



Exploring Caregiving Experiences During the 2014-2016 Ebola Outbreak in Liberia

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EXPLORING CAREGIVING EXPERIENCES DURING THE 2014-2016 EBOLA VIRUS

DISEASE OUTBREAK IN LIBERIA

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A Thesis Submitted to the Faculty of

The Harvard Medical School

in Partial Fulfillment of the Requirements

for the Degree of Master of Medical Sciences in Global Health Delivery

in the Department of Global Health and Social Medicine

Harvard University

Boston, Massachusetts.

May, 2019

Exploring Caregiving Experiences During the 2014-2016 Ebola Virus Disease Outbreak in
Liberia

Abstract

Liberia, a West African nation of 4.5 million population with a gross national income of \$370 and a life expectancy of 63 years, was afflicted by a brutal civil conflict and an epidemic of Ebola Virus disease in the past two decades. The civil war destroyed much of the country's health infrastructure. At the onset of the Ebola epidemic, the country had a dysfunctional health system that was quickly overwhelmed by the epidemic.

Prior to the civil war and its destructive consequences on health infrastructure, other transnational forces, including the imposed structural adjustment by multilateral financial institutions such as the IMF and the World Bank, and the ever-present extractive industries, wreaked havoc on the already weakened health system. It is widely known from the emergent literature, that the proximal factors that facilitated the spread of the Ebola Virus Disease Epidemic were related to the dysfunctional health system, the way infectious dead bodies were handled while observing last rite of passage. However, what is little known is what factors facilitate engagement with the formal health care system as far as Ebola Virus Disease containment is concerned.

Caregiving experiences from the 2014-2016 Ebola Virus Disease outbreak in Liberia were explored using qualitative methods. Sixty-seven in-person interviews were carried out with 20 survivors, 20 family caregivers, 15, health workers and 12 health authorities. Data were examined using category construction and thematic analysis. Findings indicate that caregiving

experiences were marred by suspicions: First, suspicion that there was a real outbreak of Ebola, next suspicion of nefarious practices within the ETUs preventing infected individuals from being confident to seek care in these units. In some cases, it took the deaths of health workers to bring people to the realization that Ebola outbreak was real, and it took perceived improved clinical care to make people access the ETUs.

Caregiving experiences varied across the entire time range of the EVD outbreak, but improved clinical care was a factor that promoted uptake of patients into the ETUs and helped bridge the distrust between the community and the authorities.

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Acknowledgements

We are grateful to all participants of this study who graciously took up valuable time to enroll in our study. Many thanks also to the Ministry of Health of the Republic of Liberia, PREVAIL. The authors would like to express their gratitude to the rank and leadership of the Survivors' Network, both in Montserrado and Lofa counties for the introductions to survivors and family caregivers.

This work was conducted with support from the Master of Medical Sciences in Global Health Delivery program of Harvard Medical School Department of Global Health and Social Medicine and financial contributions from Harvard University and the Abundance Fund. The content is solely the responsibility of the authors and does not necessarily represent the official views of Harvard University and its affiliated academic health care centers.

Part 1: Background

1.1 Vignette

Much like any other day, June 20, 2014, started as a usual work day for me in Fish Town, Liberia located in River Gee County. After performing two cesarean sections in succession, and then going on clinical rounds, I settled into my administrative duties which involved several meetings against the cacophony produced by the stream of midday motorcycle traffic just outside my office. But then, I received a call from Dr. Luke, a junior colleague, who worked in a public hospital in a mining concession. Expecting his call to contain the usual exchange of pleasantries, I was startled when he starkly described the situation that was unfolding at Redemption Hospital in Monrovia, the capital city, of Liberia. Dr. Luke was particularly worried about his mentor, Dr. Mobutu, a general surgeon who worked at Redemption Hospital and supported the newly established postgraduate residency training program in surgery. Redemption Hospital is a public hospital run by the Ministry of Health. Based in New Kru Town, the hospital is located in a slum community that stretched along the Atlantic Ocean coastline. At its full capacity, Redemption Hospital could take in around 200 inpatients at any one time.

“What happened at Redemption?” I asked. Dr. Luke explained that Jane, a staff nurse, had fallen ill, and her extensive care had involved almost the entire hospital staff. Despite their best available efforts, Jane died from her illness. Jane’s illness had first presented itself as fever, diarrhea, and abdominal pains; time after time, Jane’s colleagues repeatedly worked to manage her symptoms each day. Ahead of the rest of his team, Dr. Mobutu surmised that there was something different about this episode of illness in the Jane.

Dr. Mobutu was one of the most experienced people on the team. During clinical rounds one day, Dr. Mobutu explained to the team that based on his experience working in Uganda, he

suspected that perhaps unlike what they had assumed they were treating Jane for they were dealing with something quite different—he dreaded even to call it by name. Dr. Mobutu’s fears would later be confirmed. The news would later break that Jane had provided care for her sick relative who fled from Lofa—the county that would soon be identified as the epicenter of the first wave of the 2014 Ebola Outbreak in Liberia.

A few days later, Dr. Mobutu, self-isolated, called his mentee, Dr. Luke, with whom I had been having a conversation with. Dr. Mobutu started to experience fever, nausea, and vomiting. Dr. Mobutu and Dr. Luke continued to maintain contact with each other by telephone throughout Dr. Mobutu’s period of self-isolation.

Here were two caregivers, from the same hospital at different points: one having fought for her life under the care of her professional colleagues, and the other now self-isolated. The story of these two health workers is emblematic of the scenes that would play out continue to play out several times in different settings during the 2014–2016 Ebola epidemic in Liberia. While performing the sacred duty of providing care, family caregivers and professional health care providers were infected and many did not survive. This essay argues that in the context of deprivation, fear and rumors emerged which made it likelier that family members would need to step in to take on the duty—and danger—of caregiving in Liberia during the Ebola outbreak of 2014-2016.

In what follows, I begin by describing the events of the Ebola outbreak of 2014-2016 in Liberia. Second, I will outline the historical and political disparities in Liberia’s health care system that made the people in Liberia—including health care professionals—more apt targets for deadly infectious diseases, such as Ebola. Third, in the vacuum of preferential treatment, I will expound upon the fear and rumors that emerged: (1) the Ebola outbreak was a rumor made

up by the health authority as a strategy to secure funds from donors and (2) fear that the Ebola Treatment Units were explicitly created to harm, rather than help, the people of Liberia.^{1,2}

Fourth, I will illustrate how fear affected health care workers themselves because of their worries about being infected due to the lack of personal protective equipment.

