Title

"We Are Here," Enduring Survivorship In The Aftermath: Community Trauma, Survivor Discourse and Advocacy Post the 2014-16 West Africa Ebola Outbreak

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"WE ARE HERE," ENDURING SURVIVORSHIP IN THE AFTERMATH: Community Trauma, Survivor Discourse and Advocacy Post the 2014-16 West Africa Ebola Outbreak

by

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I dedicate this dissertation to Ishmel Luanda. This is for you. I hope you're smiling from above. I hope you're proud of me.

"I still write about the same thing, which is how people relate to one another and miss it or hang on to it ... or are tenacious about love. About love and how to survive-not to make a living-but how to survive whole in a world where we are all of us, in some measure, victims of something. Each one of us is in some way at some moment a victim and in no position to do a thing about it. Some child is always left unpicked up at some moment. In a world like that, how does one remain whole-is it just impossible to do that?"

—Toni Morrison

Abstract

"WE ARE HERE," ENDURING SURVIVORSHIP IN THE AFTERMATH: Community Trauma, Survivor Discourse and Advocacy Post the 2014-16 West Africa Ebola Outbreak

Rashon Ilene Lane

This dissertation examines survivor health through media discourse, community trauma and health social movements in the aftermath of the 2014-16 West Africa Ebola epidemic. As the largest Ebola epidemic ever recorded, the 2014-16 Ebola epidemic in West Africa left approximately 15,000 Ebola survivors. While disciplines including public health and disaster science attended to understandings of Ebola survivorship during the height of the Ebola response, limited studies attend to the social-structural aspects of survivor health long after public health and humanitarian interventions ceased. Recognizing that there is a gap in structural analyses of the Ebola survivorship, this dissertation applies a sociological analysis to examine survivor health after the 2014-16 West Africa Ebola epidemic. Engaging frameworks from disaster sociology, neo-colonialism, collective trauma and health social movement scholarship, I aim to understand the social constructions of survivorship in post-disaster phases. This dissertation project incorporates qualitative data from three datasets, a media discourse analysis (n=156), 20 semi-structured focus groups with Ebola survivors (n=100) in Sierra Leone and 15 in-depth interviews. Critical discourse analysis and grounded theory methods are used as tools for analysis in understanding the social and economic livelihood.

The three papers that comprise this dissertation examine survivor health to understand how structural inequity takes shape in the aftermath of an epidemic. The first paper describes how survivorship discourse is constructed after an epidemic ends by analyzing media narratives. This analysis found that survivor discourse reinforced body surveillance of Ebola survivors and portrayed Ebola survivors as deceptively hiding the Ebola virus. Moreover, the media emphasized the utility of survivor's bodies through a biomedical lens for the purpose of scientific knowledge production. The second chapter uses Ebola survivor narratives to understand the lived experience of collective trauma post the 2014-16 Ebola outbreak. Themes elicited experiences of community trauma that impacted community cohesion, including Ebola stigma, access to economic opportunities and survivor benefits, and the use of survivors as biocapital for the biomedical research industry. The third paper aims to describe how survivor advocacy was used advocate for policies for post-disaster health care in Sierra Leone. Findings suggest that the Ebola survivor social movement to gain access to epidemic citizenship claims for their right to health was unsuccessful due to political corruption, shifts in global health priorities, and the social and inequities of who was impacted by the Ebola outbreak in Sierra Leone.

In conclusion, I center on survivor health as a social problem that requires social analyses and solutions. Various forms of community trauma emerge for survivors of epidemics, produced by a multitude of community discordances, including stigmatization, inequities in resource allocation, advocacy for health rights and ultimately the biomedicalization of survivorship. These forms of trauma reinforce inequalities for survivors in the afterlives of epidemics. I posit that a community trauma-informed recovery approach that centers health equity in post-disaster settings is needed to address the social and structural aspects of survivorship. I recommend that public health and biomedical research move beyond describing survivor health in solely pathogenic and epidemiological framings to describe the structural, social, and economic factors that impact the livelihood of Ebola survivors.

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Chapter 1: Introduction

Statement of the Problem

In 2014, the largest Ebola epidemic began in West Africa, primarily in Guinea, Liberia and Sierra Leone. The outbreak lasted nearly two years, with nearly 30,000 cases and a death toll of 11,310 people, which is higher than all previous Ebola outbreaks combined (CDC 2016). The Ebola Virus Disease (henceforth called Ebola) was discovered in 1976 near the Ebola river in Central Africa (modern-day Democratic Republic of Congo), and several smaller outbreaks have occurred over the past 40 years. The Ebola virus is a hemorrhagic fever that is spread through contact with bodily fluids (e.g., blood, semen, breast milk) and has a 50%-90% fatality rate (CDC 2014). The complexity of the 2014-16 Ebola epidemic far exceeded public health predictions of the potential spread of the Ebola virus, and the epidemic had vast and enduring health, social and economic impacts. Though clinical trials for an Ebola vaccine were developed during and after the 2014-16 Ebola outbreak, but at the onset of the outbreak, a vaccine was not widely available to the public. During the 2014-16 Ebola outbreak, there were no government agency-approved drugs for treatment. The best tools at hand were prompt diagnosis and aggressive therapeutic treatment care management, which did improve survival rates: the 2014-16 Ebola epidemic had an approximate 50% survival rate. Given the length and spread of the epidemic, this outbreak left a larger population of Ebola survivors than has ever been witnessed before (CDC 2016).

The aftermath of the 2014-16 Ebola outbreak created a community of survivors with persistent long-term physical and mental health conditions caused by the virus (WHO 2015). Ebola survivors reported vision problems, blindness, chronic pain in previous outbreaks and the 2014-16 Ebola outbreak (Kuriansky, et al. 2016, WHO 2016). Additionally, the mental health conditions experienced by Ebola survivors include post-traumatic stress disorder, depression, and anxiety (CDC 2015; Kuriansky, et al. 2016). While the long-term physical and mental health effects of the Ebola outbreak have been researched and theorized (Kuriansky, et al. 2016), research attending to the long-term structural health consequences is limited for Ebola survivors (Jones 2011). Additionally, social framings including community trauma (Pinderhughes and Davis 2016, Veerman and Ganzevoort 2001), survivor narratives (Leydesdorff 2004), biocapital (Rajan 2006) and health social movements (Epstein 1995; Nelson 2011; Patton 2002) might provide an alternate and more nuanced perspective to understanding survivorship after public health epidemics. This is critical because in-depth knowledge of structural and social determinants of global disasters (like the 2014-16 West Africa Ebola outbreak) is as crucial as understanding the pathogenic and epidemiological pathways of infectious disease outbreaks (Jones 2011, Tierney 2016, Richardson 2020).

To better investigate the social construction of disaster survivors, I attend to how power is situated and survivor agency is portrayed. To put Ebola survivors into context, survivors of Ebola outbreak are technically those who tested positive for the Ebola Virus Disease and later were determined by laboratory confirmation to Ebola-free (Kuriansky and Jalloh 2016). The designation as an Ebola survivor is critical in survivorship studies, as biological citizenship provides access to disaster claims (e.g. financial resources, health care access) (Petryna 2002). The aim of disaster research that focuses on the sociology of survivorship is to understand how the people, communities, institutions are impacted by social inequity such as class, gender, race, or geographic location (Cutter 2003). Decades of disaster sociology research indicates that disasters exacerbate pre-existing problems for survivors, including neglecting impoverished communities, inadequate housing, poor land use and inadequate health care systems, overcrowding, among others (Disaster Handbook 2007).

The 2014-16 West Africa Ebola Epidemic in Context

Epidemiologists can best trace the start of the Ebola outbreak to a small village of Meliandou in the Guéckédou region of Guinea, West Africa, near the border of both Sierra Leone and Liberia in December 2013 (WHO, 2016). This region of Guinea shares borders with two other low-income countries (Sierra Leone and Liberia). The three countries that experienced the majority of cases during the two-year outbreak have limited public health infrastructure to respond to large-scale epidemics. The lack of healthcare infrastructure and weakened economies, coupled with two nations states (Liberia and Sierra Leone) that were still recovering from long periods of war, created an environment where the Ebola outbreak quickly became uncontrollable (Benton and Dionne 2015; Dzingirai et al. 2017; Leach 2015). From a global health response perspective, it was not until Spring 2014 to early Summer that agencies like the World Health Organization (WHO), the United Nation agencies, and the U.S. based Centers for Disease Control and Prevention (CDC) became heavily engaged in responding to the Ebola outbreak on the ground in West Africa. On July 31st, 2014, a state of emergency was finally declared for the Ebola outbreak. The Ebola epidemic was classified as both a public health issue and a humanitarian crisis (UN 2014). This precedence of declaring an epidemic conjointly as a humanitarian crisis has only been designated twice, both in the AIDS epidemic. With the Ebola outbreak costing over three billion dollars, how the resources were allocated and utilized can be considered a crisis in itself.

In Sierra Leone, the hardest hit country in the region, Ebola cases were first identified in the Kailahun District in Mid-May of 2014 (Oz 2016). 14,124 individuals in Sierra Leone were infected with the Ebola virus primarily due to the limited healthcare infrastructure to locate, diagnose, and treat patients quickly. While major public health agencies were alerted to the seriousness of the outbreak early in 2014, there was a lack of financial and human resources provided to the three impacted countries up until the Summer of 2014.

There are many speculations as to the reasons that there was such a slow response by global health agencies to respond to the 2014-16 Ebola Outbreak. For instance, some posit that the response was slow because the outbreak wasn't perceived as a threat to the Global North, while others blame the lack of responsiveness in the three West African countries. In fact, one might argue that it was not until a September 2014 Morbidity and Mortality Weekly Report for the CDC, which provided conclusions based on an epidemiological trend model that unless substantial scale-up of public health intervention occurred, up to 1.4 million cases could occur in Sierra Leone and Liberia. (Meltzer et al. 2014). By the summer of 2014, after months of virtually no assistance from the international health and foreign aid community organizations, millions of dollars were committed to the Ebola outbreak, and a mass media frenzy was well underway in Western media by the fall of 2014.

This Ebola outbreak was taken seriously once it was viewed as public health and national security threat to Western Nations (Quinn and Kumar 2014).). Globalization in the 21st century brought about international transit, which incited concerns that the Ebola virus might spread across international borders (Labonthe, Mohindra, and Schrecker 2011). As a result of Ebola being seen as an international risk and potential pandemic, the three West African impacted countries (Guinea, Liberia, Sierra Leone) received substantial economic and human resource aid from the countries that previously colonized or had some form of political influence over them (e.g., France/Guinea and the U.S./Liberia relationship). In the case of Sierra Leone, Great Britain supported the Sierra Leonean government in its Ebola response, which had spread across its 14 districts by the end of 2014. The United Kingdom's Department for International Development ramped up response and recovery efforts in Sierra Leone, in collaboration with the WHO and the CDC. At the same time, the British military increased its presence in Sierra Leone, and served as the agency to 'contain and combat' the deadly virus and provide oversight of national and local emergency response command centers.

Before during and post the Ebola Outbreak, the health care infrastructure was significantly damaged in Sierra Leone. Hospitals did not have proper procedures, resources or personnel to care for individuals infected with the Ebola virus. Consequently, many clinics and hospitals closed for a period after nosocomial infections (e.g., hospital-acquired infections) occurred. Sierra Leone’s pre-existing health care professional shortage witnessed a devastating impact. Before the Ebola outbreak, Sierra Leone had 1,153 healthcare professionals (e.g., doctors, nurses, and midwives) (Evans et al. 2015). During the outbreak, 79 doctors, nurses, and midwives were lost to the Ebola outbreak, which accounted for a 7% decrease from the pre-Ebola health care workforce (Sierra Leone Ministry of Health and Sanitation 2012). This shortage of health workers, coupled with a lack of health infrastructure (e.g., health facilities and medical supplies) left a post-Ebola Sierra Leone with mounting healthcare challenges.

Purpose and Aims

This dissertation research aims to understand how power, knowledge production, social inequities intersect to construct notions of survivor health after an epidemic ends. Using the 2014-16 West Africa Ebola epidemic as a case study, I examine how the social lives of Ebola survivors were impacted by the outbreak long after the public health interventions ceased. As a epistemological foundation, this project posits that survivorship and survivor health are socially constructed and that there is need to move beyond the medicalization of survivor health. Critical to this analysis of survivorship is how and where power and agency are situated in survivor discourse, survivor narratives and how political and economic systems exacerbate marginalization following an epidemic. To this end, in *Globalizing AIDS* Patton (2002) suggests,

> "Readdressing current inadequacies in research and care is not as simple as determining which is more powerful science or the state. We must instead describe how, in the present case, the state, science and public media overlap, detach and collide and with what effects on the bodies we are trying to protect" (p 26).

Thus, in this dissertation research, I do this work by drawing on theoretical traditions of biomedicalization, biocapital and social movements to understand how survivor health becomes recognized, understood, and deployed by the state and survivors. I selected Sierra Leone as a site of inquiry, as the country had the highest number of cases and survivors of the three primary countries impacted by the 2014-16 Ebola outbreak (CDC 2016). Additionally, I worked in Sierra Leone during the Ebola outbreak as a CDC responder conducting rapid behavioral assessments, health promotion, and epidemiology. Primary data collection occurred in one district of Port Loko, Sierra Leone, as it provides a unique opportunity to collect in-depth qualitative data at a community level. Furthermore, Port Loko is the second largest district in Sierra Leone and experienced a prolonged period of Ebola cases in the district, being one of the last districts to be declared Ebola free in the 2014-16 Ebola outbreak.

This dissertation study seeks to understand three aims:

1. To investigate social constructions of survivorship and how knowledge is produced about the health of Ebola survivors.

2. To understand the lived experiences of community trauma and structural inequities among Ebola survivors post the 2014-16 West Africa Ebola outbreak
3. To provide a historical analysis of how survivor health movements encourage policies for post-disaster health care recovery and its impact on the livelihood of Ebola survivors.

Theoretical Framings for the Social Construction of Ebola Survivorship

A Historical perspective of Post Colonial Sierra Leone

To better understand how the largest Ebola outbreak could have occurred in the 21st century, given current biomedical advances and public health knowledge, we must first take a historical perspective on colonization and its interaction with global public health. The recent historical context that shapes Sierra Leone as a nation-state includes colonization, engagement in the transatlantic slave trade, an abolitionist movement, and long periods of war. Colonialism in Sierra Leone began with the Portuguese in the 15th century, and in 1808 Sierra Leone became a British colony for over 150 years. Although Sierra Leone gained independence in 1961, like other colonized nation states, the subsequent decades contained stifling imperialism, political conflict, and civil war. The British Empire continued its indirect ruling by creating a centralized government that created clashes for political and economic control between provinces and political parties. Imperialism was exacerbated by increases in mineral mining that primarily benefited capitalists in the West and local elites (Oz 2016). Sierra Leone's decolonization process led to a one-party rule by the All People's Congress (APC) which ultimately led to an economy with centralized political and economic power in the capital of Freetown (Enria and Lees 2018). When the Ebola outbreak began in Sierra Leone, the country was still recovering from a prolonged civil ward that lasted from 1991 to 2002. The post-war country was rife with high unemployment rates, lack of education, and poor health care. According to Enria and Lees (2018), at the time of the Ebola epidemic,

> "Identities, communities, and layers of political power were once again in flux as Ebola arrived. Indeed, the outbreak of Ebola can be viewed as a tragically premature test for post-conflict institutions (p. 38)."

People in outlying areas expressed resistance to the Ebola outbreak in their communities due to their collective trauma of colonialism (Oz 2016).

At the start of the Ebola outbreak, Sierra Leoneans experienced justified mistrust of government and international agencies, due to the mass stealing of natural resources, political divisiveness, and abuse of power by the West. Nevertheless, Sierra Leone was in the midst of rebuilding it is political, economic and healthcare infrastructure when the Ebola epidemic hit (Oz 2016). For example, in the case of mental health services, the country had just established its first strategic plan for mental health in order to address post-war trauma and the lack of healthcare resources (Sierra Leone Ministry of Health 2012). However, by 2015 the high death toll from Ebola cases left Sierra Leone with insufficient medical facilities and a reluctance from sick individuals to seek medical care at clinics and hospitals (Richardson 2020).

Neocolonialism and Global Public Health

Sierra Leone's political and economic strife during decolonization provides an opening to examine public health through neocolonialist theories. Neocolonialism focuses on the use of economic, social, political and cultural policies of higher income countries (often prior colonizers) to maintain control of lower-resourced countries. In theory, while previous colonized states have gained sovereignty, neocolonialism claims that wealthy countries exert power through the control of developing countries. Liberation leaders and critical theorists, such as Kwame Nkrumah and critical theorist Franz Fanon, situate neocolonialism in conversation with theories of capitalism and pyschoanalysis, alongside cultural and economic imperialism (Nkrumah 1967). A neocolonialist's critique of public health examines how colonial ideologies, methods, discourse, science, and public health programs shape the configurations of public health and healthcare in a post-colonial era (Smith 1999). This also brings perspective on how global public health is used as an apparatus to enforce Global North norms and policies in the Global South (Nguyen 2005, Farmer 1996, Farmer 2003, Farmer et al 2006). Labonthe, Mohindra and Scherecker's (2011) examination of globalization's impact on public health indicates that public health policies contribute to significant increases in income inequality. A structural analysis of global public health outbreaks underscores that the root of the problem is structured by the political economy.

> This is the point that needs to be stressed: the roots of the problem are to be found in the developing countries themselves—in the patterns of class control over governments, assisted by governments of the North that are heavily influenced by their own dominant classes and dominant economic groups. (Navarro 2004, p. 6).

For even when global health is practiced more equitably, wherein local voices are centered, the funding streams governed by global donors leave little autonomy for countries like Sierra Leone to develop public health practice that is not rooted in the Global North's ideologies.

Utilizing Disaster Sociology to Frame the 2014-16 Ebola Outbreak

This dissertation research contributes to the subfield of sociology known as disaster sociology. The vast majority of disaster sociology research emerged in the past 50 years as the need to understand the social context around disasters increased. Historically, the first sociological studies of disasters commenced after World War II and the Cold War from a need to understand how Americans would respond to foreign attacks (Quarantelli 2005). These early peacetime disaster studies led to the establishment of the Disaster Research Center at The Ohio

State University in 1963, which paved the way for the expansion of disaster research and disaster sociology. The usage of the term disaster has no one set definition, but disaster sociologists have outlined some critical features of disasters. According to Quarantelli (2005), the central features of a disaster are:

> (1) sudden-onset occasions, (2) seriously disrupt the routines of collective units, (3) cause the adoption of unplanned courses of action to adjust to the disruption, (4) have unexpected life histories designated in social space and time, and (5) pose danger to valued social objects (p 345).

Types of disasters include natural disasters such as a hurricane, earthquakes, floods, wildfires, and environmental disasters, such as terrorist attacks or epidemics. For sociologists, central to all definitions of disasters is that disasters are a social disruption in society (i.e. for both structures and people) and lead to a sequence of negative consequences (Quarantelli 1998). Quarantelli later discusses that disasters represent vulnerability and mirror the weaknesses in social structures or social systems in society (Quarantelli 2005).

The 1980s was a pivotal period for disaster sociology in regard to both the thinking around disasters and the influx of research. The disaster sociology field experienced a parallel trajectory in its framing of disasters as the evolution of the field of sociology more broadly. While disaster sociology began with foundations in structural functionalism, it later moved into social constructionist theories, as the field progressed into the 1990s, symbolic interactionist theories informed how sociologists incorporated meaning-making into a sociological analysis of disasters (Webb 2007).

In the early years of disaster sociology, epidemics were not considered disasters – a result of the privileging of Western theories and research methods as the authoritative voice of the field. The exclusion of epidemics in disaster literature is likely because disasters like infectious disease epidemics, famine and drought are typically split across the Global North and Global South (Quarantelli 1998). Because of this Global North-South divide, research and practice in the developing world were excluded from foundational theories around disaster sociology. Disaster sociology sits at the crossroads of two fields, first as a subset of the disaster field, but also as a topical area in the field of sociology. Since around the turn of the 21st century, the disaster field has categorized epidemics as natural disasters, along with other events such as terrorist attacks and biological and radiological weapons that can cause massive scale devastation (Perrow 2007). For this dissertation research, I define the Ebola epidemic as a disaster because it created a social disruption to society during a discrete time period.

At the turn of the 21st century, eminent scholars in disaster sociology pointed out that additional research on the social construction of survivors was needed. As noted in the Handbook of Disaster Research (2007),

> The image of active survivors, rather than confused victims, is important for future research. It means that knowledge, rather than command and control, is more important in reducing the negative consequences of disasters in all types of social structures (P. xviii).

Early research in the field of disaster sociology excluded survivors from the Global South; hence it is pertinent that future research centers these perspectives moving forward in order to fully attend to power and injustice. Also, while disaster sociologists regularly include survivors in their research, there is no predominant framing or social constructionist theory in the field that critically examines the social positionality and potential inequity that survivors of disasters encounter.

A larger body of research in disaster sociology focuses on the concept of vulnerability and how individuals are rendered vulnerable during disasters (Anderson 1991, Cutter 2003, Tierney 2014). Vulnerability perspectives in disaster sociology are centered in political economy and root causes analyses that seek to identify the economic and structural origins of society (Wisner et al. 2004). Enarson, Fothergill, and Peek (2007) assert,

> ...disaster vulnerability cannot be understood outside patriarchy and the historical dynamics of global capitalism and colonialism still shaping the developing world today. Free trade policies that undermine local markets and increase pressures on men to migrate for wage work, for example, leave more women and children impoverished in unsustainable rural environments or displaced to risky urban settlements." (P. 132.)

Disaster scholars focus on vulnerable populations by identifying the conditions or places that make people vulnerable to disasters such as extreme natural events (Cutter 2003). Disaster sociology asserts that vulnerability prior, during and after disasters is a social condition that is reflective of societal values and systems of inequity (Tierney 2014).

In the wake of disasters, government agencies, international aid, and non-governmental organizations all seek to have a stake in the recovery process to help communities or nations return to their pre-disaster state. For communities that were previously under-resourced, their ability to "bounce back" from disasters is more difficult than those communities that have the financial and social capital to rebuild their communities (Aldunce et al. 2014). The concept of bounce back after disasters is centered in theoretical framings of resiliency. Resiliency is rooted in ecology theories that focus on the amount of disturbance that an ecosystem could withstand without changing self-organized processes and structures (Gunderson 2000). Ecological resiliency theories do not account for how social inequities such as colonialism, classism, and racism are ingrained and systemic in society. In this project, I do not solely rely on resiliency frameworks because the original tenets of resiliency presume that everyone has the same ability to bounce back. This would be an erroneous and neoliberal foundation on which to begin my analysis. Resiliency, as discussed in disaster research, also tends to shift the focus from structural analysis to individual-level analysis that focuses on why individuals are not prepared for disasters or hazards.

The role of disaster sociology should be to point to how disasters, specifically during the recovery stage, reinforce structural inequalities in devastated communities (Tierney 2014). Hence, I reject the ecological notions adopted in some disaster research that utilizes simple analytic framing from a dichotomous lens that communities "are" or "are not" resilient. Thus, in addition to disaster sociology, I incorporate concepts including community trauma, biological citizenship, biomedicalization, and health social movements to examine the social lives of Ebola survivors.

Disasters have a unique way of disrupting society to reveal how society functions and who and what is prioritized and valued. After a disaster is over and the focus shifts from the response to recovery, the portrayals of survivorship offer a reflection of core values in society. Epidemics vary from other natural/ecological disasters in that epidemics disrupt how medicine and individual bodies are socialized. A sociology of survivor health after epidemics can help uncover the various ways in which survivors are socially constructed both during and post epidemics. Several social determinants of the 2014-16 Ebola outbreak were quickly discovered to impact Ebola survivors, such as poverty, overcrowded living environments, and a weakened health care infrastructure (Marais et al. 2016; Snyder et al. 2014). In the field of disaster sociology, an examination of survivor health provides an opportunity to look past focusing on the medical understandings of health to understand how social, cultural and economic forces are shaped during recovery stages.

Shaping the Discourse of Survivorship

There are a lack of narratives on the social and economic lives of Ebola survivors, and this is a pattern observed previously in other epidemics (Treichler, 1987, Leach and Scones, 2013). Kenworthy (2017) notes that discourses that fail to account for social inequities are "deeply embedded in cultural beliefs regarding how power and the distribution of resources become embodied" (p 118). Kenworthy (2017) discusses that this is an example of biopolitics that illuminates how the connections between bodies, social harms and political inequities are given meaning. In her analysis of the political consequences for HIV in Lesotho, she explains that there is "…the often myoptic focus on biomedical services at the expense of attention to social needs in HIV programs" (p 118). Furthermore she notes, that "by targeting a biological condition, political and economic concerns are sidelined" (p 118). In public health epidemics discursive practices operate as a form of power wherein scientists, the media and those in power create conditions wherein they control the narrative. In describing how survivor discourse is produced through scientific knowledge production, Patton (2002) shares,

> "The changes that activism force in names and categories—in the discourse through which scientist produced knowledge about the new disease-had direct, rapid and material effects on the lives of those who already had "it"" (p 3).

However, as witnessed in the HIV epidemic, survivors and activists create social movements to shift the modalities of power that are centered in political and scientific knowledge production. Such that HIV activists, as lay experts were able to stake claim in how HIV discourse is shaped throughout the course of the epidemic (Epstein 1995; Patton 2002).

Discourse can also be shaped through media. Here too, the lack of a focus on the social livelihood of survivors can be problematic. Because there is often sharp decline of media coverage after a disaster ends, the original survivor frames produced by the media can have a permanent imprint for the general public (Ribeiro, 2018). For example, if a negative frame is established in the media, the general public might not have access to other narratives in order to create more nuanced meaning-making around survivorship. Moreover, contextual factors (e.g., racism, stigma, economic hardships, food insecurity) that survivors encounter are often missing in the reports by the media (Carpenter 2012; Davis and French 2018; Phillips, 2005, Welch 2007). Critiques of media discourse of survivors of public health epidemics in the Global South, that acknowledge how discourse is rooted in neo-colonial and non-Western hegemonic framings is pertinent (Benton and Dionne 2015, Shome 1996). For the Ebola epidemic, media discourse should acknowledge the pervasiveness of colonialism and later imperialism in lower income countries that were still rebuilding from long wars (e.g., Liberia and Sierra Leone) when the Ebola epidemic began (Jones 2015).

Infectious disease outbreaks will continue to remain as global health threats. Yet, a shift in the framing of survivor health is needed. In doing so, critical global health and neocolonial perspectives of how survivors of represented in global media might foster a better representation of survivor narratives. Critical global health and neo-colonist theorist can challenge the assumptions of survivor discourse in the media in three key areas (1) who writes the stories during and after an outbreak? (2) Who benefits from the discourse presented in these narratives? Furthermore, (3) who is missing from the stories presented? Sociology is uniquely equipped as a discipline to move beyond pathologizing survivor's bodies in order to consider social and structural elements that survivors experience.

From Individualized to Collective Trauma in Post-Disaster Settings

Trauma in the in Post-disaster settings is often conceptualized at the individual level (e.g. mental health, psychological first aid). However, collective trauma also is described as a framing of the collective impacts of trauma. Sociologist Kai Erikson (1976), describes collective trauma as, "blow to the basic tissues of social life that damages the bonds of attaching people together an impairing the prevailing sense of community" (p 194). Collective trauma focuses on the catastrophic event that fragments the basic fabric of society (Hirschberger 2018). Decades of research on collective trauma, primarily emphasizes psychological trauma and threats to social supports in their analyses (Duane et al. 2020) However, what's missing in definitions of collective trauma are examinations of the systems of oppression and structural analysis of crisis that serve as the underbelly to collective trauma. In contrast, structural violence originally conceptualized by sociologist Johan Galtung (1969) conceptualizes that violence can be orchestrated through social structures and institutions to cause harm. Structural violence asserts that violence is institutionalized through "isms" for instance racism, classism, sexism, colonialism to constrain agency among individuals (Farmer 2003, Farmer, 2006). Newer concepts of trauma contend that trauma can also be conceptualized at the community level. Community trauma asserts that trauma or an event experienced by community members has structural and social traumatic outcomes. (Pinderhughes 2015, 2017).

