UNDERSTANDING THE SOCIAL EPIDEMIOLOGY OF UNDOCUMENTED EBOLA VIRUS TRANSMISSION IN LIBERIA: AN EXPLANATORY SEQUENTIAL MIXED-METHODS STUDY

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Abstract

Introduction: Despite the high number of EVD cases recorded during the 2013-2016 Ebola outbreak in West Africa, our understanding of Ebola virus disease (EVD) epidemiology remains limited. A significant gap in the knowledge base is the prevalence and distribution of undocumented survivors. Estimating the numbers of undocumented EVD survivors, the prevalence of symptomatic and asymptomatic individuals would help correct for underreporting cases. Understanding how symptomatic Ebola cases fell outside of the containment response could bolster preparedness and reduce transmission in future outbreaks. We conducted a mixed-method study to understand the social epidemiology of undocumented Ebola infection within Montserrado and Margibi Counties, Liberia, and identify structural factors that shaped symptomatic individuals' choices to receive care at Ebola Treatment Units (ETUs).

Methods: We conducted a descriptive, explanatory sequential mixed-methods study among seropositive EVD survivors identified from the PREVAIL III (Ebola Natural History Study) and assessed factors that shape symptomatic individuals' care-seeking behaviors during the 2014-2016 Ebola outbreak in Liberia. We administered a survey questionnaire to 199 seropositive participants. We also conducted in-depth interviews with a subset of 20 symptomatic seropositive participants and 15 community leaders and members of the local Ebola response structures from October to January 2021.

Results: The study enrolled 199 undocumented Ebola seropositive individuals. 73.9% of these participants were symptomatic, while 26.1% were asymptomatic. The distribution of

symptomatic undocumented EVD survivors was much higher in Montserrado County with 63.8% and relatively lower in Margibi County, with 36.2%. Most undocumented EVD cases preferred not to seek care at designated health facilities due to fear of adverse health outcomes and the social implication of being identified as Ebola patients. Unfunded health systems created unequal access to care and a lack of trust in the care delivery system. Community denial stemmed from rumors that were not unfounded but emerged from a long history of corruption and foreign exploitation.

Conclusion: During the 2014-2016 Ebola outbreak in Liberia, symptomatic EBOV infections went undocumented. These seropositive undocumented patients preferred not to seek care at Ebola treatment centers due to fear of adverse health outcomes, distrust in the system, and social implications of the virus. More research needs to be conducted to estimate a more accurate disease burden in the West African epidemic.

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Acknowledgments

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PART 1: THE GEOPOLITICAL AND SOCIAL DYNAMICS OF THE EBOLA EPIDEMIC IN LIBERIA

Vignette

It was a bright Friday morning. The singing of birds and roaring of the ocean, just a stone's throw behind our house, continued to remind us that it was time to wake up. The night was tough; Annie has had a high fever for the past three nights. This time, it was more than just a fever. She has been vomiting and passing out fluids from 11:00 pm to 4:00 am. As I peeped through the window, children and adults gathered on the beach to do their regular daily stuff. They have come to use the toilet, which is the only major public toilet available for the Popo-beach community. On the other side of the beach, smoke filled the air as young boys and girls embraced themselves in the flames of grass [marijuana].

This morning it was not the roaring of the ocean nor the singing of birds that woke me up from the bed. Outside of the house, the sound of sirens continued to echo in my ears. I quickly put on my shorts, ran out of the house to see what was going on. As I opened the door, I was greeted by a huge convoy of white vehicles, decorated by a group of people dressed in white and blue uniforms like military personnel. Behind the cars was a huge crowd. They were community dwellers, bystanders who wondered in dismay about what was going on. It seemed as though we had have just fallen into an ambush. I was reminded of the days of the civil war. "What is going on...?" I wondered to myself.

My six-year-old son jumped out of bed; he was intimidated in his innocence about what was going on. Unable to comprehend this unusual gathering, he quickly ran inside to his mother, who was still grappling with pains all over her body. I immediately ran after him, and there he was on his mom's chest, weeping like a child who had just lost both his parents. The helpless mother managed to wrap her arm around him as a way of comforting her dear son.

"What is going on, Jerry?" She struggled to pull out those words. Her voice was faint, her face was pale, and her eyes were swollen; it looked as if she had not been able to sleep for the last three days.

"I do not know, Annie," I reluctantly replied.

I quickly ran back out; this time, it became clear to me what was going on. It was not a dream, after all. The Ebola team had come to get us! They were informed that there was an Ebola patient in our house; they had come to take away the "enemy." I was broken. I felt betrayed. In my frustration, I began to protest, like any father would do to defend his family. "Get away, get out of here. We do not need your help. We did not invite you to our home. Go, we can take care of our problems!"

It appeared, though, that all of my rantings fell on deaf ears. Three members of the crew dressed in white entered the house. They were dressed like ninjas; I could barely see their faces. They wore masks and goggles; their noses and eyes were all covered. They moved in like firefighters. I ran ahead of them as if to protect them from invading our privacy. "Get out. My wife will be fine. Even if it is the will of God that she does not survive this, I rather she dies in my arms where I can see her body and give her a befitting burial," I lamented.

The only lady among them, apparently the supervisor or counselor, asked me to step aside. She began to convince me, "Look, my brother, I understand how you feel. It is not easy for anyone in your shoes. But trust me, you are not doing well for your family at this point. Your decision to keep your wife home is not only endangering her life, but the life of your son, yourself, and every member of this community. Ebola is like DV [Diversity Visa Lottery]. Once it strikes a person, the entire family goes if immediate action is not taken. Please allow us to help

you help your wife. I can assure you she will be well taken care of, and by the grace of God, you will bring her back home sound and healthy."

I was powerless; I felt weak and beaten for the first time. I hated to think about what could happen to my Annie in an Ebola Treatment Unit (ETU). We saw how people died like chickens in ETUs; we heard stories of those terrible things that happened. But this lady, her words continued to ring in my ears. "Should anything happen to your wife and your son, will you ever forgive yourself?" Those words were hard; they pierced through my heart like an arrow. I finally surrendered, but with a pre-condition. "I have to come along with you; I need to know where you are taking my wife," I insisted. So they allowed me to come with them to the ETU, but on a different vehicle. As we drove through New Kru Town, community members came out of their homes, waving goodbye as if they knew there was no coming back for us.

In less than an hour, we arrived at the ELWA hospital. It looked like a refugee camp. People have gathered outside of the fence, anticipating their patients' return. As we approached the gate, it seemed as if they were already expecting us. Two ladies wearing all blue, with their faces covered, ran to the entrance to meet us. Only the ambulance carrying Annie was allowed to enter the fence. They quickly took her inside. I tried to follow, but the security at the entrance stopped me. You are not allowed to go beyond this point. "But why, that is my wife in there. I need to be with her. Here are her things, her cell phone, and clothes." The security guard closed the gate on me.

As I sat there looking like a fool, tears began to run down my face. My heart began to beat very fast. The sweat from my head rolled down my back. I was devastated! I felt a sense of guilt; I have betrayed my wife. "What have I done to Annie, oh my God!"

As I wept, a hand touched me from the back on my shoulders, a huge, good-looking man. "Take heart, my brother, I was once in your shoe. I know how difficult it is, but you have to accept that this is the end of the road. When they took Tina in there, I felt the world had come to an end. Every morning, I would wake up at this fence, hoping she would come out cured. But she never did! All you can do is go home and pray to God, maybe, just maybe, you will see your wife again."

I did not understand what he meant by that. But now I do. He was right. Annie never came back home. Even her body, we were not allowed to see her body, least of all think about giving her a befitting burial. I regret ever taking my wife to the ETU!

Adapted from a conversation with a 38-year-old seropositive man who lost his partner and only son to the deadly Ebola virus during the 2014-2016 outbreak in Liberia.

1.0 Introduction and Roadmap

The undetected spread of EVD cases during the 2014-2016 epidemic in Liberia was an unintended consequence of the health authorities' unjustified emphasis on public awareness rather than the significant infrastructure and human resource inadequacies. These inadequacies created by neoliberal policies and foreign exploitations often delivered undesired results, particularly poor health outcomes. The absence of equal, quality, and affordable healthcare makes it impossible for the local population to trust an essentially ineffective and dysfunctional system. The lack of public trust in the healthcare delivery system during the 2014-2016 Ebola outbreak was not in any way irrational; the history of health inequalities, poor health outcomes, and empirically unsupported claims about culture and scientific naivety fueled community apprehension towards EVD response.

In this chapter, the argument is presented, laying the foundation upon which the rest of the paper is built. Chapter 2 takes a deeper dive into the historical context that forms the narrative of this paper. Specifically, this chapter describes the background of undetected Ebola Virus Disease (EVD) transmission in West Africa, starting from the first case in Gueckedou, the Republic of Guinea, to cross border transmission in Foya District, Liberia. A dichotomy is drawn between undetected EVD transmission and initial events that shaped undocumented transmissions across West Africa. This chapter also looks at the different epidemiological outcomes of the Ebola Virus Disease during the same period across other Countries and Regions. We explore the power differential between these countries and how this might have helped define the disease outcomes. Chapter 3 delves more into the long-term effect of neoliberal policies and foreign exploitation on Liberia's health care delivery. This chapter describes how

structural violence created a compromised health system, the lack of basic social structures and individual agency to respond to illnesses, including Ebola.

Chapter 4 addresses the fundamental question of this paper "Why did EVD cases go undetected during the 2014-2016 outbreak?" We try to address this question by looking closely at the role of poor infrastructure, weak health systems, and inadequate resources. This chapter also looks at some social theories that support our argument. Specifically, the chapter discusses the "Social construction of ignorance," the "Unintended consequences of messaging," and how these social constructs led to an empirically unsupported belief that community ignorance about Ebola was the primary factor responsible for the unprecedented chain of transmission. It expands our argument on the rationale behind public fear and community perception.

Chapter 5 summarizes the main argument in this paper, its significance, and prospect for different audiences. As part of the conclusion, this chapter draws on experiences from other researchers, experts, and individuals to summarize key factors, events, circumstances that may have shaped undetected EVD cases.

2.0 Undetected transmission of EVD cases

The early Ebola Virus Disease (EVD) outbreak in West Africa can be traced back to December 2013, in Gueckedou, a southeastern district in Guinea, with the bordering district of Foya in Lofa County, Liberia.[1] Three months later, the Guinean government still could not establish a laboratory confirmation of the disease. It was not until March 23, 2015, when the Institute Pasteur confirmed the virus's first laboratory diagnosis in Lyon, France [2]. With unconfirmed laboratory results, thousands of cases would go undetected during the first year of the outbreak in the region. However, international partners, including the local Ministers of

health, later blamed the virus's unprecedented transmission from rural to urban areas on harmful traditional practices and cultural and religious factors. In other words, blaming the patients, their families, loved ones, and communities for their suffering.

In Liberia, it is believed that the outbreak began in mid-March of 2014, through cross-border activities between Liberia and Guinea. The reaction of the Government of Liberia was initially one of unresponsiveness. A month later, health authorities suggested the disease was confined and under control. Then, on May 25, the Ministry of Health reported the second wave of Ebola, again in Foya. This time the virus came from Sierra Leone [3]. This second outbreak of EVD was much more severe than the first one, with rapid escalation to thousands of cases within months. Nearly two months later, the Government of Liberia acted. In consultation with the Ministry of health and the national legislature's concurrence, the president declared a National Public Health Emergency and created a Health Task Force on July 26.[4] A 90-day state of emergency followed this in Liberia as the government stepped up its fight to restrain the spread of the lethal Ebola virus disease.

Curfews and quarantine measures were imposed on the population; civil liberties were restricted, and thousands of people were confined to their homes without food and water. Schools, hospitals, and clinics were shut down amid this public dismay. The Liberian army and joint security forces were deployed to quell all protestations.[5] The government had just established a holding center in a densely populated slum community of West Point with no essential social services, including public restrooms, safe drinking water, or essential health services. Without consultation with local community members, the center was expected to keep suspected EVD cases later transferred upon confirmation. Annoyed by the "government's action to further endanger their lives,"[6] citizens gathered in mass protest. In retaliation, military

personnel descended on the local population with live bullets, and Shaki Kamara became one of the victims of military brutality. This is an example of how public health efforts, no matter how well-intentioned, can produce unintended consequences when not taken with caution. Heated verbal altercations between citizens and public health experts and violent responses from security forces facilitated a rapid increase of fear, misconception, and suspicion.