Even as public health messaging warned against touching Ebola-infected family members, the confluence of fears and rumors about the disease along with the closure of health facilities left family members with a greater moral obligation to provide care for their loved ones even in the face of condemnation. In conclusion, the general public was alienated by the fears, rumors, and messaging of the health authorities. The dissemination of dissonant public health messages resulted in people's disengagement with the authorities and their efforts to contain the Ebola virus disease outbreak.³⁻⁵

1.2 Outbreak of Ebola Virus Disease in Liberia

Prior to the incidents in Foya and Redemption, in December 2013, several cases of a febrile illness appeared in a provincial town near the Guinea-Liberia border, and this was brought to the attention of Guinean authorities.

However, due to the country's lack of requisite diagnostic infrastructure, many of these cases were misdiagnosed. Consequently, several months passed before people came to understand that those cases were due to Ebola. In March 2014, the World Health Organization (WHO) confirmed and declared the Ebola virus disease outbreak in Guinea.⁶

Also, during that same month, Liberia reported two cases in the Liberian town of Foya, near the Guinea-Liberia border. By April 2014, Liberia's case count had already risen to 21, with 10 deaths (three of which included health workers)—it was the beginning of what would become

a tragedy throughout the Ebola virus disease outbreak in Liberia.⁷ In Liberia, health care workers were disproportionately affected, and they had a higher mortality rate. The deaths of health workers are a sharp reprimand of a system that cannot protect its treasured and scarce human resource and speaks volumes about the destitute state of infection prevention and control practices.⁸

Long before the EVD epidemic, prolonged civil war and longstanding underinvestment led to a woeful health care delivery system. During the onset of the Ebola crisis, there was a lack of public health infrastructure and adequate capacity for clinical care. We must understand what was responsible for those deficits to understand how they influenced the care choices of patients. Prior to the Ebola virus disease outbreak, several historical antecedents are responsible for the Liberian health system's weakened state.⁹ Entangled in a web of debt since its founding, Liberia has remained an impoverished country, and this has prevented its substantive investment in health care delivery and other critical infrastructure. Furthermore, until the 1980s coup d'état, Liberia was governed by an elite class of settlers known as the Americo-Liberians. The Americo-Liberians were a group of ex-slaves and free blacks who emigrated from the Americas and the Caribbean to resettle in present-day Liberia nearly two centuries ago.¹⁰ While the Americo-Liberians only constituted 2 percent of the population, they were the only ones who had voting rights. Their governance has been characterized by inequality and neglect of the welfare of the majority of indigenous people, including with regard to their health care.¹¹ The government did not prioritize health care investment. Liberia is haunted by its fragile health care system due to the lack of investment in the health care delivery sector, and this left the country unable to withstand the shock of the Ebola virus disease outbreak

The limiting factor for health is human resources, and they determine the effectiveness of a running health system. Training a nurse, midwife, or doctor takes longer to do than it does to procure supplies, bring in consultants to design complex health systems, or to get engineers to erect infrastructures.¹² Also, human resources directly affect caregiving because medical professionals are the ones who provide care. In Liberia, the reason for the scarcity of human resources for health care is diverse: the economic migration medical human resources, the higher workload from the increased disease burden, historical underinvestment in health care—due to the structural adjustment programs imposed on the country by the IMF and the World Bank during much of the 1970s.¹³

The emergence of Ebola in West Africa occurred in three of the poorest countries in the world. In Liberia, like other sub-Saharan African countries, the epidemic occurred in settings of privation and abject poverty.⁹ For the health situation in Sub-Saharan Africa, human resources are affected by three primary factors: first, the increased workloads on health workers due to the increased burden of disease; second, the migration of trained health workers away from countries and places where they are most needed; and third, the historical underinvestment in human resources for health care as imposed by multilateral donor institutions, such as the World Bank and the International Monetary Fund (IMF).¹⁰ In Liberia, the fourth factor responsible for the inadequate numbers of human resources for health care is Liberia's devastating civil conflict in the 1980s.⁸

For example, Liberia has a healthcare worker-to-population ratio of 2.8:10,000. 2.8 health care workers per 10,000 people—the global target is 23 health care workers per 10,000 people (WHO 2007); and 51 physicians serve a population of 4.3 million people—even fewer than can be found in a single clinical unit at a typical US teaching hospital.^{14, 15} Inadequate human

resources for health was not the only problem the Liberian health care system faced. As aptly summarized by the physician- anthropologist Dr. Paul Farmer, the health systems fundamental problem is that “the region lack[ed] the staff, stuff, space, and system required to stop Ebola.”¹⁶ In other words, with a physician-to-population ratio of about 1 per 100,000 people, Liberia is a country with one of the least number of physicians in the sub-Saharan Africa region. The sub-regional physician-to-population ratio average is 16.5 per 100,000. However, the situation was not always this way. For example, in 1973, there were 132 physicians in Liberia when the population was 1.7 million.¹¹ However, physicians’ migration into more affluent settings and the prolonged civil war have stymied the training of more physicians and other mid-level health workers. In response to the need to train human resources for health, Dr. Mobutu was seconded to Redemption Hospital as part of the Liberia College of Physicians and Surgeons’ effort to train a new generation of surgical residents. Dr. Mobutu’s duties included demonstrating clinical skills to junior doctors who were being trained to bridge the human resources gap. As he struggled in self-isolation, with diarrhea, fever and progressive weakness, others primary caregivers (i.e., mothers, fathers, etcetera) would have to tread a similar path of giving care to others while being infected themselves.

1.3 Caregiving in the midst contagion

Much has been written about the burden of disease and the burden of caregiving in the context of chronic diseases like cancer.¹⁷ For example, in sub-Saharan Africa, the literature is replete with accounts of the psychological and financial burden of caregiving in the settings of HIV/AIDS, tuberculosis, surgical disease and other prevalent conditions.^{17,18,19} However, there is a gap in the knowledge base concerning the burden of caregiving during the contagion in Liberia. Therefore, this essay and thesis contribute to the

scholarly literature by documenting how caregiving practices emerge in the absence of staff, stuff, space, and systems; and how public health messaging can fail to account for the interpersonal nature of illness and the human obligations of people who are ostensibly trying to help.

HIV/AIDS and tuberculosis have an insidious onset that may take several months or even years to manifest and place toil on an afflicted person. The Ebola virus disease, on the other hand, takes less than three weeks to manifest into a full-blown disease. Certainly, understanding the care experiences of those who are directly or indirectly affected, is key to discovering the key factors that shape those experiences. Thus, the results of this study will help to improve our understanding of caregiving during epidemics and to leverage this knowledge in the control of epidemic-prone infectious diseases. The knowledge gained from this research will help to mitigate the threats associated with the moral and social obligations of care provision during epidemics and in shaping disease containment in the future.

For a country to be able to manage the next epidemic effectively, it is important to learn about the important lessons of caregiving—especially those that were in conflict with the prevailing public health discourse—and to understand why the conventional public health approach can do more harm than good.²⁰ The current evidence is that human-to-human transmission fueled the Ebola epidemic and, as such, an important driver of the contagion was people's contact with the sick and the dead. However, for many, caring for the sick and giving the sacrament of last rites to the dead are at the center of a basic human relationship. Therefore, the EVD outbreak rocked the very foundation of these human relationships. It is important to understand that these difficult caregiving decisions were made in a context of fear and rumors, and this context emerged due to a lack of resources and people's anxiety about a disease that was portrayed as unstoppable and (maybe) un-survivable.

