Original Research

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Broken Promises: Diminished Quality of Life Among Liberian Ebola Survivors 6 Years After the 2014–2016 West African Outbreak

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Abstract

The 2014–2016 Ebola outbreak left thousands of Liberian survivors with severely diminished quality of life. Applying a social determinants framework, this mixed method study investigates to what extent Ebola virus disease (EVD) survivors suffer long-haul psychosocial stress, diminished quality-of-life factors, and the impact of EVD-related service provisions on their ongoing healing. We present the results of a quantitative analysis survey of data collected from 19 Liberian EVD survivors in 2022 using snowball sampling. Additionally, a qualitative analysis of survivor statements helps triangulate key statistical findings and inform causal mechanisms. Survivors report experiencing 5.25 of a total of 7 ongoing stressors (95% CI 4.65–5.85). Higher satisfaction rates of government service provision are negatively correlated with experiencing long-term stigmatization (r = -0.55), eviction (-0.45), and the inability to pay school fees (-0.33). However, most survivors rate service provisions as low, frustrated that promised services such as resettlement and scholarships often have gone unfulfilled. All survivors feel the world has forgotten about them. All suffer financial hardships. The inability to fund their children's schooling is statistically linked to experiencing 43 percent higher (2.96 points) stress than that of peers ($p < 0.05$). Due to ongoing EVD-related health complications, all survivors volunteered as human participants in the clinical trials mounted by Partnership for Research on Ebola Vaccines in Liberia (PREVAIL). Statements reflect diminishing implementation quality over time, along with instances of unethical mistreatment. Being treated poorly or being discriminated against by PREVAIL staff appears to have an 18 percent (1.27 points) higher rate of stress ($p < 0.05$). This research is one of the first studies that examines the long-term social adversities threatening survivors' long-term well-being.

Introduction

The 2014–2016 West African Ebola crisis resulted in a reported 10,672 cases of the Ebola virus disease (EVD) in the country of Liberia (Centers for Disease Control [CDC], 2015; Decosimo et al., 2019; Glayweon & Hanson, 2015; Ministry of Health, Republic of Liberia [MOH], 2014; Nyenswah et al., 2016). Approximately 5,864 people survived the disease, yet their lives were irreversibly changed once they returned home after discharge from the Ebola treatment units (ETUs). As the crisis drew to a close, EVD survivors and people living in EVD-affected homes continued to face chronic mental health issues, such as depression; physical impairments, such as blindness and body pains; and severe stigmatization by their communities, which often resulted in family abandonment, illegal eviction, physical attacks, and loss of employment (CDC, 2022; Faley, 2022; Hanson et al., 2016; Hanson et al., 2017; MOH, 2014; United Nations Development Programme, 2014). The country suddenly faced the challenge of providing critical services and legal protection mechanisms for this new disease-affected population not just in the short term but potentially long after the crisis.

The Government of Liberia (GOL), the Ebola Survivors' Network of Liberia (ESNL), the World Health Organization (WHO), the Centers for Disease Control (CDC), and international and national stakeholders came together in late 2014 to identify and assess the needs of this afflicted population. They offered short-term assistance, including food distribution, cash assistance, and temporary housing (Faley, 2022; Hanson et al., 2017; Ministry of Health/Incident Management System [MOH/IMS], 2014). By early 2015, the GOL and international partners pledged to continue supporting EVD survivors and their families over the long term by providing free medical services, mental health support, educational scholarships, cash assistance, and new governmental policies that would protect them from discrimination (Department of Global Communications, 2020; Dodd et al., 2016; MOH/IMS, 2014). Initially, international donors, such as the United States Agency for International Development (USAID) and the United Nations International Children's Emergency Fund (UNICEF), funded key Liberian ministries and agencies, international non-governmental organizations (INGOs), national non-governmental organizations (NGOs), and civil society organizations (CSOs) to cover more immediate needs of affected households, coordinated by the MOH and the ESNL (Faley, 2022; Hanson et al., 2017; MOH, 2015).

In summer 2015, the GOL's Ministry of Health (MOH) invited dozens of partners to "develop a mechanism for coordination and collaboration in support of survivors of EVD as part of the National Response … [meant to] build consensus on the priorities for support; map out current service provision to survivors, planned interventions, and support; identify gaps in services; and define [the] National Package for Resettlement of all EVD Survivors" (Partner Coordination Workshop for the Support of Survivors [PCWSS], 2015, p. 2). Workshops and focus groups were held with survivors, who traveled from around the country to share their experiences, network with other survivors, and get referrals to appropriate government and support agencies for provisions, such as education scholarships for children or mental health services for survivors (Faley, 2022; Glayweon & Hanson, 2015; Hanson et al., 2017; International Research & Exchanges Board, 2015; Mercy Corps/USAID, 2015). Eventually, the National Package for Resettlement for Survivors was completed and disseminated to key stakeholders, including EVD survivors. Nevertheless, despite the billions in foreign aid, assistance, and donations to fight Ebola and help affected nations recover that was pledged (Eghrari et al.,

2021; James et al., 2019; MOH, 2015; PCWSS, 2015), funding for survivors later dwindled. By 2016, promised provisional services became scarce. At the same time, however, research indicated that EVD survivors' health impairments and diminished quality of life (QOL) would require extensive, long-term support services years after the crisis (Courtright, 2018; Davis, 2022; Glayweon & Hanson, 2015; James et al., 2019; PCWSS, 2015).

