Community Perspectives about Ebola in Bong, Lofa and Montserrado Counties of Liberia: Results of a Qualitative Study

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Compiled by Najmeh Modarres

Field team led by Sekou W. Konneh

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1 Najmeh Modarres, Stella Babalola, Maria Elena Figueroa, Leah Wohlgemuth, Amanda Berman, Samantha Tsang, and Grace Awantang

2 Sekou W. Konneh (Lead, RECEIVE); S. Kpanbayeazee Duworko (Assistant Lead, RECEIVE)
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BACKGROUND

The deadly Ebola virus disease (EVD) that first began in December 2013 in Guinea had in several months’ time begun to spread to neighboring countries Liberia and Sierra Leone, both of which share its borders. In Liberia, Lofa County, which borders both Guinea and Sierra Leone, became the first county to have Ebola cases, specifically in the Foya District.

Up until September 2014, Liberia had been the country most impacted by the 2014 Ebola epidemic. As of late January 2015, more than 22,000 people have been infected with the disease, resulting in a devastating loss of life for more than 8,800. Shortly after the first cases in Liberia were detected in March 2014, Ebola infection has spread unabated across the country, affecting all of the 15 counties, resulting in thousands of deaths. Consequently, Ebola was declared a national emergency in Liberia on August 6, 2014.

Community perceptions about Ebola and some social norms and cultural practices can hinder, slow down or facilitate the spread of the disease. Strategic health communication can play a key role in stopping the outbreak, primarily by helping community members recognize and identify how they can modify their religious and cultural practices and behaviors—such as not directly touching loved ones who are ill or by changing the way persons who die from Ebola are treated and buried—so they and their families can prevent themselves from getting the disease. A health communication strategy will be critical to give community members a role in community-level prevention and support interventions, to equip them with the knowledge, confidence and efficacy to act, and to temper the fear that leads to panic, in turn fuelling denial, rumors and behaviors that perpetuate the spread of the virus.

As reports of reduced incidence of Ebola infection in Lofa County surfaced, there were concerns among international agencies about possible underreporting of Ebola cases and deaths. Given a lack of understanding about Ebola, stigma associated with the disease, misunderstandings about how corpses of people who died from Ebola in government facilities are treated and a general distrust of government authorities, it was reasonable to suspect that many cases of the infection were not reported.3

It is within this context that the United States Agency for International Development (USAID) asked the Health Communication Capacity Collaborative (HC3) at the Johns Hopkins Center for Communication Programs (CCP) to assist the Government of Liberia (GOL) and its partners to understand community attitudes, norms and practices related to the Ebola outbreak in Liberia. The results of this assessment will

inform ongoing and future activities on social and behavior change communication (SBCC) in response to the Ebola epidemic in Liberia.

OBJECTIVES

This study aimed to assess differences in community perceptions about, and in response to, Ebola in three counties: Lofa, Bong and Monteserrado. The assessment sought to obtain answers to the following research questions:

- What are the attitudes, community norms and practices that are related to Ebola?
- How do these attitudes, norms and practices vary within and across study counties?
- How have these attitudes, norms and practices changed over time?
- What factors were responsible for changes in attitudes, norms and practices over time?
- Which groups of people in the community continue to be most affected by Ebola and what are the reasons for their higher vulnerability?
- What are community perspectives on community readiness, collective efficacy and community resources to take appropriate actions related to Ebola prevention, care and treatment (including safe disposal of corpses)?
- How does the community relate to individuals who have recovered from Ebola and their families?

METHODOLOGY AND TIMELINE

The study took approximately two months to complete from the design of the study and development of data collection guides to the training of fieldworkers, data collection and transcription, and data analysis and preparation of a draft report.

The timing of the various activities from the study team training is described in Table 1.

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4 The purpose of this assessment was not to verify or validate claims about the reduction in incidence of Ebola in counties like Lofa.
Table 1: Timeline of EVD Qualitative Study

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>November 24-26, 2014</td>
<td>RECEIVE and CCP training: 17 local staff were selected from the three counties and trained for three days in qualitative research, understanding and using the research tools—interview guides for key informant (KI) interviews and focus group discussion (FGD) guides.</td>
</tr>
<tr>
<td>November 26-28, 2014</td>
<td>Pretesting: The study data collection guides and tools were pretested and revised.</td>
</tr>
<tr>
<td>December 1-8, 2014</td>
<td>Data collection: 39 key informants and 14 focus groups were conducted in the selected communities within the three counties.</td>
</tr>
<tr>
<td>December 9-15, 2014</td>
<td>Data transcription/translation (for Lofa) and analysis by teams in Liberia and in Baltimore.</td>
</tr>
<tr>
<td>January 31, 2015</td>
<td>Draft Report</td>
</tr>
</tbody>
</table>

Challenges to Timeline
The local team faced various challenges that impacted the response time. Internet connectivity was a challenge, particularly in Lofa where connectivity was usually operational at midnight and had extremely slow speed in the study areas. Likewise, electricity was only available from 10 a.m. to 10 p.m., when the study team was mostly in the field. Lack of accessible roads led to long-distance walks back and forth to the study sites, which frequently caused the team to miss the window of opportunity to access electricity and the Internet.

These issues slowed down the preparation and feedback of results. The search for skilled translators in QuaduGboni, Lofa County also slowed down the data collection and transcription of data from that site, in turn affecting the analysis and report writing timeline.

STUDY DESIGN
In each county, one district and two communities within the district were selected for the study (see Table 2 for a list of the counties and communities). The selection of study sites was purposive. In Lofa, QuaduGboni was selected because it was the hardest hit district in the county and known to be the epicenter of the EVD in Liberia. QuaduGboni is one out of seven districts in Lofa: it is of Mandingo ethnicity and predominantly Muslim. In Bong County, the research was done in two hard-hit
communities in the provincial capital of Gbarnga. The majority of study participants from this county were Christian. For Montserrado County, the research was conducted in two electoral districts, District 16 (New Kru Town) and 17 (Banjor), both highly affected by the EVD. District 16 is known to be predominantly Kwa, while District 17 is known to be of Mende ethnicity.

The qualitative assessment used key informant (KI) interviews, timeline analysis and focus group discussions (FGDs) to assess community attitudes, norms and practices relevant to Ebola, as well as perceived trends in these outcomes. Data were collected from a total of 39 key informants and 14 focus groups in the three counties.