1.4 Fear, Rumors in the Context of Caregiving

The Ebola Virus Disease outbreak in Liberia occurred against a backdrop of a dysfunctional health care system. Initially, there was distrust and resentment from the general public with regard to containment efforts.^{21,22} A major part of containment is isolating the infected and preventing new infections through funerary services. However, isolation measures often evoke memories of Liberia's colonial history where similar (but perhaps more draconian) measures were employed to contain the outbreaks of smallpox and influenza.²³ People's fear and distrust were created by the perception of care centers being places where the sick were isolated and deprived of necessary care. We can summarize the fears and rumors that affected people's care-seeking decisions concerning the intentions of the health authorities and the treatment (or lack thereof) received by patients.

First, at the onset of the outbreak, there were fears that the outbreak was a machination of the health authorities to extract money from donors. In more ways than one, it is helpful to consider Arthur Kleinman, Veena Das, and Margaret Lock's concept of social suffering: the "social" in social suffering refers to the social institutions, such as health authorities, that are supposed to help but instead are feared to cause harm and the social nature of suffering and, in this case, fear.²⁴

Consider Ma Siah, whose daughter, Mary, returned to Liberia from Sierra Leone, where she had been living with her aunty. Upon returning to Foya, Mary, along with her own daughter, both showed early signs of the Ebola Virus Disease. Ma Siah's granddaughter's condition worsened after a few days of home treatment, and the girl died. For fear of community backlash, Ma Siah single-handedly undertook the burial of her deceased granddaughter in the middle of the night. During the EVD outbreak, such intense emotional suffering took place on an

unprecedented scale, and Ma Siah's story broadly reveals what people had to endure to both contain Ebola and its attendant fears and stigmas.

Secondly, some people feared that the Ebola Treatment Units were deliberately established to harm the people in those units. Though seemingly extreme, from an outsider's perspective, this fear made sense to people who were trying to understand why people left for treatment at Ebola Treatment Units did not return. (Indeed, as people began to survive the EVD, these fears lessened, showing again that effective treatment reduces stigma.) It took the heroic stories of survivors who returned to the community after being treated at an ETU to dispel some of the rumors and fears. John Saah happily led me through the story of his journey to and from the ETU when he introduced himself as "one of the first survivors" in his particular town.

1.5 Closures of Health facilities and the Care Conundrum

The fear and rumors about Ebola virus disease were not limited to family caregivers and their sick loved ones. The fear and rumors about the disease also affected health care workers, including ones who understood both the disease threat and the health care system's inability to deal with it in a proper manner. Indeed, in Liberia, health care workers lacked materials such as personal protective equipment and tragically became infected themselves, and this pattern earned Ebola the nickname, the caregiver's disease.²⁵ The initial wave of shock and fear about the disease and the prospect of effectively and safely treating it led to the closure of many hospitals. In rapid succession, as the major hospitals experienced cases among their health workers, they shut down, one after the other—Phebe Hospital in Bong County, Redemption Hospital in Montserrado County, C. H. Rennie Hospital in Margibi County, and the St. Joseph's Catholic Hospital in Montserrado County, to name a few.

In addition to the fear and rumors that we discussed earlier, the wave of health facility closures presented a care conundrum that increased distrust of the health system. On the one hand, the public health messages being given out were in effect warning individuals to not touch their sick relatives, but rather to take them into care. The argument proffered by the authorities responsible for containment was that taking the infected person into care was a form of self-sacrifice for the overall good of their own families or community in general.^{26,27} However, the very institutions that were supposed to provide the care are the ones that were subjected to closures due to the infection of their staff. It is common knowledge that those facilities lacked protective equipment to protect their staff.⁸

The health system was ill-prepared to handle the Ebola virus disease outbreak. The outbreak only exposed the cracks in the health system. The closure of major health facilities deepened the population's distrust while leaving them with the responsibility of providing the type of care that elsewhere would've been left to trained and supplied professionals. By December of 2014, approximately 363 health care workers were infected in Liberia.²⁸ The realization that ill-prepared and ill-equipped frontline health workers were at risk increased fear amongst the already inadequate number of healthcare workers. By the end of the outbreak, it is estimated that Liberia lost 8% of its health workforce due to the Ebola virus disease.²⁹ The closure of health facilities due to the infection of health care workers had the consequence of squarely placing care responsibilities in the hands of family members and other caregivers.

Even more than health workers, family members were ill-equipped and not trained to handle this task. The closure of health facilities, coupled with the placement of care responsibilities into the hands of family caregivers by default, led to a false lull in the number of reported cases, because people were caring for their sick and burying their dead in secrecy.³⁰ The

health authorities' efforts to find those exposed to or infected by Ebola and their contacts was virtually impossible. Ebola treatment units were considered places of no return, to the extent that even desperately ill patients avoided them.

Caregivers described the need to care for sick relatives as a social obligation. Thus, caregiving during the Ebola outbreak, could not be delayed, deferred, or delegated. According to a 2014 report by the American Anthropological Association, caregiving disproportionately places a burden on women.³¹ Likewise, in their introduction to their edited book, *Understanding West Africa's Ebola Epidemic: Towards A Political Economy*, Ibrahim Abdullah and Ismail Rashid write:

The relegation of women to second-class citizens in society together with their invention as vectors of culture, and “natural caregivers,” placed them in the first line of the defense in the war against Ebola. As caregivers they nursed the sick, in community and the nation, with their bare hands, at a time when knowledge of the disease was hard to come by.³²

Aisha Fofana Ibrahim, in her essay in the same volume, ““I am a woman. How can I not help?” Gender performance and the spread of Ebola in Sierra Leone,” adds that additional demands were placed on women because of “the assumption of women’s responsibility for children, their disadvantaged position in the workforce, and their physical vulnerability to male violence.”³² Already, gender inequality is a risk factor for health inequality³² and caregiving during the Ebola virus disease outbreak exacerbated this relationship.

While scholars, such as Kathleen A. Alexander and her colleagues in PLOS One, echo the conventional public health wisdom that “traditional burial practices, involving washing and touching of the deceased, have been linked to 60% of Ebola cases in Guinea” and remind us that “caregiving, primarily by women, has also been associated with outbreaks,” such shifting of blame is unfair and an immodest claim of causality.³³ Rather than attribute Ebola cases and

infection to the lack of resources that make deadly traditional burial practices—washing and touching the deceased—scholars such as Alexander conclude that we must “identify more refined data on [burial] activities so that appropriate regionally and culturally specific public health practices can be developed.”¹⁸

But such regionally and culturally specific public health practices are doomed to fail if they only try to solve social and structural problems with lifestyle and behavioral interventions. Such interventions only achieve the perpetuation of what Pierre Bourdieu calls symbolic violence in that they cause people to misrecognize the source of their suffering. Such symbolic violence fits neatly into a neoliberal logic that ultimately makes people solely responsible for their own health care while absolving the government of its own responsibility. Scholars like Alexander explain that this logic conveniently works out for the powers that be by shifting blame and fault onto only individuals and their cultural practices (e.g., burials) so that governments and institutions may absolve themselves of having an obligation to intervene and correct these practices.