Public agencies responsible for collecting dead bodies, including the National Red Cross and Global Community, proved incapacitated. Bodies lingered in the streets for days before being collected,[7] thus creating another health hazard. Anna Patherick, in her 2015 Lancet publication "Ebola in West Africa: Learning the Lessons," alluded to this fact that none of the three countries (Liberia, Guinea, and Sierra Leone) had the infrastructure capacity to confirm an EVD case by March 2014. The lack of laboratory capacity, public health infrastructure, medical equipment, and the skills needed to respond to a deadly epidemic like Ebola produced unsurprising results in the three countries. However, just like most experts who have written about this topic, she attributed the lost opportunity for early intervention to a "lack of trust between local communities and health professionals."[8]

In its one-year report on the Ebola epidemic published in 2015, the World Health Organization acknowledged Sierra Leone, Liberia, and Guinea are among the world's poorest countries [9]. WHO also indicated that these countries are poor, had just emerged from war and civil conflicts, and were in many ways lacking basic infrastructures, including health infrastructures, transportation services, poor or non-existing communication services in both suburban and rural areas. These infrastructural deficits created fundamental challenges for the response teams in providing access to those populations seriously in need. For example, EVD patients' transportation from Foya to Voinjama was almost impossible, especially during the

rainy season. Samples of suspected EVD patients remained unconfirmed for days in these communities. Patients were dying of an unconfirmed illness. Local community members desperately needed to seek care for their relatives and loved ones.

2.1 Same disease, different epidemiological outcomes

In Liberia, the first Ebola case was confirmed on March 30, 2014: an 18-month-old baby who died four days later in Guinea. From Foya District, Lofa County, the virus rapidly spread to other parts of Liberia. Within the first month, there were 13 confirmed cases and 11 deaths, a case fatality rate of 84.6%.[10] WHO attributed the rapid transmission and high fatality rate to the lack of an effective surveillance system and poor health infrastructure.[11] However, elsewhere in the West, the CDC confirmed the first imported case of EVD on September 30, 2014—a man from Liberia who died on October 8, 2014.[12] Throughout the 2014-2016 outbreak in West Africa, the United States, UK, Spain, and Italy recorded 14 confirmed EVD cases with only two deaths, registering a fatality rate of 14.2%.[13] This reflects a vast disparity in the case fatality rate, one disease, two different clinical outcomes precipitated by distinct social structures. This is to make the point that diseases' outcomes are influenced by the presence or absence of basic social structures and individual agency to respond to these conditions adequately.[14]

Before the EVD outbreak in West Africa, scientific experts and pundits projected a case fatality rate of about 65%. However, those numbers were based on previous outbreaks in impoverished countries, including Zaire and Sudan.[13] The 2014-2016 EVD outbreak introduced a new dimension in measuring the impact of Ebola on the population. WHO has placed the case fatality rate at 50% average, with a fatality rate variation of 25% to 90%.[15] It is rational to say the disease's mortality varies from one region to another, based on economic and power structures.

This power differential, systematically organized against the survivability of the world's poorest, is a form of social inequality.

3.0 Crisis in Waiting: The long-term effect of neoliberal policies and foreign exploitation on health care delivery

Before the Ebola outbreak, Liberia had 50 trained physicians for its 4.5 million population, representing a doctor to patient ratio of 1:90,000.[16] With just around 293 health facilities, the majority of which were dysfunctional and lacked essential health equipment, Liberians live and an average of 7 km (or a 2-hour walk) away from a functional health center. This country was once ranked third highest iron ore producer and one of the major Rubber producers globally.[17] Liberia had a growth rate of 11% in the 1970s. But this growth was only for the minority (5%) American Liberians (Free slaves) at the helm of power, leaving the clear majority of the native Liberians in abject poverty—fracturing the Liberian society. These minority rulers were strongly protected by their former enslavers, as evidenced by the US Navy's protection of the Molatos (American Liberians) during the colonization period.[18]

In the late 1970s, Liberia gained over one billion United States dollars in foreign investment, with Firestone and LAMCO at the center stage.[19] Firestone Liberia, a US corporation established by Harvey Firestone, signed a concession agreement with the Liberian government in 1926 to operate about one million acres of farmland for 99 years at a lease cost of six cents per acre.[20] The agreement is believed to be compensation for a 5 million United States dollar loan agreement between Liberia and the US government. In 1920, Liberia secured a loan from the US government to pay off debts with other European nations. As part of that agreement, Liberian public finance was placed under the control of US administrators. The Liberia financial sector,

including the approval of annual budgets, was controlled by a Finance advisor appointed by the US government.[21] This is an example of what Mukherjee refers to as liberation struggle in her chapter on "The Roots of Global Health Inequity."[22] Like many African nations at the time, Liberia did not have the resources needed to build a sustainable and self-sufficient society. Instead, as Mukherjee argues, Liberia's resources were managed by foreign companies owned by former colonial powers and wealthy countries like the United States.

3.1 Political independence not the same as economic independence

Regardless of the substantial foreign investment, the sons of the enslavers and their accomplices (Firestone & LAMCO) continued to invest in foreign Capital at the expense of the poor, marginalized native Liberians. There were no significant investments in the local economy; raw materials were essentially shipped to build international factories with no local development for finished products. The shipment of raw materials to developed countries brought more economic dividends in favor of the investors. They spent around 100 million USD per annum to cover foreign labor—no investment in local capacity at the minimum.[23] They monopolized the importation of rice, Liberian staple food, in favor of foreign investors. In 1979, when President Williams R. Tolbert decided to shift the dynamics by encouraging local rice production, he was overthrown and killed in a Coup supported by foreign hands, just like Patrice Lumumba's case in Zaire, now the Democratic Republic of Congo.

The rebellion was led by Samuel K. Doe, a Liberian Military Sergeant trained by the US special forces. The US gave Doe financial aid in exchange for allegiance and protection of US investment interest—namely, Firestone. With Doe in charge and his preferential treatment for US investors, it meant Liberia was back at autocracy and economic slavery. The fear of complete

authoritarianism, tribalism, and economic colonialism Danny Chambers described as "the catalyst for Liberia civil war."[24] The Liberian civil war lasted fourteen years, took the lives of over 250,000 people, and caused over a million people to be displaced into exile as refugees. In addition to the physical and social impact, the civil war also ruined Liberia's economy. Massive destruction of public infrastructure, including schools and health facilities, led to a shutdown of public services. During this period, the rate of maternal and infant mortality increased to an unprecedented level "not seen in decades."[25]

3.2 Lack of Social structures and individual agency: Compromised Health Systems, a consequence of structural violence?

In 2010, Liberia ranked 162 of 169 countries in the Human Development Index, placing it among the ten poorest countries in the world.[26] A year before the Ebola outbreak, Liberia spent about $20 per person per annum on health, three times less than WHO recommendation.[27] The impact of these neocolonial exploitations, compounded by corruption and native discrimination, resulted in poor, dysfunctional health infrastructure that preceded the Ebola outbreak. A country with such an impressive investment portfolio as early as the 1950s should have had adequate resources to build a sustainable health system. But this was prevented by multiple factors.

First, foreign exploitation, in the form of neocolonial extraction. Then came the neoliberal economic theory and structural adjustment policies. These conventional policies prevented developing African nations,[28] including Liberia, from investing in social infrastructures. Liberia's public sector is responsible for providing basic needs and social services, including education, health care, and sanitation for the Liberian population. Unfortunately, the private sector was controlled by foreign influence (e.g., Firestone and

LAMCO), and IMF policies on government spending strangled the public sector. These strangling economic policies meant low healthcare expenditure, education, road, and other basic infrastructure. This resulted in brain drain (health professionals and educators), lack of functional health infrastructures in various parts of the country, bad road connectivity, and high levels of low literacy across all society spectrums.

These social inequalities resulted in a compromised health system that proved too weak to handle an outbreak like Ebola. This is what Johan Gultang referred to as structural violence. In making the distinction between personal and structural violence, Gultang argues that, unlike personal violence, the perpetrator of structural violence is not an individual but an organized system, structure, or agency. He maintains that "the violence is built into the structure and shows up as unequal power and consequently unequal life chances."[29]

Liberia, Guinea, and Sierra Leone are equally victims of structural violence and social inequalities. Three of Africa's wealthiest countries by natural resources with vast iron ore deposits, bauxite, diamonds, gold, and rubber remained among the world's poorest nations. This region also witnessed one of the deadliest armed conflicts in Africa from 1989 to 2003. Neoliberal policies such as the IMF framework and foreign exploitations made it particularly difficult for accelerated growth and development. From 2005 to 2014, life expectancy in these countries was between 58.6 to 63.3 years, literacy rate between 30-48.1%, health expenditure between 5.6% to 11.1% GDP with a hospital bed density of 0.3 to 0.8 beds per 1,000.[30,31]

This is an example of what Paul Farmer and colleagues describe as "social arrangements that put individuals and populations in harm's way." Farmer argues that "the arrangements are structural because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people."[32] For example: when people could

not go to treatments units because they were not available or they had to walk two to three hours to get there; when health facilities were regarded as death traps because they could not provide necessary services; when health workers abandoned patients at treatment centers in protest for better incentives; when individual patients could not access care because they did not have the agency to do so—these were the real consequences of inequalities created by political and economic arrangements. Is it by coincidence that these three countries were most affected during the 2014-2016 EVD outbreak? As the African proverb goes, "He who causes the cause is the cause of the problem." The source of our problem was well defined many years ago. The 2014-2016 Ebola outbreak was just a marker—unmasking the structural deficit created by systems and structures in higher places, including foreign lands. It was indeed a crisis in waiting.

4.0 Why did EVD cases go undetected during the 2014-2016 outbreak?

Multiple reports, including the WHO 2014 annual report, identified the national government's inability to confirm the Ebola outbreak as a missed opportunity and a significant factor for the unprecedented transmission observed during the early stages of the epidemic in West Africa.[33] For example, health authorities in Guinea could not immediately determine the causative agent of what was considered a novel outbreak. It took more than 90 days to confirm that the outbreak was a result of an EBOV infection.[34] Collected samples had to be transferred to the Institute Louis Pasteur for laboratory confirmation. At the same time, the Guinean government grappled with the situation. At the government hospital in Gueckedou, the number of cases with Ebola symptoms continued to swell as physicians initially suspected cholera.

Meanwhile, the wave of mysterious deaths continued to spread across the region surrounding Gueckedou. By early March, three months after the first case was suspected, the Guinean Ministry of Health sent samples to France to be tested. The results from the Institut Pasteur came back Ebola positive. On March 23, 2014, the WHO officially announced an Ebola outbreak in West Africa.[35] But it was already too late; the virus had begun to spread to other communities and cities. By the time the Guinean government confirmed the Ebola outbreak, the virus had already spread to neighboring Liberia and Sierra Leone. Unfortunately, these cases were not detected; neither were they investigated nor confirmed as Ebola.[36] The outbreak eventually became visible with multiple transmission chains, widely unprecedented that it became almost impossible to trace and track down suspected cases.

4.1 Social Construction of Ignorance

Meanwhile, public health experts and other international analysts blamed the virus's unprecedented spread on cultural, traditional, and religious factors. For example, in its January 2015 report, the WHO highlighted "cultural beliefs and behavior practices" as major factors that led to the Ebola virus's undetected transmission. WHO, in this publication, contends that in addition to other factors, harmful traditional practices such as ancestral burials, ceremonial rituals, and compassion for the sick have consistently resulted in a flare-up of new cases across various communities.[37]

The early response focused on literacy and behavior change campaigns through information, education, and communication (IEC) and behavior change communication (BCC) during the outbreak. The unjustified emphasis on population ignorance and systematic, infrastructure, and human resource incapacities further exacerbated the virus's undetected spread,

mainly from predominantly rural communities to urban areas. International responders, including the WHO, UNICEF, CDC, and HC3 (Health Communication Capacity Collaboration), established a public awareness mechanism that delivered unintended consequences for the local population. For example, early Ebola prevention messages emphasized that the disease was deadly, without vaccines to prevent transmission or therapeutics to treat infected patients. The messages emphasized the lethal fatality of the disease while discouraging long-standing cultural behaviors and patterns. The behavior-change communication strategy called for total adherence to preventive measures, reporting all suspected cases to the health authority, discouraging all forms of harmful cultural and traditional practices, including seeking care from traditional healers and avoiding bush meat.

4.2 Inadequate resources, poor infrastructure, weak system

Meanwhile, local experts and advocates continued to highlight the historical context of the situation, predominantly characterized by social and economic inequalities, structural policies, and neoliberalism. One such expert is Samuel Jackson, a Liberian economist. Jackson recounted how "Ebola exposed the Liberian government's weak institutions" to deliver essential services for the public good.[38]

As Arthur Kleinman clearly described, social suffering encompasses the various problems endured by the human person, not as a result of their own making, but as a consequence of social forces including war, famine, diseases that emerged out of political, economic, and institutional powers.[39] The majority of Ebola victims are poor people. Because they do not have the financial ability and agency, they can only afford to use crowded public transportation for the daily commute, which also puts them at risk of Ebola. According to

infectious disease experts, the virus is transmitted through physical contact with body fluids and sweat.[40] Also, these Poor Liberians live in houses with large family sizes. When Ebola affects a family member in a poor household, it usually gets transmitted to other family members. Fully aware of this reality, these underprivileged communities cannot change their living conditions. They are at risk not because they are ignorant, not because they do not believe in the existence of Ebola.[41] In reality, there is very little they can do to change the status quo.