Some pledged services were fulfilled, including free medical examinations for survivors who participated in the various clinical phases of a study conducted by the U.S. National Institute of Allergy and Infectious Diseases and the Liberia MOH's Partnership for Research on Ebola Vaccines in Liberia (PREVAIL) (Dodd et al., 2016; Eghrari et al., 2021; Faley, 2022). But many of the commitments made to survivors and their families by the GOL and international donors like UNICEF never came to fruition. When post-EVD services were offered, implementation was often reported as haphazard (Courtright, 2018; Davis, 2022; Faley, 2022; Jagadesh et al., 2018; James et al., 2019; Transparency International, 2015). A qualitative review of relevant literature, including studies and news reports, indicates there are no known studies to date examining the impacts of failed service provision expectations on survivors' long-haul psychosocial stress (PSS) and diminished QOL.

More than half a decade after the crisis, this 2022 mixed methods study seeks to address this gap in the scholarship by assessing the state of EVD survivors and their well-being today, through their own experiences and perspectives. We begin with a summary of the literature. Then, applying a social determinants framework, we present our mixed methods approach and the study's key variables. In the results section, we present the findings of a quantitative analysis of survey data collected from 19 Liberian EVD survivors. Additionally, a qualitative analysis of their statements about their shared experiences triangulates the statistical findings and informs the causal mechanisms, elaborated upon in the discussion. We conclude by offering key policy recommendations and the theoretical implications of this study.

Theoretical Framework

This research applies a social determinants framework, in which we seek to understand how the living conditions and circumstances of EVD survivors can affect their psychosocial health outcomes. Social determinants (the circumstances of patients' lives) help spawn large health inequities around the globe. People who are made vulnerable by negative circumstances such as poverty or social discrimination can experience lower life expectancy, higher rates of child and maternal morbidity, and greater burdens of disease and hardship compared to their less disadvantaged peers (Alegría et al., 2018; Allen et al., 2014; Marmot, 2005; Marmot & Bell, 2016). The concept of social gradient explains that individuals from lower socio-economic backgrounds tend to have greater health risks and lower life expectancy; the impact of their social status can increase and eventually amalgamate over time, as they experience new and old hardships. Social determinants include inequitable distribution of resources, such as wealth, rights, or access to education (Alegría et al., 2018; Marmot, 2005; Marmot & Bell, 2016). Position on the social gradient can also negatively impact a person's risk of mental health disorders, access to services, and chances for improved health outcomes (Allen et al., 2014). When considering context, culture, and political-economic factors, we find that health impairments and cumulative stress serve as "mechanisms through which the impacts of social determinants multiply across the lifespan" (Alegría et al., 2018, p. 95).

This theoretical approach recognizes that we have to look beyond healthcare access for affected populations to the social determinants of health. These can include education, employment, and working conditions, sufficient wealth to lead a healthy life, healthy living and work environments, "and taking a social determinants approach to prevention—so-called lifestyle" (Weil, 2020, p. 1119). EVD survivors and their families can experience service provisions anywhere along a spectrum of possibilities; location on that spectrum affects overall health and life expectancy. EVD is linked to long-term disabilities, but no one survivor experiences the same types of impairments, QOL factors, or severity in relation to their needed

service provision or experiences. Marmot states, "Life expectancy runs in a graded way all the way from top to bottom, and there's an even steeper gradient for disability-free life expectancy" (Weil, 2020, p. 1119).

This research conceptually links the social determinants frameworks to examine the accumulating implications of the social determinants that survivors experienced before becoming infected with EVD, as well as after ETU discharge and their access to quality EVD-related services and support over time. Figure 1 depicts four stages that an Ebola survivor lives through and how QOL either improves or grows increasingly worse as a result of which services are provided.

