

TITLE: Community-Centered Responses to Ebola in Urban Liberia: The View from Below

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All authors have completed the ICMJE uniform disclosure form at [http://www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

## ABSTRACT:

The objective of this study was to identify epidemic control priorities among 15 communities in Monrovia and Montserrado County, Liberia – one of the hardest hit areas by the current Ebola outbreak. Findings from 15 focus group discussions with 386 community leaders identified specific strategies currently being undertaken and “ideal-typical” representations of what a community-based response to Ebola *should* look like. Data were collected on the following topics: prevention, surveillance, care-giving, community-based treatment and support, networking/hotlines/calling response teams and referrals, management of corpses, quarantine and isolation, orphans, memorialization, and the need for community-based training and education. Findings have been presented as recommendations for (1) Prevention, (2) Treatment and Response, and (3) Sequelae. The study also reviewed issues of fear and stigma towards Ebola victims and survivors, examined communities could draw upon survivors as resources in the outbreak, and studied how communities could provide psychosocial support to those who have been affected by Ebola. The findings provide several models that can inform international and governmental support for community-based management of the current Ebola outbreak.

## INTRODUCTION:

The West African Ebola Epidemic emerged in the forest region of Guinea in late December 2013 and appeared to be contained until May 2014, when it started to accelerate its rate of incidence into Guinea’s capital, Conakry, and into Sierra Leone and Liberia [1]. Upon entering Sierra Leone and Liberia, the rate of Ebola transmission rapidly accelerated, resulting in 1,711 cases by August 8, 2014, when the WHO declared that the conditions for a Public Health Emergency of International Concern (PHEIC) had been met – just the third announcement of its

kind in history. In recent months, as the West African Ebola epidemic continues to accelerate, it has become apparent that the existing range of medical and epidemiological response is insufficient, especially in predominantly post-conflict contexts with exceedingly poor healthcare infrastructures [2]. With the growing awareness that continued construction of hospitals and Ebola Treatments Units (ETU's) cannot keep pace with demand [3] and a recognition of the growing fear held by local communities towards hospitals, ETUs, and new policies concerning mandatory cremation, attention is turning towards the possibility of community-based care and management [4].

This paper presents a unique contribution to these ongoing efforts. Aimed at identifying positive deviance in Ebola prevention, treatment, and response, the research study constituted the first locally-based research initiative in urban Liberia to provide an evidence-driven account of community-centered strategies to contain the Ebola epidemic [5, 6]. Unfortunately, the data collected did not achieve the goal of identifying “positive deviance,” or uncommon or innovative solutions to address Ebola, because many innovative community-based responses were derailed by external factors like a weak public health infrastructure, non-response of hotlines, or the shortage of spaces in ETUs. This paper identifies numerous incidences of positive deviance – including community self-reliance -- but situates positive deviance in a context of widespread systemic challenges.

However, when reviewed using an inductive analytical approach informed by a robust ethnographic contextualization, the data were revealing in many ways. What emerged from this study was a sense of how communities were managing the next best option -- self-reliance -- in the absence of health, infrastructural, and material supports. Specifically, community members described how they would engage in prevention efforts through training and awareness, hygiene,

surveillance, and the creation of local infrastructures; how they would engage in treatment and response through a process of isolation, quarantine, and triage; and how they would manage the sequelae of the presence of Ebola, especially among orphans, survivors (people who had been ill but had recovered), and for memorialization. The findings reported below demonstrate not only how communities are showing resilience in the face of Ebola, but also how community-based responses are, at times, an ongoing source of additional risk, and may fail to contribute to an effective epidemic control strategy.

This research gives insight into community leaders' tactics and strategies for managing the presence of Ebola in their communities, as recommended by some participatory rural appraisal models [7-9]. It contributes to a small but growing literature on local understandings and responses to hemorrhagic fever outbreaks, detailing how under conditions of extreme stress, culture can be made flexible and supple in order to accommodate existing circumstances and make allowances for extraordinary conditions [10], even while acknowledging that the local acceptability of public health messages and tactics must be taken seriously [11]. This challenges conventional thinking about the role that "culture" is playing in the ongoing epidemic. Funerary customs can be suspended. Families will break apart to protect uninfected individuals. Communities will do the best they can given the resources they have, even if "un-cultural," in moments of crisis in order to fight for a future.

However, these findings also show that the attributes of culture that public health experts often attend to in the Ebola outbreak (like hygiene practices, food practices, and death rituals) may not be the attributes of culture that matter the most in understanding how to arrive at a community-centered Ebola response. Attention needs to shift to *the culture of caregiving* that exists in Ebola-affected cities and towns. We need to better understand how strong and dense the

emotional ties that bind families and communities together are and can be, and precisely how Ebola, and the failed Ebola response, is doing violence to those social ties [12-16].