Meanwhile, still at home, Dr. Mobutu’s condition was not improving, at home. A decision was made to take him to one of the earliest established Ebola Treatment Units in the country at the time of the outbreak, while many others still had an avulsion to engaging with such units in several parts of the country. Dr. Mobutu had sacrificed his own wellbeing to impart critical knowledge to a new generation of general surgeons. However, in the end, the health care system he’d dedicated himself to improving still let him down, and he succumbed to his illness.

In conclusion, distrust played an early role in preventive behaviors during the Ebola outbreak in West Africa. However, instead of perpetuating this culturalist claim of causality¹⁸, we sought to understand what factors promoted the engagement of individuals that were infected with the

formal contain processes through a qualitative study that explored the lived experiences of survivors, family caregivers, health workers, and health authorities at the policy and management level.

Part 2: Publishable Paper

2.1 Introduction

Ebola Virus Disease has emerged as a threat that has moved from affecting small isolated rural areas to large urban centers, as demonstrated by the 2013-2016 EVD outbreak in West Africa. In urban centers, containment efforts are very challenging and require multifaceted solutions. A major part of containment is isolating the infected. However, Isolation measures often evoke memories of colonial history where similar, but more draconian measures were employed to contain outbreaks of smallpox and influenza.

Recall of these historical antecedents led to resistance and distrust among the population seeking care in isolation centers and Ebola Treatment Units. In the recent past, efforts at mass isolation and quarantine have been fiercely resisted by the population.²³

A major part of the response efforts was concentrated at breaking the chains of transmission by isolating and treating patients in specialized treatment units called Ebola Treatment Units (ETUs) to prevent further spread of infection. The received wisdom, then as now still staunchly held by some, is that Ebola has fatality rates are more than 90%. However, the mortality rate for infected patients that were medically evacuated and treated in Western countries was 18.5%.³⁴ That raises the question what we can replicate these successes in settings of poverty.³⁵

The factors that promote engagement with care in Ebola Treatment Units are poorly understood. We thus sought to document the experiences of EVD patients and their care givers in order to investigate what makes EVD patients to seek care in Ebola treatment Units.

2.2 Methods

2.2.1 Study design

This qualitative study took place in two of Liberia's 15 counties – Montserrado and Lofa Counties. Lofa County, which shares many porous official and unofficial border crossings with Guinea, was the first county in Liberia to experience a case of Ebola Virus Disease. Lofa County was chosen as a study site because it offers a largely rural setting and could be used to compare caregiving that occurred early in the outbreak (i.e., before a robust international response). Montserrado county, on the other hand, contains the capital city, Monrovia, and is a large metropolis. It was witness to the highest number of Ebola Virus Disease cases in Liberia, many occurring later in the outbreak.

In Lofa, we contacted the EVD survivors' local leadership who helped us to identify eligible participants for our study. In Montserrado, we used the data base of PREVAIL (Partnership for Ebola Research in Liberia) to identify EVD survivors, and family caregivers (close contacts).

2.2.2 Participants, sampling recruitment

We used a purposive sampling design. The aim of purposive sampling was to recruit participants that represent the full timeline of the EVD epidemic in Liberia. Our intention was to understand the range of experiences related to the beginning outbreak period to the end of the epidemic. We included EVD survivors certified by the Government of Liberia to be survivors 18 years and above, health care providers who worked in ETUs, and Mid or senior level managers who had management or policy formulation responsibilities during the Ebola Response. After obtaining the contacts of potential participants, and preliminarily categorizing them according to

an arbitrary timeline of events, we placed telephone calls to them, describing the study and offering an invitation to meet them in person to solicit their participation. During the in-person meetings, we obtained informed consent. Similarly, we approached the Ministry of Health for the names and contacts of health workers who worked in Ebola Treatment Units and Health authorities or policy makers during the EVD outbreak. We placed telephone calls to them and sought their permission to join our study. Overall, we were able to recruit caregivers, some of whose relatives were survivors, and others who had lost relatives that provided care for during the outbreak.

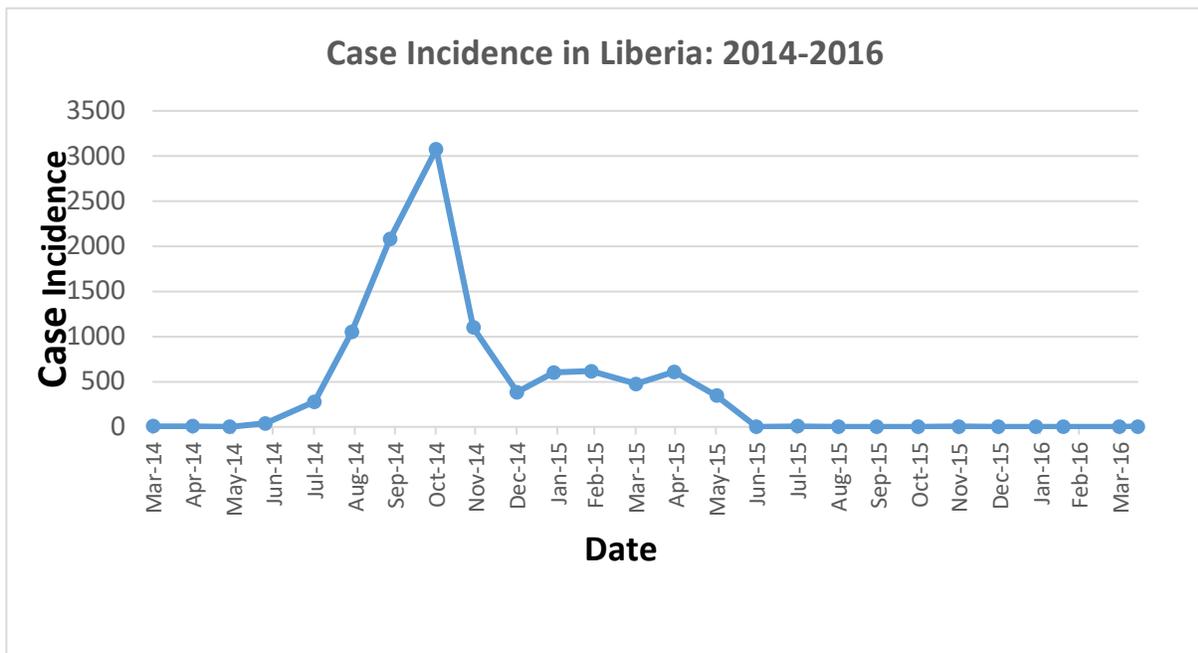


Figure 1 Epidemic Timeline for Recruitment
 Source: CDC.gov, 2014 Ebola Outbreak In West Africa Epidemic curves

| Study Site | Participant groups | Number of participants enrolled |
|------------|-------------------------|-----------------------------------|
| Lofa Site | Ebola Survivors | 10 for the in-depth interview |
| | Health care providers | 7 for the key informant interview |
| | Family caregivers | 10 for the in-depth interview |
| | Health care authorities | 6 for the in-depth interview |