Individual and collective trauma in the aftermath of the 2014-16 West Africa Ebola outbreak has been accounted for in scientific studies. James et al. (James et al. 2017.) conducted a systematic review studies related examining the psychosocial factors that impact Ebola survivors. This analysis suggests that numerous forms of individual (e.g. depression, anxiety, anger, grief, guilt, flashbacks, sadness, worthlessness, substance addiction, suicidal tendencies) and collective trauma (e.g. social isolation stigmatization and discrimination) were present after the Ebola outbreak. Since the 2014-16 West Africa Ebola outbreak, few research studies have been published on the social and economic standings of survivor communities. Yet, the lasting impact of trauma after disasters for survivors is often coupled with their pre-existing inequalities in social conditions (Adams et al. 2011). After the 2004 Hurricane Katrina disaster hit New Orleans, research on post- disaster vulnerability contends that the long-term impacts of disasters included displacement, loss of housing, economic opportunities and reduced social cohesion for the survivors of disasters (Adams et al. 2011; Shultz et al. 2013; Yamout and Chaaya 2011). There is significant evidence that points to how disasters impact survivor livelihood long term and continue to reinforce inequities in regard to social capital, physical health, mental health and their ability to recover (Norris et al 2002, North et al. 1998). Thus, long-term disaster recovery research centered in understandings of community trauma might shed light to how social inequities are operationalized within social institutions.

Survivor Led Health Social Movements

Health social movements are a focus for social scientist interested in how health activism plays a role in defining and finding solutions for health concerns (Brown and Zavestoski 2004). Brown and Zavestoski define social health movements as

> "as collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations, supporters, networks of co-operation and media" (p 679).

Over recent decades health activism emerged among individuals living with an illness, health care professionals and scientists that advocate for better health and science. This is particularly salient for population groups across the world that have historically been marginalized such as indigenous populations, Black and Brown and sexual/gender minorities. Early in the HIV/AIDS epidemic people living with HIV/AIDS advocated for health rights, access to medical treatment, inclusion in scientific research and among basic call to be treated with dignity (Patton 2002). Moreover, survivors of infectious disease epidemics such as HIV/AIDS are crucial as lay experts in contributing to scientific knowledge production (Epstein 1995).

Survivor activism is used to stake claims to rights as biological and disaster citizenship. Biological or medical citizenship is explains how individuals create forms of belonging, claim rights and demands for access to resources and health care based on a biological basis (e.g. illness state, common injury, shared genetic status) (Petryna 2004). The biopolitics of 'survivor's bodies and how biological citizenship is embodied after has been widely theorized and applied in post-Ebola and, more widely, post-disaster research (Berghs, 2016; Petryna, 2004, Richardson et al., 2017). Richardson et al (2017) suggests in Sierra Leone, civil war amputees benefited from biological citizenship as they were able to claim rights to survivor benefits. I assert that Ebola survivors as survivors of an epidemic can claim rights to biological citizenship. Remes (2016) also postulates that citizenship can be claimed through disasters. In understanding how the lived experiences of survivors is shared by the role of the state in the aftermath of disasters, Remes uses to term disaster citizenship. Remes (2016) postulates, "Disasters were moments in which ideas of the state's role in taking care of its citizens changed. As spectacles to both participants and observers, disasters helped reshape politics" (p18). Similarly, Creary (2018), uses the term biocultural citizenship to denote individuals make claims to the state based on their connection to ancestry, race and disease. Thus, in the aftermath of disasters that are varied forms and access to citizenship that survivors advocate against the state to demand claims to care and resources.

Methodological Approaches

Qualitative methods are uniquely positioned to better understand the nuances of survivor health through a critical global health lens. Qualitative research provides a gateway to understanding how and why communities are impacted by social and economic trauma in disaster settings and provide an opportunity to utilize multiple data collection methods (Phillips 2002). Qualitative methods have been employed in other health research studies of West African settings as a method to draw upon local understandings of a phenomenon (Adams 2014, Adams 2012) and have been widely used in health research as a modality to explore meaningful research questions that examine institutional, systemic and social practices (Starks and Trinidad 2007). Moreover, qualitative methods in a critical global health context can be utilized to push away from Global North discourses that project Westernized ideologies of health and illness to the Global South. In contrast to a quantitative assessment, this study provides an opportunity to move away from merely viewing survivors in global settings as statistics, which often limits lived experiences through a positivist and colonial lens. According to Adams (2014),

> Qualitative methods of accompaniment help illuminate forms of marginalized knowledge that not only make visible the political economy of relationship research but also suggest directions for sustainable ways of relating that reflect and promote the interests of broad humanity (pg.1).

Two primary qualitative methods, critical discourse analysis and grounded theory, were used to understand the research questions in this dissertation research. In this section, I briefly describe both research methodologies and how they are applied in this dissertation project.

Critical Discourse Analysis (qualitative method for paper 1)

Theories and methods in discourse analysis address the ways in which public discourse shapes social roles and the ways that identities are enacted (Starks and Trinidad 2007, Chandler, 2002; Lyons 1971; Richie 2012). I use critical discourse analysis (CDA) to understand how Ebola media framings of survivors were constructed after the 2014-16 Ebola epidemic. CDA emerged in the 1970s out of the University of East Anglia, as a response to the lack of attention that sociolinguistics paid to social hierarchy and power. Traditional discourse analysis "involves tracing the historical evolution of language practices and examining how language both shapes and reflects dynamic cultural, social, and political practices" (Starks and Trinidad 2007). Critical discourse analysis, however, takes it a step further by engaging critical theory to examine how language practices are interwoven with power and agency. CDA incorporates the works critical theorists such as the work of Marx, Foucault, Bourdieu, and Gramsci to examine how ideologies and power are interwoven into discourse; essentially this methodology seeks to connect language with the social (Fairclough 1995). Critical discourse analysis aims to:

> "…systematically explore often opaque relationships of causality and determination between (a) discursive practice, events, and text, and (b) wider social-cultural structures, relations, and processes to investigate how such practices, events, and texts arise out of and are ideologically shaped by relations of power and struggles over power; and to explore how the opacity of these relationships between discourse and society is itself a factor securing power and hegemony." (Fairclough, p. 132)

CDA incorporates the concepts of intertextuality and moreover interdiscursivity to understand the historical and social aspects of discourse (Wodak and Meyer 2001). "Intertextual analysis draws attention to the dependence of texts upon society and history in the form of the resources made available within the order of discourse (genres, discourses, etc.)..." (Fairclough, 189). Intertextual analysis can situate how discourse can help shape social and historical sources. An intertextual analysis is crucial to the study as I sought to make a connection between language, social context and how survivors' health agency is historicized after the Ebola outbreak. Similar to intertextuality, interdiscursivity highlights the importance of having a historical viewport in discourse analysis but also provides for an analysis of discursive practice and power concerning hegemony (Gramsci 1971, Fairclough 1995). CDA is used as an analytic modality to provide a more in-depth analysis of specific word combinations (i.e., frames) regarding survivors that are conventionalized in the media over time. I utilize this method to examine how language serves as a nexus for connecting the social and cultural hegemony of the 2014-16 Ebola outbreak as displayed in media discourse (Gramsci 1971). To best understand how survivors' agency is constructed, it is pivotal to examine media as a site and a mechanism of power throughout survivor life course. This analytic process as a way to search for discursive evidence to understand how media undertakes the role of constructing a survivor after an epidemic.

Grounded Theory (Qualitative method for paper 2 and 3)

Social theory was constituted mainly of grand social theories prior to the development of Grounded Theory in the late-20th-century. Developed by Glaser and Strauss (1967), grounded theory is a qualitative design that generates a general explanation or theory of a process or actions which is informed by the participants of the research (Charmaz 2006). Grounded theory, rooted in social constructionists' theory, emerged in the late 20th in the field of sociology and expanded in other social sciences. My research questions and data collection align with the basic tenets of grounded theory, as I collected and analyzed data and simultaneously explore the undeveloped social context of the lived experience of Ebola survivors. According to Charmaz, (2006) fundamental tenets of grounded theory are inclusive of:

> (1) Minimizing preconceived ideas about the research problem and the data, (2) simultaneous data collection and analysis to inform each other, (3) remaining open to varied explanations and understandings of the data, and (4) focusing data analysis to construct middle rage theories (p. 155).

Additionally, I intend to utilize data collected from this research project to inform the development of theoretical frameworks and understandings of the social construction of survivors and their narratives.

As a qualitative approach, grounded theory seeks to move beyond the description of experiences to a unified theoretical explanation. It is not the intent of this study to generate a new theory, but I do intend to use grounded theory as a method to better understand how survivors are socially constructed after the epidemiological gaze has ended. The rise of grounded theory provided a foundation for justifications for conducting inductive qualitative studies (Charmaz 2014). As the social construction of survivors post-Ebola epidemics is an emerging area of interest, grounded theory is a well-suited method to extrapolate the meaning-making of survivorship (López et al 2005).

Grounded theory as a method accounts for emergent themes and can be utilized to understand shared meanings around temporality and location-specific analyses. This was particularly is useful as I studied post-Ebola community trauma in a rural district in Sierra Leone. Grounded theory is used to develop an inductive approach that included member checking emergent categories from qualitative data collection with Ebola survivors and others engaged in the Sierra Leonean post-Ebola epidemic recovery.

Reflexivity and Memoing

Memoing was utilized throughout data collection and analysis processes (Clarke 2006), wherein I wrote ideas, codes, and reflections to help formulate my understandings of the social construction of survivorship. The analytic process of memoing includes reviewing qualitative data and refining categories and codes that will include points of reflectivity into my interaction with the data. As an American researcher trained in Western academic intuitions, I am conscious that my interpretations and ways of conducting science come with a particular set of assumptions. I acknowledge that varying interpretations can be garnered from this analysis of social constructions of survivorship. Where possible, I aimed to gather feedback from the research team in Sierra Leone throughout the data collection and analysis phase. Nevertheless, I am mindful in both data collection and analysis phases of this research, I came with a set of privileges and power that will inevitably bias the ways in which the data is interpreted.

Site Selection and Data Collection for Paper 2 and 3

Qualitative focus groups and interviews were utilized as the primary form of data collection for papers 2 and 3, respectively. I conducted fieldwork in one district in Port Loko, Sierra Leone. Port Loko was selected as a site because, during the 2014-16 Ebola Outbreak, Port Loko witnessed one of the highest rates of Ebola cases and has a high population of Ebola survivors. Additionally, by limiting this study to one district in Sierra Leone, I was able to gain a deeper understanding of the social, economic, and political constraints and opportunities that survivors in this district experience.

Informed Consent

Approval from two institutional review boards (University of California, San Francisco (IRB # 19-27517, and the Sierra Leone Nation Institutional Review Board) was obtained before data collection. Additionally, approval from the local District Health and Management Team in Port Loko was obtained before commencing data collection. All participants provided written or verbal consent before study participation.

Overview of Three Papers

The three-paper option was chosen as the best modality for this dissertation as a I use multiple methods of inquiry to address the aims of the research. In the next section, I will briefly provide detailed information on the background, data collection methods and analytic approach and significance for each paper.

In paper 1, I investigate how discourse and knowledge production of survivorship and survivor health of Ebola survivors are produced. I analyzed print media (n=156) published in the two years after the 2014-16 Ebola epidemic to explain how media frames and portrayals might ultimately influence the ways in which survivor livelihood is characterized. I propose that the framings of disaster survivors such as Ebola survivors has real life implications in how they were viewed, medicalized, and treated after the epidemic.

In paper 2, I aim to explore the lived experience of community trauma and structural inequalities among Ebola survivors post the 2014-16 Ebola outbreak. I conducted 20 semi-structured focus groups with 100 Ebola survivors in Port Loko, Sierra Leone. Participants were identified through a local non-governmental organization in Port Loko, and the Port Loko district Sierra Leone Association for Ebola Survivors (SLEAS). Each focus groups included 5 participants are were conducted with two facilitators and a translator. One of the facilitators is an Ebola survivor who provided significant input on the design and conduction of the focus groups. To better understand how trauma is structured at a community level, questions centered on how institutions such as health care, the biomedical enterprise and Sierra Leonean government as a political system impacts Ebola livelihood.

In paper 3, I aim to describe how survivors were engaged in the health social movements in the post-Ebola recovery period in Sierra Leone as a means to advocate for rights to health care services. I use 20 Ebola survivor focus groups (n=100) and semi-structured interviews (n=15) with individuals engaged in the post-epidemic recovery and Ebola survivor activism in Sierra Leone to contextualize how survivor citizenship was formed in the aftermath of the Ebola outbreak. The historical accounts that led to the litigation of a legal case against Sierra Leone's government, served as a case example of how health activism is used to access to claims afforded by survivors of epidemics.

Ultimately, this dissertation research, aims to explore the sociological implications for survivors of public health epidemics. I propose that critical analyses of survivors' social lives in the aftermath of public health epidemics are needed. As the rest of the world returns to a level of "normalcy" in post-epidemic settings, the survivors of epidemics remain impacted by social inequities.

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Chapter 2: Paper 1. More Than Useful Bodies: Media Discourse of Ebola Survivors in the Aftermath of the 2014-16 Ebola Epidemic

Abstract

The 2014-2016 Ebola epidemic in West Africa is the largest Ebola outbreak recorded in history. The outbreak killed 11,300 people, but 15,000 people primarily in Guinea, Liberia, and Sierra Leone contracted the disease and survived. Public health and disaster science attended to the understanding of Ebola survivors during the height of the Ebola response and recovery phase. However, studies on the social aspects related to survivor's health long after the public health interventions cease are far more limited. Analysis of media discourse of the survivors of the 2014-2016 West Africa Ebola epidemic is missing from scientific literature. Thus, there is a need to systematically examine media discourse, knowledge production of survivorship and health for Ebola survivors. The purpose of this paper is to explore how global media presented narratives of survivorship after the 2014-2016 West Africa Ebola epidemic. Drawing on print media from 2016 to 2018 from three online media databases (e.g., Africa Wide, lexis nexus, US Newstream), this paper uses critical discourse analysis to analyze print articles (n=156). This analysis examined the cultural ideologies that undergird the framings of survivors and how agency and inequality operate to limit an understanding of Ebola survivors. Qualitative coding following critical discourse analysis principles was applied. The results showed that media representations during the recovery phase of the Ebola epidemic omitted recognition of structural determinants of survivor health. Western media, after the Ebola epidemic, gave little attention to the lived experience of survivors. Media discourse commonly focused on the pathology of survivor health, which reinforced a need to surveil Ebola survivors' bodies. Discourses commonly emphasized the utility of 'survivor's bodies through a biomedical lens for scientific knowledge production or the production of novel vaccines. Moreover, limited texts featured or were authored by Ebola survivors themselves. This paper proposes a shift in media discourse about the survivors of public health epidemics. I discuss the need to construct survivor-centered discursive framings that move beyond their contribution to the biomedical research enterprise. This paper uses the 2014-16 West Africa Ebola epidemic as a case study but has broad relevance for post-pandemic survivor narratives, including the current COVID-19 outbreak.

Keywords: Survivorship, Ebola survivors, media, biomedicalization, discourse, COVID-19

Introduction

The 2014-16 West Africa Ebola Epidemic

As the largest Ebola Virus Disease (henceforth "Ebola") outbreak ever recorded, the 2014-16 West Africa Ebola outbreak lasted nearly two years, killed 11,310 people, a death toll higher than all previous Ebola outbreaks combined (CDC 2016). The outbreak began in December 2013 with an initial case in a small village in Guinea. However, by the Summer of 2014, the initial cases of Ebola in West Africa had become an uncontained and widespread epidemic, primarily in Guinea, Liberia, and Sierra Leone. The 2014-16 Ebola outbreak provided a larger number of Ebola survivors that enabled scientists to better understand Ebola sequelae far beyond what was previously known. In previous Ebola outbreaks, the case fatality rate ranged from 25% to 90%, whereas in the 2014-16 Ebola outbreak, about half (50%) of individuals infected with the Ebola virus survived (WHO 2020).

The approximately 15,000 individuals who survived the 2014-16 Ebola epidemic in the West African region continue to experience lasting health, social, and economic consequences. A large number of Ebola survivors experience physical health side effects, including vision problems, blindness, chronic pain, fatigue, among others. Ebola survivors also face adverse mental health conditions, including depression, anxiety, and post-traumatic stress disorder. The communities that experienced the Ebola epidemic in West Africa also "survived" as many communities experienced social and economic hardships, including food insecurity, job loss, and prolonged social stigma (Kelly et al. 2018; Kurainsky and Jollah 2016; Mayrhuber et al 2017).

Much of the world came to understand the 2014-16 West Africa Ebola epidemic through the lens of the media. At the height of the 2014-16 Ebola epidemic, major news outlets worldwide covered the increases in cases, mortality rates and highlighted the few Ebola cases outside of the three countries primarily affected. As cases waned, concerns about the epidemic reaching countries outside of Sierra Leone, Guinea, and Liberia decreased. Ultimately in 2016, the epidemic came to an end and a decline in media coverage followed. As witnessed in other disasters, including hurricanes, terrorist attacks, and epidemics, the media plays a significant role in shaping what was known about the impact of the 2014-16 West Africa epidemic and the short- and long-term implications on the communities affected (Davis and French 2008; Ribeiro et al., 2018; Vasterman et al. 2005). To that end, the survivors of disasters are often forgotten in years after a disaster (Vasterman et al. 2005). Vasterman et al. (2005) describes,

> "Media attention is out of (your own) control for several weeks; you are in the middle of a media hype. Afterwards, you wonder what this media attention meant for the survivors who were suffering from their health problems and who were looking for recognition, and what it meant for their caregivers" (p. 108).

Moreover, there is a gap in what is known about how Ebola survivorship is characterized by the media in post-epidemic periods. This study investigates how survivors were socially constructed in the media, utilizing the 2014-16 West Africa Ebola epidemic as a case example, to explain how discourse shapes knowledge production and lay understandings of survivorship.

Constructing Survivorship in the Media

While often overlooked, media narratives of survivors serve as an essential modality in understanding the societal value of and experiences of survivors of public health epidemics. Media plays a central role in creating the dominant narratives that can ultimately impact marginalized individuals through 'othering'/stigmatization by creating characterizations of survivors of epidemics as risk factors and threats to society (Jones 2011; Washer 2010). This suggests that there are ways in which power and knowledge are situated in epidemic discourse and are vital in the analysis of biopolitics within and beyond and epidemics (Foucault 1980b, Rose 2006; Rose and Novas 2005). To examine, how othering takes shape in the Media, Messner and Solomon (1993), use an inside/outside the frame analysis to examine how journalists choose to create ideological framings of subjects as the dominant storyline while ignoring other frames. An outside the frame analysis is particularly useful in the constructions of survivorship in the media as survivors are typically excluded in the writing of news media. Thus, the media has agency to ignore portions of survivorship that survivors themselves might deem important descriptions of survivor livelihood. As discourse is naturalized and sustained overtime through power relations, determining who gets agency in labeling survivorship is crucial to how survivors are viewed over time (Fairclough 1992).

For the 2014-16 Ebola outbreak, the public outside of the African context primarily came to know the outbreak through Western media. Countries outside of the three primary countries impacted by the Ebola virus generally relied on media forums, including social media, online articles, and television, to learn about Ebola survivors. These forms of media discourse help form public opinions, clarify misinterpretations, and construct stigmatization (Davis and French 2008; Reese 1991, Van Dijk; T. A. 1988). Yet, survivors themselves do typically not construct survivorship in the media. During the 2014-16 Ebola epidemic, the narratives of survivorship were systematically created by journalists, scientists, or public health officials engaged in disaster response and recovery.

The dearth of systematic analyses of the media portrayals that shaped the global understandings of Ebola survivorship after the 2014-16 Ebola epidemic has long-term ramifications for characterizations of survivors. Considerations of survivor discourse create opportunities to understand social needs and medical treatment of survivors and can also influence funding priorities for survivor communities long after the epidemic ends (Davis and French; 2008). Mayrhuber and colleagues (2017) conducted a content analysis of media reporting of Ebola survivors in Liberia and suggested that Ebola survivor media is critical in the reporting of social, economic and health-related difficulties during an infectious disease outbreak. However, the analysis conducted by Mayrhuber et al. (2017) focused on media released during the height of the epidemic and did not include the long-term effects that survivors encounter once the Ebola epidemic had ended. As limited research focuses on media discourse of Ebola survivors survivorship after the epidemiological gaze ends, such an analysis is needed because media characterizations of Ebola survivors provide insights on how knowledge production of survivorship is produced and reproduced overtime.

Media Representations of Survivorship in Public Health Epidemics

Media plays an integral role in shaping public opinions during and after an epidemic. The use of media in global epidemics has become an essential modality from which discursive notions around survivorship are developed (Farmer 1999). The global public outside of the countries where tropical infectious epidemics occur typically gain entrée to the epidemic through media forms such as video, audio, and print. These media modes align with what critical theorists describe of our understandings of how 'risk' and global risk are constructed in post-modern societies (Beck 1992; Beck 2015; Mondragon et al., 2017; Washer 2010). For example, in understanding the social construction of risk, social scientists contend that modernity has brought about a risk-averse society (Beck 1992, Berghes 2016; Leach and Scoones,2013; Oliver-Smith et al. 2017). In the context of the 2014-16 Ebola epidemic, most of the Global North and the international community at large had very little insight into the spread of Ebola during the outbreak. Yet, a sense of panic began to arise as countries feared that Ebola survivors could be a continued source of viral transmission (Mondragon et al. 2017).

The history of survivor discourses during a public health crisis suggests that the media plays a central role in how the general public comes to understand survivors of public health epidemics. In the early periods of other epidemics including HIV/AIDS, SARS, Zika, and more recently the COVID-19 pandemic, media produced discourse centered on core themes including ' 'survivor's long term sequelae, and stigmatization (Hosey and Needham 2020; Netherland and Hansen, 2016; Ribeiro et al. 2018; Treichler 1987; Washer 2004). For example, in examining the early discourse of the HIV/AIDS epidemic, Treichler points to how the social construction of those impacted by AIDS was not based on objective or scientifically determined reality, but rather these social constructions are "routinely produced within the discourses of biomedical science" (1987, pg. 265). Early in the HIV/AIDS epidemic the media framed gay men as “carriers” of HIV/AIDS (Patton 2002). During the Crack epidemic in the U.S in the 1980s and 1990s, Black women were stereotyped in the media as welfare mothers, ‘Jezebel’ and undeserving of care (Carpenter 2012). Importantly, there is a stark contrast in the characterization of primarily Black individuals who used crack in the late 20th century vs. overwhelmingly White opioid users during the opioid epidemic in the early 21st century (Hansen 2016, Om 2018). Opioid users have been humanized and the government response was to provide drug treatment services. In comparison to crack users were criminalized for their use of drugs (Rhodes 2019). Other media portrayals of public health outbreaks and the survivors of these outbreaks use terminology of going to war or "battle' with the disease. A media analysis of the Zika outbreak in Brazil revealed that major news outlets framed the Zika epidemic as war and placed the burden of the Zika response on women while neglecting to highlight social and gender inequalities (Ribeiro et al., 2018).

Discursive formations produce how were come to understand how agency is shaped for survivors of epidemics. Although, the scientific community has known about the Ebola virus since the 1970s, the 2014-16 Ebola outbreak, produced a proliferation of scientific knowledge production on Ebola survivorship (Richardson 2020). In the HIV/AIDS epidemic, survivor discourses of individuals living with HIV/AIDS shifted narratives of "carrier" and the use of stigmatizing language to current discursive practices of "people living with HIV." These discursive changes were led by HIV activists who offered critical perspectives and fought back on stigmatizing language used (Patton 2002). Additionally, media often ignores those who are in marginalized positions which serves as mechanism to limit agency of oppressed groups. In previous infectious disease outbreaks (e.g., SARS, Zika, and HIV/AIDS), and more recently in the COVID-19 pandemic (Bagcchi, 2020; Benton, 2020; Kapiriri; Ross, 2020), a 'politics of 'blame' arises whereby the responsibility or blame of the outbreak are placed upon marginalized groups. Dry and Leach (2010) denote,

> "This kind of narrative reflects the politics of blame, which typically attributes responsibility for the sources of the outbreak to a cultural minority group and neglects the influence of colonialism and the social determinants of health, including overcrowding, poor sanitation, and poverty that increase the people's vulnerability: (pg. 34).

Additionally, across prior public health epidemics, survivors often experience varying levels of stigma that impact their livelihood (Bagcchi, 2020; Baldassarre et al., 2020; Kapiriri and Ross, 2020, Sangaramoorthy et al., 2017).

The cautionary messages central across infectious disease outbreaks suggest that survivors are risky bodies, shaping the social constructions of survivorship discourse. At the height of the 2014-16 Ebola epidemic, the sense of panic across the globe incited a collective fear that the Ebola epidemic was not only a Western African concern but also a global threat (Mondragon et al., 2017). In recent outbreaks, there has been an escalation in border patrol, airport and seaport screenings for infectious disease, with increasing concerns of pathogens as a threat to global health security, individuals who are carriers of infectious diseases are viewed as a threat to national security. While previous smaller Ebola outbreaks have gone relatively unnoticed in the Global North, globalization and mass transportation creates an interconnected world wherein infectious diseases can more quickly become pandemics. Because survivors were viewed as a source for infection, the 2014-16 Ebola epidemic was a precursor to the COVID-19 pandemic in how survivors of global pandemics are perceived.

Survivorship after the Epidemic and the Epidemiological Gaze

Between 2014-16, thousands of news articles around the globe were written about the epidemic, the people it impacted, and its potential spread. As the epidemic declined in 2015, global media became less engaged in reporting the 2014-16 Ebola epidemic. Media fatigue is witnessed in other epidemics as well; in a world wherein there is a constant news cycle of varying crises, it is not atypical for a news story to fade to the background once it is no longer of interest to those who develop media content and portrayals. For example, the Ebola epidemic in the Democratic Republic of Congo began in August 2018 and was rarely mentioned in global media as cases waned. Similarly, in the recent Zika epidemic (2015) as the epidemic declined, stories focused on the epidemic, and those that survived the epidemic faded (Ribeiro et al., 2018). While media fatigue can partially be attributed to the current state of rapid news cycles in the media, social scientists who play an integral role in understanding social aspects of epidemics attribute this to the epidemiological gaze (Bell, 2013). The epidemiological gaze theorizes how epidemiology and, more widely, biomedicine serves as a knowledge production entity through its emphases on counts, trends, and patterns to describe an epidemic (Lugwig and Weinstein, 2005; Bell, 2013). The epidemiological gaze is rooted in epidemiology, which serves as the disciplinary foundation of public health research on epidemics.

The need for the social aspects of epidemics to expand beyond the epidemiological gaze is a central component of deemphasizing the biomedicalization of survivorship (Bell, 2013). I use the epidemiological gaze as a temporal framing to understand how knowledge production of survivorship is constructed after an epidemic ends within media discourse. The epidemiological gaze as a phenomenon can categorize and pathologize populations into sub-groups such as race, class, gender, etc. (Dworkin, 2005, Shim, 2014) and plays a role in when the media shifts its focus to and from epidemics. For the purpose, of this analysis, I focus on how the shifts in media content to focus on the social constructions of survivorship and not solely the quantity of media produced.

As the media primarily focuses on infection rates, deaths, and mitigations of infectious diseases, there is a need to conduct analyses that center on the social aspects of survivorship. Social scientists highlight that in previous Ebola outbreaks, epidemiological models significantly contributed to the gaze placed upon the epidemic itself and that these models should be understood as having social and political lives (Leach and Scoones, 2013). Furthermore, this data-driven gaze can shape the hierarchies of knowledge production on zoonotic epidemics, but also has the potential to shape policy actions (Leach and Scoones, 2013).

The epidemiological gaze extends beyond the disease itself to impact health status, quality of life, quality of care, and policy (Leach and Scoones, 2013; Robertson and Williams, 2017). As an epidemic ends or begins to trend downward, there is less of a need to produce media coverage on the survivors of the epidemic. There is a gap in Ebola survivor analyses that examines the role that media discourse played in shaping the lived experiences of Ebola survivorship after the 2014-16 West Africa Ebola outbreak. This is problematic because during an epidemic because the primary focus is on survivor sequalae which often obscures the role of social and economic factors like stigma, migration, poverty in understanding the lived experience of survivors as witnessed in the 2014-16 Ebola epidemic (Patton 2002). The purpose of this paper seeks to address two main research questions:

1. How does the media characterize Ebola survivorship after the 2014-16 West Africa Ebola epidemic?
2. How is Ebola survivor agency constructed through media discourse?

Methods

Sample Identification

Three online media databases (Africa Wide Information, Lexis Nexis, and U.S. News Stream) were used to collect archival media using the search terms: Ebola survivor and Ebola survivorship. The three online news databases provided comprehensive coverage of news media across various outlets and regions. The analysis was limited to news sources– because I am interested in public media perception, scholarly journal articles, reports, grey literature, and other print media were not included. I also limited the search to print media– therefore, T.V., radio, social media, and other modes of media (e.g., blogs) were not included in this study. The media analyzed were between March 2016 to March 2018, as this period includes the month after the Ebola epidemic officially ended and two years post the epidemic, as the research is concerned with perceptions of survivors after in post epidemic periods. Only media in English were included.