Finally, the data reported here are not so much a process of conjecture or experience as an indication of an emergent and half-formed plan in local communities during a time of crisis. The data, although abstracted here for the purposes of analysis, are based on real experiences of women deciding in advance to sacrifice themselves so that they can care for their family members. They show how men make decisions to struggle through illness in self-isolation in order to protect their families. And they show how a father and a son work through a careful calculus of life and death, and engage in practices of memorialization and survivorship before sickness has even arrived.

#### METHODS:

These data<sup>1</sup> were collected as part of a Government of Liberia/World Health Organization GOL/WHO rapid assessment of community leaders' perceptions of appropriate management practices for addressing the incidence of Ebola in their communities. The research teams were trained and directed by an applied medical anthropologist and conducted data collection from September 1-20th, 2014 in 15 communities of varying economic, ethnic, and population characteristics in Monrovia and in Montserrado County, Liberia. Data are drawn from focus groups, qualitative field notes, and supporting literatures. Research teams conducted 15 focus groups, one in each community, consisting of 15-20 people of mixed gender, for a total of 368 participants. All were community leaders, drawn from women's groups, youth groups, local zonal heads, political groups, clinics, church-based organizations, non-governmental

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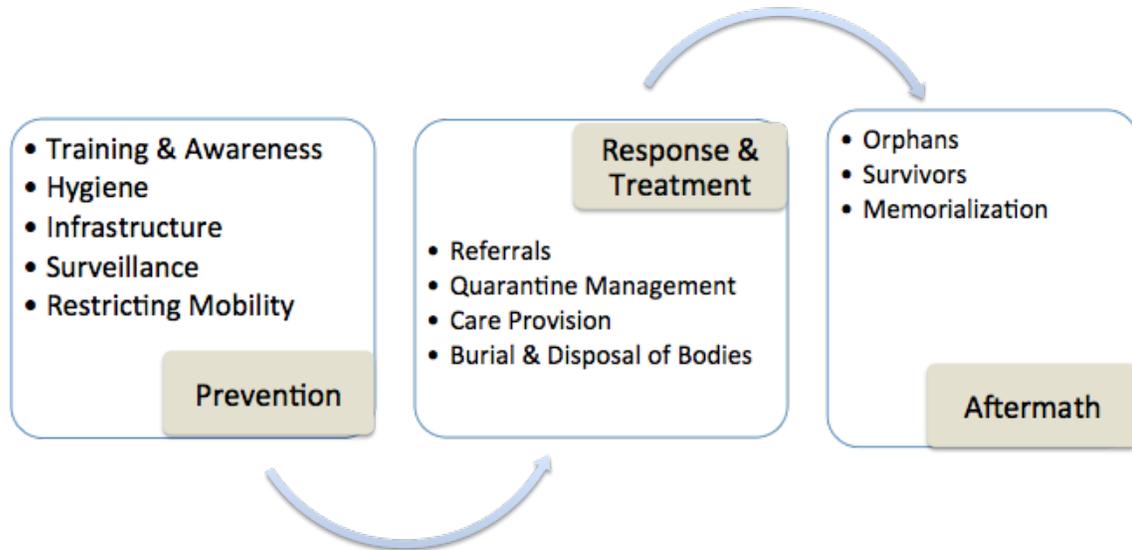
<sup>1</sup> This study received an expedited review and exemption under the University of Florida Institutional Review Board for the Protection of Human Subjects (IRB-02) #2014-U-1117.

organizations, and recreational clubs. The tone of the meetings was widely reported as cooperative and positively engaged. A team of public health and anthropological researchers at the University of Florida and at Yale University analyzed, coded, and thematically clustered de-identified focus group data in October 2014. The inductively derived social structural models represented in Figures 1-4 emerge from focus group findings and were informed by the broader literature on the current Ebola outbreak.

#### FINDINGS:

Community leaders shared with the research team their opinions regarding “best practices” concerning local community responses to the Ebola outbreak. Their feedback was analyzed for common themes, which were used to generate an “ideal-type” roadmap for community-based response to the presence of Ebola in and near urban Liberian communities (see Figure 1), including three sequential phases of action and response: prevention, response and treatment, and sequelae. Both the findings and the figures represented in this section detail community responses and suggest implications that concatenate with the existing literature on social structure, gender roles, health care capacity, and conflict histories in the region [17-22].

**Figure 1: Monrovia Community Leaders' Representation of Optimal Community Based Care August-September 2014**



*A. Prevention*

Community leaders called for prevention, above all, as the best strategy to curtail the Ebola outbreak. In this context, prevention included four key areas: (1) a sharp increase in the quantity and specificity of community-based training, (2) improved hygiene and sanitation (and the distribution of cleaning and protective materials), (3) the creation of a system of surveillance to protect the community from Ebola, to move infected individuals from the community into hospitals and Ebola Treatment Units (ETUs), and manage the removal of the dead, and (4) the development of a community-based infrastructure for the management of the Ebola sick.