Meanwhile, the most effective preventive measure for Ebola transmission is the avoidance of physical contact. An average household in the slum of WestPoint has a minimum of eight family members, two bedrooms. It is rational to say people here usually share the same bed, eating on the same plates, using the same public toilets. Ebola, in this context, can also be classified as a disease of the poor.[42] Even with the best preventive measures in place, it is improbable that the poor will fully adhere to these measures simply because they do not have the individual agency to adhere to these policies. Social injustices muted against them have compromised their unique ability to live in a healthy environment that does not put them at risk.

The consequence of colonialism and neoliberal forces are external factors that continue to drag African countries into abject poverty. The colonial powers took over their resources and directed the economy, mainly developing their external countries, to the detriment of powerless African nations. One would argue that the case of Liberia was different. No European power colonized Liberia. The American Colonization Society founded Liberia. This philanthropic group in the early 1800s came up with a plan to deal with the growing number of "free blacks" in the United States of America. It was founded as a settlement to repatriate these "free slaves" to Africa.

About sixty years after independence, Foreign powers still controlled the Liberian economy. As detailed in previous chapters, Liberia's public finance was placed under the control of US administrators. Over one million acres of land was waived to US foreign investor Harvey Firestone to establish a significant rubber-producing company: Firestone Rubber Corporation. For 99 years, Firestone manipulated the Liberian economy through foreign exploitation, building foreign industries and Capital, while Liberians were drenched in extreme poverty. No direct benefit from foreign investment meant no investment in local development. The government could not afford the financial resources needed to drive public investment in basic infrastructure, including health, roads, and education. By 2012, only two referral hospitals were functional in the country. Major health facilities lacked the human Capital, equipment, and tools needed to provide basic services to the people of Liberia. 75% of the country, including Lofa, where the first case of EVD was confirmed, remained cut off from Monrovia's capital city. Ambulance service was either non-existent or ineffective in all parts of the country. As we will see later, the two major public hospitals in Monrovia were severely overwhelmed by the number of referrals they could handle. In most of Liberia, the only alternative for care was through traditional—unorthodox methods.

Meanwhile, international monetary agencies' structural adjustment policies continued to limit this war-torn nation's ability to recover from the ashes of poverty and underdevelopment. Liberia cannot support its citizens ' health needs, with only 21USD per capita going towards healthcare in the national budget. After 165 years, the country still depends on foreign aid to manage its broken health system.

Discounting these challenges, Liberia's government introduced drastic preventive measures that stretched the suffering masses' endurance beyond elasticity with its international

partners' advice. The imposition of holding centers and quarantine measures on local populations were met with stiff resistance. Without appropriate aims and balancing measures, these control methods created a demand that the already struggling health system could not handle. Hundreds of cases were turned away because the two major facilities, John F. Kennedy Medical Center (JFK) and Redemption Hospital, could not take in more patients. Health workers who were mostly at risk and were dying in their numbers could no longer continue to risk their lives. Major protective equipment was not available during the early stages of the outbreak. Not only were Ebola patients abandoned, so were other treatable causes. One prominent scenario of this was the late Shaki Kamara's case, the 16-year-old boy shot by government security forces during a riot in the Township of West Point. According to his family, little Shaki was first taken to the JFK Medical Center, where health authorities refused him because they were out of space to admit the patient. He was later taken to the Redemption Hospital, where he remained abandoned in pain, bleeding until his death.

Mr. Blamo, Shaki's uncle, provides an account of his nephew: *They fired at him on the legs, and he was brought to Redemption Hospital on the same day. We went there, and the hospital people said we should come later, and that is how it has been since we have been coming here. He died Thursday by 3 pm. He bled for so long and ended up dying because of it. They requested blood, and no one was there to give him the blood.*

4.3 Unintended consequences of messaging

Amid these structural drawbacks, the government and partners (donors) continued to spend millions of dollars on public awareness. As recounted by WHO, public health messages and awareness campaigns "fueled despair."[37] There were posters pasted and billboards erected in

every community, discouraging people from eating bush meat. Initial awareness materials also emphasized that Ebola was deadly and had no cure. Traditional burial was highlighted as a significant factor for the rapid spread of the disease. The hopeless nature of messages, inaccessibility of treatment centers in rural areas, lack of trained health workforce, required equipment, resources, infrastructure, and negative health outcomes resulted in public fear. These response efforts, no matter how well-intended to promote preventive behaviors, produced negative consequences. As in Shaki Kamra, pregnant women needing immediate delivery were refused treatment for fear of Ebola. In some instances, they and their unborn baby died upon returning home. We saw cases where a mother reportedly died of Ebola at home, and her child was left to die with her. Community dwellers made efforts to contact the local Ebola response teams through the 4455 hotlines. Unfortunately, either they came too late or never showed up at all. I remember the case of a friend, James (not his real name). His wife showed symptoms of Ebola. He drove her to several hospitals and clinics, trying to get her into care. Most of the health centers were closed, while others refused to accept the patient. James brought his wife home; she died in his arms.

5.0 Conclusion

The socially constructed reality of local ignorance, intensified by the unintended consequences created by messaging, and the fragility of an unprepared health system shaped by structural violence, further explained why thousands of EVD cases went undetected during the outbreak in Liberia. The undetected spread of EVD cases during the 2014-2016 epidemic was an unintended consequence Salmaan Keshavjee described as "programmatic blindness." Turning a blind eye on this fundamental infrastructure and human resource inadequacies and spending

millions of dollars on awareness campaigns for behavior change further support Keshavjee's argument in the "Blind Spot." Keshavjee contends that global health interventions, no matter how well-intended, lose the service delivery objective when the behavior of donors and recipients alike are framed by ideological substructures rather than based on phenomenon outcomes.[43]

The unfounded emphasis on population ignorance in the face of fundamental infrastructure and human resource inadequacies is a classic example of what Seth Holmes wrote about in his book *Fresh Fruits, Broken Bodies*. Seth argues that health experts' professional gaze sometimes clouds their ability to see social inequalities or how structural violence produces sicknesses and social suffering.[44] As in the case of Migrant workers, impoverished communities in Liberia were blamed for their suffering and the Ebola virus's undetected transmission. They were blamed for their behavior, culture, and tradition. Although with good intentions, experts' recommendations unknowingly ignored the existing reality of social suffering created by structural violence. They, in effect, advanced the ideology of these harmful societal structures.

When I spoke to Jerry, five years after the death of his wife, he still regrets his decision to take her to the ETU for care:

> *For two weeks, I woke up every morning standing at the ELWA hospital gate, hoping and praying that Annie will finally walk out cured of the deadly Ebola virus. On each occasion, I saw families going home in tears as other patients were being brought in. Who is going to come out alive? I wondered to myself. Meanwhile, our home has been turned upside down. The Ebola people came in with their spray guns [disinfectants], they sprayed the entire house, burned the only mattress we had to sleep on, and some of our*

clothes. Even as I awaited Annie's return, I could not stop thinking about how we would continue with life.

But most importantly, the life of my wife matters to me most. One week passed, still no Annie, until one evening, the hospital people walked up to me at the fence, called me over, and said, "We are sorry, we tried our best. But Annie could not make it; she fought to survive, but God did not allow her to come out of it." I was broken down, completely frustrated! "How am I going to survive this? Our six-year-old son died four days after Annie was taken to the ETU. These were the only family members I had. I promised myself never to repeat such a mistake. So, when I got sick, without telling anyone, I ran away to my village. There I stayed for about two weeks, treating myself with country medicine [herbs]. By the special grace of God, I was able to survive.

Just like Jerry, there are many other cases where Ebola patients made a conscious decision not to seek care at an ETU or, in other instances, where their socioeconomic status or distance from a functional care facility made it impossible to seek care. Hence, the choice to turn to unconventional, unorthodox medicine, no matter how risky, was the most rational decision for these poor patients who have a severe lesson from personal experiences, not to be forgotten anytime soon. The high fatality rate validated the public perception of ETUs as "death traps," justifying the lack of trust in the healthcare system to adequately contain the outbreak and families' preference to care for their loved ones at home,[45] outside the response mechanism. Meanwhile, in countries like the United States, Spain, the UK, Italy, it was just a matter of days before the outbreak was entirely under control. Previous literature and public health experts put the fatality rate at 50%, but it was less than 15% in the US and other Western countries.[46,47] While in Lofa, ten hours drive from Monrovia, Liberia's capital city, the case fatality rate was as

high as 85%. With no Laboratory facilities to detect and confirm the outbreak, hundreds of cases went undetected. With limited resources and poor infrastructure, even patients confirmed of having the virus could not access care. In the event where these patients made it to the treatment centers, the outcomes were highly discouraging. What was meant to be a haven for EVD patients turned out to be a "death trap." Should we hold these patients, their families, local communities responsible for their suffering? What about the political, economic factors responsible for these social injustices meted against them?[41] Who bears the greater responsibility? Access to healthcare is a human right; social justice requires equal, affordable, accessible quality healthcare, irrespective of socioeconomic, political, or geographical location.

PART 2: UNDERSTANDING THE FACTORS ASSOCIATED WITH UNDOCUMENTED EBOLA TRANSMISSION IN LIBERIA.

Introduction

The early outbreak of EVD in West Africa can be traced back to December 2013, in Gueckedou,[46] a southeastern district in Guinea, with the bordering district of Foya in Lofa County, Liberia. Ebola virus (EBOV) is the causative agent of a severe hemorrhagic disease characterized by fever, malaise, vomiting, diarrhea, myalgia, rash, and coagulation disorders that can progress to shock and multiorgan failure.[48] The virus is transmitted via close contact with the blood, secretions, or other bodily fluids of infected humans and other animals, including chimpanzees, gorillas, fruit bats, and monkeys.[49] Case management is based on contact tracing, isolation of patients, and strict preventive procedures. Treatment is mainly supportive,[50] although there are several therapeutics in clinical trials.

In Ebola response, effective case management and contact tracing are two fundamental components of the overall response mechanism. These two procedures identify EVD cases (suspected and probable) and ensure patients are linked to care. When surveillance data does not reflect case prevalence, it becomes difficult to estimate the actual disease burden, making response efforts inadequate. This knowledge gap makes it particularly difficult to design an effective care delivery system that links EVD survivors to services, including specialized care for post-Ebola sequelae.[51,52] Recent studies have shown that EVD survivors continue to suffer post-Ebola complications.[53,54] This population deserves the right to accessible and affordable healthcare services, void of biases. Whether or not these shortcomings on documentation were because of structural defects or social-cultural factors remains unclear. Without understanding why and how this population was left out of the entire response mechanism, it becomes

impossible to describe the actual disease burden, effectively prepare for future outbreaks, and define care delivery targets for Ebola survivors.

Despite over 28,000 reported cases of Ebola virus disease in the 2014-2016 West African outbreak, our understanding of the social epidemiology of the disease is limited, including data regarding the actual disease burden on the population.[55] A major knowledge gap is the distribution of undocumented survivors.[56] An estimate of survivors will help correct for underreporting of EVD cases. In Liberia, the PREVAIL III study found that 11% of household contacts of EVD cases had antibody evidence of EBOV exposure. [53] Richardson and colleagues published a paper in 2014 that suggests a considerable portion of Ebola transmission events may have gone undetected during the West Africa outbreak.[57] The World Health Organization has admitted that the true burden of the epidemic "was certainly greater" than the 28,616 suspected, probable, and confirmed cases of EVD that were reported.[58] Understanding how seropositive undocumented EVD survivors felt out of the local and international response structure could help strengthen preparedness and reduce transmission in future outbreaks.

To address this problem, we conducted an Explanatory Sequential Mixed Method Study to assess the distribution of undocumented EVD survivors within Montserrado and Margibi Counties, Liberia; and identify structural factors that shaped symptomatic individuals' choices to receive care at Ebola Treatment Units (ETUs) during the 2014-2016 EVD outbreak.

METHODS

Study setting

The study was conducted in Montserrado County (home to Liberia's national capital city: Monrovia) and Margibi County, about 50KM away from the Capital. These two counties combined were the most affected areas during the 2014-2016 Ebola outbreak in Liberia.

Montserrado has a population of about 1,118,241, while Margibi's population is around 209, 923.[59] The study was conducted at PREVAIL research facilities in these two counties.

The partnership for Research on Ebola Virus in Liberia (PREVAIL), a US-Liberia joint clinical research program, was established in 2014. In November 2014, the Government of Liberia and the US Government signed an agreement to form a research partnership to investigate Ebola and test scientific intervention to support Ebola prevention and containment in Liberia.[60] As part of a long-term collaboration, PREVAIL launched three high-priority studies: PREVAIL I, an Ebola vaccine clinical trial; PREVAIL II, a multi-country Ebola treatment trial; and PREVAIL III, an Ebola natural history study of survivors and their close contacts. PREVAIL has four research sites at the following public health facilities: 1) John F. Kennedy Hospital, Monrovia, Liberia; 2) C. H. Rennie Hospital, Kakata, Liberia; 3) Duport Road Clinic, Paynesville, Liberia; and 4) Redemption Hospital, Monrovia, Liberia. Each of these health facilities has been renovated by NIAID to provide facilities capable of conducting high-quality clinical research and private spaces for collecting surveys, medical histories, and physical examinations. PREVAIL also has a coordinating center that acts as the operational hub and is located at John F. Kennedy Hospital. Those operational facilities provide a safe and comfortable environment for research activities, including a confidential storage area for research documentation.