A total of 156 print articles were utilized in this analysis. Three articles were initially pulled from Africa Worldwide, but none of these media articles met the inclusion criteria. One hundred seventy-six (n=176) articles were retrieved from U.S Newstream, and 43 were included in the analysis. Five hundred twenty-three (n=523) articles were retrieved from Lexis Nexis and 113, were included in the final analysis. Most articles retrieved were from major news outlets, including the Gaurdian, Al Jazerra, and the Washington Post.

Once queried, I exported the data into an excel database for cleaning. Articles were removed that did not specifically focus on Ebola survivors or when Ebola survivors were not the main focus of the article. A preliminary review of results indicates that Lexis Nexis and U.S. Newstream retrieved duplicate data; thus, duplicate articles were removed. If the articles were peer-reviewed or did not include substantive text related to Ebola survivors, these results were removed from the analysis for not meeting inclusion criteria.

After the initial review of articles (e.g., for duplication and topic alignment), all remaining text was transferred to NVivo 12 for analysis. Initial open coding was conducted for the framings of survivor health and survivorship. I conducted line by line qualitative coding by applying codes that emerged from the media text to create a codebook of broad coding categories. I used general coding categories to generate discourse strands, which were eventually developed overarching thematic findings. Once a set of discourse strands were created, I coded the text for structural features, meaning that I reviewed the argument that was being presented while using an intertextual analysis—a property of Critical Discourse Analysis (CDA) (Fairclough, N, 1995).

Data Analysis

This paper draws upon (CDA) to understand how Ebola survivors were depicted, and thus how the public/global perception was socially constructed, after the 2014-16 Ebola epidemic. CDA emerged in the 1970s out of the University of East Anglia because of the lack of attention that sociolinguistics paid to social hierarchy and power. Discourse analysis is a tool in social science scholarship to better understand how power and agency are situated through discourse. Words as a communication tool can persuade, inform, and uncover social phenomena (Reed, 2013, Reese, 1991). While traditional discourse analysis "involves tracing the historical evolution of language practices and examining how language both shapes and reflects dynamic cultural, social, and political practices" (Starks and Trinidad, 2007). Critical discourse analysis takes it a step further by engaging critical theory to examine how language practices are interwoven with power and agency. Critical discourse analysis aims to:

> "systematically explore often opaque relationships of causality and determination between (a) discursive practice, events, and text, and (b) wider social-cultural structures, relations, and processes to investigate how such practices, events, and texts arise out of and are ideologically shaped by relations of power and struggles over power; and to explore how the opacity of these relationships between discourse and society is itself a factor securing power and hegemony." (Fairclough, pg. 132)

I utilized CDA concepts of intertextuality and interdiscursivity to understand the historical and social aspects of discourse (Wodak and Meyer, 2001). Intertextual analysis can situate how discourse can help shape social and historical resources.

To better understand how survivors are characterized, 'survivor's voices are included in the analysis of the production of survivor discourse. In this way, this paper examines media as both a site and as a mechanism of power. This analytic process is a way to search for discursive evidence to understand how media undertakes their role of constructing a survivor narrative after an epidemic. This can include the local and global economy, policies, gender norms, and food insecurity, among other aspects. I then used an interpretive approach of "form-and meaning" analysis (Fairclough, 1995), wherein I accentuated the interdependent relationship of text with respective social domains to emergent codes in order to create media frames.

Throughout the development of themes, I intentionally identified how the role of survivor agency is constructed through the use of language. For example, in some instances, the words' victim' and survivor' are used interchangeably. Thus, in the coding and analyzing the data, if the text used the word survivor compared to victims, I explored how the language after the term ''survivor'' was described to construct claims of agency and authority (Starks and Trinidad, 2007).

Results

Three main themes emerged that represent the universal portrayals of survivorship prominent in the media after the 2014-16 Ebola outbreak. The most prominent include presenting Ebola survivorship by pathologizing survivor's bodies, such that illness frames that depicted Ebola survivors as risky bodies. Ebola survivors were represented as carriers (this parallels other epidemics-please see other literature for use of the media term “carrier”) of the Ebola virus to emphasize their potential to spread the virus. Second, central discourses in the media centered on the utility of survivors' bodies in the biomedical research enterprise or as their contribution to biomedicalization as biomedical capital. Lastly, survivor agency was rarely included in the media coverage of Ebola survivors, particularly in terms of what lived experience is like after an epidemic. Table 1. Provides a description of each theme, intended audience, how survivor agency is constructed and the frequencies of the findings.

Table 2.1: Description of Definition of Frames, Survivor Portrayal, Survivor Agency and Frequencies

Survivor Framing	Pathologizing Ebola Survivorship	Survivors as Biomedical Capital	Inclusion/Exclusion of Survivors and Survivor Voices in Global Health Media
Frame Defined	Discusses survivors as objective beings to construct the pathology of the Ebola virus in the body and the need for surveillance	Discusses survivors as their role scientific knowledge production, participation in vaccination trials or utility for the development of vaccines. Explains that Ebola survivors bodies are useful to the biomedical research enterprise	Discuses more nuanced perspectives of survivor health beyond the reporting of scientific studies or medicalization of Ebola survivors
Survivor Portrayal	As biological determinants, as pathogenic agents that might continue the spread of Ebola	As an object of the biomedical enterprise and biological capital	Portrayed Ebola survivorship as challenging
Primary Audience	Public health professionals, general public, biomedicine	General public, public health, biomedicine	Public health professionals, general public
Frequency	82% (n=127/156)	56% (n=87/156)	6% (n=7/156)

Theme 1: Pathologizing Ebola Survivorship

Much of the media in this analysis created a narrative that described survivorship as referenced through a biomedical lens, most commonly known as the Post-Ebola virus syndrome. Post-Ebola virus syndrome discourse centered on the collection of symptoms that individuals who have recovered from the Ebola virus experience. This emphasis on the biological effects of the Ebola virus produces narratives of 'pathologizing survivorship' to promote the need to surveillance or monitor bodies deemed as unhealthy and potentially infectious over time. The Post-Ebola virus syndrome, presented in the media, includes medical symptoms such as joint and muscle pain, eye problems (e.g., blindness), neurological problems, and fatigue. Some of the major headlines included language such as "Ebola's Legacy: Children with cataracts," or "Ebola leaves survivors with debilitating reminders like blindness, epilepsy," and "Progress Towards Protection from Highly Lethal Ebola, Marburg Viruses." These headlines highlight that there were significant medical challenges that Ebola survivors encountered, yet only a few of the print articles found discussed survivor livelihood beyond physical health ailments.

Table 2.2: Sample Media Headlines of Pathologizing Bodies of Ebola Survivors

Date	**Source**	**Headline Title**
2016	Scientific Daily	Progress Towards Protection From Highly Lethal Ebola, Marburg Viruses
2016	Scientific American	Why Ebola Survivors Struggle With New Symptoms from Liberia
2016	Front Page Africa Online	Liberia Female Ebola Survivors Counseled On Breast Feeding
2016	The New Dawn	PREVAIL Launches New Study In Male Ebola Survivors
2016	The Times (London)	Traces Of Ebola Virus Linger Longer Than Expected In Semen
2016	Dallas News	Ebola Leaves Survivors With Debilitating Reminders Like Blindness, Epilepsy
2017	New York Times	Ebola's Legacy: Children With Cataracts
2017	Live Science	Ebola May Linger in Men's Semen For More Than 2 Years
2017	The Washington Post	Ebola Virus Found Hiding In Lungs Of Health-Care Worker

While it might appear standard that the media would detail the Post-Ebola syndrome sequelae of survivors, I contend that this discourse might serve as a means to further a narrative that 'survivors' bodies needed surveillance overtime because survivors were viewed as potential threats to a broader population. For example, various media articles highlighted the length of time that the Ebola virus lingers in the semen of male survivors. Here an author questions, "But exactly how long does the virus linger in reservoirs in the body — and for how long can it be transmitted?" The subset of the media that attended to how the Ebola virus remains in semen for prolonged times, and have an overt narrative that there is a need for ongoing monitoring and surveillance of 'risky bodies." I interpret that the intention of the media to include language such as 'risky 'bodies' to serve as a means to describe the prolonged risk that Ebola survivors maintained even after the outbreak ended. Thus, years after the Ebola outbreak began, Ebola survivor's bodies were still being monitored to examine the possible sexual transmission of the virus. For example, this article discusses that viral load within semen and that sexual transmission can still occur.

> "Survivors suffer from neurological pains and aches, which doctors are still trying to understand. In some, the Ebola viral load is still found in semen, so the virus is also sexually transmitted. Three years after the deadly outbreak, the virus continues to affect people's lives." Al Jazeera, 2017

Sub-Theme I: Survivors as Immune Hideouts.

The persistence of the Ebola virus in the body was also described through terms such as "Immune Hideouts." Authors used terms such as immune hideouts to describe how the Ebola virus remains in the body in the immediate aftermath of the epidemic and how the science was unclear on the duration that the virus remains in the body. However, this narrative of the Ebola virus "hiding" in the bodies of Ebola survivors suggests that survivors were a potential threat to the general population, given that the Ebola virus is spread through human bodily fluids such as breast milk, semen, or in the uterus during pregnancy. For example, the media disseminated a discourse that Ebola survivor bodies could potentially be the cause of future transmission chains of the Ebola virus and should be monitored over time.

> "the uterus may be another sanctuary site for Ebola, offering the virus a safe place to hide." This article later goes on to describe 'Women's Ebola survivors bodies as "tragedy in the womb" when describing a Liberian 'woman's who child was lost during childbirth. (Scientific American, 2016).

This author went on to question if the child was stillborn because of the Ebola virus or because no one was willing to help her during the birthing process due to the stigma of being an Ebola survivor. The discourse that suggests that surveilling of Ebola 'survivors' bodies is justified and feeds into a narrative that some bodies are "risky bodies." Some media used terms like "lurk" "to insinuate how 'survivor's bodies might be deceptive in hiding the Ebola virus to suggest that there is a need for continuous surveillance of Ebola survivor’s bodies.

> "Even after Ebola disappears from the blood of a survivor, it can lurk elsewhere in the body. Tissues such as the testes, brain, breasts and joint spaces offer the virus a sanctuary from the immune system." – The Dallas Morning News, 2016

Again, an author described that,

> "…when talking about the woman who contracted Ebola from a survivor. That the virus can persist after many symptoms stop—even after a ' 'patient's blood appears clear-- makes him anxious for two reasons: If Ebola hides out in people who seem healthy, only to reappear from compartments deep within the body to make them sick and potentially contagious, it could spark more outbreaks".- Scientific American, 2016

Discourse employed by the media after the 2014-16 Ebola outbreak contextualizes how the bodies and moreover the health of survivors is negatively characterized (e.g. "hideout', 'seem 'healthy'). Moreover, the narrative of risky bodies of survivors has the potential to create false narratives and stigmatize survivors as the source of future outbreaks.

When the media describes Ebola survivor health, the discourse primarily focuses on the long term medical consequences. By primarily focusing on pathology narratives, this language has the ability to create a sense of 'othering' or stigma that shapes Ebola survivor's bodies as biologically different. In contrast, less than 10% media in this analysis describe stigma, economic and social factors that survivors experience. One such article describes that the unknown length of time that the Ebola virus remains in the body might prolong survivor stigma within their communities. "For many survivors, the physical manifestations of the disease have been compounded by the stigma encountered with their return to their communities." (Live Science, 2017)

Sub-theme II. The Social and Economic Consequences of Survivor Health.

While much of the studies spoke to the physical health or contributions to increased scientific knowledge, a subset of the media discussed the social or economic aspects of survivorship, such as stigmatization, survivor economic challenges and corruption. Specifically, four articles spoke to the challenges of survivors in Sierra Leone who have organized through a survivor association and are seeking social, economic support from the government and the legal disputes on how funding for the right to health will be provided.

Ebola survivors were known to experience stigma during the outbreak, but journalist point to how Ebola survivors experienced stigmatization after the outbreak as well.

> "People have been rejected by their families, by their friends. Everyone is afraid of Ebola and they still see them as the one who had Ebola, or infected someone else. It is really disruptive for society, what Ebola has done." Ottawa Citizen- 2016

Furthermore, Ebola survivors encountered social challenges that created long term disruptions for everyday livelihood and well-being.

> "We are seeing a lot of people who are doing great and are making a way," Kauffeldt said. "But there are still a lot of people that are falling through the cracks." Los Angeles Times, 2018

Another example discussed how the livelihood of Ebola survivors extends beyond their physical health and also is coupled political, economic, and social factors.

> "Some Ebola survivors in Sierra Leone say the local authorities have failed them. Officials promised survivors free healthcare, help with food and shelter, psychosocial support and some financial compensation, according to local news reports. Surviving health workers reportedly were promised they would receive up to $5,000 in compensation from the government." –NPR, 2017

However, three articles described potential financial corruption that took place during the outbreak that impacted survivors or how survivor legal litigation was needed to compensate survivors for any corruption that might have taken place. One source noted,

> "They had over 3000 ghost workers within three months of Ebola. What kind of heartless people can be stealing money that was sent to them to save lives? And they gave fake contracts to buy ambulances that did not work. About four months ago, the International Red Cross in Sierra Leone came out with a report that from them alone,

> $2.3 million was stolen. So you look at that as heartless. Your people are dying, and you are stealing money. And you are not paying the nurses. Even now, the Ebola survivors are complaining that they have not received some of their benefits." Daily Trust, 2018.

The dominant narrative in this theme described that Ebola survivors should be surveilled as there was a potential for re-transmission of the Ebola virus. The media focused on the pathological manifestations of post-Ebola sequalae. Ebola survivors bodies were presented as harbors of the Ebola virus. Of the media print analyzed, only four articles discussed the legal challenges or economic factors of survivors as the sole focus of the article. Meaning that while some articles might have mentioned stigma or economic factors in their article, the primary focus of the article was typically either focused on the physical health of survivors or some other area of biomedical contribution.

Theme 2: Survivors as Biomedical Capital

The utility of survivor's bodies as a vehicle to increase scientific knowledge production was a central theme in media after the 2014-16 Ebola epidemic. The media highlighted how survivor's bodies were useful in understanding the sequelae of the Ebola virus, but also how survivors contributed to expanding scientific knowledge. Eight articles pointed to how survivors were useful in Ebola vaccine research. For example, one media emphasized the usefulness of survivor's bodies to increases understanding of the sequelae of the Ebola virus by stating,

> "This time, said Scott, "There are 5,000 survivors or thereabouts in Sierra Leone and more in Guinea and Liberia. So, it's an opportunity from a research point of view to find out the full spectrum of sequelae ... the things that happen after an acute illness."

This excerpt framed survivors in an opportunistic frame to increase scientific knowledge of the full sequelae of the Ebola virus. These discourses propose that 'survivors' bodies can be a form of biomedical capital. Consequently, Ebola survivors are presented as useful bodies to increase biomedical knowledge production. Here an author discusses the large number of Ebola survivors that will be included in a study in Liberia:

> "Large-scale studies into the health of Ebola survivors had not been conducted. Until now. Last summer, the first of its kind Ebola survivor study was launched in Liberia. So far, 1,111 people who were infected with Ebola and 2,604 of their friends and family members have enrolled in the study." (Dallas News, 2016)

In these portrayals of survivors, the increase in the number of individuals enrolled in biomedical studies is characterized as a positive attribute because larger sample sizes in clinical trials often provide an increased likelihood of statistically significant differences in a study. The media included in this analysis provides evidence that Ebola survivors are encouraged to participate in medical treatment efforts, vaccines, or clinical trials.

Another article suggests,

> "Mr. Cooper explained that female Ebola survivors are encouraged to enroll in the birth cohort, virginal swipe and breast milk testing sub medical studies as this was necessary to find a lasting treatment/medical solution to their post-Ebola health complications which include persistent headache, body pains, joints pains, weakness and unstoppable erection in male survivors, and miscarriage in female. He, at the same time, admonished male Ebola survivors to enroll in the other sub-studies like semen collection/testing, eye testing and neurology (brain and nervous system). " (Frontpage Africa Online, 2016)

These narratives depict that after the epidemic ended, there was an urge to describe the urgency in studying 'survivor's bodies to increase scientific discovery through the use of clinical trials and cohort studies over time. The excerpt below describes that an Ebola survivor study in Liberia would last five years and would include not only Ebola survivors but also others in their community like friends and family members.

> "Since the Ebola survivor study was launched in Liberia last June, more than a thousand of the 'country's 1,500 Ebola survivors have agreed to take part. Their health will be monitored at semiannual checkups for five years. Each survivor is asked to bring four friends or relatives to one of the 'study's three sites. These are

> people with whom the patients have close contact but who were not infected with Ebola. Fallah says he hopes to enroll 6,000 close contacts who will serve as controls, helping researchers separate the health problems that are part of post-Ebola syndrome from the those experienced by the general population in Liberia." (Scientific medicine, 2017)

These texts provide insights into the value that the news media ascribed to survivorship and the embodied health of Ebola survivors. In this theme, survivorship is repeatedly conflated with its contribution to the increase of medical knowledge or the use of Ebola survivor's bodies to further research endeavors. During and after the 2014-16 Ebola outbreak, survivor's encounters with biomedicine and biomedical technologies (e.x. vaccination trials) did not account for the historical, social, and political conditions that contribute to the construction of disaster citizenship (Remes, 2016). The discourse formed in the media after the outbreak highlight the role of survivor utilization in scientific studies, but family members and close contacts are also discussed in their participation in control groups in order to advance scientific knowledge. However, survivor health discourse might be portrayed differently, if survivors were constructing the narrative.

Theme 3: Inclusion/Exclusion of Survivors and Survivor Voices in Global Health Media

The last theme that emerged was based on codes on who authored media articles of Ebola survivors and how frequently articles included survivor perspectives. This analysis revealed no such cases wherein survivors were the primary author (s) of global media. Over 90% of news media did not include survivor’s voices (e.g. interviews or quotes in their stories). In the instances (n=7) wherein survivors were interviewed, or quotes were survivors were included in the articles, survivors were able to share their lived experiences on how they were coping as Ebola survivors. In one such article entitled "The Forgotten Ebola Survivors of Sierra Leone" included quotes from survivors such as "But they have forgotten us ... and many are still really suffering."

Here a survivor is able to express that they are concerned that they will be forgotten globally by the general public a year after the Ebola outbreak. Yet, Ebola survivors are still experiencing health and social consequences. Another survivor in this article articulated,

> "There are some [who] have had miscarriages. There are the joint pains. Some of them are not walking properly. Some became deaf. Some are blind, others are partially blind. There are many health complications." (NPR, 2017)

Again, the Ebola survivor in this piece suggests that there are post-Ebola syndrome symptoms persist for Ebola survivors. A 2016 news article from The Guardian, described the painful legacy of Ebola survivors in Sierra Leone, who were promised free health care and social support from the previous President. An Ebola survivor and volunteer who worked with the Sierra Leone Association of Ebola Survivors is quoted as saying, "We have not yet received free medicine, and we don't want to be forgotten." In this article an Ebola survivor describes her economic challenges post-the Ebola outbreak as she struggles to pay for the medicine.

Media that include Ebola survivors or direct quotes from survivors were able to create contextualized framings the lived experience of survivor health. In comparison, the framing of news media that did not include survivors voices, are less likely to discuss the social and economic livelihood of Ebola survivors. Moreover, the when survivors’ voices are not included in stories, descriptions of post-Ebola syndrome are used to discussed how public health needs to continue to monitor Ebola survivors and are framed from an epidemiological lens. Additionally, stories that did include survivors were more likely to report quantitative scientific findings with the primary purpose to increase scientific knowledge of Ebola survivor health. The authors of these studies were primarily scientific or health journalists.

The exclusion of survivor narratives, suggest that journalist provided poor coverage of the inclusion of survivor voices in their stories. Alternatively, journalist might have deliberately omitted survivors' voices. As most journalist reported from the Europe or the United states outlets, they might have had limited access to Ebola survivors. This analysis did not include local news outlets in Guinea, Liberia and Sierra Leone thus local outlets might have included more first-hand accounts from survivors in their reporting. There is a lack of systematic analysis on the production of survivorship discourse in the aftermath of the 2014-16 West Africa Ebola epidemic. However, understandings of knowledge production of Ebola survivors might inform how survivors of other epidemics will be portrayed, including COVID-19 pandemic survivors.

Discussion

The portrayals of Ebola survivorship in the aftermath of the 2014-16 Ebola epidemic provide a distinct framing that is highly Westernized, medicalized, and is lacking in the lived experiences of Ebola survivors. Media included in this analysis primarily highlighted that Ebola survivors were potential threats to continued spread of the Ebola virus as carriers. Ebola survivors bodies were also discussed for their contributions to the scientific biomedical enterprise. To this end, Ebola survivors were framed as biocapital, and useful to scientific knowledge production. Importantly, this analysis did not include any media wherein Ebola survivors served as an author. This exclusion of survivors as agents of their own narrative creates unequal representations of Ebola survivor livelihood, through the eyes of non-Ebola survivors.

Public health and the biomedical research enterprise serve as the central governing agents to pathologizing and ascribing meaning to survivors during and after a public health crisis

(Greussing & Boomgaarden 2017). Unfortunately, the media constructed discourses that portrayed Ebola survivors as being deceptive disease carriers. These framings reinforce that Ebola survivors are risky agents that should be surveillanced (Berghs 2016). Moreover, because Ebola survivors were described framed as “risky” the media insinuated that there is a need to continue to monitor Ebola survivors. Thus, even years after the outbreak, media reinforces the need for surveillance which ultimately leads to the stigmatization of survivor's bodies as risky bodies (Mahajan, A. et al 2008). The monitoring of bodies "deemed as 'risky' creates an environment wherein individuals are reduced to subjects that should be governed through public health surveillance. Surveillance medicine as practiced in public health creates an environment wherein ' 'survivor's bodies can be monitored and regulated under the presumption that there is an increasing need to produce knowledge about the Ebola virus might spread (Armstrong 1995). However, these types of narratives have the ability to increase survivor stigma as survivors are blamed for their role in the disaster (Davis and French 2008; Kurainsky and Jollah 2016). The othering that occurs during an epidemic has long-lasting physical, psychological and social consequences for survivor's communities during recovery periods as well (Mondragon 2017; Kurainsky and Jollah 2016). This creates an unequal power dynamic wherein journalist create a frame that can potentially marginalize Ebola survivors. While the language used to describe Ebola survivors was likely intended to simply describe the pathology of post-Ebola syndrome there are embedded meanings in media discourse create unequal power structures for Ebola survivors.

Media coverage emphasized the biomedical contributions of survivors in the post-epidemic phase. The intention of these reports was to inform the public and scientific community on scientific discoveries of post-Ebola sequalae. However, biomedicalization literature suggests that there is a complex and multidirectional process wherein biomedical discourse has the ability to constructed meanings that reinforce technoscientific narratives (Briggs and Halin 2016; Clarke et al., 2003, 2010, Bell 2013; Enria and Lees 2018). In this analysis, survivors were presented as a form of biocapital. Rajan (2006) discusses that "biocapital" as a concept to describes how modern systems of capitalism and the emergence of scientific endeavors are coproduced within the political economy. This discourse analysis, suggests the potential expansion of Ebola survivor knowledge production was viewed as benefit to the biomedical community. Biomedicine was able to produce an Ebola vaccine in the aftermath of the 2014-16 Ebola epidemic. Pharmaceutical companies through global health efforts were later able vaccinate thousands of individuals in West Africa and in a recent Ebola outbreaks in the 2018-2020 Ebola outbreak in the Democratic Republic of Congo and most recently in 2021 as re-emerged in Guinea, West Africa. Media discourse suggests that health challenges in the Global South can be fixed through modern biomedical advances that are not widespread in the Global South (Amin 1973; Rajan 2006).

Social constructions of survivors through discourse– and Ebola survivors in particular – can take many forms (Mayrhuber 2017). One possible narrative centers the perspective of survivors and documents their lived experience beyond its contributions as biomedical agents. Public health discourse is contextualized by the intersection of political economy, social identities, and personal narratives, alongside epidemiological data to provide a holistic account of survivor experiences. In describing the relationship between biosocial survivorship, vaccines, and biosecure citizenship of the 2014-16 Ebola epidemic, Berghs (2016) noted that "Those same discourses of containment and biosocial risks are now being used in relation to people who have survived Ebola but have disabling symptoms (p 275)." Indeed while many scientific advancements post 2014-16, Ebola epidemic were witnessed such as survivors' antibodies being used for vaccinations, the media included in this analysis appears to neglect the importance of the survivor's livelihood. Therefore, when the media renders survivors as advancements in biomedicine, this limits their personhood to merely scientific endeavors (Berghs 2016).

Survivor's experiences as lay experts are rendered invisible in this media analysis. However, the HIV/AIDS epidemics has proven that individuals living with a disease can serve as useful contributors in biomedical advancement (Epstein 1995; Patton 2002; Rajan 2006). In the case of the HIV/AIDS epidemic, individuals living with HIV/AIDS created health movements that challenged the biomedical research enterprise, pharmaceutical companies, and Government to include them as lay experts in the scientific development process. Because there was a prominent discourse by the media biomedical advancement is valued, media on Ebola survivor activism might be a way to increase the production of Ebola survivors as scientific experts in the production of survivor health discourse.

Media coverage provided little room for survivor agency in the shaping Ebola survivor health discourse. The media provided specific narratives around Ebola survivors after the epidemic ended that were predominantly from the U.S. and European news outlets, who appear to have little to no experience with actual encounters of the individuals that chose to portray in the media. Historically, Ebola as a disease has been characterized as exotic and linked with non-Western practices resulting from traditional and local customs (Amin 1973; Césaire 1972, Joffe and Haarhoff 2002; Jones 2015). Therefore the framings of 'survivor's bodies, by those in the

Global North have potential to exert imperialism and neo-colonialist perceptions of Ebola survivors as abnormal. Biomedicine, public health, and humanitarian programs all benefit from showing Ebola survivors as different from the general population. While accounting for the medical conditions that 'survivor's experience is one form of documenting the long term livelihood during the recovery period, solely pathologizing Ebola 'survivor's bodies based on the physical manifestations fails to take into account the full experience that Ebola survivors encounter. The dominant narrative in the media I analyzed was produced by those with the power to name, scrutinize, and limit survivorship discourse. Furthermore, and perhaps just as concerning, is that once a narrative is established, there is no exact route to disrupt, renegotiate, or dismantle the discourse that is constructed (Treichler 1987). As observed other public health epidemics, Ebola survivors lacked agency in the development of the narratives portrayed in the media (Washer 2004; Washer 2006; Ribeiro et al. 2018).

Limitations

This study is subject to several limitations. First, this analysis did not include the word victim as a search term in retrieving online print articles. However, the focus of this analysis was to assess the social constructions of survivorship and how the media constructs share meaning. Moreover, the term victim inclusion might contradict connotations and entry points for analysis from the term survivor, which Ebola survivors adopted as a preferred early in the 2014-16 West Africa Epidemic. Secondly, this analysis only used print media and did not include other media such as radio, TV or social media. Third, this analysis did not include local print media from the three most impacted countries in the 2014-16 Ebola Epidemic as they were not widely available in public databases.

Implications

The media, public health and scientists alike must continue to critically assess the dominant discourse ascribed to Ebola survivorship by examining the cultural assumptions underlying media narratives and asking questions about how media produces, constructs and normalizes the discourse? And who is served by this discourse? The portrayals of Ebola survivors' lived experiences (or lack thereof) might be an example of the Global North's abandonment of the historical and intergenerational trauma instituted in West Africa through imperialism as a means to increase biocapital (Rajan, 2006; Shome, 1996). Ebola survivors in this analysis questioned if they would be forgotten. Yet, the biomedical contributions that Ebola survivors provided to the biomedical research enterprise continues to serve as a profit making entity (e.g. vaccinations, biomedical research) Ethically, in global health as a field should judiciously question how Ebola survivors will be credited for their contribution to biomedicine? To this end, Biehl and Petryna (2013) asserts,

> "Epistemological breakthroughs do not belong to experts and analysts alone. The unpredictable and cumulative experiences of people navigating health and humanitarian interventions and their aftermaths can also produce breakthroughs that demand recognition"(p. 11).