The earliest and most consistent request for assistance was a demand for ongoing, recurring technical training for Ebola management. Specifically, community leaders sought training to address key technical challenges in Ebola management:

- How to properly care for sick people

- How to isolate sick people
- How to manage quarantines safely
- How to administer community-based holding centers
- How to transport sick people safely
- How to isolate corpses
- How to bury infected corpses when corpse removal teams did not come
- How to maintain personal and household hygiene and use hygiene materials
- How to make use of available PPE
- How to properly disinfect their homes.

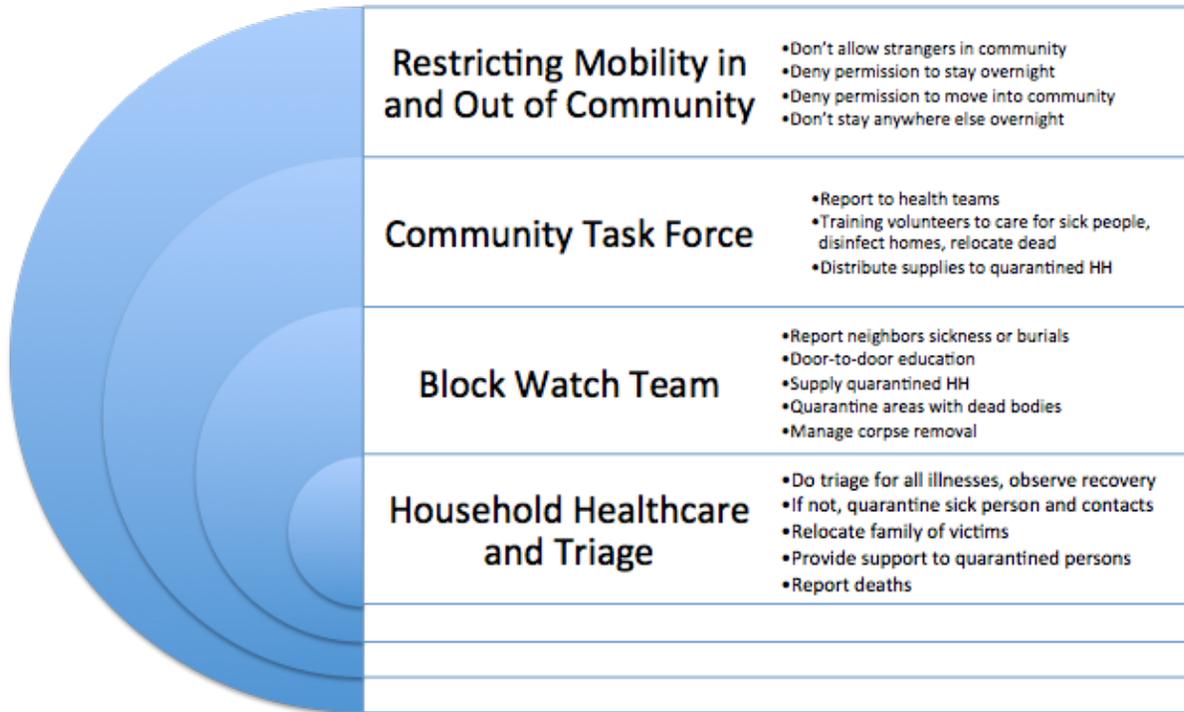
Notably, this list does not call for substantial basic training about Ebola. It does, however, indicate the kinds of challenges that they were confronting or anticipating in the local management of Ebola in their communities. Evidently, community leaders felt that they had a strong grasp on the basics of Ebola etiology and transmission. While they called for training methods that would make public health messages more palatable and effective (local languages, the use of video, door-to-door education, or billboards), the concern was not so much that people did not believe in Ebola as that people knew enough about Ebola to be afraid, but not enough to respond effectively in the absence of a functioning Ebola medical response system or general healthcare sector [21-23] (especially while lacking critical supplies). As one person mentioned about their community, “we have heard the messages but most people do not know how to practicalize them.” Training, they also felt, would counter the presence of fear in the communities and change the minds of those who continued to deny the existence of Ebola. Continuity of both message and delivery was highlighted as a critical issue. Community leaders

emphasized the need to engage with communities on a daily basis, and for the messages to be correct and similar. Proposed training modalities included: youth workshops for awareness, training-of-trainer (ToT) workshops for community-based volunteers, and separate trainings for community leaders that instructed in the *management of* the local Ebola response.