Table 1: Study Site Lofa: Qualitative Data Collection Activities by Participant Group

Table 2: Study Site Montserrado: Qualitative Data Collection Activities by Participant Group

| Study Site | Participant groups | Number of participants enrolled |
|------------------|-------------------------|-----------------------------------|
| Montserrado Site | Ebola Survivors | 10 for the in-depth interview |
| | Health care providers | 8 for the key informant interview |
| | Family caregivers | 10 for the in-depth interview |
| | Health care authorities | 6 for the in-depth interview |

2.2.4 Ethics

This study was reviewed and approved by the Harvard Medical School Institutional Review Board and the National Research and Ethics Board (NREB) of Liberia. All study participants provided written informed consent.

2.3 Data Collection

Data were collected through in-person qualitative interviews conducted in the community in the two study sites. Interviews were carried out using semi-structured interview guide that addressed the following topics: 1) experiences of care at home or ETUs; 2) caregiving experiences in ETUs and other care centers; 3) Management or Response policy formulation. All Interviews were conducted by the student Principal investigator and were audio recorded with the consent of the participants. Single interviews were conducted in places convenient to the interviewees. As some of the participants were recruited from the PREVAIL study, which required them to follow up at designated institutions, we deemed it expedient to conduct our interviews in the communities to distinguish our research from those on-going studies.

2.3.1 Data Preparation

After conducting the first ten interviews, the data transcription process was started and was done subsequently following a set of interviews.

2.4 Data Analysis:

We analyzed our data using an inductive approach to category construction and interpretation of data.³⁶ Descriptive categories were constructed to characterize participants' care experiences and their reaction to events during the epidemic. We first open coded a section of the text by identifying and naming sections of our data judged to be important to our research question. Next, we applied our open codes to a few interviews of the data set to develop our code book. Using our codes, we coded the rest of the data, using Dedoose software. Sections of texts were re-organized in terms of characterization representing care experiences to produce an initial category. Through an iterative process, these categories were defined and elaborated. Illustrative interview excerpts were identified to indicate how representative the categories were to the data. Through successive return to the data, arguments were developed based on the categories. To provide a deeper understanding of the analysis, we framed our arguments within the construct of a timeline to understand the experiences of the study participants.

Table 3: Characteristics of participants in the Qualitative Study (N=67)

| Survivors (N=20) | | Median (IQR) or N (%) |
|---|--------|-----------------------|
| Age, Years | | 37(15-49) |
| Gender | Male | 7(35%) |
| | Female | 13(65%) |
| Married | | 10(50%) |
| Education(years) | | 8.5(0-17) |
| | | |
| Family Care givers (N=20) | | |
| Age, Years | | 35.5(20-56) |
| Gender | Male | 6(30%) |
| | Female | 14(70%) |
| Married | | 11(55%) |
| Education(years) | | 6(0-16) |
| | | |
| Health Workers and Health Authorities(N=27) | | |
| Age, Years | | 40(28-60) |
| Gender | Male | 15(55.5%) |
| | Female | 12(44.5%) |
| Married | | 23(85%) |
| Education(years) | | 15(12-21) |

2.5 Results

2.5.1 Introduction

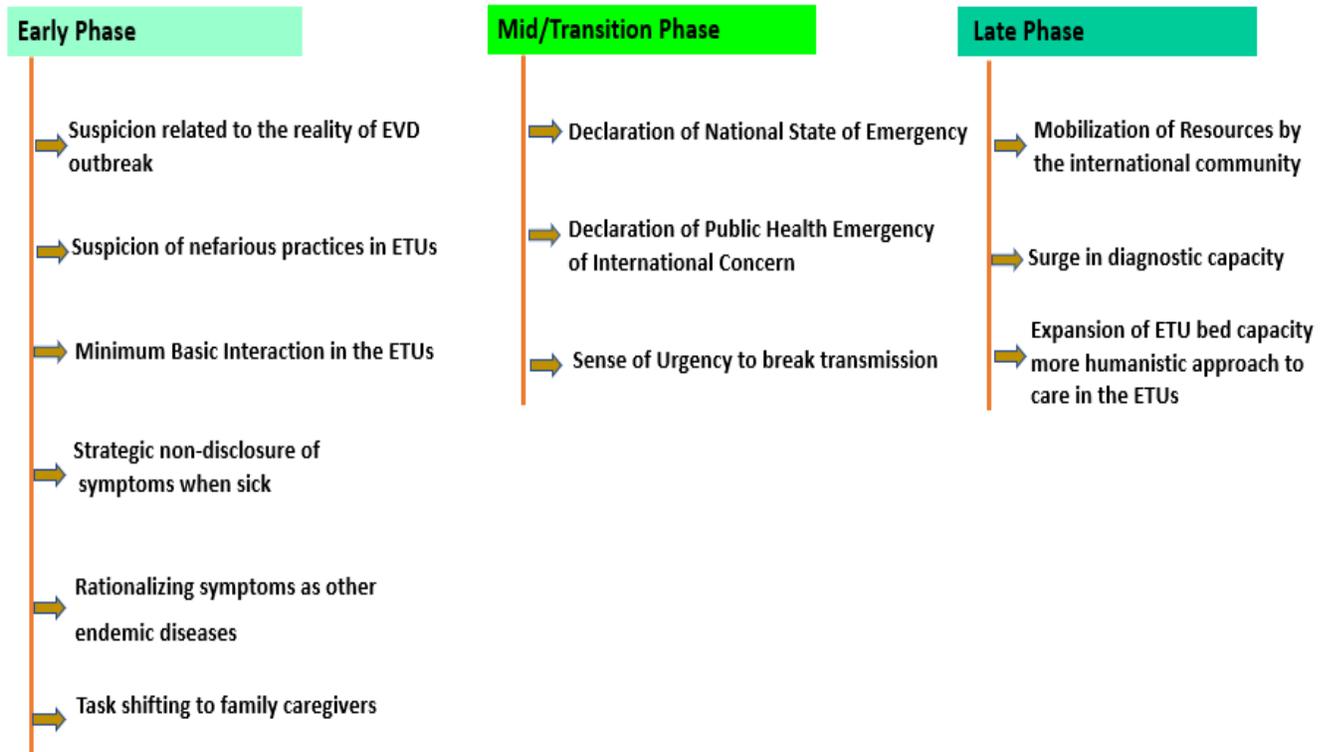


Figure 2: Introduction: Ebola outbreak phases

2.5.2 Results

Demographic characteristics of Study Participants: More than three quarters of the survivors and family caregiver participants were women. Approximately half reported to be married.