While 2016 marked the end of the largest Ebola outbreak, the legacy of the outbreak continued to live on for Ebola survivors and their communities during the epidemic's long-term recovery phase. The media maintained power in the social construction of discourses during the recovery phase. The media serves as an intermediary between the population and other systems such as the government, academic institutions. Thus, discourses presented in the media after an epidemic serve as a powerful entity in shaping social constructions of Ebola survivorship, which might influence the political, economic and social livelihood of survivors after the epidemic.

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Chapter 3: Paper 2. Beyond Surviving: Ebola Survivor Narratives of Survivorship, Community Trauma and Biological Citizenship in the Recovery Phase of the 2014-16 West Africa Ebola Epidemic

Abstract

After the 2014-16 West Africa Ebola Epidemic ended, nearly 5,000 Ebola survivors remained in Sierra Leone and encountered varying long-term social, economic and health consequences. Conducted four years after the 2014-16 West Africa Ebola epidemic ended in Sierra Leone, this research examines the social lives of Ebola survivors in the post-epidemic recovery period. Most Ebola survivors' studies focus on post Ebola sequalae and find that Ebola survivors experienced long term physical and mental health illness at an individual level. Few studies examine how structural factors including post disaster programing and aid intersect with Ebola survivor health. Building on collective trauma frameworks, this study aims to use survivor illness narratives to explain how social and structural factors such as community connectedness, access to economic opportunities, and health services contribute to survivor livelihood. To examine the long-term social implications of Ebola survivorship, 20 focus groups were conducted with Ebola Survivors (n=100) in Port Loko, Sierra Leone. Ebola survivors (< 18 over) representing10 villages were recruited through a community-based Ebola survivor advocacy group. An inductive qualitative analysis using Grounded Theory was applied to identify themes. Results showed that Ebola survivors experienced benefits and challenges in gaining access to economic resources and health care services after foreign aid was discontinued in Sierra Leone. Ebola survivors experienced varying forms of stigma that impacted their economic opportunities and created social cohesion barriers within their community. Additionally, these findings highlight how public health and biomedical research during the disaster recovery phase can serve as sites for

structural violence for survivors of epidemics, as Ebola survivors were used to increase bio capitalism within global health research. Moreover, Ebola survivors lacked power in decision-making processes to guide post-disaster relief research and programming. This study suggests a need for survivor-centered and trauma-informed recovery programs and research during post-epidemic settings.

Introduction

The largest EVD outbreak, to date, occurred in West Africa from 2014 to 2016. There were over 28,000 cases and 11,000 deaths, a death toll higher than all previous Ebola outbreaks combined (CDC, 2016). The initial response to the epidemic is viewed as a public health failure because the public health care system lacked adequate PPE, medical personnel or a public health infrastructure (e.g. notification systems, testing and laboratory equipment, data systems) and densely populated urban areas created difficulties in containing the Ebola epidemic (Benton and Dionne 2015; Biehl 2016; Dzingirai et al. 2017; Richardson et al. 2016; Wilkinson and Leach 2015). Notably, while the outbreak accounted for a high number of deaths, the 2014-16 West Africa Ebola epidemic also recorded the largest number of Ebola survivors and any Ebola epidemic to date. In Sierra Leone alone, it is estimated that there are 4,000-5,000 Ebola survivors. Collectively, known as post-Ebola sequalae, Ebola survivors experience a range of severe to acute and long term physical symptoms including arthralgia, headache, ocular symptoms, fatigue and back pain) and mental health illnesses such as anxiety, depression, posttraumatic stress disorder, suicidal ideation (Fowler, Mishra, and Chan 2016; James et al. 2017; LötschFelix et al. 2017; Shantha et al. 2016; Tiffany et al. 2016).

While the long-term pathological effects of the Ebola virus have been widely examined, most public health and biomedicine research ignores the long-term social and structural impacts of Ebola survivorship (Richardson, 2020; Richardson et al., 2016). Despite the substantial increase in epidemiological research on Ebola survivor health, few studies about survivor livelihood draw upon and center survivor narratives. Moreover, survivorship research in public health is rarely survivor-led. It is typically disseminated through academic, governmental, and non-governmental research. Thus, this research explores survivor health through a social and structural lens by engaging with narratives of Ebola survivors in Sierra Leone.

After the 2014-16 West Africa Ebola outbreak, the recovery period centered around addressing Ebola survivorship by addressing the long-term health and social needs of Ebola survivors. In Sierra Leone, public health researchers conducted studies to investigate post-Ebola sequelae and monitor the potential for continued transmission of the virus through Ebola survivors. The Ebola virus is known to endure in immunoprotective sites such as semen, breastmilk, eyes, and within the central nervous system for more than several years. (Gibrilla et al. 2017; Gibrilla et al. 2017; James et al, 2020; Thorson et al., 2016; Thorson et al. 2021). Recent findings from a cohort study of 120 men in Port Loko, District Sierra Leone, indicate that the Ebola virus persistence in semen was a frequent occurrence, with high population rates over time (Thorson et al. 2021). Post-epidemic research in Sierra Leone documented that survivors were encouraged to engage in individual risk reduction behavioral practices by enrolling Ebola survivors in studies that utilize counseling protocols (Abad et al. 2017). Other studies in Sierra Leone, such as the Ebola Virus Disease Survivor Clinic in Port Loko, Sierra Leone, provided clinical care for most survivors (n=603 of 661 documented survivors) while also continuing to monitor the clinical sequelae of participants (Mattia et al. 2016). Mattia et al. (2016) found that 76% of Ebola survivors experience joint pain (arthralgia), 60% experienced eye (ocular) symptoms, while fewer survivors experienced and auditory (24%) symptoms. Overwhelmingly, the studies conducted in Sierra Leone on Ebola survivor health in the post-epidemic phase were epidemiological studies focusing on pathology or tracing transmission points among survivors

(Gibrilla Fadlu et al. 2017; SokaMoses J et al. 2016; Thorson et al. 2021; Thorson et al. 2016; Uyeki et al. 2016).

The structural determinants that lead to the devastation of the 2014-16 West Africa Ebola outbreak have been theorized. A weakened health care system, global politics, structural adjustment policies, and the historical legacy of colonization all serve as contributing factors (Benton and Dionne 2015; Cancedda Corrado et al. 2016; M'bayo 2018; Richardson et al. 2016). Meanwhile, the social and structural barriers that contribute to and impede post-epidemic recovery, specifically for Ebola survivors during the recovery period, are sparse. There is a need to understand the economic, political and historical factors constructing survivorship after the 2014-16 Ebola West Ebola epidemic. Survivors encounter unique challenges after an epidemic, including long-term health consequences complicated by post-disaster humanitarian aid and longer-term global health programming (Kargillis, Gillham, and Kako 2014). Moreover, it's been documented that Ebola survivors encountered challenges that contribute to their livelihoods, such as stigma (Kuriansky 2016; SowS, Desclaux, and Taverne 2016), food insecurity (Kelly et al. 2018), and loss of employment (James et al. 2019).

One instance where politics and Ebola survivor health collide is in gaining access to health care in Sierra Leone After the West Africa Pandemic. Towards the end of the outbreak, the Sierra Leonean government created the Comprehensive Program for Ebola Survivors (CPES) in November 2015 to provide health care provisions for Ebola survivors. The then President Ernest Bai Koroma modeled CPES after Sierra Leone's free health care for pregnant women and children under five. CPES operated under the Ministry of Health and Ministry of Social Welfare and aimed to utilize funds from international donors to non-governmental organizations to provide health and social services to Ebola survivors. Alva et al. (2020) suggest that CPES had long-term impacts in Sierra Leone that increased access to health care services and contributed to lower levels of disability for Ebola survivors. However, in 2017 the program ended, leaving thousands of Ebola survivors without needed health care services. In 2018, Ebola survivors through the Sierra Leone Association of Ebola Survivors (SLEAS) and Center for Accountability and Rule of Law (CARL) began legal proceedings against the Sierra Leonean government to access health care services previously promised by the Sierra Leonean government. Notably, a 2015 audit revealed nearly one-third of Ebola funds in Sierra Leone were unaccounted for during the outbreak. This case suggests that the alleged financial corruption and dependence on foreign aid left Ebola survivors without health care services. Sierra Leone's Ebola survivor health care plan ultimately was at the hands of the Global North's willingness to support long-term survivor care. Thus, while historically, countries like Great Britain, even after colonization, continue to benefit from the removal of natural resources from countries like Sierra Leone even, they also continue to under develop African countries through the provision of global aid (Ndlovu-Gatsheni 2018).

Biological citizenship, Biocapital and Biomedicalization Shape Survivor Health

Health care policies such as CPES have significant implications on survivor health and also help shape how rights to survivor benefits are accounted for in the aftermath of a disaster (Petryna 2004; Remes 2015). After the Chernobyl disaster in Northern Ukranian, Petryna (2004) used the term biological citizenship to describe the interwoven nature of how survivor communities claim rights to and demand access to resources based on biological disease state. Biological citizenship highlights how collective benefit entitlements made by a biologically damaged population of survivors are applied as citizenship rights (Cooter 2008). Remes (2015) builds upon the concept of survivors' citizenship rights through disaster citizenship; in his examination of a fire in Halifax, Canada and an explosion in Salem, Massachusetts. Disaster Citizenship analyzes the responses of individuals, families, neighbors and formal organizations to a disaster and how these relationships are shaped by the state (Remes, 2015). Biological and disaster citizenship is applicable to Ebola survivors in Sierra Leone. Ebola survivors are an example of biological citizenship whose experience in gaining access to health care and livelihood in the Post-Ebola period is complicated by the under-resourcing of health care and alleged governmental corruption. Whereas, disaster citizenship posits that compromises, negotiations and contentions after disasters creates a citizenship resisted and used by the state (Remes, 2016). Biological and disaster citizenship for Ebola survivors is rooted in neoliberal global health policies and informed by historical colonialism that creates health inequities (Benton and Dionne 2015; Berghs 2016).

Another way to examine the social constructions of Ebola survivorship is through the concept of biocaptial. Biocapital is widely theorized in science and technology studies to pinpoint how the contemporary linking of capitalism and biotechnology contributes to the social inequities deployed through scientific means. Biocaptial is a major theoretical contribution in examining the afterlives of Ebola survivors in the aftermath of disasters (Helmreich 2008; Petryna and Follis 2015; Rajan 2006; Remes 2015). In defining biocapital, Helmreich (2008) explains,

> “Scholarship in the social and cultural study of biology has suggested that in the age of biotechnology, when the substances and promises of biological materials, sought to theorize the contemporary join of capitalism and biotechnology, particularly stem cells and genomes, are increasingly inserted into projects of product making and profit-seeking, we are witnessing the rise of a novel kind of capital: biocapital” (463-4).

Biocapital is deployed in the Global South through genomic and biomedical research which creates opportunities for biotechnology to serve as an agent of globalization. Through Marxist theories and Foucault's biopolitics, Rajan (2006) suggests that biotechnology shapes economic and epistemic values in the Global South. Thus, applications of biocapital claim that the biomedical enterprise is interested in the Global South because of capitalistic gain derived from research and technological advancements.

Social constructions and knowledge production of Ebola survivorship can also be analyzed through biomedicalization (Clarke et al. 2003). Biomedicalization asserts that the "bio" in biomedicalization creates multidirectional processes that intensify medicalization in new and complex ways (Clarke et al. 2003). This is witnessed in the aftermath of the Ebola outbreak as Ebola survivors are used in epidemiological and biomedical research to reconfigure and expand scientific knowledge production (Richardson, 2020). The inclusion of Ebola survivors in human clinical trials was foundational to the substantial increase in Ebola scientific studies during and after the 2014-16 West Africa Ebola epidemic, ultimately leading to the development of Ebola vaccines, increased science in Ebola transmission and Post-Ebola sequalae (Feldmann, Feldmann, and Marzi 2018; Natesan et al. 2016; Thorson et al. 2021). The interdependent relationship between profit-driven entities (e.g., biomedical enterprise, universities) and scientific advancement created a social environment wherein Ebola survivors were used for profit-making and medical improvements.

Ebola Survivorship through a Collective and Community Trauma Lens

Collective trauma for survivors of disasters has been theorized by social scientists as shocks to the bonds that create a community (Duane et al. 20200611; Ganzevoort 2001; Hirschberger 2018; Thompson 2018). Sociologist Kai Erikson (1976) examines the destruction to community bonds in the Buffalo Creek Flood and discusses how collective trauma is shaped in the aftermath of disasters. Erikson (1976) describes,

> "by collective trauma, on the other hand, I mean a blow to the basic tissues of social life that damages the bonds attaching people together and impairs the prevailing sense of communality. The collective trauma works its way slowly and even insidiously into the awareness of those who suffer from it, so it…[is] a gradual realization that the community no longer exists as an effective source of support and that an important part of the self has disappeared…" (p 153-154)

Thus, there is a history of defining how trauma impacts communities of individuals to elicit collective trauma in the aftermath of disasters.

While conceptually trauma studies originated at the individual level, trauma can be analyzed at a collective level as well. In examining how sexual abuse survivors experience trauma at micro and meso levels, Veermaan and Gansevoort (2001) use cultural psychological analyses to underscore that individual-level trauma can be conceptualized at a collective level. For survivors of the HIV/AIDS epidemic, collective trauma in the form of intersectional stigma- (e.g. the concept that multiple stigmatized identities within a person or group overlap and are co-constructed) provides a framing to understand how the interaction of multiple forms stigma produces structural inequities in health outcomes (Sangaramoorthy, Jamison, and Dyer 2017). Sangaramoorthy and colleagues (2017) describe how intersectional stigma is common among midlife and older Black women living with HIV/AIDS whereby stigma is experienced at interpersonal levels and at the community, institutional and structural levels. Their research describes that at a community level, stigmatization occurred for Black women who experienced community silence due to HIV stigma. Whereas institutional and structural stigmatizations operated within health care settings as Black women were viewed as drug users or assumed to have multiple sex partners. Yet, much of the literature on collective trauma continues to emphasize the psychological impacts of trauma.

I propose that post-disaster trauma operates at a community level, such that economic policies including disaster capitalism, denial of survivor benefits and the introduction of biomedicalization in post-epidemic Sierra Leone produced varying forms of community trauma for Ebola survivors (Adams, Van Hattum, and English 2009; Clarke et al. 2003; Klein 2007; Petryna 2004). For this analysis, I operationalize community trauma in post-disaster settings as the disruptions to social and economic institutions within and across communities rooted in social inequities. In the U.S. context, Pinderhughes, Davis and Williams (2015) describe that

> "The symptoms of community trauma are the product of decades of economic, political and social isolation, a lack of investment in the built environment, the loss of social capital with the flight of middle class families, and the concentration of poverty and exposures to high levels of violence" (p 14)

I assert that community trauma serves as a threat to community re-building in post-disaster settings in the Global South. A community trauma lens is the entry point to understanding how structural violence materializes for survivors after disasters (Adams et al. 2009; Galtung 1969; Richardson et al. 2017). Therefore, this research aims to address the following research questions:

(1) How do Ebola survivors describe experiences of community trauma in the post-epidemic phase?

(2) How can Ebola survivor narratives contribute to the analysis of survivorship beyond pathological and epidemiological framings of survivor health?

Methods

Study Design and Recruitment

To gather a multitude of perspectives while centering survivor's voices, this study employs focus groups to gather a range of perspectives on survivor livelihood (Krueger and Morgan, 1993). As much of the literature on Ebola survivor livelihood incorporates quantitative, methods (e.g. survey research, clinical studies), focus groups provide rich data to understand the multifaceted nature of survivorship. Twenty semi-structured focus groups with Ebola survivors (n=100) were conducted in March-April 2020 in Port Loko District, Sierra Leone, to explore post-epidemic community trauma factors (e.g., stigmatization, access to economic and health care resources, survivor research engagement) experienced after the 2014-16 Ebola epidemic. This focus group research aimed to provide a survivor engaged approach understand Ebola survivors' lived experiences post-epidemic. A local Sierra Leone Ebola Survivors (SLEAS) network organization and a local non-governmental organization- Collective Initiative for Development (CFID), that works with Ebola survivor communities, recruited participants. Both organizations served as partners in this research study in the recruitment, data collection and analysis phases. Participants were initially contacted in person by CFID. They were requested to participate in community meetings to assess interest and potential participation in the study. Community interests meetings were held in each village by the research team (Myself, SLEAS Port Loko, CFID) in January-March 2020. Participants were selected across all age categories (age 18 and over) and genders (male/female) to gather a diverse perspective of Ebola survivor livelihood. The research used a convenience sample of participants who self-identified as Ebola survivors. At each meeting, the research team members shared the purpose of the research, described the research design, and answered questions about how findings would be utilized.

Community interest meetings were held with each community two times before beginning the study to facilitate a shared understanding of the research process and address any concerns. Focus groups were held in a central community center in Port Loko town to provide a confidential space for Ebola survivors to discuss sensitive topics such as stigmatization outside of their community. Focus group methods provided an opportunity for ideas to emerge through interaction among participants, however, focus groups pose some limitations including participant concerns in sharing sensitive information and moving beyond normative. I aimed to minimize these weaknesses by including facilitators who are also survivors and by limiting the size of the groups so that all members were allowed to share their views.

Study Participants

Ebola survivors were from 10 communities (villages) representing 7 Chiefdoms in Port Loko district to provide a diversity of respondents and post-Ebola survivor experiences. This research study sought to recruit Ebola survivors across the age span and with equal representations of gender. Villages for recruitment were identified by SLEAS and the primary investigator, using local knowledge on villages with larger numbers of Ebola survivors and high EVD cases during the 2014-16 epidemic. This study's inclusion criteria were being an Ebola survivor (self-identified) who lived in Port Loko district and over age 18.

Development of Focus Group Instrument

Prior to commencing the study, two pilot focus groups were held with ten Ebola survivors who provided feedback on the research process, interview guide development, format and wording of questions. The primary investigator developed the first draft of the semi-structured focus group protocol, then shared the guide for review with the research team. Ebola survivor feedback and recommendations were incorporated into the initial guide before data collection.

Ebola survivors provided feedback on the location for focus groups, the focus group's length, and the main topics discussed. This iterative process provided a mechanism to incorporate Ebola survivor and local perspectives into the interview guide development and inform the study process, strengthening the data collection and enabling participation in the governance of the study. The pilot focus groups were also used to provide facilitator training on the focus group protocol, consent process and to discuss focus group procedures before commencing the study. The primary research domains covered in the focus group guide were: community resources and economy, health care access and Ebola survivor health status, and social support and stigma.

Data Collection

Focus groups lasted approximately 90 minutes and were conducted in the local languages of Temne or Sierra Leonean Krio (both languages were used interchangeably at times), as these dialects are most widely spoken with the survivors' communities. Verbal and written consent for participation, including the study's purpose, was obtained in local languages. Participants received $100,000.00 Sierra Leones (SLL) (USD= $10) for participation in the study. Focus groups were facilitated by the primary investigator, a trained local translator and Ebola survivor advocate in the community, an Ebola Survivor, and a note-taker, who made up the research team. The research study began before the COVID-19 pandemic was declared an international emergency and before there were known cases within Sierra Leone. After the early focus groups, initial COVID-19 cases were reported in the capital of Freetown, Sierra Leone. However, several changes were made to the study design to accommodate COVID-19 safety measures. First, focus groups were reduced from ten participants to five for each group. The focus groups were slightly smaller than recommended size of six to eight participants (Kreuger and Casey, 2000). The focus groups were relocated to a community center that provided adequate space for social distancing (each participant was seated 6 feet apart) with access to ventilation. As the primary investigator could not travel to Sierra Leone due to travel restrictions, she participated in focus groups through Skype. Each session was audio-recorded and professionally transcribed into English by a local transcriptionist from Port Loko district, familiar with the local dialect. All data were de-identified through the transcription process before data analysis.

After two consecutive focus groups were held, the research team would debrief the sessions to discuss any concerns about the research process or adjust the focus group guide. The primary investigator reviewed the focus group notes and developed analytic memos following Grounded Theory data collection practices. The post-focus group meetings were essential in soliciting feedback on the research process, interviewing questions, and discussing additional constructs that should be explored in the interview guide. The University of California, San Francisco (UCSF) Institutional Review Board and the Sierra Leone Office of Ethics and Scientific Review Committee Research Ethics Committee approved this study (IRB: 19-27517). This research was also reviewed by the Port Loko Department of Health Management Team and District Council before commencement.

Data Analysis

Constructivist grounded theory methodology (Charmaz 2014) was utilized as a guiding framework in this analysis. As a qualitative methodology for data collection and analysis, grounded theory enabled a rich exploration of survivor experiences through a critical global health lens. I collected and analyzed data through an interactive inductive approach. This process entailed collecting focus group data, reviewing recordings and notes, holding discussions with SLEAS and the research team and adjusting the research questions. I used Qualitative software

(NVivo version 12.0) to identify emergent themes in the data. Focus group transcripts were entered into NVivo software for data analysis. Line-by-line open or 'initial' coding was applied as a first step to carefully examine survivor narratives. Next, I refined codes before proceeding with a focused coding. I then developed analytic categories to develop the descriptions of factors that impact survivorship and identified exemplary quotes. The analytic process of memoing was used throughout the data collection and analysis phase to refine categories and codes. Memos were also used to engage in a reflective process to examine my own positions of power and bias as an American researcher. Lastly, I employed member checking throughout the data analysis phase to provide Ebola survivors opportunities to verify and assess the themes developed.

Results

Twenty focus groups were conducted (n=100), with 57 women and 43 men. All study participants were 18 or older with a median age of 36 (range 21-80 years old) and self-identified as Ebola survivors (see Table 1). Survivors were represented from 10 villages across 7 chiefdoms in Port Loko, Sierra Leone. Overall, Ebola survivors shared narratives that highlighted the ongoing legacies of collective and community trauma four years after the 2014-16 West Africa Ebola Epidemic. The findings presented are framed in two time periods. Survivors reflected that some community trauma experiences occurred earlier in the post-recovery period, such as social stigma (e.g., Spring 2016-2018). Challenges that occurred later in the post-disaster phase (e.g., 2019-2020) included access to economic opportunities and access to survivor medical care benefits. To provide a temporal framing to the concept of "long-term recovery" in post-disaster settings, survivors were asked to share the period in which their experiences occurred. Participants were asked to “think back” to establish a context to the responses provided (Kruger and Casey, 2000). I situate this analysis from a temporal standpoint as there are implications for individual needs and highlight how structurally global health and humanitarian aid fail to adequately address the long-term social determinants of survivor health. Additionally, events' timing is critical to analyzing how community trauma varied over time and is connected to how disaster and global health aid are deployed. Three overarching themes and sub-themes emerged that center on how disaster recovery processes can serve as a site of structural violence for Ebola survivors in Sierra Leone.

Theme 1. "We don't feel fine because they promised": Entrée into Survivorship Challenges and During Disaster Recovery

Ebola survivors shared narratives for how access and declines to economic opportunities impacted their livelihood in the years after the 2014-16 Ebola outbreak. Ebola survivors described how resources came from international post-disaster aid programs in Port Loko for two to three years post-epidemic. Recovery programs provided money, food, access to medication programs, business startup programs, and community infrastructure projects (e.g., water pumps). Post-disaster aid programs commenced near the end of the epidemic (late 2015/early 2016) and ended in late 2018 and early 2019. Survivors shared that to their knowledge, resources were directly distributed within survivor communities. Importantly, Ebola survivors shared a mixture of sentiments about the post-Ebola period in Sierra Leone. These sentiments range from contentment with the benefits received as Ebola survivors to disappointments that not all economic resources and community rebuilding projects materialized.

Subtheme 1: “When programs came to an end then it became difficult for us”: Pitfalls of Disaster Funding.

Survivors expressed concerns for post-disaster promises of survivor services and resources that did not come to fruition. In the aftermath of the Ebola epidemic, survivors explained that they expected long-term community resources, including access to job skills, money, and housing. Survivor concerns about community resources being discontinued stemmed from interactions with humanitarian/development aid and public health programs that promised to provide continued resources to Ebola survivor communities. Survivors expressed disappointment with organizations working with communities because they failed to address the long-term challenges of Ebola survivorship. One survivor explained,

> "We don't feel fine because they promised to give us money and we will build houses and other things and if these things don't happen and they didn't call us to tell us we just sit down with hopes. Sometimes if they said they will give you; you will go and take a debt. And in the community, when they called you in meeting, some of them will think they have given you big money and you don't want to say it." (Male, 31)

This example highlights that the participant was disappointed because they anticipated receiving additional survivor benefits after the Ebola outbreak. Participants emphasized that they later became disenchanted that Ebola survivorship would equate to the greater economic potential for their long-term livelihood. Through engagement with international organizations, some thought they would have structural benefits such as long-term health care, housing, continued skill-building and housing. They anticipated that they would continue to learn new skills and have access to Ebola-specific structural resources for survivor livelihood. Survivor benefits such as food or medication for Post-Ebola sequalae only addressed temporary needs. They were not sustainable to address the long-term financial or health needs of Ebola survivors.

Another survivorship challenge is that Ebola survivors were viewed as having access to resources (e.g., money, skill-building programs) unavailable to non-Ebola survivors. The previous quote introduces reflects resentment among non-Ebola survivors. Thus, the status of an Ebola survivor provided entrée into community aid that was unattainable to others. Additionally, survivor aid created a potential opportunity to access resources previously unavailable to communities in remote and rural areas of Port Loko, Sierra Leone, such as community centers with computers. Ebola survivors expressed that access to international aid could modernize (e.g., computers, internet) Port Loko's rural areas. A participant reflected on their community's experience with an international aid agency,

> "They promised us a lot of things and some of them fulfilled, really. But the other thing I think I am in doubt [because] they don't fulfill, because they said we will learn computer, although yes, we learn but they said we will form our own center. And they will bring a lot of thing[s] where some of us will learn tailoring, some will learn gara tie dying, some will learn welding, but as time goes by we saw some go in different places, with the hope that we will have a center. They help us but the center they would have built, the did not build it. So, that I think they were not able to fulfill." (Female, 29)

Participants described that international organizations promised to provide a central place where they would have access to improve life skills and trade programs; however, some of these promises were never fulfilled over time. For example, some survivors did receive skill building such as gara (cloth) tie-dying. Survivors also lamented that access to the anticipated health care was only available for a limited period post-epidemic. This disappointment was echoed by an Ebola survivor,

> "Well, initially, when it ended, at that moment it was not too hard, because the government made it mandatory that as long as you are a survivor, the facility is free for you. So, to be honest it was not too hard. Except when programs came to an end then it became difficult for us." (Male, 27)

The lack of access to free health care services after CPES ended meant that some Ebola survivors faced difficulty accessing needed health care services.

Subtheme 2: "They tried to improve on our livelihood as survivors": Survivor Benefit Programs.

Notably, post-pandemic programs were viewed as positive for Ebola survivors. Ebola survivors expressed an appreciation for international agencies that created employment opportunities and infrastructure building projects in local villages. Furthermore, Ebola survivors highlighted that community development programs provided income for women Ebola survivors, such as Gara tie dyeing programs. One survivor shared,

> "First and foremost, like [international agency], really they played a great role, because when they employed us, some of us have built houses, and two, even as [non-governmental agency] when they came, they gave us money, and we could say Alhamdulillah's!! It is better. Because what they have done, and some of us those money, as of to date, our wives are still doing that business with us. And three, even [international agency] as well, all that they have been supplying us, the foams [mattresses] they gave us, today, we are still using those resources. Because we sleep on them and even our wives and children use them to lie down." (Male, 30)

Participants shared that immediately after the outbreak, resources were available to Ebola survivor communities. Resources such as mattresses and household supplies were still being utilized some four years after the outbreak. Thus, having an Ebola survivor's status did come with benefits to both the Ebola survivors and their immediate families. In addition to monetary resources, Ebola-specific programs were created to provide food (e.g., bags of rice, seeds, water) and medical services to address the impacts of the Ebola epidemic for survivors. One survivor described, "They tried to improve on our livelihood as survivors, provided us with medication and food. As a lot of us were traumatized, and some were feeling dizziness and asymptomatic with some ailment.“ Two international aid organizations were repeatedly mentioned as sources of survivor medical and social services for two to three years after the outbreak.