Study Design

The researcher conducted an explanatory sequential mixed-method study design to understand the incidence of symptomatic undocumented Ebola infection within Montserrado and Margibi Counties, Liberia, and identify factors that shaped symptomatic individuals' choices to receive care at Ebola Treatment Units (ETUs) during the 2014-2016 EVD outbreak.

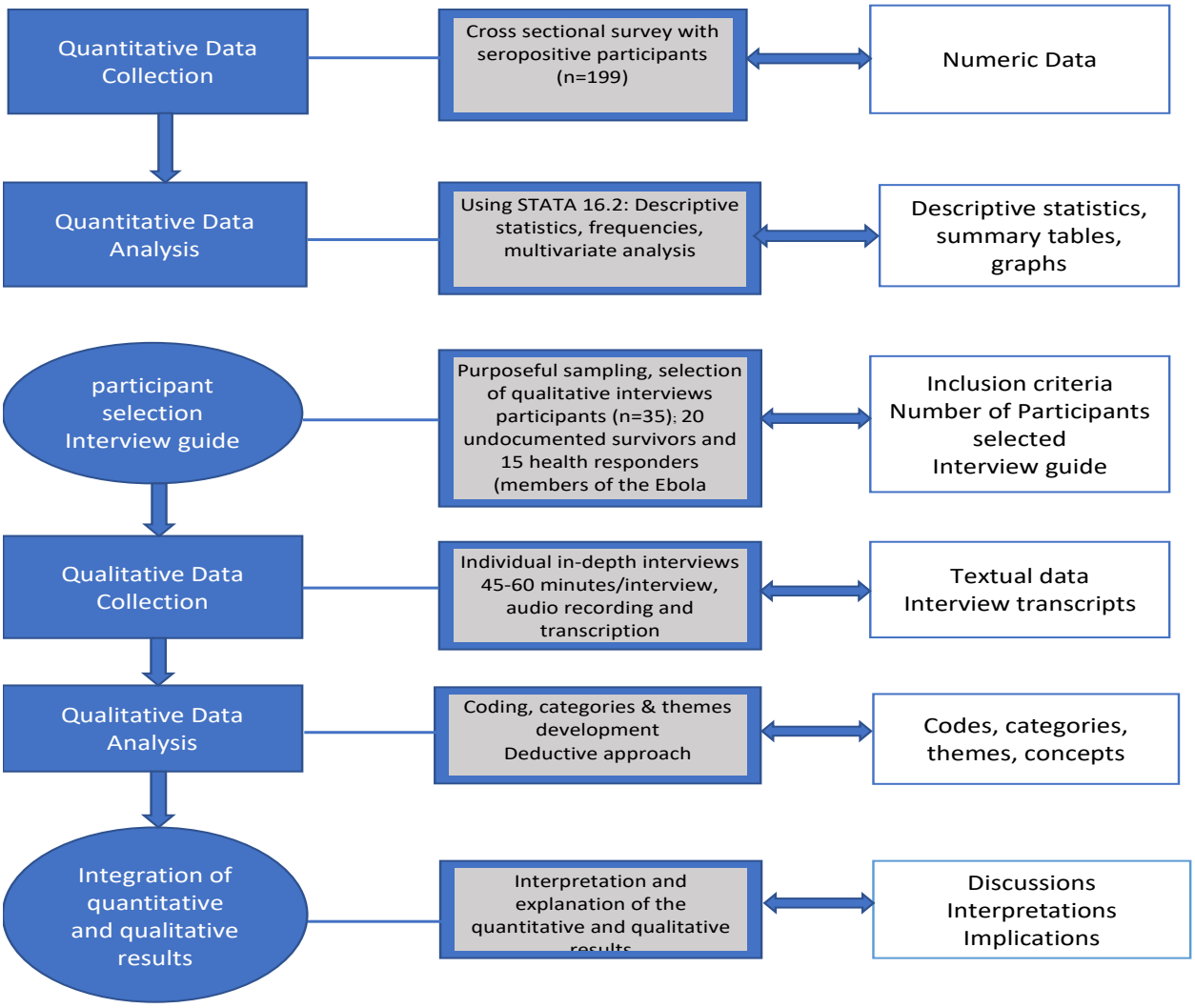

Figure 1: Summary of the sequential explanatory mixed methods design

As part of the quantitative method, we administered structured questions in a cross-sectional survey to assess symptomatology of undocumented EVD survivors from the PREVAIL III study, distinguish symptomatic and asymptomatic individuals, and identify significant predictors of undocumented Ebola Virus transmission. The study enrolled seropositive EVD survivors who participated in the PREVAIL III study (Ebola Natural History Study) in Liberia. PREVAIL is a research collaboration between the NIH and Liberian MOH. PREVAIL III is a

longitudinal study that started in June 2015 and was designed to 1) characterize the clinical sequelae seen in Ebola virus disease (EVD) patients, and 2) to assess whether survivors of EVD can transmit the infection to household and sexual contacts. To accomplish these goals, PREVAIL enrolled 1145 of the 1500 EVD survivors listed in the Ministry of Health registry and 2785 selected household members of EVD survivors, sexual partners, and other close contacts with no documented history of EVD were enrolled as controls. About 11% of these household contacts of EVD cases in the PREVAIL III study had antibody evidence of EBOV exposure.[53] This group makes up the population of our research.

We administered a survey to all participants using a structured questionnaire. We analyzed the quantitative data, used key findings to draft the qualitative interview guide, and purposely selected our individuals of interest for the qualitative interviews based on the survey results. We conducted follow-up interviews with a subset of participants to explain key findings from the survey and understand factors associated with individuals' decisions to seek care during the Ebola outbreak and its ongoing social consequences. We interviewed individuals involved in the Ebola response to gauge their perspectives on Liberia's overall Ebola response efforts. Of the total study population of 300 seropositive individuals, 200 participants were contacted and agreed to enroll in the study. Of the 200 who agreed to participate, one participant could not be interviewed due to his location and travel restrictions posed by the COVID-19 pandemic. A total of 199 participants consented and completed the survey.

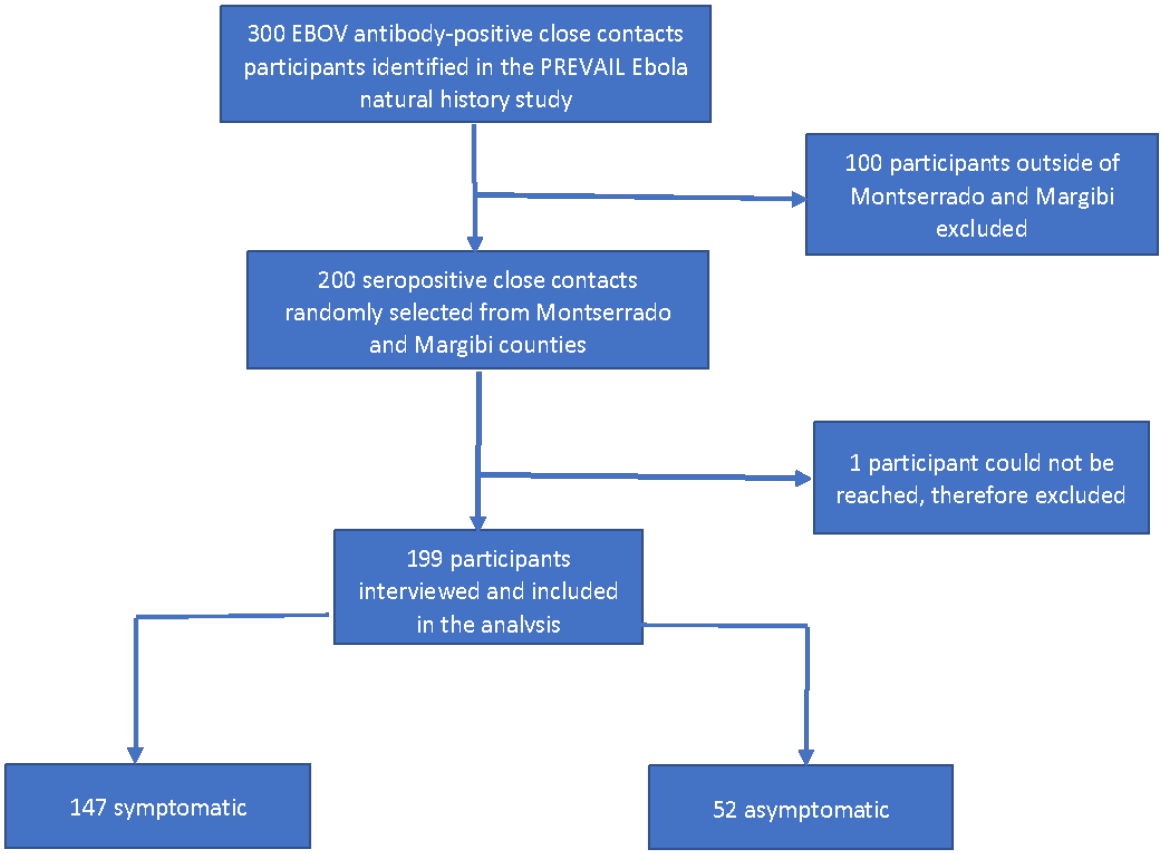

Figure 2: Participants flow chart

Excluded from the study were children under 18 years, individuals from counties other than Montserrado and Margibi, and those who refused to join the study. We conducted individual interviews with 20 symptomatic participants and 15 members of the Ebola response team to gauge their perspectives on the response system and factors that could have influenced patients' care-seeking decisions during the Ebola outbreak.

Quantitative data collection

Survey questions were developed and pretested for community inputs and to ensure local acceptability. The Ethics committee approved the validated questionnaires. Among the PREVAIL III seropositive participants who consented and agreed to participate in this study, we distinguished symptomatic infections from asymptomatic or minimally symptomatic infections

by exploring symptomatology experienced during active EBOV transmission in the participant's town or village. We did this by going through symptom/sign lists (using 2014 WHO EVD suspect definition, see SEED assessment form) and encouraging an account of their daily experience at the time. Findings from this description were used to develop the qualitative interview guide. Seropositive individuals were thus dichotomized:

1. Symptomatic seropositive close contacts: Direct EBOV exposure with a positive serological test for Ebola virus at any time-point after the possible exposure to Ebola and positive report of symptoms consistent with EVD during the outbreak
2. Asymptomatic seropositive close contacts: Direct EBOV exposure with a positive serological test for Ebola virus at any time-point after the possible exposure to Ebola and negative report of EVD-consistent symptoms during the epidemic.

Participants were interviewed in private. The survey interview lasted between 30 -45 minutes. The survey questionnaire included the covariates age, education level, marital status, religion, participants' location during active EBOV transmission in Liberia, distance from ETU or available treatment facility, primary means of transportation, and occupation. We also assessed participants income level and economic status by asking the participants for their monthly household income, type of accommodation (personal/family home vs. rented houses), house structure (zinc round, mud house, dirt brick, concrete), number of rooms per household, number of occupants, number of children under the age of five, and access to latrine facility. (see Appendix C for survey questionnaire)

Quantitative Data Analysis

We analyzed the data using descriptive statistics. Participants' demographic information was presented in summary tables with frequencies and percentages and means and standard

deviations. We also conducted univariate analysis through cross-tabulation to determine the relationship between different variables of interest. We used Descriptive statistics to report the sociodemographic characteristics and perceived factors associated with seropositive individuals' care-seeking behaviors. A Chi-square test was performed to calculate the p-values for sociodemographic and clinical characteristics of the symptomatic and asymptomatic groups. Fisher's exact test was used to calculate p-values for cell count less than five. P-value was also calculated using Z-score for two population proportions to compare the reasons for not attending a treatment facility among symptomatic and asymptomatic participants. All quantitative analyses were performed using SPSS Statistics 21.

Qualitative data collection

Participants in the qualitative study participated in an in-depth semi-structured interview that lasted 45–90 minutes. Interviews were conducted in a confidential and private space at one of the PREVAIL research sites or in a location preferred by the participants. A team of 2 interviewers administered the interviews to those who consented to enroll. A research assistant was trained to conduct the interview, and together with the Investigator, they took notes and recorded the entire conversation. Questions from the semi-structured interview guide were used to drive the discussion on the following key topics: 1) Reasons for not seeking care/attending an ETU during the Ebola outbreak. We explored stigma, fear of death, high mortality, lack of treatment, distance, distrust, fear of cost, lack of knowledge, dreadful messages, family care responsibilities, financial constraints, denial.

Participants' identification numbers from the survey were linked with the interview consent document to obtain demographic information. For cohort 1, we asked specific questions

using the interview guide to investigate factors associated with individuals' decisions not to seek care at designated treatment facilities during the Ebola outbreak.