Figure 1: *Long-Term Quality of Life Related to Disease Survivor Service Provision*
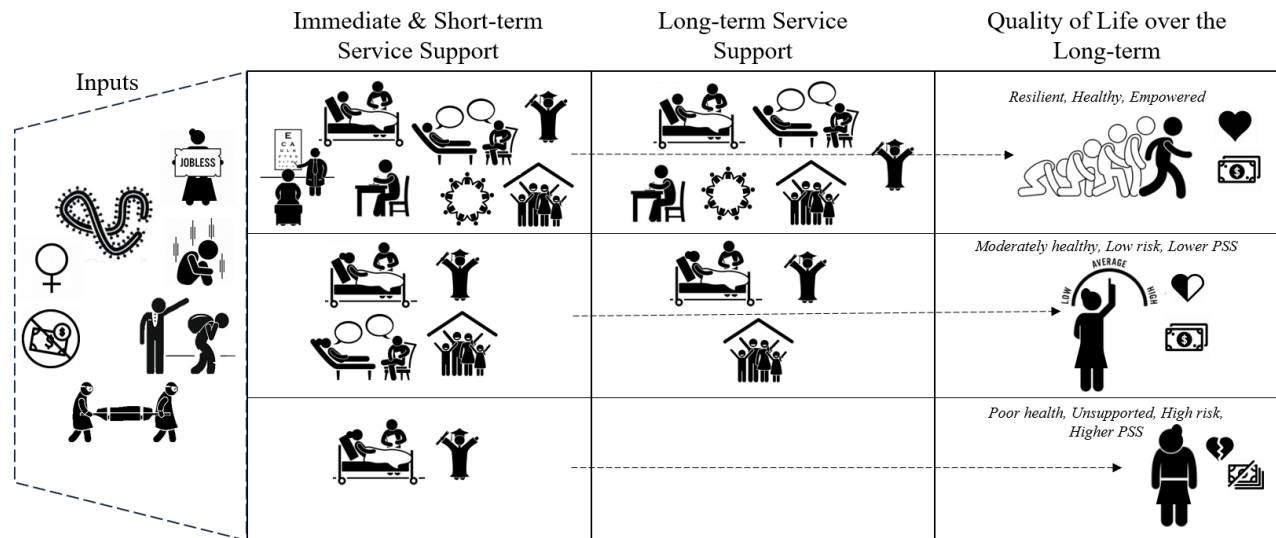
Before 2014, most Liberians' QOL was negatively impacted by extreme poverty, high illiteracy, and gender disparities, as well as by the recovering government, healthcare system, and public administration. (GOL, 2015; Ibrahim, 2019). Additionally, many citizens suffered wartime trauma or generational trauma (Kieh, 2009; Waugh, 2011), but only 1% had access to mental health services (WHO, 2017). The compounded impacts of poverty and war served as common input circumstances for the average Liberian. In this context, people who became infected with EVD could experience exponentially greater detrimental social determinants than their non-afflicted peers, including the health effects of having the disease, trauma from losing loved ones, loss of employment and housing, and social stigma as a result of their EVD status.

We may consider that survivors who received numerous immediate and short-term support services experienced some level of improvement in their QOL. As the first scenario in Figure 1 indicates, when survivors continue to receive most of these needed provisions in the long term, they are more likely to be able to rebuild their lives, heal, and become empowered and resilient as change actors in their own lives. This likely requires robust medical care, including ongoing checkups, clinical or medical treatment, and medication. They also need stable shelter, community support, educational and employment opportunities, and programs that address mental health and psychosocial stress (MHPSS) (Glayweon & Hanson, 2015; PCWSS, 2015; WHO, 2017). In contrast, if services are available only in the short term and are fewer in number, an EVD survivor is more likely to experience only moderate gains in QOL. If support services are few, temporary, and of low quality, likely leaving the patient with a lack of coping mechanisms and financial desperation, the risk of negative health outcomes is high, including long-haul EVD physical disabilities and mental trauma, all of which exacerbate over time. These issues can worsen health disparities, especially as resource supplies dwindle, regardless of public demand. This study examines common psychosocial stressors, using the

Perceived Stress Scale; common factors in diminished QOL; and the association of self-reported experiences with service support.

Literature Review

Long-Haul Implications and Needs of EVD Survivors

The literature offers evidence of the long-haul implications of EVD. Studies as early as 2015 imply that survivors displayed symptoms of post-traumatic stress disorder (PTSD), anxiety, and depression. Ebola survivors suffered higher rates of disability (an estimated 78.0 percent) than close contacts (11.1 percent) (James et al., 2019). In a randomized survey of survivors by the ESNL, 36.1% (95%CI 26.4–45.8%) of EVD survivors reported having sudden eyesight issues, including blindness, after discharge from an ETU. Debilitating body aches and/or joint pain were suffered by 64.9% (95%CI 55.2–74.6%), while 20.6% (12.4–28.8%) reported onset numbness in legs, which led in some cases to amputation (Glayweon & Hanson, 2015). Survivors mostly suffered limitations in their vision, mobility, and mental cognition a year after the outbreak. These health issues typically require long-term rehabilitation and support, or else symptoms can worsen over time (James et al., 2019).