Survivors were asked to share their experiences in how recovery agencies addressed survivor health. A survivor shared that they were providing health services “for our eyes by taking us to eye clinics and provided us with treatment. And part of the treatment we were given food and transportation to and from the health center.” This survivor's account highlights how health services and social services were linked. Over time, these resources waned as funding for post-disaster aid ended. At the time of this data collection, Ebola survivors were no longer receiving the Ebola benefits that were once provided to them, leaving survivors without functional services. Some survivors were aware that survivor services would not? continue long term. However, they also reflected on other survivor beneficiaries from the Sierra Leone Civil War (1991-2002), wherein war amputees were provided with care in the post-disaster phase. A survivor reflected,

> "For some of us know it would not last for long term taking into consideration of what happen after the end of the civil war. But many believe it will last for long and we would get similar benefits received by war wounded (amputee). They constructed houses for them, other opportunities given to them." (Male, 35)

Survivors acknowledged that biological citizenship created opportunities to access international funded health care services and humanitarian aid resources in the immediate aftermath of the epidemic. However, compared to other disasters such as the Sierra Leonean civil war, long-term aid was not considered a right of Ebola survivor citizenship.

Theme 2. "Yes, they are afraid of us:" Social Stigma and Community Resources

Ebola survivors were asked to reflect upon any experiences of stigma after the 2014-16 Ebola Outbreak ended. Respondents provided narratives is not only individually mediated through personal discrimination but also impacts social cohesion in their community and survivor economic livelihood. These forms of community trauma operate at a community and structural level such that trauma impacts financial systems, and social capital among survivors. Though survivors did describe that eventually, experiences of discrimination declined over time, these experiences stuck with them and were a prominent topic in focus groups. In general, survivors faced stigma within their villages, households, and social segregation from neighboring communities. This section describes general perceptions of stigma and two subthemes related to economic disadvantages and the weathering effect that stigma caused on social cohesion in the immediate aftermath of the Ebola epidemic. "Ebola stigma" became a common term used during the nearly three years of the 2014-16 Ebola epidemic in Sierra Leone. The focus group participants were familiar with the term "stigma" and how the discrimination because of their status as an Ebola survivor shaped their livelihood after the Ebola outbreak. And while experiences of Ebola stigmatization declined over time, the remnants of Ebola stigma in the four years after the Ebola epidemic were still salient amongst Ebola survivors at the time of data collection.

Ebola survivors clearly detailed how community members were afraid to be in their presence and how community members expressed concerns about having Ebola survivors welcomed within their community. Focus group participants spoke to not being allowed back into their homes, experiencing verbal discriminatory remarks from community members, and feeling a general unwelcomeness in public settings. One survivor described a painful experience not being let back into their family home,

> "On my return, I visited my initial residence where I lost my parents. but my uncle restricted me from entering the house because he is not convinced that I have recovered from the virus…. And I said I am confident that I have recovered after been admitted in the treatment center. But he did not believe me and insisted that I should not enter the house…" (Female, 30)

Survivors were asked to compare how their interactions were with community members prior to and after the Ebola outbreak. One survivor expressed,

> “Well anyway, when Ebola hasn’t come yet, we find out that, although we had half-half problems like malaria, cholera and others, that makes the community not fine, but it was fine when there was no outbreak, you will notice that, there is unity, there is unity, then you could see commitment to people. And we were all the same. We do not have anything like stigma or any other thing. So, the community was fine.” (Male, 34)

Here, the survivor shares how the stigma associated with Ebola contrasts with other infectious diseases such as malaria and cholera. Other infectious diseases might not be stigmatizing in Sierra Leone because they are common diseases. Alternatively, malaria and cholera are not spread from human to human contact and survivors were blamed for spreading the Ebola virus during the pandemic. Survivors repeatedly described that there was unity or closeness within their communities before the outbreak. However, after contracting the Ebola virus, they felt ostracized from their communities. Ebola survivors were aware that community members feared that they might serve as spreaders of the Ebola virus even after the epidemic ended. Survivors were often asked questions about where they were coming from, as this participant explained:

> "And I was asked several questions from people passing by, whether I am a citizen of Port Loko or I came from Makeni. The people were also scared and staring at me when they noticed that I am a survivor. They are afraid that their children might got infected with the virus when they come close or touch me…. So, they all decided not to come close or touch me. I was in this state of stigmatization when I'd a help from our sisters and who relieved me from these pains and struggle." (Female, 27)

To address Ebola stigmatization, survivors received support from other Ebola survivors, government interventions, and public health organizations that provided Ebola survivor resources and support groups after the epidemic. In describing the support of international aid organizations, one survivor acknowledged, "one of the organizations that first came to our aid as survivors to rescue us from stigmatization we are going through is [international agency]," While another survivor shared, "Well, its normal. Previously, there was separation. But through Government's intervention, there was a great awareness, and people start thinking that we are all the same." (Male, 32). Survivors described the discrimination they encountered as a source of trauma. Some discrimination was reported at an interpersonal level, but across survivors these experiences suggest that bias towards Ebola survivors impacted their ability to connect with family and that Ebola survivors experienced declines in employment and trading across villages. Having access to community programs provided outlets to discuss Ebola stigmatization in the immediate aftermath of the epidemic. Government and international agencies invested in de-stigmatization programs through community mobilization, communication campaigns and Ebola survivor support groups. The survivors in this study appreciated these efforts. Cumulatively, survivors noted that these efforts created an environment in the post-disaster phase, improved the environment for Ebola survivors and enabled them to remain socially connected within their communities.

When asked about the persistence of Ebola stigmatization over the years, Ebola survivors acknowledged that their discrimination experiences waned over time. While not all participants shared narratives of Ebola stigma, for those who did experience discrimination, most shared that they were being treated fairly within their communities at the time of data collection. Most Ebola survivors described that stigmatization primarily occurred during and in the immediate aftermath of the outbreak. One survivor shared, "Initially, we were stigmatized after we've discharged. But through sensitization, we were accepted and treated fairly and later interact with the community people" (Female, 45)

Thus, from a temporal standpoint, stigmatization was primarily described as a social phenomenon that improved over time.

> "My relationship changed. When I became infected a lot of people thought I was dead, and it was all over the news. Until later, after my recovery, that they realized I'm still alive. Some members were afraid to come closer to me. But others knew that I lost both my father and elder brother during the outbreak, and they sympathize with me come close to me. Since then my relationship changed to a positive one." (Female, 36)

Further, Ebola survivors described that through health education within their communities, they felt less segregated from their communities over time. One survivor explained,

> "Just like how it's happened, people had got the awareness due to the sensitization they gave them, because at first, they segregate us, but now they take us equally. So, the community, we are working together. So, we just take ourselves as one." (Female, 28)

Despite the decline in stigmatization over time, when Ebola survivors were asked stigmatization, survivors reported, there is still distrust among community members. Survivor shared that although Ebola stigma is not as rampant, there is still some concern that they are carriers of the Ebola virus. This was not a prevailing discourse from Ebola survivors who participated in the focus groups. Still, it is important to note that some survivors experience discrimination and that stigma could be connected to other infectious disease outbreaks such as the COVID-19 pandemic.

Ebola survivors did express varied experiences of Ebola stigmatization across participants, including experiences of discrimination within their households and negative encounters with community members and strangers. Markedly, Ebola survivor discrimination by health care providers was not commonly Ebola survivors. Several rationales might explain reduced stigmatization with health care providers. First, early in the outbreak, many healthcare providers contracted the Ebola virus and had first-hand accounts of Ebola stigmatization. Secondly, many nurses within public health centers are embedded within the community and have a rapport with community members, including Ebola survivors. Lastly, Ebola survivors noted that local health care staff were trained not to treat Ebola survivors differently by international organizations. One survivor explained,

> “Yes, [international agency] organised one training were they called all the PHU staff not to treat we special. Because that again would signal stigma. If they treat survivor because he is a survivor, especially if he come late and said you are a survivor and they drawn you and take you in for treatment everybody will notice that you are a survivor. So, they don’t make us any difference. Normal treatment was in the centers.” (Male, 50)

Thus, the anti-stigma training and programs implemented among health care staff were deemed valuable by Ebola survivors. Yet, generally speaking, Ebola survivors experienced varying levels of discrimination during the Ebola recovery period, disrupting how they normally engaged with their fellow community members.

Subtheme 1. If you do business,...it will not be successful: Ebola Stigmatization and Economic Livelihood

A subset of Ebola survivors shared how Ebola stigma impacted their economic opportunities after the outbreak. Importantly, because Ebola survivors were seen as carriers of the Ebola virus after the outbreak, some Ebola survivors noted a relationship between Ebola stigmatization and their businesses or economic opportunities. For example, experienced declines. One survivor described,

> "If you do business, it will not be successful. Except those who are far away, who don't know you will come and buy from you. Some of them who used to greet you before, will stand far away and greet you and forget about that even though they have talk to them" (Male, 27)

Ebola survivors shared narratives about the economic challenges they experienced as survivors were centered in community fears of their status as Ebola survivors. Again, a survivor describes how community fears impacted their business opportunities,

> "When I do my business, some of them were afraid to buy to me. Some of them won't talk to me. They thought when they talk to me they will get again the Ebola." (Male, 35)

Another survivor shared how Ebola stigma affected trade with neighboring communities,

> “Even to bring food and sell to us. They said they won’t sell to us because we at Gberray Junction have Ebola. Except they start meeting them in the villages and sensitize them, and they started to come back. Because they were not coming again to Gberray Junction. A lot ban themselves of not coming to Gberray Junction.” (Female, 43)

These community fears served as a source of community trauma for Ebola survivors that negatively affected potential economic earnings for Ebola survivors. Moreover, Ebola survivors shared narratives of social and economic exclusion experiences through declines in community interactions, business transactions, and trade opportunities.

Ebola survivors also shared that they experienced difficulties in their ability to work given their general decline in health due to prolonged pain, fatigue, and other ailments such as vision constraints (e.g., cataracts, blindness). Their long-term health status impacted their ability to gain economic access opportunities, including farming and domestic work within their communities.

> "Because, one it will be very hard for me to go out and search for food, because I was not in the state I was before. No those who have felt sorry will understand when you meet them for help. Some people when you explain your problems to them, they will not help you and they will go round and talk about it again." (Female, 31)

While Ebola survivors did not mention the term disability, many described the long-term health effects as a physical disability that limited their employment access. Ebola survivors often contrasted their economic livelihood to the pre- and post-Ebola phase to highlight how being an Ebola survivor impacted their daily experiences over time. These survivor discourses provide critical insights on how survivor disability status is intertwined with economic livelihoods.

Subtheme 2: I don’t have the strength to fight back: The Long Term Weathering of Social Cohesion.

Survivor narratives support the lingering effects of the epidemic, which negatively impacted their relationship with others in their community. Some survivors spoke to how the stigma of being an Ebola survivor impacted their familiar relationships or community connections. As discussed above, Ebola survivors felt isolated within their communities after the outbreak because of the ongoing concerns that they were sick, could still spread the virus, and in some cases were blamed for the duration of the epidemic in Sierra Leone. For example, one survivor explains how discrimination from being an Ebola survivor impacts daily interactions such as communal family eating practices. One survivor put it this way,

> "As I was saying initially when I discharged, I had some challenges, discrimination through my brother and family. Before the sick came, we eat on the same pan, drink on the same cup, but when the sick came, I discharged and when I come, they separated me. They have their own pan and I have my own pan. So, for that I feel discriminated within myself." (Female, 28)

Other survivors shared how their status as an Ebola survivor impacted their community relationships,

> "For me, especially the survivors who had carried age, when the organized community development programs, they were not involved as a result of them being survivors. They were not involved in decision making. Sometime, there are places of gathering they do meet, like water wells, you will hear the rumors around even when you go to pump. Some people will tell you, don't play with that pipe I want to get. Because he knows he will have to get hold of the pipe and he knows you are a survivor. So, they were not treating survivors well after the end of the sick." (Male-, 32)

Another survivor described,

> "Well this has been happening, because some people you will go to them for help, but they will watch you and when they know you have sick before, they won't help you. They will not give you what they should have given you. They will say this man had sick before so we will not help him. So will find out that it is difficult to get someone to help you." (Female, 26)

Furthermore, the stigmatization that Ebola survivors experienced created long-term distress for some Ebola survivors wherein survivors lacked the energy to "fight back" against discrimination.

An Ebola survivor shared a narrative about going to a market and the emotional toll this experience created for her:

> "Like for instance, I happened to go to the market to get some stuffs to cook. I bow to pick something from the ground. On my back, I heard a guy shouted, 'don't touch her! she is an Ebola patient'. I turned and I shed tears, because I have no option. I don't have the strength to fight back." (Female, 30)

Though not all Ebola survivors shared traumatic experiences of discrimination, Ebola survivor stigma did have an enduring effect on many participants' livelihood in this study. For those who did experience survivor stigma, those memories were still salient. Ebola survivors were able to easily recall numerous stories that immediately after the outbreak, individuals feared them. Yet, over time, stigma within and outside of their communities lessened. These narratives display that even many years after the outbreak ended, Ebola survivors could easily recall how the traumatic effects of Ebola stigma affected those social relations.

Lastly, while Ebola stigma did appear to decline over time, there was a concern that Ebola stigma could return. As the duration and timing of stigmatization is critical in situating this analysis, participants were consistently asked about when experiences of stigma occurred or if they still experienced feelings such as fear, or shame when these sentiments arose during the focus groups. Importantly, for Ebola survivors the trauma ensued by the Ebola outbreak, was not limited to the 2014-16 Ebola West Africa Outbreak. Interviews occurred at the beginning of the COVID-19 outbreak. Ebola survivors were asked to share what they knew about the COVID-19 outbreak and if they had any concerns. Ebola survivors shared that there was lingering fear on how a novel epidemic would mean for their livelihood and expressed concerns on how the SARS CoV-2 virus would impact their body. Ebola survivors expressed that they were worried that they might be dual survivors of two infectious diseases, COVID-19 and the Ebola virus. Early in the

COVID-19, pandemic survivors were aware of COVID, and how the virus spread and mitigation efforts such as physical distancing and hand washing. Once survivor shared, “This sick is a bad sick, they advise us not to go to someone’s house, let you protect yourself.” (Male, 34). Survivors recommend that community members follow COVID-19 public health messages given initial hesitancy during the 2014-16 Ebola outbreak from some communities in practicing preventative measures.

> “I want the people to take the preventive measures, like washing hands, distancing, shaking hands. So that we would be able to fight out this sick. Then denial. Because first, before Ebola overcome us in the country it was denial that caused all those things. So, denial, let them put it far from this, because corona, we have seen the damages it has caused in the western world. For we, we are praying that as we get low recordings, let it stop from that point and let it done. But there is a great problem because of this denial that makes all this sick to continue. So, the concern is, I am talking the people concern, the media people, you the SLAES, to disseminate this message that let them cut down all social activities?” (Male, 30)

Another survivor shared,

> “Well, first and foremost, to be a survivor, it’s not easy. And I will pray to God let a colleague or my enemy be an Ebola survivor of Ebola or covid-19. Because we have one slogan in Ebola survivor, “who know it feels it.” So, I will not pray for either my colleague or enemy be an Ebola survivor. Because to be a survivor, you will lose a lot of things. So, I don’t want such to happen again. So, I would like my friends or other people to abide to the rules and regulations of the medical people, to wash hands, that social distancing.so, if you don’t want to be a survivor, you need to practice the rules and regulations.” (Male, 27)

Moreover, survivors conveyed concerns about what a novel virus would mean for their livelihood.

Ebola survivors expressed worries that a novel infectious disease outbreak could bring new and unknown challenges. A survivor said about COVID-19,

> “Now, if they said another sickness has come, they will say this is how the Ebola came, people got sick, and we avoid them. So if they said another sick is coming, we still have that fear” (Female, 24)

Survivors felt a sense of connection to the COVID-19 pandemic early on because of their embodied experience as survivors of a previous infectious disease outbreak. When asked about what factors from the Ebola epidemic might influence the COVID-19, A survivor described,

> "Hand washing. People wash their hands on to this moment. Especially the PHUs (Public Health Units), after Ebola, there is still water in the PHUs. A lot of people wash their hands. There is still distrust, the habit of not trusting people still exist. Especially where they don't like you and especially when they know you are a survivor, still exist. Especially when this one is coming, they believed that, like me someone told me that they have paid us money because we the survivors are capable of passing on the sick, because we know the secret from the Ebola, so they have shown as all what we can do to pass on the corona."(Male, 43)

Here a survivor expressively points to the complicated nature of being a survivor of an infectious disease outbreak. Survivors shared that some stigma from community members still exists. There were concerns that they would be blamed for spreading the corona virus. This quote also discusses how the intersection of stigma and distrust remains complex. Community members continued to distrust Ebola survivors because of known Ebola survivor transmission. This distrust is manifested into Ebola stigmatization even four years after the outbreak. Survivors reported that community members distrusted survivors because survivors were viewed as having secret knowledge of infectious diseases (e.g., Ebola Virus Disease and SARS-CoV-2). As the focus groups occurred in late March and Early April of 2020, there were still many unknowns of how the COVID-19 pandemic would impact Sierra Leone. Yet, at the same time, survivors experienced fear that the COVID-19 pandemic could bring about similar devastations to their communities as the Ebola outbreak.

Theme 3. "It was the external people:" Survivor Engagement, in Post -Epidemic Research Survivor Engagement Post- Epidemic Research

During the focus groups, Ebola survivors were asked how they were engaged in research in Sierra Leone after the end of the epidemic. Survivors noted that primarily non-governmental organizations, including large international public health agencies and international universities, commenced research after the epidemic ended in Port Loko, Sierra Leone. These organizations primarily conducted biomedical and public health studies that examined Ebola sequelae (e.g., semen studies, eye studies). Ebola survivors were recruited into several studies after the epidemic ended based on varying interests from international researchers. Although Ebola survivors consented to participate in the studies, some participants discussed that they were not always clear on a given study's purpose. One participant noted,

> "Yes, I engaged in one research, one group of people came from, I think they are French people I couldn't recall the name again. But this research has to do with, they called we the survivors at Lungi, where they took our semen, or they took our body fluids. Like the semen, saliva, then also the anus part. Another one, we had another program, of course [international organization] implemented, where in, they do this research and we had to go to Makeni, and they do the same thing by taking the body fluids". (Male, 39)

When asked if Ebola survivors were directly engaged in the research development process, one responded noted, "No, it was the external people," highlighting that those who conducted research were not a part of the Sierra Leonean research community and that participants in the study were not engaged in governance roles such as the design of research. In fact, it was common for external researchers to conduct research with minimal survivor engagement. Survivors shared that external researchers would "place it in front of you," meaning that Ebola survivors were passively engaged in the research process. Another participant explained,

> "Well, they will make a survey. They said they will make a survey to come and ask first the beneficiaries to know what they want, but you will just see they brought things and we will not reject, and we have no choice." (Female, 44)

Yet, while survivor agency was regularly omitted in the research decision making, Ebola survivors were repetitively surveillanced and monitored in the post-disaster phase. Ebola survivors did not have the agency to guide recovery research. Many of the researchers who engaged in post-disaster research were not from Sierra Leone and represented Global North. This creates inequities in who has access to knowledge production, how research is conducted, and what data is ultimately disseminated regarding survivor health.

Participants shared that external researchers sometimes engaged local leaders (e.g., village chairpersons) or the national/local SLAES before starting research in Sierra Leone. Still, survivor communities were often not directly engaged in the design or planning of research.

> "Sometimes, they do the design and engaged with the chairpersons and review the questions. And they always seek the consent and willingness of survivors to participate in the research" (Male, 30)

Survivors were aware that they were not actively being engaged in post-disaster research. Thus, they were intentionally not in positions of power to inform the design, collection, or dissemination of research that directly impacts Ebola survivors. A survivor highlighted that:

> "No, they designed it but what I want to say is that, my concern is this, because we are the people they involved directly. So, any time they want to design a research, they should involve me. Because we might get the little to contribute to the program." (Male, 45)

Ebola survivors in this study did highlight that there were benefits in participating in the post-Ebola research process. For example, some research studies also provided health care services, including eye clinics, care for long-term pain and fatigue and regularly monitored post-Ebola sequelae. Some participants noted that access to medical care was a benefit of participating in Ebola research studies. One participant stated,

> "Yes, I was engaged on several of them, but one was [name of organization], who engaged in research to collect all the fluids which a human being has, where they will check if you have the sick or you didn't have it. So I'd undertaken all of those research with [international organization]" (Male, 31)

Another survivor responded,

> As such, I don't have any concern, because I have done that research and they said I don't have any EVD again in my body, so, I am really happy for that." (Female, 26)

Ebola survivors described how they benefited from knowing the long-term physiological health effects of Ebola in the body. Several participants highlighted that having access to healthcare services in the years after the epidemic provided them with helpful information to maintain their physical health. Health care services were typically tied to research or post-disaster funding that lasted one to three years after the outbreak. Survivors discussed that all of the research projects they participated in had ended by 2019, a year before this study began. Collectively, survivors revealed that their communication with external research after these studies ended was nonexistent.

Subtheme 1: "What happened at that research": Ebola Survivors as Biocapital

The first sub-theme centers on how survivors were used as biocapital in the post-disaster phase. As discussed in Chapter 1, biocapital refers to how the promises of biological advancement (e.g., biomedicine and technology) are intertwined with capitalist systems. Survivors being used as biocapital to increase research production is foundational to the concerns presented by Ebola survivors in this section. Ebola survivors were not engaged as partners in the governance of research. The majority of the participants in this study had participated in various forms of research after the end of the outbreak, which indicates that external researchers were eager to collect data from Ebola survivors. Several participants noted that they never saw the researchers after the data was collected, which added survivor distrust in the post-disaster research process. This is particularly disturbing given the invasive nature of the research conducted on post-Ebola sequelae, including the various semen studies among male Ebola survivors. The survivors were aware that their bodies served as the foundation to increase knowledge production on Ebola survivor health, transmission, and post-Ebola sequelae. One Ebola survivor who participated in a semen study shared,

> "Yes, to start with [international agency], we did a research of male semen, and they told us that when you discharge, it will transmit the virus to another person. So that is why they were trying to do this research. And this other one which took place in Lungi, yes, also, although it is fine for them to do this research…" (Male, 25)

Thus, Ebola survivors serve as both scientific and economic value to the public health and biomedical community. Moreover, survivors noted that the external researchers who benefited from biocapital after the outbreak did not return. Another participant noted,

> "When they come and you have explained yourself, they said they will come to help us. They gave us transport and they go. They will not come again, and you won't hear about them again" (Male, 33)

Survivors expressed apprehensions that studies' findings were not shared with participants after data collection or at the end of the study. Hence, this form of bio capitalism highlights how scientific production beneficiaries are those who designed, conducted, and profited from Ebola survivor research. Lastly, the distrust narratives shared about external research from Ebola survivors extended to this research project. When asked if survivors had questions at the end of the focus groups, some survivors questioned if they would receive feedback from the focus groups conducted. One survivor shared,

> "I have a concern over all that we have discussed. We understood from the facilitators that this is a research. We may want to receive a feedback by the end of the research. Over the years we had problems to proving us with feedback. If we receive feedback such information will be used by the chairmen should we need previous information for future purpose." (Male, 40).

This highlights that some Ebola survivors in Port Loko continue to share concerns about how research is conducted within their communities by external researchers. Given the historical neglect from Western researchers in providing information back to Ebola survivors, Ebola survivors remained leery of the continued interest of Ebola survivors by Western researchers.

Subtheme 2: “And that to Make Me to Fear”: Participant Distrust in Ebola Survivor Research

Some participants were explicitly fear and distrust in the research process, including some research projects' invasive nature. Survivors discussed how invasive procedures such as anal swabs and semen collections were particularly difficult for them. The study procedures conducted among Ebola survivors after the outbreak were unfamiliar and intrusive, particularly among men participating in the focus groups. One survivor discusses,

> "Well, my concern is one thing I'd observed during the research, we found certain things difficult to do and we look at it that it is not normal for our own setting. Especially when they said take, because they have a particular thing, they gave us to be used to insert in your anus. For me I sees it something too much to take something and put it in your anus. It like you get fluid, I see it something wrong." (Male, 38)

Several survivors centered their concerns about the research process. They expressed how they were fearful and felt that the procedures conducted were unfamiliar in their culture. For example, one survivor noted that they didn't provide all of their contact information to external researchers. Another survivor noted that they were concerned that the researchers would relocate Ebola survivors collectively away from their community to one central location. An Ebola survivor reflected,

> "Yes, when they come, I fear when they asked me questions. They said they are a particular NGO, even to give my phone number, I was afraid, and I just give one." (Female, 27)
>
> While another survivor stated,
>
> "When they come, I fear that, maybe they will try to identify us and later put us in one place. And that make me to fear." (Female, 31)

Distrust in the research process also centered around the actual procedures and what would happen to the specimens provided. Particularly, Ebola survivors were concerned with the unknowns of scientific research and expressed a lack of familiarity with biomedical research. In the example above, the survivor did not want to provide all of their information to researchers because they stated they were afraid. This occurred because survivors were not actively engaged in the research development or dissemination processes. However, it could also highlight how cultural mistrust arises when external researchers come into communities and quickly leave once. Global health researchers captured the data needed to answer public health research questions regarding Ebola sequelae and post-Ebola syndrome and never returned.

Discussion

Ebola survivor narratives post the 2014-16 West Africa Ebola epidemic serve as a dynamic resource in understanding the lived experiences of Ebola survivorship. Ebola survivors shared several lingering effects of community trauma between 2016-2020 that impact their livelihood, including social stigma, the decline in survivorship aid and Ebola survivor health care services, and post-disaster biomedicalization. Ebola survivors vastly reported many negative sides of Ebola survivorship; however, positive outcomes related to disaster citizenship were reported (e.g., time-limited access to health care, access to international humanitarian aid, survivor support groups) (Remes 2015). Most disaster recovery programs in Port Loko, Sierra Leone, ended in 2018. The resources aligned with disaster citizenship declined or were denied (e.g., access to health care) to survivors. Ebola survivors perceived that access to survivorship claims (e.g., money, health care, research participation, food, etc.) are their biological citizens' rights (Petryna 2004). Survivors expressed these denials to survivor resources impact their ability to thrive as a community of survivors. Ebola stigmatization reduced employment opportunities, decreased access to community-to-community trading, and disrupted social connectedness. Additionally, Ebola survivors highlighted that the increase in technoscientific practices instituted by the biomedical research enterprise after the Ebola outbreak contributed to mistrust of biomedical and public health research (Clarke et al. 2003). The biomedicalization of survivor's bodies served as a mechanism to increase knowledge production for biomedicine and public health, but this is detrimental to meaningful engagement with Ebola survivors in the biomedical process. To this end, survivors expressed how survivor agency and power were not considered during scientific decision-making after the epidemic.

Survivors expressed that they still have unmet social needs. Survivors reported that they anticipated that the Sierra Leonean government or international aid programs would provide long-term-survivor benefits. After a disaster, survivors often experience long-term consequences, including displacement, long-term economic setbacks, and community cohesion disruption (Adams et al. 2011, 2009). In the discussion of Chronic Disaster Syndrome, Adams and colleagues (2009) described that there are clusters of trauma and post-trauma is centered in social and political factors that are associated with disasters. Ebola survivors also describe how various forms of trauma were prolonged throughout the disaster recovery phase due to social and political influences. While humanitarian aid and global health recovery programs had positive intentions in providing survivor benefits, once removed, these programs also served as an apparatus of structural violence (Richardson et al. 2017; Wilkinson and Leach 2015). Richardson et al. (2016) asserts,

> "But government institutions are not solely to blame. The paradigm of infectious disease exceptionalism, whereby international aid is funneled into intensive responses for exceptional conditions (HIV, for example), reorients the donor gaze

> from strengthening health systems in general to mopping up preventable pandemics (7).”

Nevertheless, the removal of survivor resources created disruptions to how survivors access health care (e.g., medical treatment centers, free medication), programming for survivor stigma (e.g., survivor support groups) and gain entrée to economic livelihood initiatives. Informal access to survivor economies has been described as a means to gain access to survivor benefits (Petryna 2004). For Ebola survivors, access to informal and formal economies included smaller stipends such as travel to medical visits to free health care services. However, whereas other disasters have created more sustainable means to address biological citizenship rights, Ebola survivors were denied long-term claims to these economies (Petryna 2004; Remes 2015; Stern 2008). In Sierra Leone specifically, Ebola survivors anticipated that the Sierra Leonean government or international aid programs would support their livelihood similar to initiatives (e.g., housing) provided for amputees of the Sierra Leonean civil war. Repeatedly, Ebola survivors in this study shared their discontentment with the pattern of broken promises by the Sierra Leonean government, humanitarian aid and global public health after the outbreak.