Overview of Study Results. We frame the caregiving experiences of our participants according to a time scale construct which we divide into three phases: Early phase, mid or transition phase, and late phase. The early phase contains 5 themes that characterize the unique drivers, manifestations and personal and public health effects of the ‘suspicion’ that marked this period of the epidemic. The transition phase consists of 4 categories that describe the abysmal situation

defined by a set of local and international interventions and related practices. ‘The late phase of the epidemic consists of 3 categories that describe the surge of response actors and strengthening practices that led to improved clinical care.

Early Phase

A. Suspicion related to the reality of Ebola

Some participants in this study reported that they thought Ebola Virus Disease was a construct of the health system devised by the Government of Liberia to solicit money from donors. As a result, their first reaction to the outbreak was outright denial that this disease outbreak could be considered ‘real.’

The first time they said that there was a certain sickness in town called Ebola, I didn't believe it. We thought it was the Ministry of Health people trying to make money by giving people injection in the ETU. For me I did not believe in Ebola at all until the health workers started dying too, then I said to myself, these people will not kill their own friends for money (–Survivor, male Age 40).

B. Suspicion of nefarious practice within the ETUs

Over the short run, realization that the EVD outbreak was not a hoax, did not readily translate into admission of patients into treatment units. Some study participants expressed further doubts and speculated that something sinister was going on in the ETUs. Refusal to seek care in ETUs expressed by study participants was allegedly for reasons of suspected nefarious practices, in these treatment units. Participants explained that communities accused the authorities of setting up treatment units for the purpose of isolating and eventually administering deadly injections or poisonous medications to infected patients. Participants also proffered the suspicion that ETUs were established for the purposes of ‘organ harvesting’ as another argument that nefarious practices were occurring in treatment units. These rumors were fueled by the

number of people who succumbed to death in these early ETUs. Suspicion around ETU practices hindered engagement with the formal care centers. In the words of one interviewee:

When I took the medicine, I still wasn't getting better. The running stomach was getting worse. Someone from the community called the chairman and told him that I was sick. At that time, I did not want to go to the ETU because I was afraid to die there. They say the people were taking organs from people and they won't give your body back to your family because they did not want the family to find out. They also talked about certain tablet that they were giving to people in the ETU to kill them. We only used to see them taking people from the community and not bringing anybody back, so I was afraid to go to the ETU. (– female survivor, age 32).

C. Strategic non-disclosure of symptoms

As part of avoiding engagement with the formal care bureaucracy, some study participants strategically chose not to disclose their symptoms. Others would go at great length to altruistically self-isolate so that they could avoid protecting their families from the social repercussions of housing a family member linked to EVD. For some study participants this manifested itself in avoiding disclosure of symptoms to the family until the very last moment. This reaction was at once protective act of care and preservation for the family and a push back against concern and fear about the abysmal lack of care within the early ETUs:

I called my mother telling her to pray for me that I wasn't feeling okay but didn't tell her what was happening and didn't tell my father because he has pressure. With all the effort in concealing the information, my story was widely spread to the extent that it reached my father and when he called me, I only told him that they took me for check-up, and I was going to return (–Survivor, female, Age 35).

When my little sister also fell ill because of the stigma and gossip[that] was going around about my family, my wife who, previously used to cook and share food with the community members, when she gave anyone food, they threw it away right in front of her saying if you eat the food you will get Ebola disease. So, when I got sick, I decided that I will not let them know of it. That's how I hid my sickness from my neighbours (–Survivor, Male, Age 34).

D. Rationalizing Symptoms as other endemic diseases

Participants who experienced EVD during the early period of the outbreak describe took concrete actions intended to circumvent admission to ETUs. Our participants noted that some individuals rationalized that symptoms – including fever and diarrhea, were not unique, and in fact were in line with symptoms of other familiar, endemic diseases. Convinced their illness is due to malaria, they would hide symptoms from family members, conjecturing that a quick trip to the drug store or pharmacy would suffice. Others who disclosed symptoms to their family members often decided together as a family unit to deliberately hide the presence of symptoms from neighbors and authorities.

When I got sick, I refused to think about Ebola. All I know that I had malaria. The first think I did was to buy amodiaquine(anti-malarial) from the drug store and I took it for three days. I have been having fever headache and vomiting before... (-female survivor, age 38).

E. Minimum Basic interaction in the ETUs

Infected study participants who made it to ETUs or care centers during the early days of the outbreak, portrayed a rather bleak picture of isolation bereft of proper care. They described minimal basic human interaction as the norm for providing care within the ETUs. Health workers kept a considerable distance while providing basic care, even behind the veils of their protective suits. Providers' minimalist approach to interacting with them resulted in daily practices that diminished the dignity of patients, impeded recovery. In order to avoid close contact, patients reported that attending health workers threw food at them, or placed it far away so that patients had to crawl to obtain it:

Caregivers kept a distance from us while providing meals about 4-6 ft away. It was a struggle to collect meals due to severe weakness. Sometimes you had to crawl to collect your meal. The monitoring system at that time in the ETU was not strong. Healthcare providers would come around 8 AM and you would not see anyone until say around 1 or

2 PM. A lot of people lost their lives as a result of this practice, I'm talking about in the period of June (2014). So, even the medications were not given on time; poor medical monitoring system at that time (-male survivor/health worker, age 35).

The maintenance of physical distance also impeded the provision of basic clinical care. Patients reported that medications were not served on time, and they had to wait for hours for an IV bottle to be replenished.

Well, in the ETU at that time, hmmm care involved starting intravenous lines and putting up fluids because [patients] were losing fluids and electrolytes, they would give 1000ml of RL (Ringer Lactate). When that finished, you don't see health care providers around. The fluid would be seen cartoons in the cabinets, but there is no one to administer the fluid again because it took long time for health care provider to enter the ETU. It was so long for another change of shift as a results other patient did not get their next medication.

Patients were not transferred in a timely manner to available beds and found themselves languishing in the hallway. One patient paints a grisly picture of being left in the hallway amongst those who had died from the disease:

At Redemption [Hospital] there was no care as I rightly said. We were placed in a corridor where they had dead bodies. I had no strength so where they placed me was where I remained. The only thing I received from Redemption [Hospital] was a bottle of mineral water that was thrown to me by a nurse to drink because she was afraid of where I was lying down. I managed to crawl and held the bottle of water to drink and while drinking it I had my mouth on the ground because there was not strength. Actually, my strength was gone.

