might point to you will not appear in the report. We will keep the records and tape recordings in locked files and only staff from this assessment will be allowed to look at them. Your name or other facts that might point to you will not appear when we report the findings of this assessment.

I observed the process of consent. The form was read to the study participant and the participant was given the chance to ask questions, appeared to accept the answers, and signed to take part in the study with his/her signature or thumbprint.

Witness _____ Signature/Thumbprint _____ Date: ____/____/____

DD MM YYYY