For cohort 2, we gauge their perspectives and impressions of Liberia's overall Ebola response efforts and how that may have informed care-seeking decisions during the outbreak. (see Appendix 4 for interview guides)

Qualitative analysis

Each interview was audio-recorded and transcribed word for word. The analysis was performed using the Dedoose. Steps in the qualitative analysis included: 1) Reading through individual transcripts and taking down notes and ideas that emerged out of the data; 2) open coding of the data and labeling; 3) verifying the codes and developing a code book; 4) piloting the codebook to ensure it is applicable to the rest of the transcripts; 5) using codes to develop categories and themes by combining similar codes; 6) connecting themes and constructing concepts and theories from themes through deductive reasoning. The credibility of the findings was secured by triangulating different information sources, member checking, codebook validation, detailed descriptions of the categories, presentation of evidence through quotes illustration, and debriefing with team members.

All transcripts from the audiotape were reviewed. A subset of transcripts was open coded to identify emerging ideas that explained the perceived factors that influenced individuals' decisions for not seeking care at the ETUs or designated treatment facilities during the Ebola outbreak in Liberia. These initial concepts were reviewed and subsequently revised into a codebook. The draft codebook was piloted, revised and the final version was used to code the

entire dataset. Then the coded data was deductively analyzed to generate key descriptive concepts through an iterative approach.

We then integrated the quantitative and qualitative results through a joint display technique confirming this mixed-methods approach's outcomes[61]. The qualitative findings are displayed side-by-side with the qualitative results. (See table 6)

Ethical Consideration

The study was approved by the Harvard IRB and the University of Liberia-Pacific Institute for Research (UL-PIRE) IRB. All participants signed informed consent before joining the study.

RESULTS

Quantitative findings

The study participants include seropositive undocumented EVD survivors in Montserrado and Margibi counties. We contacted 200 individuals to participate in the cross-sectional survey, and 199 participants responded, representing a 99.5% response rate. Among the 199 participants interviewed, 39.2% were between 18-30 years, 30.7% were between the ages of 31-40 years, 16.6 were 41-50 years old, while 13.6 were > 50 years old. In terms of gender representation, 46.7% were males, while 53.3% were females. The majority of the participants (64.8%) were from sub-urban and slum communities in Montserrado County, while 35.2% were from Margibi County (rural Liberia). The average monthly household income of participants was $98.23, while the average household occupancy was about eight persons per household.

Table 1: Sociodemographic characteristics of study participants

(n=199)

Characteristics	Mean	Std. Deviation	Minimum	Maximum
Age of the respondents	36.22	12.757	18	82
Participant monthly income*	$98.23	$99.738	$0	$560
Household occupants	7.7487	1.95845	3.00	15.00
Number of meals per day	1.57	.507	1	3
Number of rooms in participant house	2.5980	.66606	1.00	4.00
Number of children under the age of 5 in the household	2.3920	1.15345	1.00	7.00

Table 2 describes participants' demographic characteristics and the distribution of symptomatic and asymptomatic Ebola virus infection stratified by gender and location. The majority of the participants (73.8%) reported experiencing symptoms consistent with Ebola infection during active Ebola virus transmission in Liberia; only 26.2% were reportedly asymptomatic during the Ebola outbreak. The majority of participants (81.4%) reported having some exposure to the virus, while only 11.1% did not record any exposure. Meanwhile, 7.5% were not sure if they have had any exposure to the virus during the outbreak. Also, 32.6% of all participants included in the analysis reported family members as the possible source of exposure, 29.6% reported an EVD patient, 17.6% reported friends, and 16.6% reported others as possible sources of exposure.

Table 2: Sociodemographic characteristics, stratified by asymptomatic versus symptomatic participants

Characteristics	*Overall (N=199) n (%)*	*Symptomatic (N=147) n (%)*	*Asymptomatic (N=352 n (%)*	*p-value**
Age Group				
18-30	78(39.2)	56(38.1)	22(42.3)	0.6520
31-40	61(30.7)	47(32)	14(26.9)	
41-50	33(16.6)	26(17.7)	7(13.5)	
>50	27(13.6)	18(12.2)	9(17.3)	
Gender				
Male	93(46.7)	67(45.6)	26(50)	0.5828
Female	106(53.3)	80(54.4)	26(50)	
Education Level				
No Education	37(18.6)	28(19)	9(17.3)	0.5242
Some Primary School	38(19.1)	30(20.4)	8(15.4)	
Some High School	94(47.2)	65(44.2)	29(55.8)	
Some University	30(15.1)	24(16.3)	6(11.5)	
County				
Montserrado	129(64.8)	94(63.9)	35(67.3)	0.6626
Margibi	70(35.2)	53(36.1)	17(32.7)	
Occupation				
Farmer/Business	50(25.1)	41(27.9)	9(17.3)	0.2420
Health/office/Teacher	20(10.1)	13(8.8)	7(13.5)	
Miner/Rubber worker	18(9)	13(8.8)	5(9.6)	
Housewife/Domestic worker	37(18.6)	29(19.7)	8(15.4)	
Unemployed	37(18.6)	29(19.7)	8(15.4)	
Driver	10(5)	5(3.4)	5(9.6)	
Security officer	27(13.6)	17(11.6)	10(19.2)	
Religion				
Christianity	111(55.8)	85(57.8)	26(50)	0.05412
Islam	39(19.6)	32(21.8)	7(13.5)	
Others	49(24.6)	30(20.4)	19(36.5)	

*Chi-square p-value

Among the many reasons reported by participants for not attending ETU, fear was recorded as a significant factor that informed patients' decision not to seek care at EVD care facilities. About 22.6% of the participants reported fear of dying as a significant factor for their decision, 20.1% reported fear of being stigmatized, while 7.0% reported fear of contracting Ebola as a major factor. Other factors reported include distance from the Ebola treatment center (10.6%), lack of trust in the government (9.5%), did not believe Ebola existed (9.5%), high mortality (7.0%). In the bivariate analysis, we realized that reasons for not attending an Ebola treatment facility varied among symptomatic and asymptomatic participants. There was no significant difference between those who reported fear of dying in the symptomatic group (42.2%) and the asymptomatic group (57.8%), p-value = 0.139. However, there was a significant difference between those who reported stigma as a factor in the symptomatic group (95%) and the asymptomatic group (5%), p-value = 0.00036; those who reported lack of trust in government was significantly higher in the symptomatic group (79%), compared to the asymptomatic group with only 21% (p-value = 0.00036); More people in the asymptomatic group (78.6%) reported fear of catching Ebola as a major factor for not seeking care compared to 21.4% of symptomatic individuals (p-value = 0.0025). More participants (79%) in the symptomatic group did not believe that Ebola existed compared to 21% of asymptomatic individuals (p-value = 0.00036). There was a significant difference between those who reported stigma as a factor in the symptomatic group (95%) compared to 5% of individuals in the asymptomatic group (p-value = <0.00001).

Table 3: Reasons for not attending an Ebola Treatment Unit, stratified by symptomatic versus asymptomatic Ebola virus infection

Reasons	Overall N=199 n (%)	Symptomatic N=147 n (%)	Asymptomatic N=52 n (%)	p-value
Afraid to Die	**45 (22.6)**	19 (42.2)	26 (57.8)	0.139
Afraid of community stigma	**40 (20.1)**	38 (95.0)	2 (5.0)	<0.00001
Due to distance from the ETU	**21 (10.6)**	20 (95.2)	1 (4.8)	<0.00001
Did not believe that Ebola existed	**19 (9.5)**	15 (79.0)	4 (21.1)	0.00036
Lack of trust in government	**19 (9.5)**	15 (79.0)	4 (21.1)	0.00036
Afraid to catch Ebola	**14 (7.0)**	3 (21.4)	11 (78.6)	0.0025
High mortality	**14 (7.0)**	14 (100)	0 (0)	
Responsibility to take care of an Ebola patient	**9 (4.5)**	7 (77.8)	2 (22.2)	0.0183
Childcare responsibility	**7 (3.5)**	7 (100)	0 (0)	
Went to a religious healer instead	**5 (2.5)**	4 (80)	1 (20.0)	0.0574
Family care responsibility	**2 (1.0)**	2 (100)	0 (0)	
Believe in traditional healer instead	**2 (1.0)**	2 (100)	0 (0)	0.0455
No means of transportation	**1 (0.5)**	0 (0)	1(100)	0.1585
Responsibility to take care of a non-Ebola patient	**1 (0.5)**	1(100)	0 (0)	0.1585

**P-value is calculated using Z-score for two population proportions*

The clinical characteristics of participants show that 81.4% of all respondents reported some level of exposure to Ebola during active EBOV transmission in Liberia. 64.2% of all individuals reporting exposure to EVD lived in Montserrado, while 35.8% lived in Margibi County. There was no significant difference between the rate of exposure reported in Montserrado (80.6%) and Margibi (82.9%), p-value = 0.772. Major sources of exposure reported include family members (36.2%), EVD patients (29.6%), friends and neighbors (17.6%). Self-

reported exposure to EBOV was much higher among symptomatic individuals (82.1%) compared to asymptomatic individuals (17.9%); p-value = <.0000.

Table 4: Clinical characteristics of participants per geographical setting

Characteristic	*Overall (N=199) n (%)*	*Montserrado (N=129) n (%)*	*Margibi (N=70) n (%)*	*p-value**
Symptomatology				
Symptomatic	147(73.9)	94(72.9)	53(75.7)	0.663
Asymptomatic	52(26.1)	35(27.1)	17(24.3)	
Exposure to EVD				
Yes	162(81.4)	104(80.6)	58(82.9)	
No	22(11.1)	14(10.9)	8(11.4)	0.772
Not sure	15(7.5)	11(8.5)	4(5.7)	
Source of Exposure				
Family member	72(36.2)	43(33.3)	29(41.4)	
Friends/neighbors	35(17.6)	25(19.4)	10(14.3)	0.606
EVD patient	59(29.6)	38(29.5)	21(30.0)	
Other	33(16.6)	23(17.8)	10(14.3)	

**P-value is calculated using Chi-Square*

Qualitative findings

Symptomatic Ebola patients' care-seeking behaviors were influenced by several factors underpinning the 2014-2016 Ebola pandemic. We analyzed qualitative data for 20 seropositive undocumented symptomatic individuals who participated in the in-depth interviews and 15 local Ebola response team members.

Table 5: Social Demographic characteristics of qualitative interviews participants (N=35)

Characteristics	**n(%)**
Age	
18-30	9 (25.7%)
31-40	10 (28.6%)
41-50	10 (28.6%)
>50	6 (17.1%)
Gender	
Male	19 (54.3%)
Female	16 (45.7%)

Education Level	
No formal Education	6 (17.1%)
Some primary education	8 (22.9%)
Some high school education	15 (42.8%)
Some university education	6 (17.1%)
Marital status	
Married	7 (20%)
Cohabitating	12 (34.3%)
Single	16 (45.7%)
County	
Montserrado	23 (65.7%)
Margibi	12 (34.3%)
Religion	
Christian	22 (62.8%)
Muslim	9 (25.7%)
Other	4 (11.4%)

Six key themes emerged from participants' descriptions of their perceptions and experiences about the Ebola response in Liberia and factors that influenced care-seeking behaviors during the 2014-2016 Ebola outbreak. They are represented as themes A-F below.

A. Negative health outcomes

Most of the participants reported in their interviews that their decisions to report EVD cases or seek care at the Ebola treatment centers were influenced by the negative treatment outcomes from these facilities. According to them, many patients lost their lives at the ETUs and health centers during the Ebola outbreak. They indicated that **i**nitially, ETUs were associated with possibility and care, but because of the adverse health outcomes that were associated with the lack of care within ETUs, public opinion rapidly shifted. As a result**, p**atients and their family members chose to seek alternative avenues because they were afraid that they might not return alive when their loved ones go to these facilities. These health facilities lacked the resources and expertise to handle Ebola cases, evidenced by the fact that most of those who went to the treatment centers did not survive.

At that time, I did not know much about the ETU, but the worst thing about it is that two of my sisters went to the ETU, they never came back; they died. My older sister, when the ambulance carried her, they never came back; she died. So, three of my relatives were taken there, and they all died. Because of this, when I felt sick, they took me to the herbalist and did their traditional things. Even when my woman got sick, and the ambulance team came for us, I refused to go. I did not want to go because I never knew if my wife was going to survive. So, …what if she does not come back just like my three sisters? I did not trust the ETU. So, when they carried her and later came for me, I said no, let the woman come from there let me see her result first.

-40 years old seropositive male participant

B. Mitigation strategies out of step with fundamental practices and beliefs

Participants reported that health responders and care providers, including international partners, introduced untraditional EVD preventive/control measures without considering local priorities and practices essential to individuals in these communities. Over 50% of the participants indicated that the government, through the Ministry of Health, introduced "burning of bodies" (cremation) without having a conversation with the locals to understanding the tradition and local norms regarding burial and how that could impact the public health response efforts. No matter how well-intentioned, some of these measures did not go down well with the affected communities. According to participants, most patients, families, and community members refused to adhere to this practice because it did not align with practices and long-held traditions vital to these communities. As a result, there was a lack of public cooperation, which led to the community's refusal to report suspected EVD cases.