This lack of timely attention to care extended to ambulances. Participants reported being transported in ambulances in groups, bundled together with other sick people. Others report arriving at the hospital by ambulance, only to be abandoned for hours in the ambulance itself.

Yes, at Redemption Hospital. When Saah Joseph ambulance carried us, we spent from the morning up to 6 PM and no one came to us. We were 7 different people on the ambulance. The nurse who rode on the ambulance came later and saw us and she was surprised to still see us on the ambulance. I told her since they brought us no one has come to us. The baby skin was burning with fever; she brought some medicines to be given to the baby and went back into the hospital blasting at the staff for not responding to us. They took about an hour to get dress and came to spray us before allowing us in. when we entered, there were no medicine, and no one was even caring for us. I later got a call from a lady who is Moses' relative; she promised to send some medicines which

she did but the doctors at the hospital refused to allow the medicines in. Within that time, my baby started convulsing and a man who was observing us asked what happen and I told him that my baby was dying. He asked the nurse to give me water to sponge bath the baby, but the nurse instead gives urine that was in a bucket. I hurriedly place the child into it not knowing it was urine. The lady again called her people she knew, and they went there for us on a Sunday after spending three days there without treatment. Monday morning, the baby died at JFK. Through God's grace me, my son and little brother survived.

F. Task Shifting to family caregivers

Taken together, the aversion of EVD patients to being transferred to ETUs led to a situation where the tasks of caregiving became entirely shouldered by families. Family caregivers attempted to access medications at pharmacies or drug stores in order to relieve the symptoms of their loved ones. They ministered to their sick family members, providing food and water, bathing them, and washing their personal effects. Distinct from the distant approach adopted in ETUs at that time, caregiving within the home was performed with compassion and closeness that was both deeply humanistic, and highly problematic for the spread of EVD within families. Most families provided this intimate care without any personal protective equipment. Some of these caregivers explained that they suspected that their relatives might be infected with Ebola, and they were aware that their provision of care would leave them open to infection. Yet they felt a moral obligation to care for their relatives in their homes, rather than surrendering them to the formal health care system.

They were all helping to feed me, wash my clothes, clean my vomit and they did almost everything for me. Every time I vomited, my woman was always willing to clean the place and wash the clothes, but she was infected by the Ebola virus (–Male survivor, age 42).

Yes, during that time they say when somebody get Ebola "don't touch the person." When the person vomit, don't touch the vomit (vomit) and toileting (stool)? Even don't go near the person? But that's my daughter, what will I do? If my daughter was going [to] die, maybe myself was going [to] die, for that, I left everything to God (–Female caregiver, age 58).

Mid/ Transition Phase

A. Declaration of a National State of Emergency

Health authorities described the situation that led to the declaration of a 90-day state of emergency by the Liberian President to be the time when Monrovia, the capital city was inundated with cases of EVD. The declaration of the State of Emergency, the health authorities explained set the stage for the invitation of the international partner.

Another health authority praised the President's decision to declare a State of Emergency but was quick to point out the disadvantages to the overbearing implementation of the State of Emergency, particularly the curtailing of certain civil liberties. The use of force in the response had the potential to further incense the population also had implications for community engagement. The authority's sentiments are thus summarized:

Well, there was a political will from the presidency; however, instead of taking advice from the [Ministry of Health] they started to do their own thing. The first step they took was to deploy the military to places. Ebola outbreak is not warfare. They went to West Point and forcibly quarantine the residents. This resulted into a shooting incident and casualty. You cannot do that. Ebola is already a tough situation. That's how Shaky Kamara got killed. That was not the best strategy.

On another note, it did not escape a participant to note that the government first took political leadership and organized an advisory committee before international assistance was requested. The president was at the forefront of this leadership:

Couple of things that turn the situation around. That sense of emergency was created, every sector, the national leadership was threatened, and the president had to declare a humanitarian crisis, Ok, as such also requesting assistance from the international community. Another thing which I can safely say turn things around was the national leadership. The President took prime interest and wanted to see the outbreak to an end. She [the president] a presidential advisory committee on Ebola (PACE). This was a committee that met daily at the highest level. We also evolved from an Ebola Task Force, with the help of the USA Center For Disease Control (CDC), to what we now called the Incidence Management System (-Health Authority, Male, age 45).

C. Sense of urgency to break transmission

Participants who were part of the policy making team speak of the need for an increased sense of urgency in order to break the chains of transmission. They further describe this time as the time during which infection rates had spiraled out of control and the international community had rallied resources to help the affected countries. Authorities painted a picture of desperation and chaos in the country. The ETUs were reportedly overwhelmed, overcrowded, and there was also a period of introspection as summarized by this participant's description:

We did not have adequate treatment facilities. Lab results were taking days or weeks to come in. There was not onsite diagnostic capacity, the ETUs were over-filled to capacity and people were refusing to give up their dead. In cases where the family were willing, the dead body management team did not have the capacity to respond to all the calls from the various communities. The initial assurances that the contact tracers give to the families is that we need to monitor you so that when you become symptomatic, we can take you to care early. Because the system was overwhelmed, we could not take the sick, and if they died in the community, we could not remove the bodies. The community did not take kindly to the lapses (–Health Authority Male, Age 45).

We then realized that EVD is about speed, speed and precision. In order to stop the ongoing transmission, we had to go faster than the disease. Our major objective then was to break the transmission. There were a lot of things we had to grapple with: culture, tradition and the rest of it (–Health authority, Male).

Late Phase

A. Mobilization of resources by the international community

Health authorities explained that the declaration of the state of emergency, coupled with the World Health Organization's (WHO) declaration of Public Health Emergency of International Concern (PHEIC), as being the nexus that spurred the international response to the epidemic, and with it, inflow of resources, supplies and organizational capabilities. The Center for Disease Control USA, for example, was credited with restructuring the Ebola Task Force as

the Incident Management System, devolving the Ebola Task Force of its technical responsibilities to ensure organizational efficiency.

Another thing which I can safely say turn things around was the national leadership. The President took prime interest and wanted to see the outbreak to an end. She [the president] established a presidential advisory committee on Ebola (PACE). This was a committee that met daily at the highest level. We also evolved from an Ebola Task Force, with the help of the USA Center for Disease Control (CDC), to what we now called the Incidence Management System. So, we re-organize the entire leadership and command structure. We now had the PACE at the Presidential level, and the IMS at the response/implementation level. (-health authority, male age 45).

During the outbreak, we got lots of supplies; the Chinese were the first to bring us supplies during the response, and we got lotd of supplies in country that we continued to use even when the outbreak was declared over.(- health authority, female, age=60).