The key informants were men and women who are familiar with their community and have continuously lived there over the past year. They were vocal and willing to discuss freely about the Ebola situation. The informants did not speak about themselves, but provided their views on what is going on in their community.

Both the KI interviews and FGDs were audio-recorded. In addition, detailed notes were taken during the interviews and FGDs. Data were further organized into matrix tables at the end of each day to facilitate the provision of rapid feedback on emerging themes warranting exploration to the study team.

RESULTS

The analysis was done using data in transcripts provided by the local research team, RECEIVE, in Liberia. Coding of the transcripts was done both in Liberia and Baltimore. Categories for data coding were identified based on the reading of two transcripts by each member of the coding team and to represent key factors related to the evolution of Ebola prevention, care and treatment. Ten over-arching themes were used to code and organize the data, including 1) knowledge, 2) beliefs, 3) community organizing and leadership, 4) current patients, 5) survivors, 6) orphans, 7) health services, 8) burials and cultural practices, 9) information needs and credible sources and 10) context for change. The results presented below are organized by these ten categories.

KNOWLEDGE OF EBOLA

Perceived Causes of Ebola

For all three targeted counties, respondents described Ebola as a “deadly disease that kills,” and cited symptoms such as red eyes, headache, vomiting, running stomach, fever and bleeding. Causes of Ebola were believed to include “bush meat, such as fruit bat and monkey” (Montserrado County, female KI, age 59) and social
actions, “shaking hands and touching infected people” (Montserrado, Banjor, male FGD participant, age 26-63).

The way Ebola is perceived by communities is revealed through the ways it is defined and described by community members. For example, the high infectiveness of the disease was likened to “chicken sickness,” referring to the way that having in a coop one chicken sick with a disease usually quickly leads to other chickens in the coop also falling sick with the same disease. The rapid spread of Ebola was also described as “family visa,” which is a local reference to the diversity visa (DV) program that is popular among Liberians who want an immigrant visa to relocate to the United States. The implication is that when one person in a family is infected with Ebola, other members of the family will contract it or be involved in some way, a process that is similar to the DV program that also usually incorporates all members of the family wanting to travel to the U.S. Thus, Ebola is also conceptualized as a group illness or a disease that affects the family. To elaborate further, in the Kpelle language Ebola is called “Ju pa,” which means to “kill the whole family.” Last, Ebola was also defined by its symptoms and consequences. To illustrate in the Mandingo language, it is referred to as “Esaebola,” meaning “you toilet, you die,” or “Korba,” which literally means “stomach running” or diarrhea.

Prevention Activities

Activities to prevent getting Ebola were described by participants as washing hands, not touching the dead or sick, not eating bush meat, avoiding mass movement of people, hugs and hand shaking, contacting local health teams or Ebola task forces, and conducting contact tracing. At the onset of the outbreak, respondents stated there was little individual knowledge and information among community members and health workers on how to prevent getting sick. Consequently, there was confusion regarding appropriate preventive measures.

When Ebola first came into this community around July, people, including health workers, were confused because there was no prior knowledge on how to protect ourselves (Bong, Civil Compound, male health worker KI, age 36).

Participants stated that prevention activities were delayed and began after many deaths had already occurred in the communities in the initial months of the outbreak. The increasing mortality rate generated an increased threat perception within local communities that changed initial feelings of denial and disbelief about the reality of Ebola to realizations and acceptance that Ebola was a real threat and a risk to one’s health and life. This is illustrated in the quotations below:

Before, we did not believe that Ebola was real. After so many deaths, followed by awareness on prevention from the health teams, such as washing hands, no touching dead bodies, avoiding sick persons, we believed...The changes came
after two months in September 2012 (Lofa, Barkedu, male FGD participant, age 42-80).

We really started following these safety rules around early August, owing to the high deaths in our community at the time (Bong, Civil Compound, male health worker KL, age 36).

It has changed. Before, people were in denial, but now they are playing by the rules...Since September because people believed now that Ebola is real (Montserrado, New Kru Town, Christian religious leader KL, age ).

However, the above informant also pointed out that there are still pockets of denial in communities and “some community members still don’t believe that Ebola exists and they are not observing the preventive messages. Because they lack knowledge about Ebola prevention (and) they are giving first aid treatments without prevention.” The important role played by communication activities and information resources is evident in the above statement. The perception is that denial of Ebola persists among uninformed individuals, who, by virtue of not having correct preventive information, continue to practice behaviors that increase their risk of getting sick.

Respondents demonstrated good understandings of appropriate prevention measures to reduce personal risk for Ebola. Adoption of prevention activities became common once communication activities and information related to protecting one’s self were provided by health workers. This point is illustrated further in the statement below:

To protect ourselves from getting Ebola, we are seriously following the preventive measures given by the health authorities, such as frequently washing our hands, not shaking hands with others, not providing care to sick people at homes without proper protection, not touching dead bodies, avoiding the body fluid of sick and dead people, and not eating or hunting bush meat... (Bong, Civil Compound, male health worker, age 36).

In addition to individual prevention efforts, respondents realize that prevention must be a community effort that starts with involving community leadership. They also realize that community members should be vigilant and should encourage others in their community to be consistent in implementing preventive measures. These thoughts are relayed in the illustration below:

On prevention, we are working with our community leadership and other...to continuously encourage our people about all the preventive measures that are available to us, such as not allowing strangers in our household, calling the health team to provide care for the sick (Bong, male FGD participant, age 34).

Informants described an acceptance of the new social norms developed to reduce the threat of Ebola “because it has reduced the death rate in our community” (Lofa,
Barkedu, female FGD participant, age 19-50). A respondent from Lofa, where at the time of writing has had zero Ebola cases for over a month, described that she felt:

*Calmed down now because we have handled all our contact tracing, and we still with washing of our hand and avoiding each other* (Lofa, Barkedu, female FGD participant, age 19-50).

In other words, providing resources and information that equipped individuals with the means to protect themselves from the perceived threat of Ebola restored a sense of “calm” in place of the erstwhile “confusion” that characterized the pre-prevention environment.