Stigmatization, even four years after the Ebola outbreak, was connected to experiences of Ebola survivorship. Survivors reported that stigmatization declined over time, yet their experiences were multifaceted during the recovery phase. First, Ebola survivors shared that Ebola stigma created disruptions for economic opportunities (e.g., unemployment, declines in trade, discrimination among business owners). Secondly, Ebola stigmatization impacted the community cohesion (e.g., verbal abuse, isolation, survivor discrimination) such that stigmatization can operate at structural levels that move beyond the impacts on psychological well-being. For example, survivors described that other community members did not want to engage in business with them or that individuals did not want to hire them after the outbreak. James et al. (2019), through a systematic review of studies on the psychosocial experiences and coping mechanisms among Ebola survivors, similarly reported that community stigma occurred in the 2014-16 Ebola Epidemic aftermath. In James et al., (2019) review of Ebola stigmatization, other studies also reported that Ebola survivors reported challenges in finding employment and reducing their economic livelihood. However, most of the studies that collect socio-economic data on survivor livelihood were reported through survey research (James et al. 2019.; Richardson et al. 2017; Secor et al. 2020). Thus, the present study contributes to the growing literature on the relationship between Ebola stigmatization and socio-economic factors by incorporating survivor narratives. In-depth qualitative data of survivors of epidemics provides opportunities to capture the nuance of how economics the interconnectedness of disasters and disaster recovery for disaster survivors (Kargillis et al. 2014).

Encounters with the biomedical research enterprise were recounted by survivors as both beneficial for survivor livelihood and as a source of structural violence. Academic researchers and global health non-governmental organizations provided health care services and participant incentives (e.g., food, money, transportation) through research programs. Survivors viewed their access to research incentives due to their status as biological citizens (Petryna 2004). While there are benefits to participating in post-disaster research, survivors also reported high levels of mistrust of the procedures being conducted, and some survivors reported that they felt that medical procedures were invasive. Survivors were strategically deployed in large-scale clinical trials after the Ebola outbreak for knowledge production means (Adams 2002)Yet, the biomedicalization of Ebola survivors also creates inequities in scientific production in the Global

South (Clarke et al. 2003; Escobar 2017). The exclusionary practices of global public health research being conducted on and not with the Ebola outbreak survivors served as a form of epistemic violence (Esbobar 2017, Rajan 2006, Richardson 2020). The biomedical research enterprise worldwide has a legacy of not engaging research participants (Escobar 2017; Meléndez-Badillo 2020; Patton 2002; Richardson et al. 2016). Primarily white researchers from the Global North led research studies in Sierra Leone after the epidemic, yet never sought to transition their epistemic agency, social capital, or the financial capital (e.g., research grants) to Sierra Leoneans. Research grants, scientific publications, and the development of technoscientific practices all serve as varying forms of capital that global health scientists use to build their careers.

Ebola survivors noted some positive outcomes to their communities that served as lessons learned for future infectious disease outbreaks. First, survivors noted an increased awareness of the need for infection, prevention, and control procedures. Secondly, Ebola survivors reported an increased understanding of how infectious diseases spread. Third, community members were more likely to listen to public health messages regarding prevention strategies after the Ebola outbreak. This research took place in the early months of the COVID-19 pandemic. Ebola survivors were keenly aware of how the COVID-19 pandemic might impact their livelihood. Yet, the lessons learned from the 2014-16 Ebola Epidemic have successfully mitigated the spread of COVID-19 in Sierra Leone. To date, Sierra Leone has reported approximately 4,000 (n=4,068) COVID-19 cases and less than 100 deaths (79 as of May 7, 2021) (internal CDC report, 2021). Still, Ebola survivors expressed fears that the COVID-19 epidemic might bring about new forms of stigmatizations alongside worsened health and socio-economic challenges for Ebola survivors.

This might suggest that community traumas associated with Ebola Survivorship never fully dissipate.

Re-imagining Disaster Recovery for Survivors of Public Health Epidemics

Disaster sociologists critique the ‘build back better’ mantra in disaster recovery literature and practice because often, historically marginalized communities never bounce back (Aldunce et al. 2014; Tierney 2012). In the example, of disaster recovery for Sierra Leone post the 2014-16 West Africa Ebola outbreak, the potential for a better health care system was never realized. Furthermore, lower-income countries like Sierra Leone are left to reproduce Global North ideologies of recovery, without the means to implement such programming (Ndlovu-Gatsheni 2018). This, too, is how neocolonialism is practiced by deploying Global North ideologies, discourse and programs tied to international funding (Amin 1974; Asgary et al. 2015; Biehl 2016; Césaire, 1950). Thus, the promise of proper health care Ebola survivors was isn't uniquely connected to the 2014-16 West Africa Ebola epidemic. Instead, it is ubiquitously tied to how global health operates within lower-income countries. Global disaster recovery programs are often implemented by the Global North, under the guise of global public health; which generally are viewed a public good. However, in practice, as most foreign aid is channeled through entities including the World Bank, and International Monetary Fund, public health priorities are co-opted by economic policies that are tied to conditions that support free trade, reduction of the welfare state and privatization social services (Berghs 2016). Thus, global aid directed to governments in lower income countries is often scaled down, or inequitable terms (e.g. high interest rates) are applied.

In recent decades, trauma-informed care has been applied as a framework that acknowledges the role of trauma in an individual's life, primarily the provision of health care services. Trauma informed care operates as an overarching framework that emphasizes the impact of trauma and guides the general organization and behavior of an entire system (Hopper, Bassuk, and Olivet 2010). This study demonstrates that community trauma is influenced by structural adjustment policies, complex economics systems that funnel aid to lower-income countries and long-term stigmatization. Thus, I posit that a community trauma informed approach to disaster recovery in post-epidemic phases is needed. As community trauma in the post-Ebola period was orchestrated though various forms of injustices in the Global south, such as the under development of countries in post-colonial times.

Previous global HIV/AIDS research uncovers how forms of community trauma presented here are present in HIV/AIDS epidemic. Kenworthy (2017) discusses the need for HIV competent citizens (e.g. lay citizen scientist) because of their contributions of particular forms of biomedical knowledge. In Kenworthy's research she questions how non-governmental organization are rendered visible as community members were unaware that some HIV/AIDS programming existed. However, the Ebola survivors in this study were aware of that survivor resources were available but similar to Global HIV/AIDS programs, the scale down or closure of humanitarian programs systematically dismantles the distribution of resources for survivors (Kenworthy 2017). Moreover Kenworthy highlights that there were concerns about HIV/AIDS programs in Lesotho coming to an abrupt end due to reductions in funding from the Global North which is similar to Ebola survivor narratives. The decisions to dismantle global aid to the Global South, are deliberate and often political in nature. Policy makers in the Global North use terms as 'empowerment' and country ownership as a means to withdraw economic aid, yet local governments in the Global South often are not in the position to render aid to vulnerable communities (Esser 2014; Kavanagh 2014; Kenworthy 2017).. Furthermore, extensive HIV/AIDS work lays a foundation in how stigma can impact economic livelihood (Tsai et al. 2017). Global HIV/AIDS research suggests that the deployment of livelihood programs are useful in addressing HIV related stigma at a community level (Kelly, Weiser, and Tsai 2016; Stangl et al. 2013; Tsai et al. 2017). Similar to the findings in this dissertation research, Tsai and colleagues point to how stigma is multidimensional operating at a various levels (e.g. structural, public, enacted, internalized, and anticipated) during the ongoing U.S. opioid epidemic. (Tsai et al. 2019). This current study supports that multilevel stigma interventions are needed especially those that address community level stigma (Rao et al. 2019).

A community trauma informed recovery framework prioritizes economic resources and policies that addresses how the political and structural disruptions are dismantled through disasters. In the Global south, this can include restructuring the neoliberal deployment of humanitarian aid, which often serves as a band aid approach to recovery. Importantly, practices that underscore survivors' health and well-being by creating long-term provisional services of health care for survivors, especially in under-resourced communities. Expansion of economic investments such as microfinancing programs for survivors should be developed, such that when community economic disruptions occur, communities can remain stable overtime. This framing acknowledges that disaster capitalism extends to the profiteering of the biomedical research enterprise guiding by for-profit entities. The biomedical research enterprise serves to benefit financially, and otherwise from the bodies of the epidemics survivors. Thus, ethically, there is a need to create policies that protect survivors from the trauma that the biomedical enterprise inflicts upon communities. To this end, a community trauma informed recovery framework centers the role of survivors in the recovery process, including post-disaster research, rights to survivor benefits, and equitable humanitarian aid allocation. This includes creating survivor-led research that intentionally addresses ethical dilemmas (e.g. survivor mistrust, survivor agency) in Western research. Examining the multiple levels (e.g. individual, institutional, structural) of survivor health is essential in any disaster recovery period and is particularly salient for survivors of epidemics. I propose that a reimagining of disaster recovery practices is needed that promotes a culture of ethical survivor led research, survivor engagement, and community healing.

Limitations

This study is subject to at least five limitations. First, the focus groups were slightly smaller than the recommended size of six to eight participants for focus groups. However, scholars in qualitative data collection suggest that small focus groups of four to six participants are often more comfortable for sharing in-depth insights (Krueger and Casey, 2000). Additionally, small focus groups provide participants with intense or lengthy experiences to share narratives, which occurred during this data collection. Second, the focus groups were not stratified by age, gender or other social hierarchies. This served as a limitation, as some survivors might have been hesitant to share personal experiences with those who are outside of their social groupings. Slightly more women participated in the focus groups than men to ensure equal representation across gender. All participants held the shared experience of being an Ebola survivor. Third, I did conduct an analysis to understand differences across villages or chiefdoms. Fourth, the focus groups were conducted during the early stages of the COVID-19 pandemic which created limitations in allowing me to participate in-person. I participated via Skype and by phone, reviewed the focus group notes after each session and debriefed with the facilitators to address any questions regarding data collection or interpretation of the focus group discussion.

Fifth while I have experience working in Sierra Leone and Port Loko district, I was still viewed as an outsider to these communities. My training, epistemological views and lived experiences can serve a limitation in interpretations of the focus groups. Member checking was used as one method to address this limitation.

Conclusion

Grounded in Ebola survivor narratives, I centered on how disaster recovery programs serve as sites for community trauma for survivors. This study theorizes that community trauma in post-disaster settings in the Global South is executed through vicarious methods in the name global health and humanitarian aid. Researchers and public health practitioners from the Global North continue to deploy trauma in the Global South communities when they conduct research on and in survivor communities centered in Western ideologies and practices. Namely, survivors deserve to be centered and actively engaged in the design, deployment and dissemination of global public health efforts in the Global South. This study has implications for current research for COVID-19 survivors (known as long haulers) who not only experiences physical health symptoms (e.g., cardiovascular, respiratory, neurological, psychiatric, renal, dermatologic, etc.) but encounter economic and social difficulties (e.g. job loss, social isolation, long term disability). Future studies should explore how a community trauma-informed approach to disaster recovery might mitigate the structural violence that occurs for survivors of public health epidemics. The denial to survivor benefits, Ebola stigmatization, and the biomedical enterprise served as a source of structural violence. I propose that a revised approach to disaster recovery in the Global South should incorporate community trauma-informed recovery practices.

Table 3.1: Participant Characteristics of Ebola Survivor Focus Groups

Total number of participants	(n=100) no./%
Gender	
Female	57
Male	43
Age	
18-24	9
25-34	33
35-44	32
45-54	19
55 and older	7
Chiefdom (Community)	
Bene-Loko	
Port Loko City	10
Maforki	
Gbereh-Junction	10
Rogbanthai	10
BKM	
Romeni	10
Marampa	
Mamusa	10
Labour Compound	10
Kafu-Bullom	
Sumbuya	10
Lokomasama	
Kigbal	10
Koya	
Masiaka	10
Matherie	10

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Chapter 4: Paper 3. The Right to Health: Survivor Advocacy for Health Care Access in Sierra Leone Post the 2014-16 West Africa Ebola Outbreak

Abstract

After the 2014-16 West Africa Ebola epidemic in Sierra Leone, over 4,000 Ebola survivors experienced long term Post-Ebola clinical sequalae. Towards the end of the Ebola outbreak, the Sierra Leonean Government sponsored the Comprehensive Program for Ebola Survivor Program (CPES) to provide long term health care services to Ebola Survivors. CPES was short-lived and ended in 2017, less then a year after the outbreak ended. In subsequent years, Ebola survivors in Sierra Leone have advocated for their right to free health care "rights to health, right to life." While no previous studies have explored Ebola survivor's role in health social movements to understand survivor citizenship claims, I apply the concept of biological citizenship to understand how Ebola survivor health social movements. This study aims to explore the process undertaken to access survivor citizenship claims through legal means. Through in-depth interviews (n=15) with major actors (e.g., public health, researchers, policymakers, advocates, etc.) in the disaster recovery process and 20 focus groups with Ebola survivors (n=100), I explore how survivors stake claim to survivorship citizenship in their pursuit to access free health care in Sierra Leone. I argue that based on biological citizenship tenants that Ebola survivors were justified in their health activism efforts. However, several pitfalls emerged in the Ebola survivor legal case including, a redefining of survivor health, the absence of a survivor led litigation, and a lack of social and political capital. The examination of the Ebola survivor-led health activism is an instrumental entry point in understanding the long-term social, political, and health impacts of Ebola survivorship in Sierra Leone.

Introduction

In the aftermath of the 2014-16 West Africa Ebola epidemic, Ebola Survivors experienced varied health, economic and social challenges that impacted their livelihood. There are over 11,000 documented Ebola survivors, which is larger number of survivors than any previous Ebola outbreak. In Sierra Leone alone, it is estimated to be 4,000-5,000 Ebola survivors many of whom still experience varying levels of post-Ebola clinical sequalae—known as post-Ebola syndrome. Post-Ebola syndrome includes lingering symptoms including, blindness, neurological issues, inflammation, muscular and joint pain, lethargy depression, anxiety memory problems, insomnia among others (James et al. 2020.; Keita et al. 2017; PersYves-Marie et al. 2017; Scott et al. 2016). In Sierra Leone, the epidemic further weakened a fragile health system, as many health care personnel were infected with the Ebola virus, and the Ebola response was heavily dependent on international donor funds. Once donor funds were removed, health facilities were again challenged with operating on limited financial resources provided by the Ministry of Health and Sanitation (MOHS). Ebola survivors depend on care from Primary Health Units (PHUs) within districts to access care for their ongoing chronic conditions (Alva et al. 2020).

In the immediate aftermath of the epidemic in Sierra Leone, Ebola Survivors used a variety of resources to support health care and social needs. International government agencies (e.g. United Kingdom's the Department for International Development [DFID], United States-Agency for International Development [USAID] and the Centers for Disease Control and Prevention [CDC]) primarily from the United Kingdom and the United States provided post-Ebola recovery funding. Other large and small non-governmental organizations provided Ebola survivor livelihood programs (e.g. financial resources, support groups) and medical care after the outbreak , lasting for approximately one to three years. Additionally, a number of Ebola survivor research studies, provided clinical treatment such as eye clinics, for Ebola survivors. A recent study of Ebola survivors in Sierra Leone suggest that decreases in funding led to a decrease in declines access to available medications, and lower quality of care for survivors at PHUs (Alva et al. 2020). This is largely due to the ending of Sierra Leonean Government, Comprehensive Ebola Survivor Program (CPES), which provided health care services for Ebola survivors from late 2015-2017.

Sierra Leone's Comprehensive Ebola Survivor Program (CPES)

In November 2015, as Ebola cases waned in Sierra Leone, the President Ernest Bai Koroma, announced that the CPES would be put in place to support Ebola survivors. The goal of CPES was to provide free health care for all Ebola Survivors through MOHS facilities in all 12 districts across Sierra Leone. The program was modeled after Sierra Leone's free health care program for children under five and pregnant women. The program aimed to reduce the financial and logistical burden to accessing health care for Ebola survivors by increasing the health capacity at local facilities. Additionally, CPES provided survivors with specialized care with include mental health, neurology, ophthalmology, and reproductive health among others (Alva et al. 2020). CPES also aimed to reduce the risk of an Ebola epidemic resurgence by providing health promotion through sexual risk reduction (e.g. counselling and viral persistence testing). As the epidemic in Sierra Leone came to an end in 2016, rumors persisted that Ebola response funds were being mismanaged and in 2017, the CPES came to an end due to lack of funds to cover the care of Ebola survivors. Curiously, in 2015, the Sierra Leone Auditor General produced a report that reported 14 million dollars were unaccounted for during the 2014-16 West Africa outbreak. As an internal body to the Sierra Leonean government, the Auditor General is the institution responsible for financial accountability, performing audits and sharing financial statements. Ebola survivors and survivor activist alike argue that the Ebola funds should have been used as intended. Ebola survivors demanded accountability and wanted to know what happened to the large international donor funds that were to be used to support Ebola survivor livelihood.

Legal Actions for Ebola Survivor's in Sierra Leone's Rights to Health Care

In December 2017, soon after CPES came to an end, a Centre for Accountability and Rule of Law (CARL) in collaboration with the Sierra Leone Ebola Association for Survivors (SLEAS) began legal action to gain access to health care services for Ebola survivors. There was jurisprudence from the Sierra court which required CARL to file for legal action within three years after the cause of action arose. This began at a politically risky time for those litigating the case, as Sierra Leone were to hold elections in the coming months (March 2018). There were political implications for the employees of CARL and even for survivors who might experience retaliation for suing the government. Ebola Survivor activists contend that it was politically incorrect to bring a case against the government of Sierra Leone, when the previous ruling party was the cause of Ebola funding corruption. However, as time for the current ruling party quickly came to an end, CARL decided to proceed with litigations later in 2018. From December to March 2018, CARL went across the country as part of their investigation to gather input from survivors and to identify survivors who could join the legal action suit. CARL identified many Ebola survivors who were interested, but only a few came on board as activists who would join a formal litigation. In March 2018, CARL filed their legal applications in the Economic Community of West African States (ECOWAS) courts. CARL and Ebola survivor advocates decided to move forward with ECOWAS in hopes to have a fair chance with their legal case on the "right to health, and the right to life" for Ebola survivors. Legal experts felt that they could win in the ECOWAS court through advocacy undertaken around issues of accountability, right to health, right to life with the assistance of survivor health social movement. Ebola survivors or their families had not received any compensation or legal refunds due to the corruption. For CARL, this was not only about prosecuting the previous administration, but they wanted to set a precedence for future administrations.

Health Social Movements

Notably, HIV/AIDS activist since the early 1980s have actively engaged in health movements and to access health and advocated for their role as credible participants in knowledge construction (Epstein 1995; Patton 2002). AIDS activism communities including those from Lesbian, Gay, Transgender, Black and Brown communities organized on the foundation of distribution just health care services were needed in order for their communities to survive (Patton 2002). Patton, highlights that "these first groups arose explicitly because the government was doing little more than counting cases, but they also cemented and reproduced the bonds that corresponded to the form of community envisioned by minoritarian rhetoric" (p 11). HIV/AIDS activist demanded recognition by the state, and also galvanized community donations, formed non-profits in order to address needed social and health issues. The HIV/AIDS activists played a major part in conforming traditional notions of social movements and health. After the 1984 Carbide chemical plant explosion in Bhopal, India, survivors, litigated a case that serves as a model for environmental legislation (Fortun 2001). In Advocacy After Bhopal, Fortun (2001), explores how advocacy and competing power domains operates within a complex global system. Her work centers the conventional notions of ethical dilemmas and accountability for survivors in order to emphasize that survivor advocacy is often wrought with challenges (Fortun 2001). The recent environmental disaster, the Flint Michigan water crisis in United States was first identified through epidemiological investigations of high lead levels in children, (Hanna-Attisha 2018). Historical and modern racism through racial segregation, deindustrialization, and an economically depressed central city, led members of the Flint community to advocate to have (Sadler and Highsmith 2016). The flint water crisis highlights how activism between community members and key research activists joined together to advocate against the government for basic infrastructure development such as replacement of lead pipes.

Health social movements can also be embedded in broader social movements. Sociologist, Alondra Nelson describes how the Black Panther Party's broader struggle for social justice included advocating for access to health care, including free clinic services (Nelson 2011). Moreover, the U.S.'s the free school breakfast program that still exist in the American education system, was originated by and modeled after the Black Panther Party's initiative in the late 1960's -1970's to provide free breakfast in historically underserved communities. Similarly, Creary (2018) discuses how social health movements can be embedded in larger cultural social movements, in her analysis of racial justice for Afro-Brazilians. Creary, conceptualized the term 'biocultural citizenship' to examine how individuals living with Sickle Cell Disease (SCD) in Brazil to use race, citizenship, biological determinism, ancestry, and health to construct citizenship through a political lens. She argues that activist in Brazil SCD movement intentionally uses Blackness to make claims for health rights (Creary 2018). Biocultural citizenship stands on the idea of "biological and cultural difference that is coproduced by the State and Afro-Brazilian citizens" (p 123) Creary (2018) sheds light on how biocultural citizenship stands at the nexus of biological and cultural identities to produce a health social movement. In Brazil, Afro-Brazilians used their biocultural citizenship is used to make or avoid claims in advocating for health care rights.

Epstein (1995) describes how juxtaposed to scientists being the primary sources of knowledge construction in the HIV/AIDS epidemic, individuals living with HIV/AIDS challenged the epistemic practices of biomedical research. Lay activist challenged the concept of "scientific expertise," typically claimed by academic, governmental, and biomedical standards and asserted that those living with a disease also are credible experts in the scientific research process. The tensions of who can serve as credible knowledge producers in biomedicine is one example of a health social movements. Patton shares, "Where activists saw communities ripe for ideological transformation, epidemiologist saw collectivities linked through common behavior and a virus" (p 12). In the HIV/AIDS epidemic, people living with HIV/AIDS continued to push the scientific conceptualizations and proclaimed that political and social conditions were as important as medical condition (Patton 2002). The idea of biological citizenship is discussed throughout this dissertation. Survivors of epidemics have the ability to stake survivorship claims due to their common disease state (Petryna 2004). In addition to their common disease state, in Sierra Leone, Ebola survivors have a shared experience of being neglected by the government and being denied health rights claims. Thus, patterns of structural violence are deployed through the lack of health care, limited treatment options and the persistence of social inequities through the removal of a Ebola survivorship program (Petryna 2011; Richardson et al. 2017).

The documentation of health social movements for survivors of epidemics are vital in in describing how vulnerabilities during and after an epidemic are created inequitable political systems. Dzingirai (2017) argues that addressing the fundamental structural drivers of disease vulnerability is vital addressing zoonotic diseases in Africa. Dzingirai et al, (2017) state,

> "Far from being a thing of the past, the Ebola outbreak has revealed starkly how these histories continue to shape patterns of development, producing vulnerability in the region and making it difficult to respond both to epidemics such as Ebola, and to a lesser extent to ongoing endemic diseases such as Lassa fever. Most critical have been post-colonial development pathways which have fostered inequality and failed to address corruption or elite capture of resources, combined with a systematic underinvestment in state institutions precluding the establishment of resilient health systems, livelihoods and living conditions."

There is a gap in historical analyses of the Ebola survivors activism in the aftermath of the 2014-16 Ebola outbreak in Sierra Leone. Thus, I apply the framework of biological citizenship to understand Ebola survivors activism. In Petryna's analysis of the post the nuclear explosion at the Chernobyl reactor in Ukraine, individuals claimed welfare rights from the government to health services and social support due to their damages to their biological bodies (Petryna 2011; Rose and Novas 2005). The concept of biological citizenship asserts that the denial of biomedical resources is a violation of health and human rights and moreover social equity. Though my own research with Ebola survivors I assert that Ebola survivor's activism to stake claim to survivor health is a form of biological citizenship. Thus, Ebola survivor citizenship fits within the framing of biological citizenship as Ebola survivors have a common biological disease state and common post-Ebola sequala. Applied in this paper, biological citizenship provides an anthropological framing to understand the nexus of politics, survivor citizenship and the need for survivor advocacy in a post- Ebola Sierra Leone. The aim of this paper is two-fold. First, I seek to provide an historical account of the health advocacy efforts undertaken after the 2014-16 West Africa Ebola outbreak, in effort to access Ebola survivor's right to free health care. Second, I seek to understand what political strategies were deployed that rendered or inhibited Ebola survivor activism.

Methods

Data Collection

Twenty focus groups with Ebola survivors (n=100) and 15 semi-structured interviews were conducted to explore how Ebola survivors were engaged in social health advocacy in the aftermath of the 2014-16 Ebola outbreak. The use of mixed qualitative methods (focus groups and interviews) helped explicate how Ebola survivors communities were engaged in legal systems, how they continue to continue advocate for health rights and how the CEPS policy evolved. All focus groups were held in a community center building in Port Loko, Sierra Leone in March and April 2020. Data collection was conducted in collaboration with two research assistants, and an expert translator. This research team included the a member from the Port Loko affiliate of SLEAS, and a local Non-Governmental Organization (Center for Development Initiative) who implements survivor livelihood programs in the communities where survivor recruitment took place. Additionally, a translator who previously worked with the U.S. Peace Corps translation service for several years and speaks the primary local languages in the Port Loko district (e.g., Temne, Sierra Leone Krio, Loko) served as a focus group facilitator. The research team had prior experience collected focus group data and were all from the district where the data collection took place. Two pilot focus groups were held with 10 Ebola survivors (five in each group). The pilot focus groups were used as a facilitator training and to gather feedback on instrument guide from Ebola survivors. Recruitment efforts for each this study are described in chapter 3 of this dissertation. Focus group facilitators described the research and obtain consent for participation. Each session was between 75-90 minutes in length.

The interview guide addressed a comprehensive set of questions on survivor livelihood including social stigma, economic challenges, physical and mental health and access to health care. Facilitators asked questions about the health care that Ebola survivors accessed after the outbreak, the quality of the care and how they viewed the CPES program. Focus group notes were reviewed by the research team after each session. After two consecutive focus groups, the research team met to discuss emerging topics, and addressing any concerns with the guide. Focus groups were recorded and professionally transcribed into English by a local translator from Port Loko, Sierra Leone.

Fifteen in-depth interviews were conducted among individuals engaged in the 2014-16 Ebola epidemic recovery. Individuals represented varying professions and levels of engagement including Ebola survivor activists, public health practitioners, legal advocates, government officials, non-profit professionals, and researchers. Convenience and sampling was employed, whereby I interviewed individuals who were known to be stakeholders in the recovery process or refereed to me by other interviewees. Interviews were approximately one hour and conducted between October 2019 to October 2020 in-person, via phone and zoom. All interviews were de-identified to provide confidentiality of interview respondents. Scientific Ethics approval for this research was granted by the Government of Sierra Leone - Office of Sierra Leone Ethics and Scientific Review Committee and by the University of California, San Francisco's Institutional Review Board (IRB # 19-27517).

Constructivist Grounded Theory Coding and Analysis

Using systematic analytic strategies of grounded theory, conducted an inductive analysis. Following a grounded theory practice, I conducted open or 'initial' coding as a first cycle process to carefully examine the text. Line by line coding was conducted to reveal what is happening in the data and pull together a description develop an initial set of codes. The next level of analysis includes re-checking codes and conducting member checking from participants. During the data analysis, I sought to compare findings from focus group and interview data to tease out how responses might vary, to validate emergent themes and resolve inconsistences. I used memos and reviewed notes as analytical tools. Memos were useful in contextualizing data and exploratory interpretations before proceeding with further with additional data collection. I ceased data collection once theoretical saturation was reached, meaning additional data did not provide additional understandings of the categories I identified. Lastly, I proceeded with an iterative process of code refinement to develop broader themes that answer the research questions posed in this dissertation project.

Results

This section provides a summary analysis of focus group and interviews conducted. I created a timeline of the events, based on respondents narratives of the events that led to the legal case pursued against the Sierra Leonean government. Figure 1 provides a timeline of events in Ebola survivor activism during the Ebola recovery period. The findings in this sections suggest that, Ebola survivor activists felt betrayed by their government due to government corruption. In contrast, Government officials stated that Ebola survivors health care was folded into regular health care services. Extended narratives highlight that Ebola survivors continued to have challenges in accessing health care services once the CPES ended. Moreover, Ebola survivors maintained that they have the right to survivor citizenship claims and that health care is a human right. The legal pursuits for the right to health proved to be challenging for survivor activists.