Normally in our society, as per our culture and tradition, we do not burn dead bodies. And so, when the government introduced the measure through the Ministry of health, it created serious confusion, and community members were resisting. One of the things that made communities oppose this measure is that there was no prior community engagement done to sit with the people and let their voices be heard before coming with such an untraditional measure. So, it really took us time to convince people about the relevance of what we were doing to prevent the community from the virus.

-46 years old female community health worker

C. The "Ebola Business"

According to our seropositive participants, the Ebola outbreak was characterized by mistrust. This was not just a making of the epidemic but a consequence of a long history of foreign exploitation and corruption. According to them, containment measures were viewed as exploiting the public to gain local and foreign interests. These perceptions, they said, led to public fear and derailed public trust in international partners and distrust in the medical community. They further explained that most of them preferred to self-medicate instead of going to the ETUs because they did not trust the health workers at these facilities, who they believe were only concerned about making money and not saving lives.

I preferred to stay at my house and buy enough pills because I did not trust those at the ETU and those treating the Ebola patients. I felt like they were only carrying people to the ETU to die because the more people who died, the more money they received. So, I rather send my pills to the pharmacy.

-37 years old male seropositive participant

Members of the local Ebola response team informed us that many patients and community dwellers saw the Ebola outbreak as a money-making scheme intended to create more wealth for western experts and their local associates. According to them, the public's general perception was that the government and key political players received money from international partners to infect more people with the virus. This perception created more distrust in the system; hence, some people refused to report EVD cases or seek care at the ETU/health facility.

> *Okay, you know other people did not believe in this whole Ebola thing. Even some of the so-called educated people felt like the whole Ebola thing was a business, and we were only doing what we did because of money. According to them, Ebola made so many people rich overnight. They believed that the more people who died, the more money health workers would get. They said the government was also getting money from WHO and others. They saw the Ebola thing as a business, so they said, "once many people died, the government and health workers will receive more money; that is why they want more people to die."*
>
> *-46 years old male community worker*

D. Underfunded health system creates unequal access to care

According to participants' views on the health sector, they believe the lack of sustainable investment in the health sector has created an inadequate system for providing care for the population. According to them, the underfunded health system was already overly stressed with an enormous need for clinical care and proved too weak to handle a major Ebola epidemic. They further explained that health facilities turned patients away because they lacked the space, trained staff, and medical tools required to diagnose and provide care to EVD patients. However, some

patients saw these shortcomings as being abandoned in hospitals, triaging care which they attributed to favoritism. According to them, this led to a distrust of the hospital system to care for people with Ebola.

> *The health sector in this country is seriously challenged. When patients go for care at JFK and other big hospitals and do not have money, nobody cares to look at them. Healthcare in this country is only for the rich. Poor people who are sick and cannot afford to pay their medical bills are abandoned on their sickbeds. Even during Ebola, those who had contact or knew a big person in the ETU were given extra care and attention. The health system is constrained. We do not have trained doctors and nurses. The hospitals in this country are not equipped to take care of cases like Ebola. These are things that caused more people to die during the outbreak. And because of these problems, it was difficult to trust the health system.*
>
> *-34 years old female seropositive participant*

Participants recounted how patients had to go from one health facility to the other in their effort to access care. But on some occasions, these people were denied due to the lack of space or capacity. They narrated that because some hospitals did not have the tools needed to screen EVD patients, they sometimes wrongfully diagnosed patients.

> *When it started, she went to the first hospital, but the people did not accept her. So, we went to another clinic. It was there that they said she had typhoid. Because that time all the hospitals were closed. They were not accepting sick patients. The people said no medicine; they were not working again. So, when she came back after two days, they took her to town; we went to Sam's clinic, they denied her. They said that we should not enter. So, there was one clinic on the gobachop field called Mala clinic there they accepted her*

and gave her treatment. The doctor said it was typhoid, but because of the plenty of medicine she took, that's why she came down with vomiting and a running stomach. But when she came home, the sickness continued. We tried the country medicine too, but it did not work. So, she finally died in the car on her way to the hospital.

-50 years old community health worker

E. The communication crisis

Most participants recounted that Initial messages and communications strategies were confusing and inconsistent. They explained how the messages were focused more on the negatives than promoting the opportunity to prevent the virus transmission and provide care for EVD patients. This created more fear, public distrust and motivated residents to stay away from the ETU/care centers. They described how communication materials emphasized harmful traditional practices, that Ebola was deadly and had no cure. The hopeless nature of these messages coupled with negative health outcomes resulted in public fear. And because of that, more people were confused and suspicious about the whole response mechanism.

But one key issue had to do with information dissemination. The initial messages that went out from the beginning were confusing and contradicting. Even those who were involved in creating awareness had a problem with some of the messages. People focused too much on the negative messages. For example, they will tell you that Ebola is deadly; it has no cure. The symptoms of Ebola are symptoms of other health conditions that we were already used to – fever, headache, diarrhea, body pains, vomiting. These are all common symptoms that are easily treated. So, for people to believe that those were symptoms of Ebola was not an easy thing. Instead of encouraging people to seek care at

ETUs and health facilities, the information people were discouraging them from seeking care. Because if you tell someone that this sickness is deadly and has no cure, do you expect that person to go to the hospital when they suspect that they have that particular sickness? So, these are some of the things that created problems.

-26 years old female seropositive participant

F. "Everybody was afraid of one another."

Ebola created fears and resentment among friends, families, and community dwellers. Participants narrated how community dwellers feared patients diagnosed with EVD or those associated with Ebola due to stigma and negative perceptions of EVD. According to them, just the name Ebola was like a nightmare. People did not even know whom to trust anymore.

They were afraid of us because the people who showed these signs were the Ebola patients. Everybody was afraid of one another. It is more like this coronavirus even when you just put water in your mouth and throw it out, and people will be afraid of you.

-29 years old male seropositive participant

According to most participants, the situation was so complicated that there was no one to trust. Everyone was a suspect.

No, at that time, there was no one to trust, especially in my hometown. Because what happened is that when people started to die in the town, everyone said I carried Ebola in the place, and my life was threatened. So I did not even dare to say I will discuss my fear or problem with anyone from that town, not at all. I was stigmatized; even friends who and I used to do things in common also stopped speaking to me. But I only trusted in God and tried to stay by myself.

-49 years old female seropositive participant

Even the doctors at health facilities were afraid of patients because the name Ebola carried the burden of guilt and was negatively associated with stigma.

> *My sister, her son, and my other son were taken. My sister did not want to go without seeing her brother. But she later agreed, and they were taken to ELWA. Fortunately for me, one died, and two survived: my sister and her son. That is how I passed through Ebola. But I became like an outcast. People became afraid of me, including my own brothers, because of my association with Ebola patients. Even my sister, who survived, said the doctors and nurses at the hospital were also afraid of them; no one came close to them.*
>
> *-55 years old male seropositive participant*

Participants recounted that everybody was afraid of one another because nobody wanted to be identified as an Ebola patient. Even in the marketplaces, people identified as EVD survivors or their family members were ostracized to the extent nobody wanted to receive money from them. As a result, when people got sick or survived the virus, they preferred to keep it secret. According to participants, this is one of the major factors that prevented people from reporting EVD cases.

> *You may be able to go a whole day without food. When you pass by, and people in your community start to point fingers at you, referring to you as an "Ebola person" knowing what Ebola is, this was so frustrating. Our people went to the market but could not get served. They used microphones to drive them away. During labor, women went to the hospital, and they were turned away because "Locals village was branded an Ebola village." Where to go? Nowhere. Even our gardens, nobody came to buy from us.*

Because of this, people started to hide their sick family members; they refused to report suspected cases.

-65 years old male community leader, member of the local response team

Table 6: Joint display of social and structural forces that shape healthcare-seeking behaviors

Key findings from qualitative and quantitative data	Supporting quotes from qualitative data	Outcome
1. Afraid to die Fear was reported as one of the major factors that informed participants' decision not to seek care at treatment centers. About 22.6% of respondents reported fear of dying as a major factor in their decision. While 20.1% reported fear of being stigmatized, and 7.0% reported fear of contracting Ebola as significant factors. **[Negative health outcomes]:** Participants were afraid to go to the ETUs due to the negative outcomes associated with the Ebola treatment center. They believe that most of those who went for care at these facilities never came back. Hence, they refused to attend these facilities because ETUs were considered as "death traps."	*Because the first set of people that went to the ETU never came back. So, people now saw ETU as a death trap; when you go there, your family won't see you again.* 26 years old seropositive female participant	Concordant
2. Lack of trust in government Participants reported the lack of trust in government as one of the many factors that influenced their decision not to seek care at ETU. This was mostly common among symptomatic participants (79%) compared to asymptomatic participants (21%); p-value = 0.00036. [**The "Ebola Business"]**: According to respondents, there was a huge distrust in government and the "system" because of what the public perceived to be the "Ebola business." They believed the government used the Ebola epidemic to acquire money from international partners to the detriment of many Liberians who lost their lives at the ETUs and elsewhere. Other people declined to seek care at these centers because they did not trust the government and the level of care provided at the treatment centers.	*The government was doing their own thing; …the government was influencing what was happening because the more people that died, the more money the government received from partners, including the WHO. …in fact, the Government designed their own medication that they were using at the ETUs to inject and kill more people…* 46 years old male community health worker	Concordant + expansion (additional information)

3. Did not believe that Ebola existed. A good number of participants, 9.5%, did not believe that Ebola existed. Up to 79% of those who did not believe that Ebola existed were symptomatic, while only 21% were asymptomatic. **[The Communication Crisis]:** However, the qualitative data show that this denial or disbelief was because of misinformation and what they considered as inconsistency in messaging. According to participants, initial messages during the outbreak were misleading and created more confusion that made people not believe that Ebola existed.	*Wrong messaging and lack of information…also led to many people denying the Ebola situation. For example, from the beginning, they told us that when you see an Ebola patient, the person will be bleeding, with blood from the ears, eyes, nose, mouth…. everywhere. That was the first information… So when Ebola started, and people started seeing patients who were only vomiting or having headache or fever, people would say, "no, mehn, this is not Ebola. Look at the person's eyes all clear, no blood coming from the ears or nose.* *33 years old female seropositive participant*	Concordant + expansion (additional information not found in Quan)
4. Distance from ETU Participants (10.6%) reported distance from ETU as one of the factors for their non-ETU attendance. Of all those who reported distance as a major factor, a huge majority were symptomatic (95.2%), with only 4.8% being asymptomatic. Findings from the qualitative data **[[Negative health outcomes**] indicate distance was a challenge that participants recognized but made efforts to navigate. As such, it was not a reason for not attending ETUs and therefore did not impact their care-seeking choices.	*They encouraged us to send the people (patients)... Despite our distance from Monrovia, we tried our best to send our people to the ETU. But we later realized that ETUs were more like death traps because more people died at the ETU than at home. Can you imagine we sent 24 patients there, and only four survived?* 65 years old community leader/health worker	Discordant + additional information (introducing nuance)
5. Stigma Over 20% of all participants reported stigma as a reason behind their decision not to seek care during the Ebola outbreak. About 95% of these people were symptomatic, while only 5% were asymptomatic. Results from the qualitative data support this finding - [**"Everybody was afraid of one another"].** The Ebola outbreak created a chain of fear and resentment even among close friends and family members. EVD patients refused to disclose their status. Community dwellers declined to report cases because they feared of being classified as a suspected case.	*Because Ebola is not something to play with, it's like DV (diversity visa lottery); when one person has it, everybody in the family is at risk. …I was afraid of the community stigma. I didn't want anybody calling the Ebola people for me.* 28 years old male seropositive participant	Concordant

DISCUSSION

This mixed-methods sequential explanatory study aimed to investigate participants' experiences and perceptions about Ebola containment measures and identify factors that influenced patients' decisions for not seeking care at treatment facilities during the 2014-2016 Ebola outbreak in Liberia.

Overall, the study found 73.9% of undocumented seropositive participants to be symptomatic, while 26.13% were asymptomatic. These findings are consistent with a study conducted in Sierra by Eugene Richardson and colleagues.[62] Quantitative results show that the distribution of symptomatic undocumented EVD survivors was much higher in Montserrado County with 63.8% and relatively lower in Margibi County, outside the outskirt of Montserrado with 36.2%. These findings support initial findings from the PREVAIL Ebola Natural History Study, although the prevalence rate was much higher than the PREVAIL III findings. In the PREVAIL study, 47% of antibody-positive close contacts (undocumented survivors) reported symptoms consistent with EVD during active Ebola transmission in Liberia.[53] Undocumented Ebola patients who go undetected during an epidemic transmit the virus to families, friends, and other community dwellers, which leads to an undetected chain of transmission. These undocumented cases have significant public health implications and are highly essential in estimating infection rates and defining containment measures. Recent events in the DRC and Guinea suggest that EVD cases' resurgence could be associated with viral persistence among survivors[63], justifying the need to document and account for all EVD cases and survivors. EVD cases that go undetected and undocumented survivors could pose a public health risk for future outbreaks. As already proven elsewhere[64], these undetected cases could lead to unexpected chains of transmission similar to what is now occurring in Guinea.