**Treatment of Ebola**

In the early stages of the outbreak, community members stated they treated their sick family members as per their usual custom of care. This behavior may have been reinforced by denial, lack of information and prevention resources, and the absence of Ebola treatment units (ETUs) to transport sick individuals. Montserrado communities described using elements of the Ebola kits in the following illustration:

*There were no ETUs to take infected persons, as the results, families were providing care for their sick relatives at homes and burying their dead as usual* (Bong, Civil Compound, male health worker KI, age 36).

*Initially, we gave care to the person while in the protective clothing and called the health team* (Montserrado, Banjor, male FGD participant, age 26-63).

Normative practice in the communities for treating illness, including Ebola, was the use of herbs (*jologbo*) or other available medicine.

*We used to care for our sick people by buying Flagyl, tetracycline, Paracetamol, ORS and B2* (Lofa, Barkedu, female FGD participant, age 19-50).

However, respondents perceived this practice was changing as a fear of people who are sick has resulted in herbalists not wanting to treat sick people.

*People treated other sickness with traditional herbs. This has changed because of the outbreak of Ebola. Herbalists are afraid to treat sick people.* (Bong, female health worker KI, age 50).

Now, respondents stated that people routinely reach out to their local health center or ETU for treatment of Ebola. There is a changing norm where the responsibility for treating the sick has shifted from the family and home-based care to ETUs.
Before we give traditional herbs and tablets to our sick people, but now the ambulance carry the sick people (Lofa, Barkedu, Elder KI, age 63).

Before community members and traditional leaders give home care to the sick, most especially country herbs for treatment. We the religious leaders pray for the sick by laying hands. It has changed. Now when someone is sick, we call the health team (Montserrado, Banjor, male pastor, age 39).

BELIEFS ABOUT EBOLA

Spiritual Origins and Conspiracies

Respondents expressed varied beliefs about the cause or source of Ebola, including perceptions that Ebola was a curse or trial from God, a way to remove peoples’ kidneys, a man-made disease designed to generate financial gain and an attempt by the government to generate funds from the international community. Rising mortality rates from Ebola influenced a change in these beliefs about conspiracies and spiritual vengeance; respondents perceive that currently there is widespread local acceptance that Ebola is in fact a real disease.

The people in this community first believed that Ebola was a man-made virus, made for financial reasons because the more people died the more money government will get from donors. However, this belief system has changed to a larger extent owing to the number of deaths we experience in our community in late July when the first case was discovered in this community (Bong, Civil Compound, male health worker KI, age 36).

Is Non-Discriminatory

Respondents described some initial perceptions that Ebola only targeted specific individuals or communities.

The beliefs of the people have changed dramatically because from the beginning we had the notion that it was a Lofa County disease but news about the disease spread so fast from Lofa, to Monrovia, Firestone and then right in our backyard at Phebe...Ever since the disease appeared in our community, everybody now believes that Ebola is real (Bong, Civil Compound, quarter chief KI, age 54).

They used to think that the sickness was for us only but now they can come around us...since August (Lofa, Barkedu, female FGD participant, age 19-50).

This illustration shows that distance and lived experiences shaped individual beliefs about Ebola. When it was rampant in distant areas, individuals from communities that were unaffected had difficulty both acknowledging the reality of Ebola and
conceptualizing it as a threat to personal health. However, with the onset of disease in their own community and closer proximity to the illness, individual beliefs about threat and vulnerability changed, in turn influencing changes in preventive behaviors.

Reports of the non-discriminatory nature of Ebola infection also resulted in individuals believing that Ebola constituted a real public and personal threat, as evidenced in the statement below:

*In Banjor community, after the death of a health worker named [deleted name]...From that moment some people started to believe that Ebola was real* (Montserrado, Banjor. Imam KI, age 49).

**A Disease to Be Feared**

Communities felt threatened by the rapid spread of the disease through their communities and across counties. This fear played a role in changing individual beliefs about Ebola.

*Four months ago, fear was in the community. People were dying on a daily basis. We were rejected by other people. There was no treatment center* (Bong, male FGD participant, age 25).

There was also fear of infected relatives and community members, which ultimately led to stigmatization and abandonment of sick individuals and often those associated with them. In some cases, entire households would be shunned because one of their members was ill or had died from Ebola.

*Yes, my brother was showing some symptoms of Ebola, weakness, vomiting and red eyes and was taken to a private clinic for treatment. His case was a probable case because he was not tested, but died. The family actually abandoned him due to fear of contracting the virus; the community members also avoid us due to the same fear* (Montserrado, New Kru Town, mixed FGD participant, age 47-64).

*We feel bad and think that when infected with the virus, you will die and you are a source of transmission of the virus. Therefore, community members abandon you for fear that you may spread the virus* (Montserrado, New Kru Town, mixed FGD participant, age 47-64).

*The fear is even extended to the family members of the victim* (Montserrado, New Kru Town, mixed FGD participant, age 47-64).

Respondents perceived that the fear of stigmatization by one’s community continues to play a role in why individuals hesitate to seek help for themselves or
relatives when they are exhibiting symptoms of sickness. As one participant points out, stigmatizing behaviors have not changed.

*People do not feel comfortable asking for help because they are afraid of being stigmatized or avoided by people...and it has not changed overtime* (Montserrado, New Kru Town, male KI, age 36).

**COMMUNITY ORGANIZING AND LEADERSHIP**

*Task Forces*

Community organization and mobilization through task force activities have played a crucial role in Ebola prevention activities within communities. According to study participants in all communities selected in the three counties, the task forces were established specifically to deal with EVD. No such structure existed prior to the outbreak in these communities. Respondents described the community task force as playing very important roles between August and October 2014. Their roles have been primarily to educate about the Ebola disease and to motivate the community to help stop its spread by adopting prevention- and treatment-seeking practices. Community task forces were described by respondents as ‘enforcers’ or ‘influencers’ through their activities, as well as the first point of contact for reaching the national Ebola emergency hotline, for reporting Ebola cases or deaths, and for arranging burials.

*Community task force are creating house-to-house awareness that has led to the prevention of Ebola in our community, along with community leaders, MSF and community health team* (Monteserrado, New Kru Town, Christian religious leader KI, age).

*Because of the massive education on the prevention of the Ebola. Thanks to the community task force, religious leaders, community leaders who are the driving force this initiative* (Montserrado, Banjor, male pastor KI, age 39).