Most survivors reported facing financial hardship due to their disease status. EVD left 13.3% of survivors in the study (95%CI 6.3–19.7%) widowed, often facing the loss of the family breadwinner. Immediate job loss was reported by 54.9% (45.6–64.4%) of survivors. Moreover, resettlement proved a challenge, due to stigma. Survivors reported physical and psychological abuse by family and community members, often as a means to make them move upon recovery: 12.5% (5.7–19.2%) reported physical abuse, and 14.6% (7.4–21.8%) reported psychological abuse (Glayweon & Hanson, 2015; MOH/IMS, 2014).

Gender served as an additional social gradient, as women in Liberia tend to have a lower rate of employment and face high rates of gender-based violence and discrimination (Abramowitz & Moran, 2012; MOH/IMS, 2014; Organisation for Economic Co-operation and Development [OECD], 2023). These issues frequently became magnified for women in EVD-affected homes. They often reported high rates of community and family stigmatization, which was statistically higher for female EVD survivors compared to women who were non-EVD-affected (Hanson et al., 2016). Children who were survivors or who lived in EVD-affected homes reported high rates of withdrawal, anxiety, worry, poor sleep habits, and discrimination. Moreover, many had issues reentering school due to lack of household income, as EVD often claimed one or more breadwinners, or because of being chased away by school staff and other students, who feared infection (Decosimo et al., 2019; Hanson et al., 2016).

In the years following the crisis, survivors continued to face anxiety, anger, guilt, sadness, substance abuse, flashbacks, and self-harm. Some were able to develop positive coping mechanisms. Proven strategies included engaging in EVD survivor associations, participating in EVD prevention and control interventions, and religious activities (Decosimo et al., 2019; James et al., 2019; MOH/IMS, 2014).

Services Promised to Liberian EVD-Affected Populations

In the later phases of the epidemic, the MOH, the Ministry of Gender (MOG) and INGOs such as ChildFund helped survivors by facilitating the following:

1. Temporary employment as caregivers, nurses, and workers in ETUs and quarantine centers (MOH/IMS, 2014)

2. One-time cash assistance (typically around $85–150 USD), as well as provision of food items and non-food items, such as cooking pots and clothing (MOH, 2015; PCWSS, 2015; Plan-Liberia, 2015)

3. Training for community leaders, first responders, governmental community health volunteers, and religious groups to support EVD survivors and to further advocate for reintegration into their communities (Carter Center, 2015; PCWSS, 2015)

4. Psychosocial and medical support services to EVD survivors and children and parents of EVD-affected households and communities (Decosimo et al., 2019; Hanson et al., 2016)

Most of these initiatives were funded for 3 to 6 months and ended by mid-2015 (PCWSS, 2015).

A handful of long-term initiatives were also implemented. The GOL planned for EVD-affected people to receive integrated comprehensive low- to no-cost health services, particularly for orphans and families directly made vulnerable by Ebola. Survivors were also to receive long-term specialized patient care with provisions for MHPSS. In particular, PREVAIL was launched to help survivors and to research Ebola. Coordinating with the GOL and ESNL, PREVAIL recruited an estimated 1,500 EVD survivors and 6,000 close contacts (household members and/or sexual partners) (Dodd et al., 2016; Eghrari et al., 2021; Faley, 2022; Fallah, 2015). The study design included screening all recruited participants for a history of family illness, as well as conducting a physical exam and blood tests. Some also were provided eye examinations. Ebola survivors and those who had entered an ETU but may not have had Ebola were asked to visit a PREVAIL clinic at 3, 6, and 12 months, followed by 6-month visits for approximately 5 years. Participants often had to travel long distances to complete these exams. The program had different phases. For instance, PREVAIL I was a randomized phase 2 trial of two vaccines to prevent EVD. PREVAIL II was a randomized trial of investigational therapeutics in patients with acute EVD. While survivors received medical checkups, few were randomly selected for medical treatment, and most served as participants/human subjects in the program's medical research (Browne et al., 2018; Dodd et al., 2016; Eghrari et al., 2021; Faley, 2022).

Additionally, the National EVD Resettlement Plan sought to ensure that survivors and EVD-affected households benefited from economic empowerment efforts, including educational scholarships for adults and orphaned children; job creation, cash grants, and small business grants estimated at approximately $6000 USD per person; training for survivors to work in healthcare and clinical case management; research participation; shelter provision, including relocation if needed; and livelihood and vocation training support (Faley, 2022; PCWSS, 2015). Affected children were to be placed in safe and appropriate homes, prioritizing family reunification. EVD-affected children were also to receive long-term educational scholarships from UNICEF and other agencies. All survivors were promised food security packages, access to cost-free healthcare, and support for MHPSS (CDC, 2023; Davis, 2022; Faley, 2022; Hanson et al., 2016; MOH, 2015).