In the quantitative phase, five major themes emerged as factors for not attending ETUs: fear, lack of trust in the government, stigma, denial, and distance from treatment centers. These findings support previous reports on the motivators for care-seeking decisions.[65] The qualitative interviews intended to explore further and explain these findings revealed that six reasons supported participants' health-seeking behaviors during the Ebola epidemic. Key findings from these interviews suggest that participants' decisions were informed by negative health outcomes birthed out of an underfunded health system. Participants who were symptomatic and had some exposure refused to go to the ETUs out of fear that most of their family members and friends who went to these treatment facilities did not survive, giving rise to a general perception that ETUs were mainly associated with death. This concept is supported by the quantitative findings, with over 42% of symptomatic participants reporting fear of death as a significant factor for not going to the ETUs for care. Analysis of qualitative data revealed that all participants were afraid to die. Adverse health outcomes at the ETUs informed this fear.

Lack of trust in government and the care delivery system stemmed from public perception of the EVD response as “Ebola business.” Disbelief that Ebola existed was higher in symptomatic individuals and lowered in the asymptomatic group. Community denial stemmed from rumors that were not unfounded but emerged from a long history of corruption and foreign exploitation. Perceptions regarding "the Ebola Business" are one example of how rumors grow out of lingering dissatisfaction. Multinational companies had always manipulated the local economy through foreign investments [28], building foreign industries and capital, while the local population remained in poverty. There has always been an unpleasant history of medical experimentation[66], which also gave rise to an unusual but logical suspicion of the health care system.

The quantitative findings revealed that participants lacked trust in the government and did not believe that Ebola existed. The qualitative findings support this outcome, indicating that participants believed the whole Ebola thing was a money-making scheme intended to create wealth for people in higher positions and their international counterparts. Unwholesome dealings of corruption and foreign exploitation resulted in public fears and derailed public trust in the governance system, international partners, relief agencies, and the scientific and medical communities. These perceptions are well-grounded in the history of the political economy.[26,27] Liberia, before Ebola, has been subjected to structural adjustment policies which prevented sustainable investment in healthcare capacity and infrastructure development.[67,68] When Ebola struck, there was already a major gap in service delivery across the country. The doctor to patient ratio was one of the worst in the region.[69,70] There was already a brain drain in the health sector. Most of the post-war infrastructure facilities were either non-existent or dysfunctional—these challenges cumulated into a systemic failure to provide equal access to health care for the entire population. Health workers had to triage care, making use of whatever resources were available. From 2005 to 2014, life expectancy in Liberia was between 58.6 to 63.3 years, literacy rate between 30-48.1%, health expenditure between 5.6% to 11.1% GDP with a hospital bed density of 0.3 to 0.8 beds per 1,000.[71] These social inequalities resulted in what participants regarded as selective care or favoritism and adverse health outcomes at the treatment facilities. When people could not go to treatment units out of fear that they may not have survived, when health facilities were regarded as death traps because they could not provide necessary services, when health workers abandoned patients at treatment centers, these were the actual consequences of structural injustices created by political and economic arrangements.

The quantitative findings also show that fear of community stigma was more common among symptomatic people than asymptomatic individuals. This suggests that symptomatic people suspected that they had been exposed to the virus but made a conscious decision not to report themselves to the ETU due to fear of being stigmatized.

The study also found that Ebola created integrated fears, resentments, and stigma among families, friends, and neighbors. [72]

Findings from the quantitative and qualitative data are primarily concordant, with a few nuanced outcomes. The quantitative findings revealed distance from ETU as one of the factors that influenced care-seeking behavior. However, the qualitative results showed that distance was more of a challenge and not necessarily a predictor for seeking care. Distance between facilities meant patients had to make long journeys to gain entry to ETUs; regardless, people persisted, hoping to get the needed care and attention. Unfortunately, most of those patients who made it to the ETUs never came back alive.

Another characteristic that emerged out of the qualitative finding was the communication crisis. While this concept does not appear directly in the quantitative results, it explains why community stigma was so high and why people became suspicious and distrustful of the government. At the onset of the epidemic, public awareness and sensitization messages were largely inconsistent and confusing. The focus of these messages was to emphasize the deadly nature of the virus instead of promoting the possibility of prevention and care. These messages' despondency created more fear, public distrust and influenced people's decisions to stay away from the ETU/care centers. These findings are consistent with WHO 2016 report.[73] This study shows that the unintended consequences created by messaging, and the fragility of an unprepared

health system shaped by structural violence, further explained why symptomatic participants exposed to Ebola chose not to access care at the ETUs during the Ebola outbreak in Liberia. A study conducted by Robert A. Blair and colleagues in Liberia found that citizens' refusal to comply with containment measures was predominantly because they did not trust government institutions' capacity and integrity in the EVD response. Contrary to previous assertions that noncooperative stance resulted from population ignorance,[74] this study proves the role of trust in adherence to public health policies.[75] Also, findings from a study conducted by Vinck P. et al. in the DRC suggest that EVD patients and community dwellers consciously avoided accessing medical care because they did not believe Ebola existed.[76] However, our study brings out a divergent dimension to this analysis, emphasizing that trust is not a default factor. It is built over time, and the lack thereof is a consequence of deeply rooted historical antecedents. As Eugene Richardson et al. argued in their article "Ebola and the narrative of mistrust,"[77] the beginning of mistrust is the political and economic history of a "rich land with poor people," a history clouded by colonial exploitation, western supremacy, and corruption. Structural determinants and social inequalities informed care-seeking decisions during the outbreak in an underfunded, unsophisticated, and inadequate health system.

Limitations

This is the first study in Liberia to describe the distribution of symptomatic undocumented EVD survivors and identify perceived factors associated with care-seeking behaviors during the 2014-2016 Ebola outbreak. However, there were some study limitations. Because this mixed-method study was conducted among seropositive individuals in two counties (Montserrado and Margibi), the findings are not generalizable. Also, symptomatology was recorded based on self-report. Given that participants' experience of these events runs as far back

as five years ago, their recollection may not be as fresh, hence a potential for recall bias. To minimize this, we triangulated our data collection methods to corroborate reported measures and validate findings.

Further studies are needed to explore the overall prevalence of undocumented EVD cases within the general population. The mechanism by which undocumented EVD cases felt out of the response structure is highlighted here but not exhaustive given the study's sample size. A seroprevalence survey with an anthropological approach that describes the political, social, and epidemiological interactions will help fill this gap.

CONCLUSION

Symptomatic undocumented Ebola survivors in Montserrado and Margibi Counties, Liberia, preferred not to seek care at designated health facilities due to fear of adverse health outcomes that overwhelmed these treatment centers, the lack of trust thereof, and the social implications of being identified as an EVD patient. The high fatality rate at these facilities validated the public perception of ETUs as "death traps," justifying the lack of trust in the healthcare system to adequately contain the outbreak and families' preference to care for their loved ones at home, outside the EVD control structure. Ebola surveillance must account for all cases to estimate the actual burden of the disease within the population. Documenting and following up on all survivors' health status will prevent another epidemic's resurgence within this population. Lastly, EVD preventive and control measures should consider local priorities and practices essential to individuals in these communities. Epidemiological dynamics are not exclusive of affected populations' socioeconomic and geopolitical histories but are deeply rooted in historical antecedents – foreign exploitations, corruption, and neoliberalism.

More research needs to be conducted to estimate a more accurate disease burden in the West Africa epidemic. This is critical to the success of future surveillance efforts and preventing the re-emergence of EBOV in the region.

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APPENDICES

Appendix A: Cohort 1 Consent Form

Cohort 1 Consent Form

Eugene Richardson, MD, PhD
Principle Investigators (PIs): Mosoka Fallah, PhD, MPH

Co-Investigator: Barthalomew Wilson, MPH

Protocol Title: Understanding the Social Epidemiology of Undocumented Ebola Virus Transmission in Liberia

FOR QUESTIONS ABOUT THE STUDY, CONTACT: Dr. Mosoka Fallah, 0888349115/0775299799, or mfallah1969@gmail.com; or Dr. Eugene Richardson, Harvard Medical School, +1 954 7017111.

This consent form will give you the information you will need to understand why this study is being done and why you are invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts you may have while participating. We encourage you to ask questions at any time.

DESCRIPTION: You are invited to participate in a research study about Ebola because you were shown to have Ebola antibodies in the PREVAIL III study. We are conducting this new research because we want to find out why some Ebola survivors went to treatment centers and why some did not. We also want to understand how this may have impacted documentation of EVD survivors and the overall response efforts. Findings from this study will be used to advance recommendations for future response and EVD containment

During this interview, 2-3 members of the study team will ask you questions about yourself, about symptoms you may have had during the Ebola outbreak, why you did or did not look for care during the outbreak, and what you think the effects of the epidemic have been. As part of this study, we will also collect information about you from other PREVAIL studies you have participated in. This may include information that can identify you, such as your name, demographic information, and serology results. Your study information (no blood specimens will be drawn) will be placed in a secure electronic system for use by other researchers. It will not include your name. Researchers must request permission to look at the information in this system. They may then use the information for future research. This allows the information to be shared broadly for research purposes. This information cannot be traced back to you. You will not get any information about future research. Your coded data might be sent to other scientists that we work with for research. We must get approval from the Liberian and US ethics boards that review this study before we share samples and data with other researchers. Other information, such as your sex, age, or health history might also be shared, but your name will not.

RISKS AND BENEFITS: You may experience emotional distress from retelling your memories of the outbreak. You are free to skip any question that you do not feel comfortable answering.

If you experience any of these risks, you can seek out resources at the local free clinic. We cannot and do not guarantee or promise that you will receive any direct benefits from this study. However, it is our hope that this study will help define strategies for future EVD containment.

TIME INVOLVEMENT: Interviews will take between 30 minutes and 2 hours.

PAYMENTS: You will receive $5(US) for any inconvenience participation in the study may have caused.

PARTICIPANT'S RIGHTS: If you have decided to participate in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

The results of this study may be presented at scientific or professional meetings or published in scientific journals. However, your identity will not be shared. Only Drs. Fallah, Richardson, and Barthalomew Wilson will have contact with you and will have access to your information.

We will not tell other people about you. You have the right to refuse to answer particular questions. If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the University of Liberia Institutional Review Board (UL-IRB), Tel: +231-777-697-606/+231-886-697-606).

You will be given a copy of this consent form if you wish.

Signature of Participant

- This research study has been explained to me, including risks and possible benefits (if any), other possible treatments or procedures, and other important things about the study.
- I have had the opportunity to ask questions.
- I understand the information given to me.
- I agree to take part in this research study and agree to allow my health information to be used and shared as described above.

_____ _____

Signature of Participant (or thumbprint) Date

Statement of study staff obtaining consent

- I have explained the research to the study subject.
- I have answered all questions about this research study to the best of my ability.

_____ _____

Study staff obtaining consent Date

Appendix B: Cohort 2 Consent Form

Cohort 2 Consent Form

Eugene Richardson, MD, PhD

Principle Investigators (PIs): Mosoka Fallah, PhD, MPH

Co-Investigator: Barthalomew Wilson, MPH

Protocol Title: Understanding the Social Epidemiology of Undocumented Ebola Virus Transmission in Liberia

FOR QUESTIONS ABOUT THE STUDY, CONTACT: Dr. Mosoka Fallah, 0888349115/0775299799, or mfallah1969@gmail.com; or Dr. Eugene Richardson, Harvard Medical School, +1 954 701 7111

This consent form will give you the information you will need to understand why this study is being done and why you are invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences, or discomforts you may have while participating. We encourage you to ask questions at any time.

DESCRIPTION: You are invited to participate in a research study because you identified as a member of the Ebola management team who supported EVD response efforts during the 2014-2016 EVD outbreak in Liberia. We are conducting this new research because we want to find out how Ebola virus is transmitted in communities. We also want to find out why some Ebola survivors went to treatment centers and why some did not. You will be asked to answer questions about your experience during the previous Ebola outbreak.

During this interview with you, 2-3 members of our research team will ask you question about yourself. We will also ask you questions about your role in the 2014-2016 EVD response, your experience working with Ebola patients, what factors made it possible or difficult for EVD patients to seek care at the Ebola Treatment Units (ETUs), and what you think the effects of the outbreak have been. We will store your information for a very long time to use for future research on Ebola. Your stored information will be marked with a code and not with your name. Only researchers linked to this study can get the codes.