*We call on the town chief, who calls the task force for the sick person...* (Lofa, Gbebedu, male KI, age 58).

*Role of Leaders*

The study participants described their leaders as the chiefs or religious leaders in the community. They were also described as the driving force of the community task force groups. These leaders were often the first person to be contacted when there was an Ebola-related issue and many respondents cited good leadership as a reason why they had fewer Ebola cases than before and fewer cases than other counties.
As a quarter chief, there is a surveillance team composed of youth that keeps track of strangers entering the community...In getting Ebola sick people to the ETU, I am the first line of contact. Anyone showing signs of Ebola the case is first reported to me before calling the ETU (Bong, Civil Compound, quarter chief KI, age 54).

We call the town chief. Sometimes the secretary for the paramount chief [deleted name] (is) who call the health workers. Yes, when he call we see them right away...We heard about 4455 but we never used it, we can only call the town chief (Lofa, Barkedu, female FGD participant, age 19-50).

The communities that have fewer cases are because leaders were actively involved with spreading preventive messages than communities with high cases. Some communities have good leadership and they put all preventive measures into place and other community leaders do not enforce these preventive measures. Community members and chairpersons are the ones that initiated this (Montserrado, New Kru Town, mixed FGD participant, age 47-64).

From the above illustrations, it is evident that good leaders and leadership were perceived to include delivery of strong communication messages about prevention and new cases, and enforcement of preventive measures. Good leaders also had a communication strategy and pathway for community members to follow to keep a flow of information about the status of Ebola in their communities.

Respondents also described the role religious leaders have played to mobilize communities and support community efforts. They described how religious leaders used their church or mosque networks as a communication platform for encouraging behavior change, educating their community and mobilizing support for Ebola patients and survivors.

Yes, we always discuss Ebola amongst ourselves at community meetings and at home with our families. We also have the presence of some religious groups that are helping in this fight and these groups, such as BOCA (Bong Christian Association), are also involved in Ebola discussion at all levels in the community including discussion with children (Bong, Civil Compound, quarter chief KI, age 54).

As a pastor, I have established special service to help fight against this Ebola virus. During the service, we pray against the virus and raise offering to support community initiatives. For prevention, we give buckets to members of the community and give financial support to people who have recovered from the virus. We also have an evangelism team that provides psychosocial and spiritual support to the victim (Montserrado, Banjor, male pastor KI, age 39).
Yes, as imam, I use my sermon to create awareness [of Ebola]. I called 4455 (the health team) since August. I embrace them [the survivors] and tell them it was Allah who save them since September. Since August, I call the Ebola respond team (Montserrado, Banjor, imam KI, age 49).

Especially in Lofa, religious leaders such as the imam5 (Muslim religious leader) were described by respondents as the first point of contact in the community, as an educator who reiterated and reinforced prevention messages from health workers, as well as the leader of prevention activities in the community, as illustrated in the quotation below:

As an imam, I don’t only pray for my people, encourage them to keep washing their hands, they should not touch sick people and dead bodies. In the morning, I walk in the community to see whether people have Ebola buckets in front of their houses. Those who don’t have, I tell them to get one and at times I recommend them to the Red Cross people to provide for them and they do get (Lofa, Barkedu, chief, imam KI, age ).

If I find that someone is sick, I report the sick person to the Imam who then will call health team in the community (Lofa, Barkedu, female KI, age 58).

Overall, community members described discussions around Ebola taking place in religious sites (churches, mosques), community town halls, community associations, door-to-door activities and open air areas, such as football fields and markets.

In some communities, the community members have taken the initiative to develop additional initiatives to those implemented under the leadership of their leaders’ task forces. Respondents described how many youth and women formed their own groups to assist where there were gaps in the mobilization against Ebola.

Young people are involved with door-to-door awareness to ensure that there are hand washing stations at each house. All regular community meetings begin and end with Ebola awareness and community update. Participation is always encouraging, especially when it comes to item distribution (Bong, Civil Compound, quarter chief KI, age 54).

Federation of Liberian Youth (FLY) also has youth mobilized in the community conducting training for community (Bong, mixed FGD female participant, age 54).

5 In QuaduGboni, Lofa County, it is difficult sometimes to distinguish between the elders and Imams as most often, they are used interchangeably. The reason for this interchangeability is that in many instances it is elders that become Imam figures. Also, please note that the study done in QuaduGboni is not a representation of Lofa as a county; the area was primarily selected because it was highly hit by the Ebola virus. It must be clear that the two communities (Barkedu and Gbebedu) are in the same district (QuaduGboni) dominated by the Muslims and ethnic Mandingoes. In terms of beliefs and practices, they may be different from the other parts of Lofa.
CARE FOR EBOLA PATIENTS AND SURVIVORS

Access to Health and Support Services for Ebola

Before health education on Ebola prevention reached communities, community members often treated their sick ones at home. Over time, and especially in Montserrado County, Ebola kits were distributed and often used as first aid for suspected Ebola cases until help arrived.

Community members are careful with Ebola patient, but give first aid to keep the victim up until the health team arrives (Montserrado, Banjor, male pastor KI, age 39).

If someone in my house come down with the virus, I first isolate the person and use the protective kits we received from MSF France to give first aid. In the kit there are gloves, plastic suit you can wear to protect yourself while giving care to the sick (Montserrado, New Kru Town, mixed FGD, age 47-64).

The protective kits have really been a help to us, because the patient need some level of care before the health team can arrive. Such first aid treatment help encourage the person (Montserrado, New Kru Town, mixed FGD participant, age 47-64).

Respondents described how, since September, community members would isolate a suspected Ebola case and contact the health team, “People who are quarantined and have the symptoms of the virus are place in a separate room and call the hotline and provide food and care until the health team arrived” (Bong, Millionaire Quarter, health worker KI, age).

SURVIVORS

Stigma

Respondents believed that even though the acceptance of survivors had positively changed over time, not all community members felt comfortable with survivors returning to their community. Community members did report being comfortable dealing with survivors, however, there were still concerns that not all survivors were actually Ebola-free, even when they presented a government-approved certificate.

Yes! A certificated patient who returns from Foya health center came and spread the virus. All his family died, community members quarantined members of that household and stay away from them (Lofa, Barkedu, male FGD participant, age 42-80).
We eat together, but always careful thinking they could spread the virus further (Lofa, Barkedu, men FGD, age 42-80).