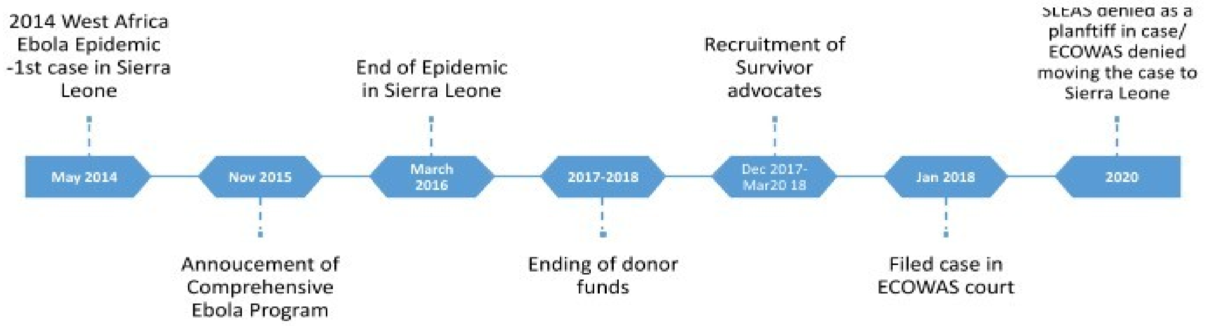

Figure 4.1: Timeline of Events Impacting Ebola Survivors' 'Rights to Health' in Sierra Leone

Defining Survivor Health in the After the Ebola Outbreak

To better under why there was a need to advocate for the health care rights of Ebola survivors in the Post-Ebola recovery period, I will first describe the health and social challenges that Ebola survivors experienced. These findings suggest that there was a need for a Comprehensive Ebola Survivor Program in Sierra Leone. An Ebola survivor explained,

> "Especially, we the survivors, the health system, we still have problem with the health system. Especially those that were complaining about eye problems, joint pains. Some of them who did hard work. Like for me, I am a welder and I cut a lot of irons, you will find out that in the morning, I would have general body pain." (Male, 35)

When I asked a government official who led the Ebola response Sierra Leone's capital and later led CPES about where were common Ebola survivor challenges, he stated

> "Yes, all part of that consortium to complement government's effort in providing care for these survivors. So, there were a lot of other issues also. They had also what we'll call psychosocial support for them, because they needed a lot of counseling because a lot of them are having insomnia, they were having suicidal tendencies because some of them have lost everyone. Both mom, dad, the kids. And then for adults they've lost their wives. Some lost their husbands, brothers and sisters. So, there was a lot of psychological issues." (Government Official)

A survivor advocate shared similar sentiments,

> “the major issue was the issue of health complications and difficulties with the integration. Because after we survived, an issue of side effects came in with the joint pain, the eyesight, so cataracts on the eyes, insomnia problem, sleeplessness, erection problem on the male survivors, abnormal menstrual problem with female survivors and also skin disease and entire depression.”

Concerns for Ebola survivors extended beyond health concerns as survivors also experienced stigmatization, divorce and isolation from their communities. The President of SLEAS shared,

> “So there comes in a lot of suspicion that survivors are suspected people. So most of the people move away, people who don't like to associate themselves with survivors, especially the male survivors. Because after we were discharged, a message was given or a recommendation was given by WHO, later on, the CDC shared about the fragment of the virus in the semen of the male survivors. So the messaging was not that well comprehended from our people in the community. So they misinformed. They misunderstood the whole thing, that all male survivors are sources of infection. So that comes in problems with even our relationship-wise. Some of our spouses move. They divorced with some colleagues, male survivors. So life became so difficult.”

While Ebola survivors noted,

> “the major issue was the issue of health complications and difficulties with the integration. Because after we survived, an issue of side effects came in with the joint pain, the eyesight , so cataracts on the eyes, insomnia problem, sleeplessness, erection problem on the male survivors, abnormal menstrual problem with female survivors and also skin disease and entire depression. So we started experiencing that from 2015. And it's also backed by stigmatization because on the time of integration, integrating back to our various communities, some communities and people, we are fortunate. But some communities somewhere aren't fortunate because the action of the community members were too poor since survivors were another source of infection.” (Ebola Survivor Activist)

Survivors, researchers, activists and government officials alike acknowledged that Ebola survivors encountered not only physical health symptoms, but also psychological trauma, stigma and economic impacts after the outbreak. A member of a local District Health Management Team (DHMT),

> “So, it's no surprise that they had some psychological trauma when they came out. They had a lot of other comparative to challenges. The challenges survivors faced,

> I'll put it into two broad categories. One would be returning back, integration, back into the society. It was an issue because people were afraid. That was one thing. So, they had integration and stigma associated with them. And then their livelihoods was also an issue because most employers didn't want them coming back. If they were business people, people did not trust money to them, to the business anymore. There was an issue. So, stigma cuts across both the integration back into society and their livelihoods." (Government Official)

Thus, there was a clear need to have post-Ebola survivor health care and social livelihood programs to address the multitude of factors that that Ebola survivors experienced. All individuals interviewed expressed a clear need for survivor health care.

The Sierra Leonean government ended CPES in 2017, but they originally set the initiative in place as a mechanism to monitor the health of survivors and provide adequate care. A government official shared,

> "So, we established counseling centers around where they'll be coming and then they'll be counseled. And then also we established what we call the National Semen Testing Program, because we wanted to see if there was any risk to society. So, we have what we call Project Sierra at that time, where it was we were testing the semen of male survivors within their reproductive years. I think from 13 to 65 or something like that."

Another Government official engaged in response efforts reported,

> "And then we also had a National Semen Testing Program, which looked at body fluids of both males and females for the persistence of the viral fragments. We had that also for survivors. So, CPES was launched and launched country-wide, everywhere. We trained, I think it was 273 health workers were trained in providing special care for survivors."

Here it was acknowledged that they was an initial plan in place by the government not only to examine viral load of the Ebola virus but that there was a need to increase the health care worker infrastructure to provide special care for survivors. Thus, CPES served to improve the public health system in Sierra Leone. Although access to free survivor health care was time-limited in

Sierra Leone, survivors shared that they valued the program and did not experience stigmatization during the deployment of CPES. A survivor recalled,

> "Actually, they were treating us well because I could imagine, there was a time, I was coming from work and on way home, I had an accident. And immediately [international agency] vehicle came on the scene, they met me lying. They took me and come with me. The way the nurses were treating me, the way they feed me, I thank God for that. Hadn't been our bosses, I would say my life would have left there or another vehicle would have come and hit me. But since they took me to the hospital, I was able to respond to good treatment. The nurses really take good care of me."

Ebola survivors reported experiencing fair treatment when accessing health care services. Survivor narratives consistently shared concerns about the lack of free health care services and that the potential of a better health care system after the 2014-16 Ebola outbreak never fully came to fruition.

"But it seems things were going backwards:" Post Disaster Survivor Health Care.

As a social institution, Ebola survivors described how the Sierra Leonean public health care system served as an opportunity for post-disaster improvements for the health of Sierra Leoneans. However, the expectation by global public health practitioners of a health care system that would "build back better" was never realized. At least for Ebola survivors, The 2015, Comprehensive Ebola Survivor Program was to provided free health care services for Ebola survivors. When, I asked a Clinician engaged in Ebola recovery initiatives about CPES, he shared,

> "It was an amazing policy. The good thing was I was part of the quantification exercise when we were doing quantification for the procurement of drugs for survivors too. We updated the essential there at least to improve psychotropic drugs for survivors. That was amazing, because, well, I mean I was a program manager so it was one of the things that I proposed that survivors should have free healthcare services, and then it was accepted by the government. So, it was amazing for me." (Government Official)

Ebola survivors discussed how they were provided access to survivor clinics with the National Comprehensive Ebola Survivor program after the outbreak, which included monitoring physical health symptoms and post-Ebola sequelae. Some Ebola survivors were provided access to free prescription medications through an international non-profit that also provided care clinics and access to clinical care through donor sponsored research programs. Overwhelmingly, Ebola survivors appreciated the health care services that international aid organizations provided, but were ultimately disappointed when CPES and international services ended – particularly because the challenges of being an Ebola survivor persist. One survivor explained,

> "… a good number of we the survivors in Sierra Leone still have health problems. The free health care is not functional and anytime we visit these health facilities, they will tell us that there are no drugs available. And most time we were given a drug prescription sheet by the community health officer (CHO) to go the pharmacies. During the Government's CPES (Comprehensive Program for Ebola Survivors), through [international non-governmental agency], there were services to access free drugs, but these facilities are no longer available."

Survivors were keenly aware that they were promised access to free health care services through the Sierra Leonean Government's CPES. Sentiments of disappointment were voiced among Ebola survivors that the short-lived CPES program did not provide free access to public-sector health services in the years after the epidemic. Survivor's discourse centered around the unmet promises for the rights to health through the provision of CPES. Thus, the health care resources rendered to Ebola survivors through post-disaster aid, then discontinue, is a site of trauma for Ebola survivors. One survivor put it this way,

> "I have greater expectations. As Ebola survivors, we would have been given much attention and government would have prioritize the provision of constant health care service which is free and of quality. But it was not happening. And after [international non-governmental] have [phased] out, we could not afford to buy the prescribed drugs."

Similarly, another survivor shared concerns that improved health care promises never came to fruition in the post-disaster phase:

> "During Ebola, health facilities were strengthened. But it seems things were going backwards. Now, the Public Health Unit [PHU] in charges are not working we could not access free drugs in some of the health center. And we were always told that our services are over. So, we are asking for Government intervention."

Ebola survivors expressed that though they faced continued need for long-term health care services to address post-Ebola health complications, the Government failed to address these needs. Several survivors lamented that they still experience physical pain and cannot access adequate health care services due to the lack of resources available within the Sierra Leone's public health care system. As one survivor states,

> "Especially, we the survivors, the health system, we still have problem with the health system. Especially those that were complaining about eye problems, joint pains. Some of them who did hard work. Like for me, I am a welder and I cut a lot of irons, you will find out that in the morning, I would have general body pain."

When I asked one Sierra Leonean Government official, how they managed Post Ebola sequalae, he acknowledged that overtime Ebola survivors were not provided with Ebola specific health care services. He states,

> "But then as government we're like, "You know what? The sequelae of Ebola, it's not different from other disease around. So, we do not think we need special clinics for them. Why don't you just come in as normal patients and they'll be treated in the general outpatient department as normal patients, and then they'll have access to whatever care they require?" Because just to ensure we train our health personnel to recognize survivors that, okay, they have special needs, and to help them move through the outpatient quickly." (Government Official)

As the Government holds decision making power in how survivor health is defined, the Government used their agency to define that Post-Ebola sequalae is no different symptoms of other common illness experienced by those in Sierra Leone. Defining survivor health is a modality of power employed by the government to circumvent provided survivor citizenship claims for survivors. This differed from Ebola survivors and activists that claimed that they deserved to be rendered health services for their unique illnesses and their status as a Ebola survivor. One activist, shared,

> "Well, that's one. Survivors are going through or are having the challenges that other populations are facing, especially the health aspect, but yet we have specific challenges as a result of Ebola that other populations are not going through. And obviously, they really want to understand or get an idea of some of those challenges in question."

The government and Ebola survivors also differed in what the concluded was the Government's role in continuing the CPES.

> "So all they could say was they wanted the government to take ownership of it and continue funding it. So the government could roll the other phases of it or the government would integrate it into their normal system. There were a lot of issues where we engaged with DFID because they were funding the CPES program. But since DFID pulled out, then everything ended."

Thus, while the Government posited that they ended the program because it posited that a specialized program was no longer needed Ebola survivors, Ebola survivors maintained that some form of a long term health care was needed. When asked if the DHMTs continue to have Ebola survivor health integrated in district level support, the government official noted, "So, I can tell you what happens in my district. We still have a focal point for survivors within the district and management team. It deals with survivors who are around. Yeah." However, when probed further about whether Ebola survivor health is a focus of DHMT's across Sierra Leone. The respondent noted, "All DHMTs had focal point for survivors. Whether they're now active, I wouldn't know, because as I told you, their reporting has stopped and we don't have that information anymore." This highlights that there was variability in how post-care for Ebola survivor health was maintained across Sierra Leone. Moreover, there were no longer systems in place to report or monitor survivor health at the National level. The official also shared that reporting ended in 2017-2018 and program implementation of the unit who coordinated all activities for Ebola survivors was dismantled because it was tied to international donor funds (e.g. USAID, DFID).

Some expected that Sierra Leone's health care system would vastly improve due to the increased resources provided during the Ebola outbreak, but participants in this study suggests that those expectations were not realized. Participants noted that was no long term infrastructure for in place to adequately fund the health care system. A legal advocate put it this way, "But unfortunately seems to me that once Ebola finished, international community came in with all the fire extinguisher type of mentality to the problem." When asked about if the health care systems had improved since the end of the Ebola outbreak, A survivor activist shared,

> "That's done, we've almost certainly gone back to the old ways of doing things. There's a level of consciousness, which is good, but I mean, about Ebola or other viruses, but really practices haven't quite changed. But in part, because really resources do not accompany practice or the lessons that we've learnt or we are supposed to. So if healthcare workers know that for every patient, you have to act, but if the glove is not available... I see people really recycling gloves, make an effort to do what they've been taught, but it's just difficult for them. So yeah, for the country, we lost human beings and the value, I mean, every human life is important but we lost professionals, we lost mothers."

When CPES ended, Ebola survivors were disappointed that health care services were no longer available and the government rescinded on their promised to provide health care for survivors. Moreover, survivors and activist felt that the actual reasons that the Government-led program ended was due to corruption and international donors pulling out of Sierra Leone. Survivor activists were adamant that the government should be held accountable for their mismanagement of funds. An attorney litigating the case against the Sierra Leonean Government noted,

> "So that for me, really grabbed my attention and I felt that there was clearly an accountability issue, there was a rule of law issue, there was a human right issue. As far as I know, no international or local tribunal has ruled that corruption is a human rights, but clearly they've ruled on certain rights. For example, right to education is a human right. And a government in Nigeria obviously, was heard to have violated right of certain communities, their right to education by mismanaging funds allocated, and to a state government to provide education services. So I mean, as a lawyer myself, I took interest in that and I thought that there was need, I mean, to file a public interest action"

These sentiments were the basis of how activists formulated a legal case to claim rights to health care.

Good Intentions Aren't Enough, Legal Rights to Health Care for Ebola Survivors.

The Sierra Leonean Government, had good intentions in providing care for Ebola Survivors, but good intentions were not enough. CPES ended in 2017 and attempted to integrate into standard health care by MOHS. In describing the Governments plan, an official noted,

> "Yes, I was also part of that to ensure it was integrated. So, we had a reintegration plan, because remember the support going into the consortium was folding up. So, we had a transition plan wherein we ensured that all the support be integrated into the Ministry of Health. So, for the survivor advocates, they were absorbed into the Community Health Workers program. For those who were trained, they were put in the general, outpatient department, right? And then it became a policy now for all survivors to access free healthcare services going forward for the rest of their lives. So, now it's part of our policy now." (Governmental Official)

However, in actuality, Ebola survivors did not receive the same level of care. Ebola survivors reported that the government discourse after CEPS centered shallow promises that were not backed by funding. Here an Ebola survivor explains the implications for Ebola survivors,

> "Because I remember always many instances where we are at the Ebola treatment and the healthcare workers, they will have a sit-down strike. So we were there suffering, people were dying there. Nobody was there to attend to them because they're expecting their risk allowances and those risk allowances were delayed and

> they were not paid. So these are all contributing factors that contributed to the death of so many people. And our right to health, they did not mean those policies. So that means it's also another negligence to their side. And we're talking about 4,052 that survived the virus in the whole country. That's a huge number compared to the other African regions. So we have all this that we feel left out. (Male, 38)

Survivors demanded that they were entitled to survivorship claims (e.g. healthcare, social services) because the government failed during and after the outbreak to care for its citizens.

In 2015, a second audit indicated that that funds have not been properly accounted for. Yet, the anti-corruption commission Sierra Leone did not indict anyone for the financial mismanagement. The mismanagement of funds was a key factor in what sparked the initial desire to litigate a legal case against to the Sierra Leonean Government.

> “For us, it was the opinion of the Auditor-General that if the funds had been properly managed, if the wastage... and clearly she didn't use, I mean, she, the Auditor-General didn't use the word fraud, but I have gone as far as calling it fraud. The wastage and fraud or mismanagement that characterized our response had been reduced significantly. The government would have responded. The response would have been much better and more effective, meaning we could have saved lives.” (Survivor Advocate)

Another legal advocate shared,

> “So we would have thought that every penny, every dime would be utilized for what it was intended for. And then the Auditor-General, that's the head of the audit service, put out a report saying that the funds were not being properly managed by those who have been tasked or charged to the responsibility of managing the funds.” (Legal Advocate)

Rightfully, health activists thought that the funds allocated for the Ebola outbreak should have been used for the intended purpose. Ebola survivors and activist were disappointed in the lack of liability of the Sierra Leone government to care for its citizens. Advocates in Sierra Leone felt that if funds had been managed properly the Ebola response would have been coordinated in a more efficient manner and lives could have been saved. Thus, the CARL sought to pursue litigation. In explaining the motive to move forward with the lawsuit, a Lawyer shared,

> “So we felt that if nothing was done about it, it was going to impose in not only the administration at the time, but future administrations to get away with literally murder, literally murder. And so that was why we felt... Even if and we can talk about our strategy, we might not win in the court room, but I'm pretty optimistic, and I'm convinced that we have the strong case. So, but our strategy is that even if we do not win in court room, we can win out of the court room through the advocacy that would be undertaken around the issues of corruption, accountability, right to health, right to life and all the mobilization that we've been doing around these issues.”

A case on the right to health and the right to life came about on the legal claims that Ebola survivors were being denied, human rights through a legal clause in ECOWAS for ‘the right to life’ and the ‘right to health’. A legal advocate explained the claims of right to life in their cases as exposing an employee, [in this case two health care professionals] to life threatening situations in the way that could have cost the person his or her life. He shared,

> “If you employ someone and you are required on that human rights standards to give the person the tools where to do the job in a way that protects him, especially in certain fields, such as healthcare, aviation. I mean, they are different.”

The two plaintiffs in the case were hospital workers who claimed that they did not have personal protective equipment, lacked adequate training and education needed to care for Ebola patients and government hospitals were short staffed and thus they worked overtime. CARL decided to move forward with a legal cases by moving forward with a case with two Ebola survivors who were health care professionals. Ebola survivors had not been compensated any funds as a result of the Governments lack of protection, corruption and survivor advocates felt that this was prime time to proceed with the legal process in January 2018. Because of the rights to health violation, the plaintiffs wanted the Sierra Leonean government to (1) produce a declaration that they had violated the rights of the survivors for the right to life, (2) declare that government failed to comply with procurement and accounting standards, which would have provided the financial resources to give health care workers the tools needed to manage the Ebola outbreak (3) order the government to undertake reforms, both declarative institutional reforms, including, having a standalone body or unit within the government agency responsible for emergency response, (4) financial compensation to at least the two survivors and others who joined the case, (5) free health care, (6) free social services.

Building A Survivor Led Health Social Movement.

CARL did not include the national Ebola association (SLEAS) in the court filling, because of political conflicts of interests, and SLEAS did not have the proper association status as a corporate affairs organization to be included in the ECOWAS case. In the years, at the Ebola epidemic, SLEAS received funds from the Ministry of Social Welfare, thus it was deemed inappropriate for SLEAS to sue the government when they were receiving funds from the government at that time. A legal representative shared,

> “Once we filed, with the association now felt, "We want to be part of this. We want to be part of this." Because originally, I mean, we could have gone with the association but, I mean, we didn't have time. They needed consultations, they are obviously, it wasn't back then politically correct for them to have... because they were getting some support really from the Ministry of Social Welfare back then. I guess that support was largely... they needed to... the big guys, the invisible ones in the association. spread across but they were loyal to the minister at the time. So we felt that trying to make them an applicant in that case, would have needed more time, more consultation from... So we just left them and went with two survivors.”

This is an important juncture in Ebola survivor activism in Sierra Leone, as the legal experts moved from having the case being led by SLEAS to only including two plaintiffs.A government official also confirmed that the Ministry of Social Welfare partnered with SLEAS to support livelihood in the recovery period.

> “So, as a government, one of the Ministry of Health and Sanitation, we partnered with the Ministry of Social Welfare, Gender and Children Affairs looking at both livelihoods of the survivors and their health. So, it was a two-prong attack. So, social welfare looked at the livelihoods of survivors whereas the Ministry of Health looked at the health needs. So, comprehensive program for Ebola survivors was borne out of that. We had support initially from DFID, and then from USAID, supported or complemented government efforts in providing services.” (Government Official)

Thus, SLEAS was challenged with needed to advocate for health care access and rights and also wanting to side with the Sierra Leonean government in hopes that some livelihood programs would continue. SLEAS later noted that they wanted to be a part of the legal case in the ECOWAS court system. However, the Sierra Leonean government would not authorize their application because they did not have the corporate affairs documentation needed by the courts. A member of SLEAS explains,

> “No, we are not ECOWAS because rejected the associations application that we are not a juristic person that we don't have legal mandate to sue them, simply because of our corporate affairs company document that we don't have. The core of that, we are still, we are hopeful. All these weeks we are still working on it. But before then, my trip to Abuja after the rejection, the courts made a recommendation to the government lawyer. They said, "We would advice, you go back to Sierra Leone and negotiate with these people, including the association."

The momentum to engage a large number of survivors and build a survivor-led health social movement declined during the legal battle from March 2018 to 2020 when I conducted interviews. SLAES and other survivors remained interested in the outcome of the court proceedings, but were not actively engaged in the day to day work of the case. A legal advocate suggested that the only way that the Sierra Leonean government would have been more apt to respond to survivors request were if it impacted government officials political opportunities for getting re-elected. However, the two primary political primary parties in Sierra Leone typically are split across the two major ethnic groups (Temne and Mende). Because Ebola survivors are still split across ethnic groups, it wasn't a viable political option to request Ebola survivors to support one political party, as Ebola survivors were more likely to remain loyal to existing political party affiliation.

In 2019, the ECOWAS courts requested that CARL attempt to come to a resolution with the new administration of the Sierra Leonean government outside of court. However, those efforts to were unsuccessful. CARL felt that they were able to represent the claims of the two survivors in court, but outside they were not able to represent the voice of all Ebola survivors. A CARL representative shared,

> "So we said, "Listen, okay we cannot speak for survivors in terms of what they really want out of this process." When we went to court, we had a set of relief, we exactly knew what we wanted, but what out of court settlement do, is that they also offer an opportunity to get what you couldn't otherwise get from the court. So we held several rounds of consultations across the country."

Although, CARL attempted to re-engage Ebola survivors in the legal process to access claims, perhaps they had lost momentum due to the length of time since the end of the Ebola outbreak. Up until 2020, SLEAS continued to request ECOWAS to include them in the CARL led litigation, and the president of the SLEAS would even attend the court hearings in Abuja, Nigeria. However, SLEAS petition was continually denied. When asked about where SLEAS as a representative body of Ebola survivors in Sierra Leone stands in pursing legal action, the member of SLEAS stated,

> "But since we came back, the same neglect continue. They didn't take it seriously and nobody talked to us. Nobody even ask about the way forward, how we are doing, what is happening. But that's why we still want to go back to the court and we are preparing. Very soon we'll move forward, If only it would have been to our own expectation, we are thinking of the government not to give us cash in the negotiation. But we are only expecting services like healthcare, scholarship opportunities; economic empowerment."

In February and August, 2020 the ECOWAS court again dismissed the application of SLEAS and rejected that the proceedings be moved to Sierra Leone and. In 2020, lawyers requested that the case be moved to Sierra Leone , to allow for the witnesses to come forward to testify and due to the national public interest in Sierra Leone.

Social Inequities Reproduced in Sierra Leone.

The Rights for survivor livelihood in Sierra Leone were steeped in class and income inequities. The nature of the Ebola outbreak was such that poor communities were disproportionately affected by high Ebola cases. Overcrowding in households in rural and urban areas, less access to personal protective equipment, water and poor sanitation conditions all served as drivers for increased Ebola cases in poor communities. There was a clear difference in how the Ebola outbreak impacted poor versus middle-class and affluent communities. A legal advocate shared,

> "So Ebola, you are better placed to say that, but you can see if you look at demographics and income levels, you'll see that the worst hit socially vulnerable, the poor, they literally... those who lived in poor communities. I mean, during the entire the period, I drove myself, I didn't give anyone a ride. I asked my wife, and because we had our two year old kid, she basically resigned to take care of him. So I could protect myself, come to the office. So I could afford that, but we still have people out in the community, in public buses and all of that. So it really affected [them]... [apart from the healthcare workers, the doctors who went close] I mean, how many middle class, affluent people..."

Those with access to social and economic capital fared better during the Ebola epidemic. The class inequities witnessed during the Ebola epidemic were extended in the Ebola recovery period for Ebola survivors. Respondents shared that the Sierra Leonean Government abandoned the people of Sierra Leone, because most Ebola survivors did not have the social or political capital to advocate for biological citizenship claims.

Because the epidemic disproportionately impacted poor communities during the Ebola outbreak, those of higher social and economic status were unlikely to actively engage in the health activism for survivor rights. When I ask a the lawyer litigating the legal case what was the long term impact of the epidemic for Ebola survivors, he responded.

> "Their average lifespan, I would suggest has reduced significantly. And so of course, it means that poverty... I already said that they've gone poorer, because they can't pick up jobs and they can't even do jobs that they would do without anyone hiring them. So individually, it's bad for them. For the country, obviously it means, if you think about all the image, hopefully that will go away with time. But we lost a lot, it hit our economy back then badly, really. And whether we have recovered, or maybe fully recovered from that, but it will take time for us to recover from that."

SLEAS through survivor livelihood programs attempted to address the needs of those in lower social positions. When asked about the social conditions of Ebola survivors from poorer communities, A SLEAS activist shared,

> "So they are struggling with that really. And there is no one actually providing. So what we did as an organization or my own strong push is to see ... I was looking at different aspects. One, for people to go back to normal life, life after Ebola. In that case, those that were farmers, for them to be supported with seedlings so that they can continue their farming. And we also do advocate for skill training opportunities like the carpenters for them to be trained, the masons, I mean, those that are interested in completing to learn, those that are interested in driving. And indeed, we are able to get some few who we enrolled into various sectors."

Interviewees reinforced that structural inequities were reinforced when Ebola survivors lost the ability, experienced Ebola stigmatization that impacted their livelihood. Furthermore, the in-and-out nature of the Ebola response didn't rebuild communities in a means that produce sustainable infrastructure. In describing the role of humanitarian and international government's role in emergency response, an individual who worked in Sierra Leone Ebola response referred to these emergency response organizations as 'mushroom agencies' because of their history of quickly leaving lower-income countries at the end of a disaster.

> “A lot of agencies left, OXFAM, UNICEF CDC closed down [in Port Loko], and Restless Development moved out , the mushroom agencies closed down…that’s what we call them. Those that start when something happens, because they want funds, so they act, they do their deeds, but after everything they just close down.” (Non profit staff)

Respondents were naturally disappointed that international organizations were not committed to the long-term recovery of Sierra Leone’s health infrastructure after the outbreak. Unfulfilled promises and the removal of financial commitments were observed among the Sierra Leonean government and international agencies. Respondents highlighted that given the billions of dollars allocated to the 2014-16 West Ebola epidemic and the numerous organizations that worked in Sierra Leone during and after the Ebola epidemic, they anticipated improved health care and social services would occur in Sierra Leone.

Discussion

After the 2014-16 West Africa Outbreak in Sierra Leone, Ebola survivors engaged in in health advocacy to demand rights to biological citizenship claims as Ebola survivors. Initially, the government sponsored CPES program was envisioned as a mechanism to provide health and social services for Ebola survivors. However, in less than a year into the policy’s implementation, government officials redefine survivor health in order to deny health rights to Ebola survivors. Ebola survivors were justifiably concerned that not only were they now denied free-health care, but that the prospect of an improved health care system in Sierra Leone in the near future was diminished. In the years after the Ebola outbreak, through informal and formal actions, Ebola survivor activists demanded that the Sierra Leonean government provided long term health care for Ebola survivors .

In the aftermath of disasters, government agencies, international aid and community organizations seek to recover and rebuild systems to their pre—disaster state. For Sierra Leone’s health care system, there was an expectation that government run clinics, hospitals and emergency response infrastructure could drastically improve with the surge of international donors during the Ebola response (Abdullah and Rashid 2017). However, most international agencies either left immediately after the outbreak or remained for one to two years. Moreover, those that did remain budgets were significantly reduced in the recovery period, which impacted their ability to provide Ebola survivor health care services or livelihood programs. Civil society programs funded by organizations such as the World Bank, IMF and Western donors are based on structural adjustment policies that deepen versus improve the historical structural violence deployed in African countries like Sierra Leone (Abdullah, and Rashid 2017). However, The Sierra Leonean government played a central role in hindering the potential for an improved health care system. Two financial audits conducted during the outbreak suggested that financial mismanagement occurred. These funds were never recovered or accounted for and these millions of dollars could have been used to invest in the health care infrastructure and ultimately could have improved the livelihood of Ebola survivors.