To prevent the incidence of Ebola in their communities, community leaders argued that heightened attention to sanitation should be maintained to prohibit the spread of the virus through bodily fluids. Governmental, NGO, and bilateral support was requested to sponsor heightened sanitation in private and public latrines, to include the distribution of buckets, ash, and bleach for washing, and locally obtainable personal protective equipment (PPE) gear like raincoats, rain boots, and plastic bags. As some demanded, “we need the same PPEs given to the medical doctors and nurses to be given to the community.”

Sanitation alone would not get the job done, however. In order to protect the community from the introduction of Ebola from outside, and from the spread of infection from within through poor control practices, community leaders called for the *third* aspect of prevention highlighted in this study - heightened surveillance efforts, and reported those efforts in which they were already engaged (see Figure 2). The ethos behind this was strong. As one community member said, “as a community we keep watch over each other.” As Figure 2 demonstrates, community leaders’ accounts of optimal community-based Ebola surveillance included a four-tiered system of surveillance that was designed to prevent introduction of the virus into the community, facilitate reporting, disseminate information, sustain house-to-house monitoring, and support whistle blowing when community-members were non-compliant with EVD prevention protocols.

**Figure 2: Monrovia Community Leaders' Detail of Optimal Community-Based Ebola Surveillance August-September 2014**



The first level of surveillance involved the exclusion of “strangers” from the community, the restriction against letting others sleep in one’s home (for fear that they might be running from the presence of Ebola infection in their own home), and the mandating of a 21-day waiting period for those who wished to move into the community to insure that they were Ebola-free [10]. The second level of surveillance included the formation of a community task force that would enforce the exclusion of strangers, and would also assume a leadership role in prevention (like keeping community members away from sick people or the dead). The community task force was also suggested to be responsible for alerting community members to the presence of Ebola, monitoring the health of the sick and their family members, engaging in reporting, and managing resource provisions for community-based quarantines and isolation. At a third level of surveillance was the block watch team. Community leaders suggested that block watches could

go house-to-house to monitor the sick, refer new cases to health facilities, and identify efforts to conceal sickness or burials. Fourth, individuals within households were expected to invest in their own domestic surveillance for Ebola by reporting cases of illness within their household, removing themselves or their family members from the possibility of contagion upon discovering sick individuals, and even isolating themselves so as not to infect family members.

As one might expect, the division of labor suggested in community surveillance was implicitly -- and sometimes explicitly -- gendered. While women and men were both included in the community leadership focus groups, ethnographic evidence supports the inference that men were expected to constitute the majority of members of community task force teams, block watch teams, or community action teams to keep strangers out and engage in reporting and whistle blowing. Women, on the other hand, would be more likely to be expected to engage in domestic surveillance, as they monitored the physical wellness or illness of family members while they washed, clothed, and fed children, spouses, siblings, and elderly persons. Therefore, a point of caution must be noted here -- as Danny Hoffman has written, the mobilization of young men in these communities can, and often does, involve a range of martial and surveillance-like behaviors that can turn rather quickly into a remilitarization of social organization [24]. As a counterpoint, the domestication of surveillance among women caring for the bodies of others within households can put women at a greater risk of infection, especially under quarantine and isolation conditions.

Fourth, community leaders correctly argued that substantial investments in infrastructure and systems were required at the local level, recalling Paul Farmer's much circulated call for "staff, stuff, and systems [4]." They requested government and other organizational support to create community "holding centers" to serve as interim sites for the sick and dead while waiting

for Ebola response teams and/or burial teams to arrive. They demanded a hotline system that prioritized rapid response to local communities' calls to place sick people in hospitals and ETUs and remove bodies. Community leaders also recommended a broader local communications infrastructure, including a better-staffed call center, more ambulances, the establishment of mobile clinics or the reopening of local community clinics that had closed their doors, more testing centers, and finally, the training of additional health workers and burial teams. These health workers, they insisted, need to be paid and given adequate benefits.