We feel happy, but avoid them until after three months, the concern we have is that we are not sure they totally free from Ebola even if they have a certificate. The survivors are members of the tracing team. This attitude is changing for we even pray together in the mosque (Lofa, assistant town chief KI, age 38).

The stigmatizing behaviors against Ebola survivors were driven by uncertainties and to some extent, disbelief among community members that survivors are truly infection-free and without transmission potential. Many community members expressed concern over the fact that survivors can still pass the EVD through sexual intercourse. Since sexual intercourse is a private activity, some wondered why the survivors could not be quarantined for the additional period of time before they were allowed to return to their communities.

In some communities, in spite of the warm welcome given to survivors, there is still a community-led quarantine for at least 21 days after their return from the ETU.

We give them a high welcome but we quarantine them until after 21 days, we believe them when we saw the certificate given to them by the government (Lofa, Gbkedu, elder KI, age).

We quarantined them for 21 days before we started interacting with them, so behavior is positive (Lofa, Barkedu, female FGD participant, age)

Nonetheless, many community members described the integration of survivors in a positive manner, but expressed concern over their livelihoods, such as having psychosocial support, food and basic supplies to start over.
We feel happy when survivors return home from the ETU because of the education we are receiving on the status of survivors. Now my concern is how the survivors can restart their livelihood because they lost almost everything. (Montserrado, Banjor, male pastor KI, age 39).

**Role of Survivors in the Prevention Response**

Within the community, survivors were often described as an integral part of the Ebola response. They were considered credible sources of information about Ebola infection and leaders often involved them in educating the community and encouraged to share their stories.

The attitude and reactions have changed, now community members are encouraging survivors to tell their stories, give them food, clothing and incorporate the survivors in the community task force. (Montserrado, New Kru Town, mixed FGD participant, age 47-64).

Community leaders ask him/her [survivors] to educate community members on the care and treatment in the ETU (Montserrado, Banjor, imam KI, age 49).

Ebola survivors participate in community activities, depending on the way in which people will show love and care for them (Bong, female health worker KI, age 50).

**ORPHANS**

As with survivors, community members described an initial rejection of orphans for fear that they would transmit Ebola. Respondents perceived that over time, community member feelings and attitudes have changed and there is now a general acceptance of orphans of Ebola. Nevertheless, most communities have yet to establish a formal institutionalized support system for the care of Ebola orphans. While in some cases individual community members assist the orphans with food and other basic necessities, in general, the orphans are either left to fend for themselves or become the charge of relatives. In a few cases, community leaders mentioned that they sought help for the orphans from international non-governmental organizations (NGOs).

Some community members help to provide food for them and seek help from other NGOs (OXFAM, Save the Children). It has changed a little bit since November (Montserrado, Banjor, male FGD participant, age 26-63).
The family members are the ones who take care of the orphans. The community members do nothing for them (Lofa, Barkedu, female FGD participant, age 19-50).

HEALTH SERVICES

Liberia did not have a strong health system prior to the Ebola outbreak. As stated earlier, respondents described the main form of care for the sick in communities prior to the Ebola outbreak was home-based care and the use of traditional herbs.

Trust in ETUs and Health Workers

Respondents perceived that ETUs were not immediately trusted and they were initially viewed as “death traps.” Moreover, not all communities had immediate access to an ETU when Ebola infection spread to their communities. Respondents stated that at the onset, health care workers and nurses did not want to interact with Ebola patients, and those that did, treated the patients badly. These initial experiences negatively influenced willingness to use health services by individuals who had symptoms of Ebola, as illustrated in the quotation below:

The nurses (are) in the habit (of) rejecting and avoiding the patients. Sometimes patients are abandoned and are treated very badly since the Ebola came. Community members were afraid to seek treatment from that hospital because the outbreak started in that hospital (Bong, mixed FGD participant, female, age 31).

Respondents also perceived that during the initial period of the outbreak, health workers lacked the knowledge regarding how to manage patients with the disease and also were not equipped with prevention and treatment resources, such as protective gear.

The increase in the number of Ebola survivors being treated in ETU played a big role in building trust and forging more positive relationships between community members and their health team. Montserrado community members described:

A lady renting in my house was vomiting, stomach running with red eyes with fever. She was taken to the ETU early and tested Ebola positive. Members of our family initially encourage her to go for early treatment. Later when she returned the family welcomes her with joy. The community members also embraced her and learn from her experience (Montserrado, New Kru Town, mixed FGD participant, age 47-64).

This illustration also implies that survivors may have contributed to changing perceptions of ETUs and health workers treatment of Ebola patients by sharing their success stories of survival with family and community members when they
returned home. Thus, communication in itself has played an important role in changing perceptions of ETUs, and in increasing their acceptance by community members as trustworthy places for the treatment of Ebola. These perceptions are relayed in the excerpts below:

*Trust in the ETU has changed, because there are more survivors now. Before, people feel that the ETU was a death trap because of the news coming from there that people weren't taken care of and were sprayed to death. The change started in September to present* (Montserrado, Banjor, male pastor KI, age 39).

*Yes, people believe that seeking help will save their lives. The many success stories from the ETU have caused lot of changes* (Bong, female health worker KI, age 35).

Since September/October in Montserrado and Bong, and August in Lofa, respondents perceive that community members have increased use of ETUs and health and information services, such as the national Ebola emergency hotline and health clinics. These changing perceptions were heavily influenced by the return of Ebola survivors from ETUs.

*Yes, people can now take sick family members to the ETUs because there is now an ETU. It is very spacious with improve treatments from good doctors. Patients are now surviving and returning to the community unlike before when the death rate was very high due to poor treatment by untrained and scary staffs. The sick regardless their status had no choice, we trust the ETU now with the level of staffs and equipment they have to deal with the situation* (Bong, Civil Compound, male health worker KI, age 36).

*People in this community would take sick patients to ETU because we want them to live and we don’t want them infect other community members...and it does not matter who the person is once you are a member of this community we are willing to carry you...(Yes) people are now having trust in the ETU because since September people have survived and came back* (Montserrado, Banjor, imam KI, age 49).