Issues With Long-Term EVD Service Provisions

A 2017 study of 160 governmental and voluntary Liberian social workers indicated that some GOL initiatives were being implemented adequately, including the new education policy for EVD-affected children to have equal opportunity to enroll and attend school as non-affected peers. Additionally, GOL County Health Team & Ministry representatives continued efforts to promote survivors' reintegration and put an end to illegal discrimination. The social workers found, however, that most EVD survivors and their families were not receiving any support for MHPSS. Moreover, most EVD-affected homes in their catchment area could not afford school fees for children, and most EVD-affected children, including survivors, had not received GOL/UNICEF-pledged scholarships, with no explanation as to why (Hanson-DeFusco, 2019).

There appear to have been numerous instances in which committed EVD-related funds and projects were dropped by donors and implementers, or implementation quality was poor and mismanaged, or funds went missing, often related to instances of corruption. Early on, agencies such as Transparency International were calling on Liberia, Sierra Leone, Guinea, and the United Nations to conduct and make public comprehensive auditing of all Ebola emergency funding. By March 2015, as the crisis drew to a close, there was only one audit

in Sierra Leone and none were reported in Liberia or Guinea (Transparency International, 2015). The General Auditing Commission in Liberia concluded that nearly $1 million USD of approximately $13 million spent by the National Ebola Trust Fund in 2014 was not accounted for, that management was "marred by financial irregularities and material control deficiencies" (Giahyue, 2015, para. 3). There were also various rumors throughout the response that other funds went missing, including a sizeable portion of UNICEF scholarship funds, but that this was hushed up to mitigate public outrage (MOH/IMS, 2014).

The Red Cross publicly acknowledged that more than $5 million USD of aid to West Africa went missing due to fraud and corruption, including from overpriced supplies, salaries for ghost aid workers, and fake customs bills (British Broadcasting Corporation, 2017). In Sierra Leone, President Ernest Bai Koroma announced free healthcare for EVD survivors through the Comprehensive Program for Ebola Survivors (CPES). Government ministries were to use funds from international donors to provide these services. But a year after the EVD outbreak, USAID and DFID support for CPES dwindled, and soon the program ended, along with many other West African programs supporting EVD-affected populations (Courtright, 2018). In addition to discrepancies in promised services in the short run, there are indications that Liberian EVD-related policies and programs committed for the years after the crisis also fell short, causing frustration for many survivors, who felt abandoned or misled (BBC, 2017; Courtright, 2018; Davis, 2022; Faley, 2022; Hanson et al., 2017; MOH/IMS, 2014).

Purpose of the Study and Research Questions

Research on populations affected by HIV/AIDS and COVID-19 indicates that deadly diseases can have long-haul implications with continued negative effects on infected peoples' lives (Anabwani & Navario, 2005; Banati & Idele, 2021; Okoro & Whitson, 2017). However, proper medical, sociopolitical, and economic services can help mitigate these effects. Based on this premise, the purpose of this study is to explore the long-haul psychosocial health implications for Liberian adult EVD survivors and their diminished QOL in relation to EVD-related service provision and policies that were implemented from 2016 to 2022. This mixed-method study asks the following questions and poses related hypotheses.

1. Research question 1 (RQ1): What are common long-haul scaled psychosocial stressors (measured by the Perceived Risk Scale) that EVD survivors face in 2022 as a direct result of their disease status?

    Hypothesis 1 (H1): Liberian EVD survivors (ages 18–65) report moderately high levels of PSS as a result of long-haul effects of the disease.

    Hypothesis 2 (H2): Survivor PSS (aggregate and disaggregated items) is positively correlated with diminished QOL factors (eviction, stigma, unemployment, financial instability).

2. Research question 2 (RQ2): How does the provision quality of EVD-related services and policies (planned and/or implemented) impact EVD survivors' diminished QOL experiences (measured by common hardships experienced) and PSS?

    Hypothesis 3 (H3): Higher satisfaction rates of service provision are negatively correlated with negative QOL factors.

    Hypothesis 4 (H4): Higher satisfaction rates of service provision (governmental and PREVAIL) are negatively associated with survivors' PSS (aggregate and disaggregate).

This study tests H1 by quantitatively measuring PSS levels by asking if participants report experiencing seven specific stressors (see Table 1) and then totaling the number/percentage of stressors that they report having. We use the seven stressors in the official MOH PSS training manual developed during the crisis, which pulls from various studies on psychosocial stress (Decosimo et al., 2019; Foa et al., 1993; Foa & Street, 2001; Hanson et al., 2016; Hanson-DeFusco, 2022; Hembree & Foa, 2000; MOH/IMS, 2014; Plan-Liberia, 2015).