### *B. Response and Treatment*

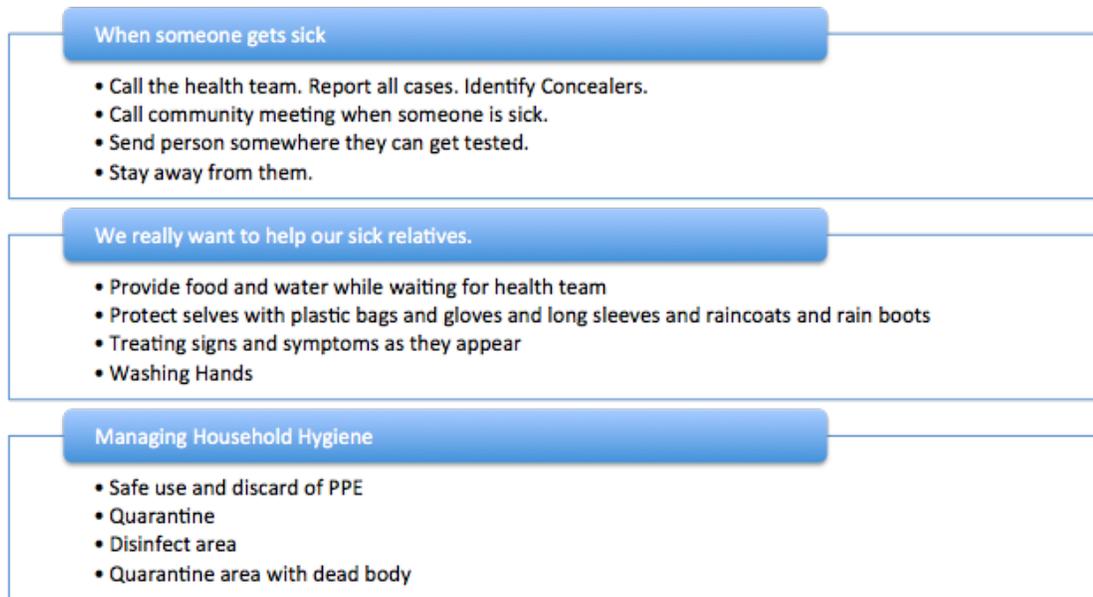
Nearly all of the demands for the infrastructure improvements noted above derived from *the experience of and local reports of* failed response in the months of July, August, and September 2014. When community leaders called for the creation of a communications infrastructure, it was because their calls to hotlines had gone unanswered. When they called for the training of community members to provide care to the sick, manage holding centers, administer quarantines, and isolate or bury the dead, it was because they had experienced the social, medical, and ecological consequences of response teams *not* arriving in a timely manner or failing to arrive at all. Moreover, the anonymity of the removal process terrified individuals, and played a role in their decisions to avoid ETUs and hospitals and to engage in secret burials. In one case, a community leader reported losing an infected individual who had left the community for an "unknown destination." After going from hospital to hospital, there was no record of that individual's registration, death, or departure.

Consequently, when community leaders engaged in discussions of "best practices" regarding response and treatment, it must be acknowledged that community leaders agreed that

the true “best response” was to obtain care in a hospital or ETU, to seek the removal of sick individuals by health care teams working for the government, and to engage in proper burials that reduced disease transmission. *But*, absent the likelihood that these resources were going to be in place, community leaders engaged in positive deviance in the sense that a process of recommendations for how a community might best manage the presence of Ebola infection, and the disposal of infectious corpses. In the absence of open clinics and hospitals, residents are trying to assume responsibility for all aspects of healthcare in their local communities. Everything that follows in this section builds upon this premise.

In order to ascertain how community members were likely to respond to illness in local communities, researchers asked a series of questions pertaining to their identification and management of illness in family, friends, and neighbors. This section details how community members prioritized the triage and treatment/care of indeterminate sickness and mortality in their communities (see Figure 3).

### Figure 3: Monrovia Community Leaders' Narratives Describing How to Triage Sickness in Household Context, Aug-Sept 2014



Community leaders were quick to highlight the unnecessary morbidity and mortality due to preventable and treatable diseases, injuries, and basic health problems that were caused by the widespread closures of medical clinics and hospitals [25]. In the absence of better options, most community leaders concurred that community members would be impelled to provide the best care they could offer for their families within their homes. Demands for guidance abounded: “We need to know how to protect ourselves while taking care of the sick.” “We want training and materials for how we can handle ourselves and the dead.” In order to align local realities with public health messages that were seeming increasingly unreasonable due to their disjuncture with available services, they asked that community taskforce members be trained in basic health care provision, treatment of symptoms, and corpse removal.

When someone within a household falls ill, community leaders reported that they are first cared for within the home with palliative care. The person is administered “first-aid treatment,”

including locally available pharmaceuticals, herbal remedies, oral rehydration solution, the provision of fluids, and the early administration of anti-malarials. It is not expected that any single household will be able to provide all of these interventions. After some time passes, if the sick individual does not improve, community leaders expected caregivers to take a sick person to a hospital, or call the health team. There was a general consensus that if a person did fall ill, it *had* to be reported to health teams, *and* the news needed to be circulated among the community, so that they could respond and take precautions.

The technical details regarding the proper handling of sick community members at home and in transit was ambiguous among respondents because it was ambiguous in the community. Transportation was seen as a probable vector for infection. Leaders recounted examples of virtuous individuals walking to the hospital or carrying sick children rather than traveling by taxi or asking for help, demonstrating community understanding of the risk of transmission once an individual falls ill. Other messages surrounding physical contact are ambiguous. As some respondents noted, one message said, “Don’t touch,” while another said, “Touch, but use plastic gloves.” The lack of consistency is leading to considerable experimentation and innovation, but it is also elevating local perceptions that the message “Don’t Touch” is impractical and unhelpful in the context of local communities.