*Yes! We called ambulance to take them to Foya (ETU) where our survivors are treated* (Lofa, Gbebedu, female chair KI, age 48).

Through the above illustrations, respondents perceived that community members have more faith in the skills and motivations of the health workers caring for Ebola patients, and a movement from avoidance of ETUs to help seeking from these treatment units. Community members have made a stark reversal from prior characterizations of ETUs as “death traps” of no return to new perceptions of ETUs as being a place of hope “where our survivors are treated.” ETUs are perceived as not just a treatment unit, but also a place where those sick with Ebola get “to live” and “come back.”
**National Hotline for Ebola**

Soon after the Ebola crisis in Liberia was declared a national emergency on August 6, a local cell phone company was commissioned to set up a national hotline with the code 4455. The first calls started coming in on August 8. The call center was quickly linked to the Ministry of Health and Social Welfare dispatch for the ambulance services, and it is now being communicated as the national hotline for Ebola and future health services. Focus group participants were asked what number they used to ask for help, and KIs were asked specifically about the number 4455 and how it was used.

In Montserrado and Bong, participants gave examples of calling 4455 for help, but there were mixed feelings on the level of response.

*The response teams are not trusted because they do not come when called, even through the present Ebola hotline. This same number, the hotline, was used when a lady in the community (who) was stooling and vomiting; and also when another woman died. They delayed when they turned out (Bong, female health care worker KI, age 35).*

*Yes, 4455 is the national Ebola task force hotline number given by the government. Yes, I trust its service though sometimes they come quick and sometime they delay (Montserrado, Banjor, imam KI, age 49).*

In the case of Lofa, the mobile phone numbers (of community leaders) were used to call for help. Some respondents had heard of the national hotline number, while others were not aware of it. It seems that in the study sites in Lofa, the leaders (e.g. town chief) were in charge of making the call for help. The reason for this pivotal role of the chief in Lofa might be cultural. In Lofa, customs and norms dictate that the elderly and leaders are greatly respected. In Lofa, traditional leaders, such as chiefs, play a pivotal role in community mobilization and governance.

*I heard about 4455 on radio but never call the number. [name deleted], the paramount chief secretary, does all the call for help. Health worker comes immediately (Lofa, Barkedu, elder KI, age 63).*

*We call the Town chief, who later call the county Task force. No, we haven’t heard of 4455. Yes we trust the Number the Town chief can use, because of the quick response (Lofa, Gbebedu, male FGD participant, age).*

**BURIAL AND CULTURAL PRACTICES**

Throughout all selected communities across the three participating counties, respondents reported that traditional and religious burial practices have stopped.
This is another example of changing norms and practices due to the communication received about Ebola. The burial teams who are managed by the health teams or community task force\(^6\) are now in charge of the burial process. This change was reported at the height of the Ebola crisis. Community and religious leaders were instrumental in making this change in burial rites possible.

*The change of burial rites at the time of the heat of Ebola was because of Ebola awareness by health team* (Lofa, Barkedu, male FGD participant, age 42-80).

*The community is no longer involved in burying of bodies we call the government burial team to help. People are now avoiding the sick and the dead. The Community Leaders have been making these changes to happen* (Montserrado, Banjor, male FGD participant, age 26-63).

In Bong and Lofa counties (where this is allowed), respondents reported that the community or family members of the victim still play a role in digging the grave, but with the burial team doing the actual burial.

*Nowadays, the health team is responsible for all burials. Community members contribute by digging the grave. No wake keeping and this was the mandate form the government through the health team* (Bong, Civil Compound, male KI, age 50).

*The government handles all burials...Others have played a part in ensuring that our community Ebola victims were buried by helping to dig their graves...No wake keeping, Government of Liberia takes care of burials.* (Bong, female health worker KI, age 50).

A key difference between Monteserrado County from Bong and Lofa counties has been that in Monteserrado, the corpses of community members who were suspected, probable or confirmed cases of Ebola were cremated. Cremation is still a point of contention for many study participants as evidenced in the statement below:

*The government should stop the burning of bodies because it is not part of our culture.* (Montserrado, New Kru Town, Christian religious leader KI, age).

**INFORMATION NEEDS AND CREDIBLE SOURCES**

Respondents stated that communities would like more information about prevention activities, treatment such as vaccines, contact tracing and information about whether Ebola case numbers are decreasing and when the epidemic is likely

\(^6\) In Bong County, the health team was the equivalent to the task forces in both Monteserrado and Lofa Counties.
to be over. There is also an interest in understanding better the origins of Ebola and how it spread to Liberia.

People want to hear that Ebola has cure, Liberia is free from Ebola, normal activities in Liberia are ongoing (that is, people are carrying out their life like it was before the Ebola outbreak)...People want to know about where Ebola came from (Bong, female health worker KI, age 50).

People want to listen to preventive Ebola messages from radio...People want to know as to whether people are avoiding public gathering, and decrease in Ebola cases (Montserrado, New Kru Town, Christian religious leader KI, age).

We would like to listen to messages of hope and support to eliminate Ebola from Radio, NGOs, and Health workers...any information about Ebola is good what we mainly want to hear is that Ebola is finish (Lofa, assistant town chief KI, age 38).

Religious or community leaders, health care workers, community task forces, survivors and local media/radio programs were identified as credible sources of Ebola-related information.

People trust tribal groups, community leaders and neighbors and they are willing to hear them speak about Ebola. The credible sources in this community are the Community task force and NGOs. Community members don’t trust the Government. People in this community want to hear about preventive messages from radio, and health workers. People want to know as to whether there are decrease in Ebola cases and increase in survivor rate. About prevention...going to the hospital to seek treatment and increasing preventive messages (Montserrado, male youth leader KI, age 26).

We normally get information on Ebola from the health team in our community, Ministry of Health and Social Welfare staffs and the Liberia National Red Cross group in our community and the local media is also another source (Bong, mixed FGD participant, male, age 34).

People trust Ebola survivors because they will give their experiences. The credible sources are the same Ebola survivals (Montserrado, New Kru Town, Christian religious leader KI, age).

**CONTEXT FOR CHANGE**

Community members described hearing about Ebola as early as April 2014, predominately through radio and from others in the community. The uptake of prevention activities were described as taking place between August and September...
2014. Increasing numbers of sick people and deaths in the communities were said to have become evident in August in Lofa, and in September and October in Montserrado and Bong. The change of burial rites and referring community members to the ETU started in approximately September. Mobilizing community task forces and many of the community activities had begun in September and October 2014.