B. Surge in Diagnostic capacity

Health authorities pointed to the availability of onsite diagnostic capability as another game changer during the late phase. The time it took to confirm suspected EVD patients was shortened. Part of the international capacity building that followed the call for help, was the specialized lab capacity made available through the United States Military:

Once we had international help, and the US Navy set up some regional labs, and we had onsite diagnostic capacity, we had adequate ETUs and Dead body management was being carried out by The Red Cross and Global Community, people were not refusing to surrender their dead, to these trained people. The lab turnaround time was shortened as eight hours, from several days when there was no lab available in country. There was improvement in case management and light at the end of the tunnel (- health authority, male, age 45).

C. Expansion of ETU beds more humanistic approach to caregiving

During the time of the influx of resources, additional ETUs were constructed, and through division of tasks, different organizations took on the responsibilities of running these ETUs. The health authorities also describe the availability of human resources, from abroad and locally, for

the new ETUs that were constructed. With the additional personnel came the need for training prior to deployment:

Once the president announced that she needed help then of course all the international partners were pulling in; but that was good. We also noted that they recruited and started training people in Belgium to deploy. The first group of people that came were Africans and young doctors. Some of them were not physicians and we couldn't just take them to be placed in an ETU to work. We insisted that we should have an in-country training before deploying people; so that helped us to develop the hot and cold trainings and all the trainings that went on through the Ebola process in the country. People who were even trained out of the country were asked to come back and be trained in country before taking on what they needed to do. (-health authority, female, age 60).

With provision of personal protective equipment, and proper training, health care workers gained a new confidence that brought them physically closer to the patients. With the new proximity, intravenous fluids were changed regularly, meals were provided three times daily. And snacks were provided in between meals.

After our own discharge, other people who became infected received better care than we did. The fear had now reduced from the international intervention and provision of adequate supplies My own experience was that the environment was improved, and the number of staffs increased and the time for monitoring and caregiving increased that Is what I look at to make the comparison. (-survivor, male, age 32).

Participants explained that psychosocial support was also provided during this time. One participant vividly recalled being told to believe in God and that if she does, she would survive.

When I was taken to the ETU, I could not walk by myself and every time the nurses bring my medication, they will help me to sit before taking the medication. They could help to make me stand up, they will help me walk to the toilet, and they were giving me encouraging words by counselling and it really helped me build the hope that I could survive. The counselling the provided made me to stop worrying at the time. (-survivor, female, age 28).

Taken together, the availability of supplies, psychosocial support, and the proximity of care shifted the paradigm of care in the Ebola Treatment Units and helped to rekindle patients' spirits.

These new conditions contrasted with the conditions of the ETUs of the early phase. A more humanistic approach to caregiving was the new norm

In the ETU we were taken care of. They fed us three times a day by giving us break, juices, coconut water, spaghetti. Our medications were given four times a day; in the morning, afternoon, evening and night. They give me drip [intravenous fluid] twice along with other medications (-survivor, male, age 32).

When I got sick, the actual reason I opted to go to the ETU was because my little brother was there and confirmed positive so I wanted to get the same treatment [that] he was receiving in the ETU because we later heard that he was improving.

2.6. Discussion

This qualitative study explored caregiving experiences during the Ebola Virus Disease outbreak of 2014-2016 in Liberia. Here, we note early phase participants for whom suspicions characterize their interface with the public health messages, and containment efforts. Those who were taken into isolation describe being taken to treatment units bereft of proper clinical care. In contrast, following resource mobilization by the international community, and strengthening of the Ebola response structures, those who suffered Ebola during this time describe a more humanistic approach to care and an overall improvement in care environment.

Our study found that distrust played an early role in preventive behaviours during the Ebola outbreak in West Africa. However, if one ends the analysis here,³⁷ then it perpetuates culturalist claims of causality.³⁸ Another way to view this distrust is that it is a sophisticated critique of centuries for colonial and neo-colonial extractive activity.¹⁰ For example the concession-loan swap that give Firestone, the American rubber giant one million acres of land at six cents per acre for a period of 99 years is emblematic of such exploitative polity of the neo-colonial relationship that Liberia would have with America.^{10,39} The profits generated from these extractive companies are repatriated to the United States. For example the profits kept in Liberia

and paid to the Government of Liberia was equivalent to three times the total income of the Liberian treasure in 1951.⁴⁰ Similarly, the revenues of the Liberian Mining Company exceeded the revenues of the Liberian government in 1960.⁴⁰ We are here that such arrangements do not leave room for the government to be able to address the huge unemployment of its youthful population and provide befitting health care for its citizens. The resulting anger and discontent provoke distrust in the governing establishment.

We also found that improved clinical care is a magnet that bridges trust and draws infected with Ebola patients to Ebola Treatment Units for isolation and care. Early during the outbreak, stigma, denial, and distrust made patients to have a high aversion to admission in ETUs, at least in their logic, from which they were seldom discharged. Although, trust seemed a rare currency during this time, the perceived quality of care in the ETUs made it impossible to achieve this objective. This was despite the fact that isolation was a demonstrably effective way of breaking transmission.⁴¹ Our study is not the first to recognize improved clinical care as “trust currency” to bridge the distrust gap between the responders and the affected communities. The Medical Charity, MSF, in their intervention in the Marburg Hemorrhagic Fever epidemic in Uige, Angola, in 2005, recognized this in their lessons learned. MSF concluded that more interventional medical care in the Marburg outbreak, was not only cardinal improve survival, but also instrumental in improving acceptability of other interventions.⁴²

Several other evidence-based control measures have been recognized. These control measures include case management, infection prevention and control practices, surveillance and contact tracing, a good laboratory service, safe and dignified burials and social mobilization and ring vaccination of close contacts.⁴³ The extent to which each intervention has been purported to contribute to the control of the epidemic has been widely studied through various

epidemiological modelling. For example, it has been suggested that stopping community transmission in Liberia was the key intervention.⁴⁴ However, none of the above-mentioned strategies would be successful if the trust of the community is not gained. Our qualitative study shows that the offer of perceived improved clinical care in the ETUs gave hope to EVD infected patients and enabled the engagement of the community with other control measures such as contact tracing. Trust once gained, allow engagement of the community for the other interventions in the package to work.

For many of the Ebola infected and their families, the limited available choices at the onset of the outbreak, created a moral quandary: Should you risk taking your relative to an ETU where their chances of return were next to none?⁴⁵ Should you provide home-based care and risk the option of them dying in an environment where they are surrounded by people who love them?

2.6.1 Study Limitation

The findings of our study are not generalizable, as this is a qualitative study; however, our primary aim was to have an in-depth understanding of participants' unique care experiences during the EVD outbreak of 2014-2016. Secondly, our finding of improved clinical care in ETUs during the latter part of the EVD outbreak, is based entirely on the subjective descriptions given by study participants long after the fact, as such could be subject to recall bias.

2.7 Role of funding source

This research was supported by the Department of Global Health and Social Medicine at Harvard Medical School. The funders had no role in the study design, analysis, or the preparation of the manuscript.

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