Thus, communities were caught in a Catch-22. Many community leaders *were* afraid of continued epidemic spread in their communities, and they believed that health workers had better training, medicine, and materials to support sick people [26]. Conversely, as one research team member commented in her field notes, many reported that if a relative or neighbor was ill, only half of respondents indicated that they were likely to call a health team hotline or encourage that person to go to a hospital or Ebola Treatment Unit (ETU). There were good reasons not to. By

the time of this study (early-mid September), many individuals had gone to hospitals and ETUs, and had never returned, or had been turned away from multiple facilities due to lack of beds. Still others were concerned that their loved ones' bodies were being dissected for body parts after death [27].

In the data from this study, a broad subset of respondents - mainly women - reported that they would care for sick family members, and preferred to do so inside the home. They described a plan for isolating themselves with their sick family member[s], while providing the best locally available appropriate care they could offer (see Figure 4). As one woman noted, "It will be impossible that my child or husband is sick and I refused to touch them. I do not have the courage or heart to do that." An elderly woman reported her intention of making her own PPE from locally available materials. "I will find my own PPE (using a raincoat, plastic bags on hands) and care for sick relatives like I saw on television. If the person is not getting better, I will hold them (with the plastic still on my hands) and take them to the hospital." These women respondents showed an intense conviction that they should care for their families, and showed a desire to do so, despite risks to their own health.

Approaches to home-based care and a graduated triage approach was decidedly gendered; and as a result, it is apparent that home-based care constituted a zone of risk for both predominantly female caregivers and for their dependents. This has had a known impact on women's vulnerability to Ebola infection [28], but it may have also had unrecognized repercussions on infant and child mortality in the context of the Ebola crisis. Community leaders reported that, after parents infected with Ebola had been removed to hospitals or had died, their children were placed under community quarantine for 21 days. During this time,

“Many of these children do not survive their quarantine periods; they just cry to death because no one can provide care from the outset. Community members are unable to help because of fear of the Ebola virus. Babies and young children are dying, not from Ebola, but because there is no one to care for them and the health workers’ response to these children is too slow.”

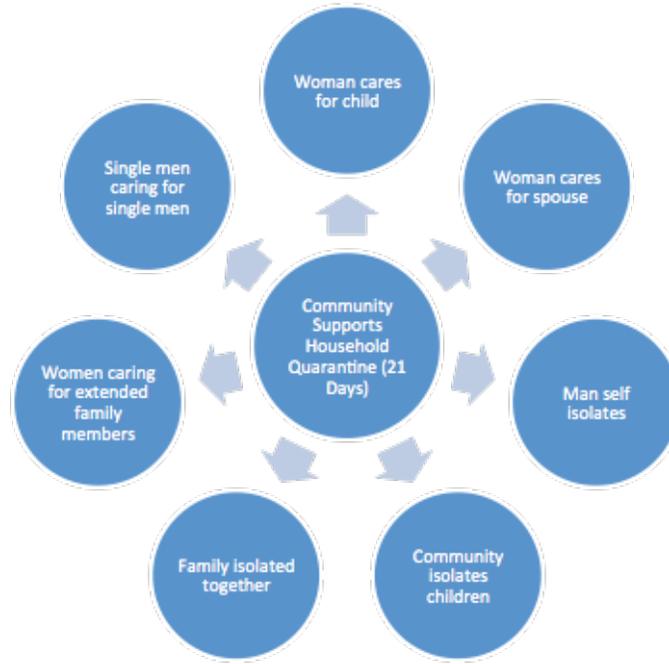
The reported deaths of young children under quarantine paint a challenging picture to communities’ descriptions of providing care (food and water) to local families and children throughout the quarantine period. It also easily facilitates the inference that, given women’s greater involvement in the direct support of children’s diet and healthcare, women’s higher rates of mortality may be due, in part, to women’s greater reluctance to seek early treatment for Ebola out of fear for children’s lives and well-being under the likely quarantine that would follow their departure.