*The knowledge of Ebola has changed greatly since late August to September, due to the preventive measures taught by the community task force* (Montserrado, Banjor, male FGD participant, age 26-63).

*The belief of people have changed due to the high death rate in August, since then, people belief started to change in early September* (Montserrado, Banjor, imam KI, age 49).

*Our beliefs started to change in August when we saw our brothers’ and sisters’ dead bodies being carry away in pick-up truck like dirt. We couldn’t believe people dying at such an alarming rate. From that point community members started taking the preventive measures seriously* (Montserrado, Banjor, male pastor KI, age 39).

In summary, respondents perceived the main contextual changes associated with information received about Ebola and their own experiences to include increased knowledge of Ebola prevention measures; varied beliefs about Ebola, increased adoption of Ebola prevention measures; trusting attitudes towards ETUs and better relationships with health workers, increased use of ETUs to treat sick individuals, reformed burial practices, increased community participation in prevention activities and decreased use of traditional herbs for treatment; and less fear and increased acceptance of survivors with somewhat decreased stigma.

**POTENTIAL FOR SUSTAINABILITY OF BEHAVIOR CHANGE**

There appears to be an acceptable level of understanding, not just of the causes of Ebola, but also of the consequences of adopting certain preventive behaviors. Witnessing multiple deaths within the community and subsequent exposure to Ebola care and prevention health messages have led to an increased understanding of Ebola prevention measures. It is unfortunate that many people had to die before an appropriate response of community education was put in place. Nonetheless, in many communities people are now making the link between the causes of Ebola, its effects and the consequences of adopting preventive behaviors.

Some community members articulated that they now felt confident that Ebola would be defeated because prevention behaviors were commonly being practiced by community members.
We are very confident that we will get rid of Ebola because we are observing all the preventive measures. (Montserrado, Banjor, male FGD participant, age 26-63)

The Ebola numbers are reducing due to regular hand washing, no shaking hands, no bathing dead bodies (Lofa, male FGD participant, age).

Nowadays, people in this community are washing their hands regularly, avoiding sick people, not allowing strangers, not eating bush meat, avoiding public gathering and calling health workers when people show signs and symptoms (Bong, KI, female health worker KI, age 50).

Not only have people started to link the practice of appropriate prevention behaviors to decreased risk, they are also linking continued vulnerability to the lack of these behaviors. For example, young people were perceived to have continued increased vulnerability to Ebola due to their preference for social gatherings and group-based activities, and their resistance to the routine use of prevention measures. These thoughts are outlined in the illustration below:

Disbelief, denial, lack of knowledge: the young people are more vulnerable because of high social engagement like doing burial, shaking hands and watching games in video clubs. Why? Because of their social gathering and not adhering to the preventive methods by the health teams (Lofa, Barkedu, youth leader, age 27).

In addition, respondents believed that individuals are now increasingly more conscious of the need to change some of the local cultural customs and practices that have potential to increase one’s risk of contracting Ebola, as evidenced in the example below:

Communities with less people sick are not involved with traditional and religious practices like community having more people sick (Montserrado, Banjor, male FGD participant, age 26-63).

Respondents have identified communication with leaders, health workers and community members as an important tool for both identifying Ebola cases and promoting prevention measures. Communication and information networks, approaches and processes have been established in these communities to strengthen the response to the epidemic. There is potential to capitalize and diversify the use of these structural resources toward a long-term goal of socio-behavior change for risk reduction, health promotion and disease (Ebola) prevention.

Respondent perceptions noted above indicate that there is an emerging potential for introducing social behavior change interventions for the creation of a ‘new normal’
that protects communities and their members from Ebola, and also promotes healthy protective behaviors. The knowledge within communities of how traditional practices perpetuate risk, and evidence of changing attitudes and beliefs about ability to protect and survive Ebola can be a strong foundation for behavior change interventions that programs should acknowledge and use to their advantage.

Summary and Recommendations

This study used qualitative methods to assess community attitudes and norms related to Ebola in three counties in Liberia. The findings highlight some of the changes that have taken place since the outbreak started and ongoing challenges and concerns.

Correct knowledge of Ebola and its transmission and prevention measures has improved and the current general perception is that Ebola knows no borders, no one is immune from risk and it poses a real threat to everyone. Knowledge and the practice of prevention methods appears to be particularly high and links have been made to the role some traditional practices have in the spread of the disease. In addition, community members have been accepting of changes needed to their treasured customary practices, such as treatment and preparation of dead bodies and burial practices. Nevertheless, study participants stated that there is still a need for information about Ebola and how to prevent infection for some segments of the population, such as among youth. In addition, individuals need information about the status of Ebola in their community and the country; for instance, is the disease waning or increasing and are there hopes for a cure?

Recommendation
Community education and information resources must continue to dispel rumors and myths about Ebola. Target groups with specific information needs must also be considered to increase prevention behaviors among those with increased vulnerability, such as youth. Keeping individuals informed about the changing status of Ebola in their communities could be a great motivational tool for continued community involvement in grassroots activities.

One key finding that is common to all study communities was the changing role of community leaders in the fight against Ebola. Many community leaders have had active roles at the fore of community prevention efforts, some even routinely making community walk-throughs to personally assess compliance and intervene as needed. Religious leaders across all counties reportedly preached Ebola-prevention and care messages to their congregations and were a credible source of prevention information for many community members. Many community leaders have also become the primary communication conduits for the flow of information from their
communities to health authorities. Respondents described community leaders as having a cardinal role in the fight against Ebola and in buttressing the efforts of the Government of Liberia and its international partners. Though limited in terms of medical knowledge, these leaders (e.g., chiefs and religious leaders) have been pivotal in mobilizing community resources and providing succor to residents, including those who become sick of the deadly Ebola virus.