As there is no baseline, we compare contemporary average levels of PSS to rates reported in a 2015 study of EVD adult survivors. We further consider which stressors are the most prominent. Secondly, to address RQ2, service provision is measured by whether each survivor (target beneficiary) reports receiving specific provisions as promised by government policies and international stakeholder agreements, when, and to what satisfaction level, the null being that survivors who report poor service provision statistically experience significantly higher rates of PSS and diminished QOL. This study is not inclusive with regard to ethnicity and multi-cultural awareness. Lastly, we further analyze the qualitative statements of the survivors to triangulate the quantitative findings and explore their experiences in greater depth. This mixed method design can help inform causal inference (Dunn, 2017; Shadish, 2010; Shadish et al., 2002).

Table 1: *Study Variables*

Variable	Description	Type
Psychosocial stress	Individual reports still experiencing, as a direct result of EVD status: Anger, sadness, withdrawal, poor eating habits, poor sleeping, anxiety/extreme worry, flashbacks. Disaggregated (yes 1, no 0); aggregated total of 7 possible psychosocial stressors.	Dependent variable(s)
Quality of life indicators due to disease status	Experience ongoing stigma (yes 1, no 0)	Binary
	Financial issues or not enough work (yes 1, no 0)	Binary
	Been illegally evicted (yes 1, no 0)	Binary
	Working before you got sick with Ebola (yes 1, no 0)	Binary
	Level that government policies supporting Ebola survivors helped individual (1 not at all; 2 somewhat; 3 a lot)	Binary
Service provision experiences	Received assistance (stipend, foodstuffs, etc.) after being discharged from the ETU (yes 1, no 0)	Binary
	Level of satisfaction with this assistance, on a scale of ☹ (not at all 1) to ☺ (extremely satisfied 5)	Scaled
	Individual and/or family member in household participated in PREVAIL study; if yes (1), what year?	Binary; numerical
	Dropped out of PREVAIL during project (yes 1, no 0)	Binary
	Rate your experience with PREVAIL as a participant (0 very poor–3 very high)	Scaled
	Reports experiencing poor or inequitable treatment by PREVAIL staff (yes 1, no 0); explain	Binary
Demographics	Have biological/born or adopted children you care for? (yes 1, no 0)	Binary
	If you have children you are responsible for, do they currently go to school? (yes 1, no 0)	Binary
	Gender: Male (1) Female (2) Other (3)	Categorical
	Age (years)	Numerical
	County live in (name)	Categorical
Resiliency statements	World forgot about us. (yes 1, no 0)	Binary
	Ebola changed everything. (yes 1, no 0)	Binary
	I am an Ebola hero. (yes 1, no 0)	Binary

Methods

Context

This 2022 research used a mixed-methods design, utilizing semi-structured snowball surveying of Liberians who are Ebola survivors. The project received ethics approval from the University of Texas—Dallas (IRB#22-528). The primary investigator (PI) worked as an EVD responder with the MOH, MOG, and ESNL throughout the Liberian crisis. This study builds on some of her previous research on EVD-affected people (Decosimo et al., 2019; Hanson et al., 2016). Additionally, one of the co-investigators is an EVD survivor, with medical training and field survey experience of EVD survivors. All investigators designed the survey, incorporating feedback from ESNL and GOL representatives. The survey captured data from Liberian survivors who voluntarily consented to participate.

Participants

Of the 25 people who opened the survey, a total of 19 participants confirmed they are Ebola survivors, consenting to participate in the survey to capture self-reported information regarding their experiences as survivors since the outbreak in 2014–2016. All information is de-identified and anonymous. Participants are Liberian survivors who are currently between the ages of 18 and 65. Survivors were recruited from two Liberian counties: Montserrado and Margibi. Several people did not consent and two were not survivors; thus their data was fully excluded from the study. Of the participants, 14 (73%) are female. Participants' ages range from 25 to 49 years old, with nearly half qualifying as youths (under 35 years old) per age categorizations of the GOL. All participants report first exhibiting Ebola symptoms between July 31 and November 11, 2014; all appear able to recall the exact day that they first became sick. All participants report having one or more children, biological or adopted, typically due to the loss of parents during Ebola. Of the participants, 16 (84%) had steady work before the 2014 outbreak, indicating that they may come from moderately low- or middle-income backgrounds. They were also able to access the study online, indicating that they are at least semi-literate and live in urban settings where Wi-Fi is available.

Instrumentalization

Psychosocial stress scales are frequently included in studies that examine psychosocial stress reported by individuals who have experienced horrific events. These scales are also used to help diagnose post-traumatic stress in resource-poor environments, where access to mental healthcare professionals is limited (Foa et al., 1993; Foa & Street, 2001; Hanson et al., 2016; Hembree & Foa, 2000). PSS scales that capture issues such as poor sleep, anxiety, and social withdrawal are useful means for assessing stress, helping researchers understand how different circumstances may influence individuals' feelings and perceived stress (DAS, 2022). This research builds specifically on previous research in Liberia examining PSS levels and diminished QOL in Ebola survivors and their families; it uses a government-authorized PSS scale for non-clinicians (Decosimo et al., 2017; Hanson et al., 2016). The full semi-structured survey is presented in the Appendix.