There was a third category of responses, however, that indicated the existence of a third path for Ebola response in the community. This approach entailed isolation of an infected individual, without providing treatment to him/her, or referring him/her to a healthcare facility. As one person noted, “If my son is sick, I will run away from him. I am not a health worker to tell whether it is ebola or malaria. It will be better he dies alone and I be left behind to care for his sisters and brothers.” **The intention of this statement sounds chilling, but its meaning is complex, and resembles the calculations made among family members considering the futures of a person who appears to be terminally ill, and has little likelihood of treatment or survival. The retreat and isolation of sick individuals was characterized as a protective measure for the community, and as an act of generosity from sick individuals to the**

**community. Survivors characterized their own survival as a strategy for honoring and caring for the families of people who had died.**

The process of quarantine required careful oversight and supply, and community-leaders had given careful thought to how they might best support individuals and families in isolation and quarantine. In community leaders' discussions, it was apparent that they sought to be able to position the community at the center of the Ebola treatment response by managing the health and safety of quarantined families through food supply, illness surveillance and oversight, reporting, the provision of medical supplies, and communication and information. **There was a strong willingness on the part of the community to serve as a central axis for interaction between the state and local individuals and families by doing the work of organizing food, medical, hygiene, and PPE distribution, case identification and surveillance, multi-level communication and reporting, and patient and corpse conveyance.**

**Figure 4: Gendered Configuration of Ebola-related Caregiving in Community-Based Household Quarantine Scenarios August-September 2014**



### *C. Sequelae*

In the aftermath of an Ebola incident within a highly affected community, the legacies are likely to be drastic and long-lasting [29]. This dataset identifies three critical issues pertaining to the sequelae of Ebola: (1) the reintegration of Ebola survivors into local communities, (2) the care and management of “Ebola orphans,” or children who have lost one or both parents to Ebola, and (3) memorialization of individuals who have died of Ebola.

The findings indicate overwhelming support and acceptance of Ebola survivors in the community. Ebola survivors were widely recognized as being an asset in the fight against Ebola. They were seen as being an embodiment of positive messages suggesting that early treatment could allow one to survive Ebola, and they were referred to many times as “ambassadors” of

Ebola awareness, as “living testimony to the Ebola crisis,” and as positive role models. Within focus groups, survivors already appeared to be accepting their positive role model status, and offered vignettes like the following:

- (1) I am a native doctor (herbalist). I used to heal sick people before I got sick with Ebola. After I cured a few people, there was one person who I was asked to treat. Before I got there the person had already died. I didn't touch the dead body. When I started feeling sick and noticed that I was showing signs of Ebola I walked to the hospital all by myself. I care for my family and didn't want to get them infected. I was also afraid to get other people infected, so I didn't ride a taxi or motorbike; I walked to the ETU. From the beginning, I was discouraged, I lost hope because people who were in the same room (on different beds) died. I spent six days and started recovering. I was given material to use (gloves, PPE, chlorine) and asked to help anyone that I saw showing the signs of Ebola and encouraged people to go to the ETU early.
  
- (2) Survivor statement V2: It was traumatic for me but I thank the Almighty God and the medical staff at ELWA for surviving this outbreak. For me when I started feeling sick, I went to the treatment center right away to seek early treatment. I think that is how I survived. Most of the people who come to the center do not come early to get help, and I think that is why people are dying. My advice to people is that they should seek early treatment when they start to feel sick and see signs and symptoms of Ebola.

Although some community leaders mentioned that they were afraid of survivors, most indicated that they welcomed the return of Ebola survivors into their community. They acknowledged that they understood that they were no longer infectious, and that these individuals could not be re-infected with the virus. There were also public concerns voiced about the fact that the Ebola virus was found in semen for up to three months following infection, and that these individuals must take care to avoid sexual relations. Others conflated this three-month time period with the perception that these individuals were still infectious, and recommended that they be placed in a halfway house for the three months following an infection.

The care of children orphaned by Ebola was widely regarded as a communal responsibility. Some community members mentioned that children would be brought into their homes and families, noting, “The children become our children. These children are our own because their parents are no more.” Another commented that the community leaders must, “encourage people to take children whose parents have died of Ebola as their own, because we have lived in the same community for years and they are like family to us.” Recalling the war and the fragility of life in urban Monrovia [17], one individual noted, “We have done it before. We will take care of the children. Education, feeding, and shelter.” Several respondents mentioned that children required psychosocial counseling to recover from “traumatization” due to having lost their parents, and they recommended that NGOs make counseling available to Ebola orphans in communities and in orphanages. They also stipulated that orphans should not be forced to endure stigma or discrimination because their parents had died of Ebola.

Despite the will to care for the children, there was considerable concern about the economic, emotional, and residential burden that additional children would pose. In the event that children had extended families elsewhere, communities felt that they should be united with

them, and that NGOs must assist with “family reunification.” Others called for the creation of orphanages within their communities so that community members could oversee the development of the children, while delegating financial and educational costs to NGOs, UNICEF, the World Health Organization, and the MOHSW. The majority of individuals, however, seemed to hope that children would be able to stay within the community, but would receive financial support for their clothing, food, and education from governmental, non-governmental, ecumenical, and charitable sources.