Across all of the three counties, leaders have ensured that their community members had access to Ebola awareness campaigns, task forces were formed to enhance the MOHSW efforts for the evacuation of the sick and those who died from Ebola were removed and buried safely. Providing support to orphans of Ebola and quarantined families were other tasks that devolved on leaders. Some activities carried out by the Ebola task forces could never have occurred without the facilitation of community leaders. A typical example was the role of the task force in working with the community to allow Ebola burial teams to operate and accept different ways of burying the dead that are not consistent with local cultural practices. In addition to the backing of community leaders, another reason that task forces were effective was because it was community-owned, comprised of community members and therefore, considered credible and probably also more acceptable.

**Recommendation**

Involving community and religious leaders in the fight against Ebola has proved to be an effective strategy for mobilizing the community around a common cause. Community leadership is a structure that is well established, with defined roles, and a credible source of authority and succor within the community. It is important to continue to involve these leaders in Ebola prevention, care and treatment, and communication messaging—they are potentially the strongest link to community members and can help to broker community support, mobilize community resources and help to navigate cultural barriers to effective program activities. Nonetheless, the ability of leaders to play the key role expected of them should not be taken for granted. It is important to assess their capacity for expected roles prior to engaging them in an appropriate response. It may be necessary to build their capacity or conduct prior advocacy towards them. Even as the Ebola cases subside, leaders should be supported in their roles to make sure social and behavior change challenges continue to be addressed in a culturally holistic manner.

The successful use of community task forces in the fight against Ebola also has implications for future programing around Ebola and other health issues. The community task forces were specially set up and largely comprised of members with no medical background. There was a level of commitment within the task forces that led to success probably because the members were from the community
they served, had witnessed first-hand the havoc wrought by Ebola, and had a vested interest and inherent motivation to see the epidemic curbed.

**Recommendation**

Community task forces should continue to be part of the response to Ebola and other health issues. They can also become strong grassroots networks for dispersal of correct and accurate information. However, it is important that the members are carefully selected to include people who not only belong to the community but also are committed to the cause. It is equally important that the task force members are credible community members and have the appropriate training for the tasks expected of them. International organizations and NGOs working on the Ebola response should work through these existing community infrastructures, as it is more likely to lead to a trusted and prolonged, continual engagement within the community.

It is important to recognize that the health system in Liberia was already weak before the outbreak of Ebola. At the time the first cases of Ebola were detected, health workers were ill-prepared to deal with the situation. They lacked the necessary knowledge and equipment, thereby putting their lives and those of their patients at risk. Due to this situation, many people that sought Ebola care at the health facilities did not survive, sending the unfortunate message that Ebola was not a disease that the system was able or willing to address. This further fueled mistrust of health facilities and reinforced myths and rumors about the disease.

There are changes in community member perceptions of health services for Ebola. As health workers became better equipped to deal with the disease and as services improved, more Ebola survivors returned home, strengthening hope and trust in the work of ETUs. The study showed that communities are increasingly embracing the services of ETUs and are more proactive in contacting them about suspicious cases of Ebola. This changing relationship with health services and workers has been instrumental in facilitating trust between the two parties and increasing the use of health services—for instance, there are perceived increases in community contacts with ETUs about suspect cases and their willingness to expeditiously transport the sick to health service sites for treatment.

Timeliness of response is critical in emergency situations. Unfortunately, the response was delayed in Liberia and many people that could have survived died. The main lesson for the future concerns the state of preparedness of the health system to deal with a new health problem and quickly mobilize internal and international resources to address the situation.

**Recommendation**

Health workers in Liberia will benefit from training in emergency preparedness. The required capacity strengthening could be provided as part of pre-service or in-service training. It is also clear how
communication can play a role in the re-building of health systems for the next possible outbreak or epidemic; as the 4455 hotline continues to become operational across the country, many parts of the country remain without service and it is essential that linkages be established at the community level to local health care providers to ETUs and Community Care Centers. Communication can play an important role in educating people about emergency planning and what they should and should not do during an outbreak, and how to respond when there is no access to the national hotline.

There is emerging evidence from this study that supports reductions in stigmatizing behaviors toward Ebola patients, survivors and families with active or a history of Ebola infection. This appears to be associated with increased community understanding of the cause, prevention and transmission of Ebola. In addition, increased survival among Ebola patients is fostering the understanding that Ebola may not necessarily be a death sentence. According to study participants, in some communities Ebola survivors were considered an integral part of the prevention response and were active in helping to educate the population about the disease. While communities for the most part are increasingly accepting Ebola survivors and welcoming them back to the community, there are still lingering concerns about their Ebola-free status and their potential to transmit the virus through sexual intercourse up to 90 days after they have been declared Ebola-free. In some communities, Ebola survivors are subjected to community-imposed quarantines upon their return.

**Recommendation**

There is need for community education to correct prevailing myths and rumors about Ebola transmission and on what it means to be Ebola-free. Activities and messages designed to promote compassion for Ebola survivors and orphans are very relevant. It is also important to encourage the involvement of survivors in the response to curb the spread of the disease. Given the positive development around Ebola control, allowing survivors to share their experiences publicly may help to demystify the disease. Additional research should be done on what survivors and orphans experience during their post-infection “reintegration” process back into the community. This may provide information underlying the stigmatizing behaviors of some community practices and give guidance to programs aimed at reducing stigma.

After a dramatic struggle and the painful loss of thousands of lives, there are perceptions among individuals that and end to Ebola is not only possible, but that it may be near. However, some concerns remain that the future might present a new set of challenges for preventing disease outbreaks and epidemics. Specifically, community members were worried about the future ability of the Liberian government to keep Ebola out of the country in a sustainable manner given the poor health system and the general poverty within communities.
Recommendation
Establishment of a national emergency preparedness plan may help to allay some of these fears. Keeping Liberia Ebola-free should be communicated as a priority and responsibility for all in Liberia. The role that communities already played in the response thus far should be given greater visibility and recognition. Moreover, community members should be educated on what they can do individually and collectively to keep Ebola and other outbreaks at bay.

This research focused on communities that were hard hit by Ebola and does not take into consideration communities with the lowest disease burden, such as Maryland and Grand Gedeh.

Recommendation
Exploring factors responsible for the low prevalence of Ebola in the low disease burden counties may be a useful research endeavor. As Liberia moves into the next phase of restoration and rebuilding, follow-up research should be done on the needs of the communities and leaders, what worked and what did not, and how and if they were able to maintain their changed behaviors. There should be continuous monitoring of the after-effects of Ebola prevention messaging and how it has impacted community norms and behaviors.