Data Collection

After approval by the university internal review board in March, the survey was launched on Qualtrics from May to July 2022, using a snowball approach, on the Liberian Ebola Survivor group and Ebola Information Facebook pages. Snowball sampling (or chain-referral sampling) is a nonprobability sampling method in which initial study participants share the study with acquaintances to expand recruitment. Use of social media in snowballing can be an effective means

of facilitating the distribution of the digital survey to hard-to-reach populations (Chambers et al., 2020; Dusek et al., 2015; Leighton et al., 2021). The survey included an informed consent process and was fully anonymous, excluding all identifiable data, such as name, birthdate, and location, to protect participants. Due to privacy and ethics concerns, neither the data nor the source of the data can be made available.

The survey was translated into both standard English and Liberian English. The instrument asked participants to report if they are experiencing any of the following stressors as a direct result of their disease status: anger, flashbacks, poor sleep, anxiety, withdrawal, poor eating (overeating or undereating), and sadness. This study scales the total number of stressors that each participant is experiencing (up to 7 total). Cronbach's alpha was conducted to assess for inter-rater reliability (0.43). Scales with a small number of items can be associated with lower alphas (Perry et al., 2004). We therefore used both scaled PSS levels and individual stressors in the analysis. Survivors were also asked about their QOL, including their financial situation, work experience, experience with stigma within their communities, and ability to care for their children (if applicable). Third, we asked about their personal experiences and perceptions of government and international Ebola-related programs, including PREVAIL.

The results section presents quantitative and qualitative data. All open-ended statements made by participants are assessed for naturally occurring trends that can be quantitatively codified. The survey sample size is limited and not randomized. Descriptive statistics and correlation analyses performed using Stata provide indications of ongoing diminished QOL, poor service experiences, and high PSS. We conducted bootstrap regression modeling to further test statistical significance. The qualitative analysis of this study plays various crucial roles, including triangulating the quantitative findings. More extensively, however, survivor statements explore in depth the meaning behind their life experiences as Ebola survivors, their struggles, and their needs over half a decade after being discharged from an Ebola Treatment Unit (ETU). As this study implies, their disease status continues to have a significant impact on their QOL.

Results

Long-Haul Psychosocial Implications

The statistical analysis indicates that, on average, the 19 survivors report suffering from 5.25 of the 7 stressors (95%CI 4.65–5.85), or 75% aggregated PSS, as a direct result of their EVD status in 2022. These stress levels appear higher than PSS levels among Liberian female adult survivors captured in 2015, who at the time reported experiencing 36% of total possible stressors, compared to non-EVD peers experiencing significantly less PSS (13%, $p < 0.05$) (Hanson et al., 2016). Therefore, we posit that EVD appears to have long-haul psychosocial effects that may increase over time for adult survivors. Figure 2 indicates that the most common long-haul stressors appear to be anger (94.4%, 95%CI 82.7–99.9%), flashbacks (94.1%, 81.6–99.8%), and anxiety (88.2%, 71.2–98.9%).

Figure 2: *Percentage of Liberian EVD Survivors Reporting PSS Due to Disease Status in 2022*

Category	Value
Anger	94.4
Flashbacks	94.1
Anxiety	88.2
Withdrawal	76.5
Sleep	70.6
Sadness	41.1
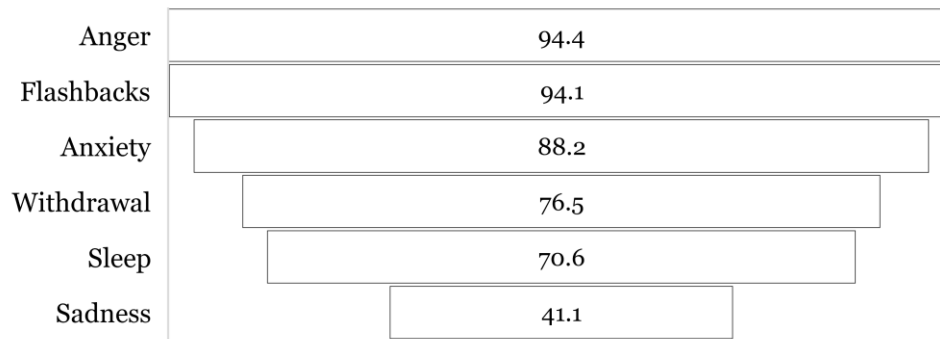
Female survivors tend to suffer significantly higher PSS rates (5.58 symptoms of a potential 6, compared to men who report suffering 4.25 on average (t = 2.33, p < 0.05). These PSS findings indicate that there is a pressing need for ongoing MHPSS services. Yet, to what extent have these services been provided?