Your study information will be placed in a secure electronic system. We may share this information with other researchers who might want to conduct future studies on Ebola. Information, such as your gender, age, or personal history might also be shared, but your name will not be shared with anyone outside of the research team. Researchers must request permission to look at information in this system. They may then use the information for future research on any topic. This allows the information to be shared broadly for research purposes. This information cannot be traced back to you. The only risk of allowing us to store your data would be an accidental release of your identity.

If you change your mind and decide you do not want us to store your data, please let us know. We will do our best to follow your wishes but cannot promise that we will always be able to destroy your data.

RISKS AND BENEFITS: The risks associated with this study are minimal. There are no direct benefits to you for participating in this study. However, whatever we learned from this study will help provide recommendations for better EVD care/treatment in the future.

TIME INVOLVEMENT: The in-depth interview will take between 90 to 120 minutes.

PAYMENTS: You will receive $5(US) for any inconvenience your participation in the study may have caused.

PARTICIPANT'S RIGHTS: If you have decided to participate in this project, please understand your participation is voluntary, and you have the right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

The results of this research study may be presented at scientific or professional meetings or published in scientific journals. However, your identity will not be shared**.** Only Drs. Fallah, Richardson, Mr. Barthalomew Wilson, and Mr. Joseph Boye Cooper will have contact with you and will have access to your information. We will not tell other people about you. You have the right to refuse to answer any particular questions.

If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the University of Liberia Institutional Review Board (UL-IRB), Tel: +231-777-697-606/+231-886-697-606.

You will be given a copy of this consent form if you wish.

Signature

- This research study has been explained to me, including risks and possible benefits (if any).
- I have had the opportunity to ask questions.

- I understand the information given to me.
- I agree to take part in this research study and agree to allow my health information to be used and shared as described above.

_____ _____

Signature of Participant (or thumbprint) Date

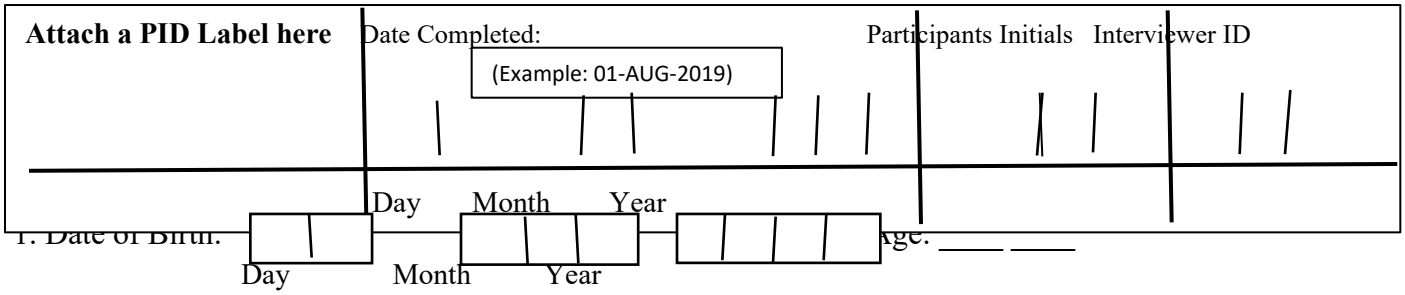
Statement of Study Investigator Obtaining Consent

- I have explained the research to the study subject.
- I have answered all questions about this research study to the best of my ability.

_____ _____

Study Investigator Obtaining Consent Date

Appendix C: Survey Data Collection Form



2. Gender: 1 ☐ Male 2 Female ☐

3. Last type of School completed:

0	☐ formal education	5	Some High School ☐
1	☐ me primary school	6	Completed High School ☐
2	☐ Completed Primary School	7	Some University ☐
3	☐ Some junior High	8	Completed University ☐
4	☐ mpleted Junior High	9	Vocation Training ☐

4. County _____ District _____ Village/Town _____ _____

B. Primary Interview Questions

1. Was the seropositive participant asymptomatic, symptomatic or minimally symptomatic?
   1 Symptomatic ☐
   2 Asymptomatic ☐
   3 Minimally symptomatic ☐

2. What symptoms (self-reported) did you experience during the time of active

EBOV transmission?

1. Fever 0 No ☐ Yes ☐
2.
3. Loss of appetite 0 ☐ 1 Y☐
4.
5. Nausea 0 No ☐ Yes ☐
6. Vomiting 0 N☐ Yes ☐
7. Diarrhea 0 N☐ Yes ☐
8. Headache 0 N☐ Yes ☐
9. Abdominal pain 0 ☐ 1 Y☐
10. Muscle pain 0 ☐1 Yes☐
11. Breathing difficulties 0 N☐ Yes☐
12. Hiccups 0 N☐ Yes ☐
13. Shortness of breath 0 N☐ Yes ☐
14. Joint pain 0 N☐ Yes ☐
15. Unexplained bleeding 0 N☐ Yes☐
16. Red eyes 0 N☐ Yes ☐
17. Fatigue 0 N☐ Yes ☐
18. Sore throat 0 N☐ Yes☐

3. Did you know that you were exposed to Ebola?
   1 ☐
   2 ☐
   3 ☐sure

4. Source of exposure
   1 ☐ily member
   2 ☐ds/community dweller
   3 ☐EVD patient
   4 ☐er

5. Why didn't you attend an ETU (mark all that apply) (2=No; 1=Yes)

1. Lack of trust in the government Yes ☐ No ☐
2. Went to a traditional healer instead Yes ☐ ☐
3. High mortality Yes No ☐ ☐
4. Didn't believe that Ebola existed Yes ☐ No ☐
5. Facility too distant/no transport Yes ☐ ☐
6. Went to a religious healer instead Yes ☐ No ☐
7. Childcare responsibility Yes ☐ ☐
8. Work responsibility Yes ☐ No ☐
9. Family care responsibility Yes ☐ No ☐
10. Responsibility to take care of Ebola patient Yes ☐ No ☐
11. Responsibility to take care of another patient (non-Ebola) Yes ☐ No ☐
12. Afraid to catch Ebola Yes ☐ No ☐
13. Afraid to die Yes ☐ No ☐
14. Afraid of community stigma Yes ☐ No ☐
15. Was too tired to go Yes ☐ No ☐
16. Due to distance from the ETU Yes ☐ ☐
17. No Means of transportation Yes ☐ No ☐
18. Did not have money for transportation Yes ☐ ☐
19. Other (please specify) _____

Attach a PID label here

C. The following questions refer to the time of the Ebola outbreak

1. What was your marital status?

0 ☐ married 2 Se☐ated 4 Wido☐

1 ☐ried 3 Divo☐ 5 Cohabiting (☐g together)

2. What was your occupation? (mark all that apply) (2=No; 1=Yes)

1. Farmer Yes ☐o ☐ 2. Office worker Yes No ☐ ☐
3. Housewife Yes N☐ ☐ 4. Teacher: Yes No ☐ ☐
5. Business Yes ☐ No ☐ 6. Unemployed Yes ☐o ☐Small business Yes No ☐ 8. Do☐stic help Yes No ☐
9. Student Yes No☐ 1☐river Yes No ☐ ☐
11. Miner/rubber worker: Yes ☐ ☐Professional health worker Yes No ☐ ☐
13. Waiter/waitress Yes N☐ 14☐ommunity health worker Yes No ☐ ☐

15. Security officer Yes N☐ 16☐rtender Yes No ☐ ☐

17. Other (please specify) _____

3. Did you provide care to any Ebola patient during the outbreak?

1 ☐s 3 ☐an't remember

2 ☐

3b. If yes, in what capacity?

1 ☐other 3 guard☐ 5 None ☐

2 ☐ther 4 Nurs☐ctor/lab tech/HW 6 Othe☐ecify) _____

Attach a PID label here

4. What was your religion?

1 ☐ Christianity 3 ☐ Bahai

2 ☐ Islam 4 ☐ No religion

3 ☐ Traditional beliefs 6 ☐ther (specify) _____

5. How far from the nearest ETU did you live?

1 ☐ 0 – 10 Km 3 ☐ – 100 Km

2 ☐ 11 – 50 Km 4 ☐ 100 Km

6. What was your primary mode of transportation

1 ☐lking 2 taxi ☐ 3 Bus (co☐ercial)

4 ☐torbike 5 Keke☐ 6 Other (pleas☐ecify) _____

7. How many people were living with you in the same house? ___ ___

8. What kind of accommodation did you have?

1 ☐nted house

2 ☐rsonal/family house

9. What type of house did you live in?

1 ☐ ncrete house 2 Mud ☐ se 5 Thatc ☐ mboo house

2 ☐ t bricks house 4 ☐ inc round house 6 Other ☐ ecify) _____

11. What was your family monthly income (in money)? _____

12. How many people rely on this income (on average): ____ ____

Attach a PID label here

13. What kind of fuel did your family primarily used for cooking?

1 ☐ Wood 3 Gas ☐

2 ☐ Coal 4 ☐ ther (specify) _____

14. On average, how many meals did your family eat per day? ____ ____

15. How many rooms did you have in your house? ____ ____

16. How many people lived in your house? ____ ____

17. How many children under the age of 5 lived in your house? ____ ____

18. How many children between the ages of 5 and 15 lived in your house? ____ ____

19. Did you have a latrine? (1=Yes; 2=No)

1 ☐ s 2 No ☐

20. If yes, what type of latrine did you have? (CHOOSE ONE)

1 ☐ latrine (wood)
2 ☐ latrine (cement)
3 ☐ le in the ground
4 ☐ sh toilet
5 ☐ er, specify: _____

21. Did you have a radio? (1=Yes; 2=No)

1 ☐ s 2 No ☐

Signature:_____Date: _____

Appendix D: Cohort 1 Interview Guide

Hello, my name is Barthalomew Wilson (introduce other team members). I am a student from the Harvard Medical School. I would like to learn about your experiences during the 2014-2016 Ebola outbreak in Liberia.
In this interview, we will discuss your experiences as an EVD survivors, what was it like contracting the virus and how you received care and treatment during this period.
The interview should take about one hour. Any information you give to us will be kept confidential. Reports from this study will not identify any single person. If you do not like any of the questions, you do not have to answer them, and you may stop the interview at any time.
Do you have any questions before we begin?

1. Please tell us a little bit about your family (roles of family members)
2. Before the Ebola outbreak, how did you or your family members receive treatment for other illnesses?
   (b) Who made the decision?

I am going to ask you few questions about your experiences during the Ebola outbreak.

3. How did you know someone had Ebola?
   (b) What symptoms made people afraid in your community? Why?
4. What was it like to have lived or come in contact with people who had Ebola?
   (b) Please share with us your interactions with some of those people
5. Did you ever suspect that you had Ebola during the outbreak? what made you think so?
6. Could you please describe for us how Ebola patients from your community received treatment during the outbreak?
7. How easy was it for EVD patients to access care during the Ebola outbreak? Why?
8. During the outbreak, who did you talk to about seeking care, why?
9. What was the community perception about ETU?
   (b) Did that impact your decisions to go to the ETU during the Ebola outbreak?
10. Please explain any concerns you may have had about attending the ETU.
11. Did you ever go to any other health facility during the Ebola outbreak to get treatment for another condition other than Ebola? Why?
12. How did community perceptions about Ebola impact your decision to seek care?
13. How do you think your decision for not going to the ETU impacted your own health?

14. How are EVD survivors treated by people in your community? Please share your experience with us.
15. What do you think about the way the Ministry of Health responded to the Ebola outbreak?
16. Is there anything else you would like to share with us regarding your experience during the Ebola outbreak?

Thanks for taking up your time to talk to us. Please feel free to contact me if you have any question(s) about this interview.

Appendix E: Cohort 2 Interview Guide

Hello, my name is Barthalomew Wilson (introduce other team members). I am a student from the Harvard Medical School. I would like to learn about your experiences during the 2014-2016 Ebola outbreak in Liberia.

In this interview, we will discuss your experiences as a member of the Ebola response team in your community, what was it like being part of the Ebola task force and helping with case management, contact tracing, case investigation and the general EVD response.

The interview should take about one hour. Any information you give to us will be kept confidential. Reports from this study will not identify any single person. If you do not like any of the questions, you do not have to answer them, and you may stop the interview at any time.

Do you have any questions before we begin?

1. Please tell us, what do you do for a living?
2. Prior to the Ebola outbreak, what were you doing to survive?
3. How did Ebola impact your life?

4. What are some of the things you remembered from the Ebola outbreak?
5. In what way were you involved in the Ebola response?
6. Could you please describe for us how Ebola patients from your community received care during the outbreak?
7. What did you see as a major challenge for responders?
8. What were the major community concerns?
9. How did those impact adherence to Ebola control measures?
10. What factors influenced community decisions to/not to adhere to public health measures?
11. What was the community perception about ETU?
    b) How did that impact people decisions to go to the ETU?
12. Did any of your friends or family members get treated at the ETU? Why?
    b) Who made the decision?
13. What is your perspective regarding the way the government responded to the outbreak?
14. Is there anything else you would like to share with us regarding your experience during the Ebola outbreak?

Thanks for taking up your time to talk to us. Please feel free to contact me if you have any question(s) about this interview.