Programs and policies such as CPES support survivors in accessing disaster citizenship claims are essential for survivor livelihood in the aftermath of disasters. For example, in the aftermath of Hurricane Maria in Puerto Rico, programs were put in place to acknowledge how culture, economics, and politics caused suffering among citizens (Meléndez-Badillo 2020). A Legal and Psychological Clinic (LPC) was an initiative commenced to tackle the local problems that community members encountered in accessing the economic assistance they were entitled to after the Hurricane (Meléndez-Badillo 2020). Moreover, this program recognized the collective impact of trauma after a disaster creates long-term trauma. Programs like LPC help participants increase survivor’s knowledge of their rights to disaster citizenship claims, yet they also sought to diverge from the neocolonial nature of traditional recovery programs administered by the United States government. To this end, Patton (2002) argues that post- or-anti colonialist, postpositivist theories of society and social changes are needed versus traditional approaches that are steeped in a legacy of imperialism. Disaster recovery programs are often centered in Western ideology and deployed through global health approaches in the Global South. Because international recovery organizations are often responsible serving the needs of survivors (e.g. housing, food insecurity, health care), yet often serve as a “mushroom agencies” in that they are not sustainable in lower-income countries, it is pivotal to engage epidemic survivors in the development of recovery programs.

The Sierra Leonean Government was able to exert agency in asserting their own definitions of what post-Ebola syndrome illnesses are viewed as unique to the Ebola survivorship. As some post-Ebola symptoms can be viewed as common chronic illnesses (e.g. fatigue, pain, mental health illnesses), the Government sought to limit the designation and allocation of resources for special programs such as CPES. In the aftermath of the Bhopal chemical disaster, constructions of pain and suffering were also conflated by scientific and social order (Fortun 2001; Petryna 2011). Petryna explains,“ Given the array of scientific and medical uncertainties, old measures of suffering lose their meaning and validity. Into that void come new biological definitions, some by change, others by design” (p 13). In the case of the Sierra Leonean Ebola outbreak, the re-defining of survivor health was primarily used to conceal mismanagement of disaster funds. There is possibility that the government will not be held accountable for mismanagement post-recovery funds. More concerning is that the government holds power in re-defining survivorship to deny survivor citizenship claims to health.

Social health movements are often met with government opposition (Creary 2018; Fortun 2001; Patton 2002; Petryna 2011). In Sierra Leone, Ebola survivor's efforts to access long term health care and social services were removed by Government leadership due to lack of funds. Ebola survivor activists in Sierra Leone attempted to implement a variety of tactics with the government (e.g. negotiations with the Government, lawsuits, social mobilizations). Unfortunately, these actions have largely been unsuccessful as there has been no recourse for Ebola survivors in accessing Ebola survivor health care and the Sierra Leone's governments did not provide payments for their mismanagement of disaster funds. The two Ebola survivors who sued the government have yet to receive monetary compensation, and Sierra Leone has yet to reinstate a national Ebola survivor program. Petryna (2011) discusses how law, medicine and corruption intersect to disenfranchise survivors and suggest that remediation models are needed. Unfortunately, the remediation model used in Sierra Leone seems to have been unsuccessful as the legal pursuits, led by CARL were unable to galvanize substantial Ebola survivor support once SLEAS was unable to join the litigation in the ECOWAS court. Health social movements perhaps are most suitable to deliver change when survivors are able to galvanize enough grassroots support exert pressure on scientists, the government, and corporate entities to acknowledge both their existence and their rights to health. In the HIV/AIDS epidemic, people living with HIV/AIDS created HIV/AIDS organizations, solicited community donations and asserted their role as lay scientific experts to combat the discrimination they encountered by government institutions (Epstein 1995; Patton 2002). The denial of health and social services claims, after the Ebola outbreak impacts those in marginalized positions (e.g. poor, women, orphans) disproportionately. These inequities largely persist because institutions are not held accountable to legal systems and corruption remains unchecked (Petryna 2011).

Limitations

This analysis is subject to at least three limitations. First, data collection used a convenience sample which might limit the perspectives included in the analysis. Second, situating the CPES as the only driver of Ebola survivor activism limits other activities that Ebola survivors might have engaged in that addresses biological survivorship citizenship claims. Lastly, Fieldwork in Sierra Leone was limited as I was unable to remain in Sierra Leone due to the COVID-19 pandemic.

Conclusion

Years after contracting the Ebola virus, Ebola survivors continue to experiences post-Ebola syndrome, including both medical and social ramifications. After the 2014-16 West Africa Ebola Epidemic, Ebola survivors in Sierra Leone were neglected by the Sierra Leonean government, and the numerous organizations that worked in Sierra Leone during and after the Ebola epidemic. Ebola survivors and activists in Sierra Leone posited that health care is a human right that everyone should be accessible to them as epidemic survivors. Epidemic survivorship is a unique form of disaster and citizenship in that epidemics are uniquely tied to a disease state, but survivorship can also be redefined through political means. The emergence of novel zoonotic and infectious diseases that as global health threats are not new and will likely continue overtime. Currently, we are witnessing the challenges that COVID-19 pandemic survivors (e.g. long haulers) experience, and it is unknown if what all of the long term COVID-19 health consequences might be. For, example in the United States, early in the epidemic it was questioned if COVID-19 diagnosis will one day be viewed as a pre-existing condition. Long haulers have established online support networks to share their stories, learn from one another but also to create a group of biological citizenship to support health activism (Perego et al. 2020; Taggart et al. 2021). As the world begins to envision a post-COVID era with the availability of COVID-19 vaccines, it is important that public health is mindful that survivors of epidemics are often left unattended for once the disaster has so-called ended.

Survivor-led health activism provides opportunities for marginalized groups ignored by the state to share that experiences of trauma lingers long after epidemics end. Thus, there is a need to attend to how epidemic survivorship claims are valid and their claims deserve future attention of public health scientists and humanitarians. Social scientists, including disaster sociologists are uniquely positioned to analyze and report to various circumstances that survivors of epidemics experience that reproduce social inequities.

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Chapter 5: Conclusion

The 2014-16 Ebola outbreak halted everyday life in three West African countries (Guinea, Liberia, and Sierra Leone) for two years. Towards the end of the 2014-16 Ebola West epidemic in Sierra Leone, public health officials carefully counted down the days to March 17, 2016 when the country was declared Ebola free. But for survivors of the Ebola epidemic the trauma they experience continues to linger years after the devastating public health epidemic. During an interview, with the President of the Sierra Leone Ebola Association for Survivors, he described the post-epidemic experiences of Ebola survivors in this way,

> “But for us, even if Ebola is gone, no Ebola, but our lives are still miserable. Ebola is gone but the scars remain. People are still struggling with their livelihood, struggling with their healthcare, and also even their integration or protection”

His quote suggests that for survivors of epidemics, the trauma doesn’t end when the epidemic is declared over. Survivor narratives point to how trauma linters for survivors of disasters, and that trauma operates at social, economic, and political levels.

This dissertation research focuses on survivor health and uses the 2014-15 West Africa Ebola outbreak to explore how survivorship is socially constructed as a public health problem. The first paper provides the foundation for this dissertation by examining media discourse of Ebola survivorship. This analysis examined narratives in the media to elucidate that Ebola survivors were portrayed as stigmatized bodies and useful for increasing knowledge production in biomedicine. The second paper utilizes narratives to share accounts of community trauma from the perspectives of Ebola survivors. The third paper examines how survivor advocacy was deployed in attempt to gain access to survivor citizenship claims. This dissertation research fills this gap in the sociological literature and moreover disaster sociology by developing a deeper understanding of the lived experience of survivors after a disaster, including the social production of stigma, engagement of survivors in post-disaster research and lingering needs of Ebola survivors once global health and humanitarian aid is withdrawn.

Survivor Knowledge Production and the Role the Media in Survivor Discourse

My dissertation posits that knowledge production of survivor health was operationalized through multiple mechanisms. In Chapter II of this dissertation, I examined the media as an apparatus for creating survivorship discourse. The media operates at institutional, organizational, and individual levels to serve as agents of power because they can define the reality of the lived experience (Reese, 1991). I described how the media as an institution and journalists as individuals, held power in creating the narratives of Ebola survivors (Farmer, 1999; Jones, 2011). Discursive strategies and cultural metaphors have the ability to inflict structural violence and create social, political harms and inequities on bodies (Farmer, 2004, Kenworth 2017). Kenworthy (2017) suggest that “At the root of such discourses are deeply embedded cultural beliefs regarding how power and the distribution of resources become embodied” (118). The frame that the media created, primarily aimed to produce an outsider frame of Ebola survivors that suggests that the survivors were harboring a deadly virus and should be viewed as ‘risky bodies.’ Media portrayals of the 2014-16 West African Ebola Epidemic were presented as either uniquely "African" or as a rare tropical disease" Ebola," that most Westerners would never encounter (Césaire, 1972; Mondragon, 2017). As Kenworthy (2017) details, these discursive notions have real implications for how humanitarian aid is rendered and contributes to the relegating of those in marginalized positions.

The work of othering through discourse is often to deployed to displace blame onto individuals for the social conditions they encounter versus an analysis of the systems and institutions that render them vulnerable (Davis & French 2008, Solman & Henderson, 2019, Tierney 2012). Sprecher (2017) proposes that this stigmatizing discourse might prolong trauma for Ebola survivors. Ebola survivors lacked agency, as authoritative voices to create personalized accounts of Ebola survivorship in Western media. Their lack of representation in the development of media created a void in describing the lived experiences of Ebola survivors. Thus, there is a need for increased representation and centering of voices from marginalized communities in the Global South in prominent Global North media. Moreover, ideologies central to Global North media that center imperialist and post-colonial framings can be destructive to how we view those who live in the Global South (Amin, 1973; Césaire, 1972). In describing media misrepresentations of community members of the 2018 Ebola outbreak in the Democratic Republic of the Congo, (Richardson 2019), explains "these ahistorical analyses are a form of neoliberal propaganda that serves to efface the determinants of mistrust that Congolese conspiracy theories are indeed critiquing" (p 104). Feminists scholars posit that there is a need to situate the social location and reveal the power dynamics associated with the construction of survivor narratives (Hill-Collins, 1998; Naples, 2003). Because Global North media plays such a dominant role in what we know about public health epidemics in the Global south, future research must continue to deconstruct what narratives are being depicted and critique the Western ideologies these narratives are steeped in (Jones, 2011).

The findings of Chapter II suggest that the media can improve in both humanizing Ebola survivors and creating space for Ebola survivors to produce their own narratives of survivorship. The media should move beyond public discourse that pathologizes survivors as risky or that emphasizes the utility of survivor's bodies for science. A reimagined role of the media should include portrayals of Ebola survivor's livelihood beyond that of being useful bodies for the biomedical research enterprise. For the media, this requires reflexivity of all levels of media (e.g., journalists, media outlets that cover epidemics, the media as an institution) to be held accountable in its role of discursive formations.

Knowledge Production through Biomedicine , Biomedicalization and Biocapital

Chapter II also describes how Ebola survivors were portrayed in the media as biomedical capital and as means to increase scientific advancement. Survivor health is increasingly shape by biomedicalization practices, which are fortified through global public health and biomedical research (Clarke et al. 2003; Rajan 2006; Richardson 2019; Richardson 2020). The biomedical research enterprise serves as a knowledge producing entity that creates social categories and constructs meaning making that shape how we come to define and understand survivors of disasters. For example, in examining the AIDS epidemic, Treichler points to how the social construction of individuals living with HIV/AIDS was not based on objective or scientifically determined reality, but rather these social constructions are "routinely produced within the discourses of biomedical science" (1987, pg. 265). The biomedical discourse portrayed of Ebola survivors implied that Ebola survivors serve as means of production in the biomedical research enterprise through their role as research participants. Patton (2002) suggests, that as witnessed in the HIV/AIDS epidemic these biomedical thought styles can produce disastrous policies. Patton (2002) explains,

> ”They always underestimate the power of medical thought styles to structure the terms through which bodies become visible as the locations of disease of an epidemic. Political economy and civil rights claims treat bodies after they have emerged as visibilities--- workers, blacks, queers. Medical thought -styles form at least part of the screen through which unarticulated masses of protoplasm pass to becoming bodies of a certain type, in a certain place” (p 26).

Thus, it is not to be underestimated that the knowledge produced around Ebola survivor health can have a negative effect on future Ebola survivors, if research is misaligned, misinterpreted and continues in deploy colonial science. This subjugation of survivors, in scientific knowledge production minimalizes survivor livelihood to that of serving as biocapital (Rajan 2006).

In chapter III of this dissertation, Ebola survivors echoed the sentiments of being used as biocapital. They shared that international researchers would come to do their research never return. This too is a form of coloniality and epistemic violence (Richardson 2019; Richardson 2020, Rajan 2006). In fact, a representative of SLEAS recognized how post-Ebola research inflicted trauma on Ebola survivors, and proclaimed SLEAS no longer supported the participation of Ebola survivors in research studies. As he shared,

> "The research as far as we declared, we declared a war against research. All we cares about, it's about our recovery, and our recovery and also care for our members rather than research. We are not really pleased. They want to know everything or they want to everything of us…. Because sometime the semen's program were often during the holy month of Ramadan, that they call people during the holy month. There was all those things, where we are against some of those things. Most often they don't try to understand the feelings of the participants. The participants petitioned their stake. Before, in most cases coming down for them to know about what the participants are going through, what are they feeling? They don't care. All they want is to just achieve and get the research done. Also feedback, that's also another thing, after the research finished, they don't give us any feedback, how it was, how it happened."

Focus group participants shared common themes of not being engaged in research, expressed fears about the intrusive procedures and not feeling respected or engaged in the research process.

The colonial nature of clinical science in the Global South, creates complex transactions, wherein scientific studies can bring in needed medical research, but this is at expense of using individuals in the Global South as test subjects (Patton 2002, Rajan 2006). For example, given the nature of the recovery process, clinical trials also served as a modality for survivor care as some studies provided clinical treatment such as eye care and provided participation incentives (e.g. money, travel stipends, food). Survivors shared that clinical research in the post-Ebola period served as treatment apparatus for Ebola survivors. The biomedical research enterprise did provide needed care that the Sierra Leonean government was unable to supply. These accounts are supported by biomedicalization literature that suggests that there is a complex and multidirectional process from which medicalization is constructed, reconstructed and practiced (Adams 2002, Briggs and Halin, 2016; Clarke et al, 2003, 2010, Bell, 2013; Enria and Lees, 2018). In centering post-colonial technoscience, Adams (2002) suggests that there are alliances between the state, financial markets, and measures of medical efficacy that shape inequity. Colonial science in global public health enables the biomedical enterprise to profit from knowledge production and scientific practices in the Global south which ultimately support carceral regimes produced by scientific systems (Adams 2002). This implies the infusion of the biomedical research enterprise in Sierra Leone after the Ebola outbreak can produce multiple and somewhat complicated outcomes for survivor health. Biomedicine, can serve as site of structural violence (Richardson 2020) while continuing to be source of economic relief and address Ebola survivor clinical sequalae.

As research was connected to global research funding, once these scientific endeavors concluded, survivors were unable to access the clinical treatment, drug procurement and social support systems that survivors desperately need for their long-term care. However, biomedical studies' goal is to contribute to knowledge production and not to sustain the health of the survivors. Hence, even while the biomedical research enterprise benefited from Ebola survivor studies (Rajan 2006), they were not committed to remaining in Sierra Leone. From an ethical standpoint, ethics is typically understood to emphasis potential harms or adverse outcomes that scientific procedures might produce. However, as scientist must also attend to the ethics of survivor participation in trials and how the removal of biomedical studies leaves survivors without adequate treatment options. The research produced by the studies in the aftermath of the 2014-16 Ebola outbreak are overwhelmingly focused on the pathology of the disease, which were not particularly impactful for the everyday livelihood of current Ebola survivors. Moreover, Ebola survivors reported that they did not receive the results of these studies, and wanted to know the outcomes of the research that they participated in.

Positioning Post-Disaster Trauma at the Community Level

While trauma is often conceptualized at the individual or collective level in post-disaster settings, Chapter III of this dissertation suggest that trauma can also be operationalized at the community level. Trauma in research studies after the Ebola epidemic were defined primarily in psychological terms (James et al. 2017.). By defining trauma through mental health clinical diagnoses, this negates that Ebola survivors experience other social and economic challenges. Ippolytos Kalofonos (2008), suggest “By targeting a biological condition, political and economic concerns are sidelined” (p 8). Yet, Ebola survivors were able to provide narratives that suggest that governments, biomedicine, public health and humanitarian aid all serve as a vehicle for inflicting community trauma and that this lasted years after the outbreak. Richardson et al (2017), suggest that even the words ‘outbreak’ and “epidemic’ can serve as symbolic violence as they create an illusion that there is an is an end to the suffering that Ebola survivors experienced in Sierra Leone. My analysis conducted three years after Richardson et al (2017), supports this ideology that post-epidemic trauma doesn’t have an exact end point and that structural violence can persist long after an epidemic is declared over by public health officials.

Due to the fragile health care system and the public health infrastructure, in Sierra Leone was dependent of international aid during the Ebola response. Benton and Dionnel (2015) suggest that structural adjustment policies and post-war aid dependency served as a mechanism to intensify the spread of Ebola during the 2014-16 Ebola outbreak. These same structural adjustment policies continued serve as structural violence in the aftermath of the epidemic (Abdullah and Rashid 2017, Richardson et al 2017). Abdullah and Rashid (2017) also discuss that through structural adjustment policies, the capitalist state continues to fail to meet the needs of those impacted by Ebola epidemic in Sierra Leone. They contend that structural adjustment policies did not assist in rebuilding a broken health infrastructures, inadequate drug supple or the lack of qualified personnel. In the focus groups I conducted with Ebola survivors, they supported that the lack of a true post-disaster recovery program left them without the drugs they needed and that local health clinics did not have the infrastructure to adequately care for Ebola related illnesses. In Sierra Leone, these inequities are predicated by decades of structural adjustment policies by the World Bank and International Monetary Funds dating back to the 1980s that led to reduced incomes of the poor and layoffs of key medical personnel (Howard 2017; Kieh 2017) speaks to the role of the capitalist state in Liberia during the Ebola outbreak and suggests that systemic and structural transformation in a post-Ebola era are needed because of corrupt practices that include stealing public funds, extortion and fraudulent procurement.

The legacy of neoliberalism in Sierra was further complicated by the government corruption during the Ebola outbreak which left Ebola survivors without a comprehensive health care program. Ebola survivor narratives served as a useful method to collect data on how post-disaster financial mismanagement impacted survivor livelihood. Ebola survivors shared that the removal of the Comprehensive Ebola Survivor Program (CPES) and international aid disrupted their ability to fully recover after the Ebola outbreak. Some Ebola survivors are no longer able to work do long-term illnesses caused by the Ebola virus. Ebola survivors expected to receive long-term care, but with the CPES ending, survivors were left without adequate support for their livelihood. Ebola survivors described that global humanitarian program and the Sierra Leonean government was not sustainable. Amos (2017) describes the inability humanitarian aid to sustain programs in lower-income countries as a humanitarian disaster. The reliance on humanitarian aid creates a circular dependance, such that countries like Sierra Leone are always in a financial stage of life support. Hence, while donor contributions are often viewed as necessary to improve the quality of healthcare in lower-income countries, countries like Sierra Leone become entangled in an interdependent relationship with higher income countries. While these donor contributions are needed to improve quality of care, they also hinder lower income countries' ability to invest independently in their own health systems (WHO 2012). Even with the best of intentions, government sponsored programs, humanitarian and disaster recovery aid offered short-term fixes that only addressed the needs of survivors for a limited period.

Ebola survivors shared to how survivor stigma operates at a structural level. Survivors shared narratives of how Ebola stigmatization impacted their long term ability to gain employment and affected their trade opportunities with other communities. While Ebola stigmatization did decline overtime, Ebola survivors still were worried with how they are viewed by community members. In discussions of Ebola survivor vulnerability and agency. Ibrahim (2017) explains,

> “It was about thinking of how the disease had affected a survivor’s sense of self, their perceptions of how they are viewed by others, and how well they are able to reinsert themselves in the community” (p 174).

Initially after the outbreak many Ebola survivors experienced challenges with social cohesions and other community members feared that they might still be able to transmit the virus . Thus, fear and stigma intersected for both Ebola survivors and non-Ebola survivors. Survivors were also concerned that they could transmit the Ebola virus, which was a heavy responsibility to hold that they might continue to serve as carriers of a deadly virus. A survivor activist I interviewed, described the relationship between stigma and social integration as such,

> “And it's also backed by stigmatization because on the time of integration, integrating back to our various communities, some communities and people, we are fortunate. But some communities somewhere aren't fortunate because the action of the community members were too poor since survivors were another source of infection. So there comes in a lot of suspicion that survivors are suspected people. So most of the people move away, people who don't like to associate themselves with survivors, especially the male survivors. Because after we were discharged, a message was given or a recommendation was given by WHO, later on, the CDC about the fragment of the virus in the semen of the male survivors.”

Situating stigma as a problem of survivor recovery is discussed by other researchers. In a systematic review of Ebola survivor and psychosocial and coping mechanisms, Ebola survivors across 24 studies reported that there variability in experiences of stigmatizations (James et al 2017). 30-70% of Ebola survivors in several countries (Guinea, Liberia, Sierra Leone and the Democratic Republic of Congo) in quantitative studies reported instances of Ebola stigma. Importantly, my study did not seek to quantify how many survivors experienced stigma, yet, it did point to how stigma impedes social and economic livelihood after the epidemic. In post recovery periods, there is a need to there is a need to continue to support Ebola survivors in anti-stigmatization programs (Barry 2017, Ibrahim 2017, James et al 2017).

Survivor Rights for Biological Citizenship

Chapter IV examines Ebola survivors social health activism for their rights to health. During and after the 2014-16 West Africa Ebola outbreak, the lack of accountability local and in the international community to monitor the distribution of funds was problematic (Benton and Dionne, 2015; Leach, 2015, Abdullah 2017). I chose to undertake an analysis of the Ebola social health movement using a biological citizenship, as a means to understand how survivors opposed the Sierra Leonean's governments denial of survivor's rights to health. Epstein (2005) suggests, …"An analysis of patient groups and health movements is crucial for understanding the consequences of these manifold biomedical transformations, especially including the resistances that have arisen in response to them" (p 7). Medical treatment activism forces new understandings of survivor health by investigating government and scientific nomenclature to deny survivors claims to access health services (Patton 2002). Petryna describes how survivors post-Chernobyl used various remediation models to advocate for the material basis for health rights. Similar to Chernobyl survivors, Ebola survivors in Sierra Leone encountered inequities in the distribution of entitlements due to persistent corruption and failed operations by the Government and the global health community. For the Ebola epidemic, health is uniquely intertwined to politics as two audits conducted during the Ebola response revealed that there was government corruption or mismanagement of funds that were intended to serve the people of Sierra Leone, including Ebola survivor health care. As was witnessed after the 2010 Haiti earthquake, government and private corruption coupled with mismanagement of funds are a perfect gateway to expose the deficiencies of disaster governance (Tierney 2012). Individuals interviewed in Chapter IV affirmed that Ebola survivors were had rights to free health on the basis of biological citizenship (Petryna 2011).

Lastly, the emphasis of social inequalities in Chapter IV, seeks to highlight how one's inability to access health care systems after epidemics can serve as an indicator of the unequal distribution of wealth between class (high/middle vs lower), and geographic regions (Global North vs Global South). Over the past two decades, the reproduction of social inequities within healthcare systems has become a critical area of analysis in understanding global epidemics (Farmer 1996, Maternowska 2006). For example, it has been noted that during the 2014-16 Ebola outbreak certain groups more than others, such as the poor and health care workers who serve the poor, were more likely to be impacted by the virus, which is also reflective of other global infectious outbreaks (Abdullah and Rashid 2017, Farmer 1996). Quinn and Kumar (2014) point to how differences in access to and quality of health care systems in global settings after disasters can worsen increased health inequities. The Global Report on Infectious Disease of Poverty (2012) further reiterates that the global political economy shapes how funding supports health care systems in lower-income countries (WHO 2012). In Chapter 4, I highlight the attempts to access biological citizenship claims through legal pursuits with the ECOWAS court system were unsuccessful to date. I conclude that it is likely that the Ebola survivor health social movement did not have enough social and political capital to access their rights to health via free health and social services. To my knowledge, there are no existing scientific papers that offer an analysis of the Ebola survivor activism in the aftermath of the 2014-16 West Africa Ebola outbreak, thus paper contributes to building the scientific knowledge on social health movements.

Study Implications

This dissertation seeks to move beyond epidemiological and biological understandings of survivor health to draw upon medical sociology to better understand how survivorship is socially constructed. I employed a holistic examination to survivorship by applying disaster sociology, biological citizenship and post-colonial theories throughout the dissertation. I explored knowledge production, community trauma and health social movements as ways to contextualize the lived experiences of 2014-16 West Africa Ebola survivors in Sierra Leone. This dissertation research suggests that there are several aspects that contribute to survivorship in post disaster settings. First there is an interconnected relationship between the political economy of post-disaster funding that shapes how survivors will receive funding for their health and livelihood needs. In the case of Sierra Leone, the lack of continuous funding, coupled with the mismanagement of post-disaster funds at various levels ultimately led to an exacerbation of community trauma for survivors. While trauma during and post the Ebola epidemic was theorized at an individual level, much less research existed on how post-epidemic trauma obstructs communities through a structural means. Given that disaster recovery is multi-layered , community trauma serves an useful analytic framework to explore survivor health in post disaster settings.

I also acknowledge public health's role in the deployment of surveillance and research, contributes to biomedicalization of survivors and positions survivors as biocapital. The Global North, profited from research conducted on Ebola survivors, but this research contributed minimal improvements for the everyday livelihood for current Ebola survivors. While biomedical advancements might provide long term solutions to unknown scientific phenomena, the tradeoff is that current survivors are subjugated as mere study participants. Hence, I assert that survivor-led research in the Global South is needed to reduce the epistemic violence deployed by the Global North. Ultimately, I situated how public health and biomedical research as entities can serve as critical modalities of power in inflicting community trauma after an epidemic. Future research should attend to the specific ways that global aid, neocolonialism, and the underfunding of health care systems in the Global South creates and reproduces poor health for communities such as the Ebola survivors. This study contributes to sociological research at the intersections of disasters and global health science and practice. My dissertation research adds to the disaster sociology literature by taking a structural lens to recovery of the 2014-16 Ebola epidemic in Sierra Leone.

A year and a half ago, I couldn't have imagined that another horrific infectious disease outbreak would impact the world in the way that the COVID-19 pandemic has in many countries. Over the past year, I've often reflected on how COVID-19 survivors might encounter similar challenges as survivors of the 2014-16 West Africa Ebola outbreak. During and after the COVID-19 pandemic, I believe that there is a need to critique survivorship discourse, push back against biomedicalization of survivor health and to advocate for survivorship claims for their rights to health. I also contend that the analytic tools (e.g. discourse analysis, survivor narratives) used in this dissertation can be applied to other forms of survivorship including survivors of mass shootings, state sanctioned violence against Black and Brown people in the United States, natural disasters, and other epidemics.

When I started this dissertation research, my research question was simple, I wanted to know what happened to Ebola survivors in Sierra Leone. I was interested in how social and medical institutions shaped survivor livelihood. This dissertation project serves as an entryway to understanding the complexity of Ebola survivors in Sierra Leone. At the end of each Ebola survivor focus group, facilitators asked Ebola survivors what they wanted the world to know about ‘what it is like to be an Ebola survivor.’ I would like to end this dissertation with their words in the hope that Ebola survivors will not be forgotten.

> “I am a survivor of Ebola. I will tell the people that, yes, we have got the Ebola but that is not the end of our life. So, we are still in the community, let them hold us with two hands”
>
> “For the Ebola, when it outbreaks came it was not easy for me. Because you will sit in your treatment center and you will see fifteen to twenty dead bodies for the day. But I thank God to come out and continue. But for this epidemic [COVID-19] which has overcome the entire world. Like China they have lost a lot of lives, Italy, and other countries. So, if that sick has come, let them tell the people that to become a survivor is not easy.”
>
> “First and foremost, I want to honestly say thanks to those who have been helping us before, and I want to let people know that we exist, and we have needs and our needs are plenty. Like some want to go to school, others want to do business, others, before the outbreak they have everything, but after the outbreak, everything gone. We have orphans in the community that need help. Please don’t forget us. We are here.”

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