The data from this research indicated little ambiguity about the need for some form of widespread and public memorialization of the lives lost to Ebola. Community members called for: a National Memorial Day; the construction of a statue in the middle of the community; a formal memorial service at the end of the outbreak; a parade; or a day called “Black Day” to be recognized by law. Community members also recommended that a mass grave be built with a headstone inscribing the names of all who had died of Ebola, and had been cremated. The goal of this memorial is to provide family members with a space to “remember” and pay tribute to their loved ones by visiting the grave and laying flowers. Additional suggestions were practical, and included providing scholarships, financial aid, general support, and counseling to Ebola orphans.

#### LIMITATIONS:

This study had several limitations. First, the number of participants in the focus groups was large (15-20). In order to address this issue, the PI stationed four research assistants around the group in order to capture the responses of all participants. Second, the data collected were speculative, in that they were based on respondents’ knowledge of Ebola, on community and government messages that they had received about Ebola [Abramowitz et al. draft], on resources

that they sought for their communities, and on their experiences with Ebola and non-related Ebola morbidity and mortality. These factors cannot be disaggregated due to the method of data collection. Therefore, community leaders' feedback is regarded by the researchers as an "ideal-typical" representation of what a community-based response to Ebola *should be like*, rather than a factual account of how these same communities *actually responded* to the incidence of Ebola.

#### DISCUSSION:

While the research reported here makes considerable strides in helping to understand how local communities in Liberia do respond, or envision their response, to Ebola, this information must not be mistaken as an indication of community political, medical, or social empowerment or institution-building. These communities are not empowered, they are desperate, and are finding resources from within their communities to compensate for the collective failure of state and international institutions to implement systems of surveillance, treatment, and response. What we are observing here is epidemic response in a state of medical statelessness [30].

Compounding their desperation is the fact that health sensitization efforts continue to emphasize the 'low-hanging fruit' of public health communications [31] - "What is Ebola? How is it spread? What are the symptoms? How long does it last?" But community health messaging is essentially failing to provide the kinds of 'higher-order,' practical information and training that communities are desperate for -- "How do I manage a family of children, including infants and toddlers, in quarantine?" "How do I transport someone to a hospital or clinic without promoting infection?" "What capacities need to be built to support a holding center?" "What does my community do with an exposed and infectious body when the health teams do not come to collect

it?” “What can I do to make sure that you don’t lose or steal my father/brother/sister/mother at your health facility?”

Engaging local communities in Ebola response will require answering their challenging questions about their encounters with systemic failures. Communities are seeking guidance for how to proceed with a sick individual when they are turned away from hospitals, for building and supporting holding units in communities, and for reporting deaths when their calls to hotlines go unanswered. The global health response needs to consider what it would mean to put into place surveillance and reporting mechanisms in which community-based leaders have the ability to directly account for health, illness, or death of every individual in the population, through the creation of a health identification number, through a creation of health census lists, or through some other mechanism of reporting and marking. In a context in which every death is an Ebola death because there are no community-based testing facilities for Ebola, every death needs to be counted as worthy of being reported. (And when everyone has a number, everyone counts.)

But can locally affected populations, in effect, govern themselves by engaging in medical self-surveillance, self-management, and self-triage? The ethnographic evidence suggests that they can indeed do so [32-33] and the public health literature has previously examined the implementation of international health regulation guidelines for infectious disease surveillance among regional networks, and local surveillance in other hemorrhagic fever outbreaks in Africa [34-36]. In the long term, equipping local communities with the material and knowledge resources to respond to Ebola within their own communities can help build a surveillance infrastructure that can inform a stronger post-epidemic state architecture, though certainly comes as a “add on” to supporting medical infrastructure and professional surveillance mechanisms,

which must also be prioritized [23]. In the short term, however, the shifting of surveillance responsibilities to highly structured hierarchies within local communities can also politicize micro-networks of communities in ways that may result in violence or remilitarization of disenfranchised youth communities [37]. That risk can be moderated, in part, by ensuring that required daily resources like food, medicine, housing, PPEs, and other resources are in abundance, and are not the subject of competition within and between groups during the epidemic.

The study also suggests that the gendered distribution of morbidity and mortality in this Ebola outbreak is strongly associated with existing relations of caregiving and with the distribution of labor in community surveillance and response. The most important thing to understand about culture and caregiving is that women are not going to abdicate the role of primary caregivers. Indeed, the data collection exercise offered direct insight into the fore-planning process that many women are engaged in right now about how they will respond if and when Ebola arrives in their households, families, and social networks. Resources must be set into motion to support men and women in their community-allocated surveillance roles and to support women in their caregiving roles, in order to engender support for local-international collaboration and connect the Ebola response effort to the lived experiences of local persons.

My colleagues and I will be addressing issues of funerary practices and memorialization in a forthcoming paper, but regarding survivors and orphans, we can draw lessons from the large literature on AIDS in Southern Africa.

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