Long-Term Diminished Quality of Life

An initial quantitative analysis of data indicates that of the 19 survivors, 35.2% report experiencing stigma, and 29.4% continue to face issues of illegal eviction. Strikingly, these rates appear to be similar to reported rates of stigma and eviction in 2015 (Glayweon & Hanson, 2015; Hanson et al., 2016; James et al., 2019). A pairwise correlation analysis further indicates that, overall, aggregated PSS and disaggregated PSS stressors are not significantly correlated with experiencing disease-status stigma or illegal eviction (see Table 2). However, survivors who report currently experiencing stigma are more likely to suffer from ongoing sadness (r = 0.47).

Table 2: *Correlation Analysis of Psychosocial Stressors Among Liberian Ebola Survivors in 2022*

	Total PSS	Anger	With-drawal	Poor sleep	Poor eating	Anxiety	Sadness	Flashbacks
Quality-of-life indicators (report experiencing = 1/no = 0/no statement = blank) - *Point biserial*								
Disease-status stigma	0.06	0.19	-0.17	-0.06	-0.13	-0.11	0.47**	0.19
Eviction due to Ebola	0.34	0.16	0.36	-0.15	0.28	0.24	0.31	-0.39
Financial/work insecurity currently, due to Ebola	-0.40*	-0.30*	-0.46**	-0.06	-0.30*	-0.11	0.13	0.19
Unable to afford schooling for child(ren)	0.53***	-0.09	0.66***	0.17	0.08	0.43**	0.21	-0.09
Disease service provision (report experiencing = 1/no = 2/no statement = blank) - *Point biserial*								
Received immediate services after ETU	-0.41*	-0.09	-0.14	-0.16	-0.28	-0.09	-0.44**	-0.06
Dropped out of PREVAIL study	-0.45*	0.31	-0.25	0.15	0.20	0.20	-0.18	0.14
Unequal or poor treatment by PREVAIL	0.56**	0.19	0.12	0.48*	0.40*	0.27	-0.12	0.19
Quality of service experiences - *Pearson's R*								
Satisfaction w/ service provision (1 = low, 5 = high)	-0.24	-0.01	0.17	-0.10	-0.48*	0.38	-0.77***	0.05
Satisfaction w/ PREVAIL experience (1 = low, 3 = high)	-0.26	-0.05	0.01	-0.03	-0.32	0.13	-0.02	0.26
Resilience statements (made = 1/not made = 2/no statement = blank) - *Point biserial*								

World forgot about us.	0.06	-0.06	0.45*	-0.16	0.30	-0.09	-0.30	-0.06
Ebola changed everything.	-0.18	0.30	-0.12	-0.21	-0.17	0.11	-0.27	-0.18
I am an Ebola hero.	-0.08	-0.54**	-0.20	-0.17	-0.35	-0.13	0.07	-0.09

Note: $^*p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$. *Italicized* = correlation analysis.

Many of the survivors' statements detail how ongoing stigma affects not only their own lives in 2022, but also the lives of members of their household, including their children.

> "As a survivor ... [I] go through pain, trauma, stigma from Ebola." – 34-year-old woman

> "My children are reminded always of being Ebola-affected when they're in confusion [in conflict] with others kids on campus." – 49-year-old woman

Notably, testimonies by other survivors indicate that stigma surrounding their children may be on the decline, indicating an increase in potential policy success.

> "Early during 2014-2015 the[re] was stigma, but now no one can stigmatize him [my son]." – 31-year-old woman

> "[My children] are welcome like other kids in school." – 38-year-old man

Survivors' long-term financial insecurity and inability to fund children's schooling appear pressing on individual PSS levels. Financial insecurity is negatively correlated with withdrawal, anger, and poor eating habits, as well as overall stress levels. Most survivor statements indicate they were able to gain only temporary employment through EVD-related programs that were eventually terminated and have not worked since, because of their disease status.

> "Only PREVAIL was able to employ me after Ebola, but later terminated the contract." – 37-year-old woman

Parents with no employment also appear to face graded levels of stress in their inability to care for their children. Their statements of financial insecurity often are tied directly to personal tragedies such as food insecurity, the loss of a household breadwinner who died from Ebola, taking in EVD-affected orphans, and disease-related stigmatization.

> "[I have] no funding, [because I am a] single mother [and] lost my husband to Ebola, so I can't afford sending all the kids." – 36-year-old woman

> "[I have] no work since Ebola ended so I survive on garden to feed my kids ... The help I need now is the orphan I'm caring for needs to go school, no good sleeping place and also business to feed on." – 49-year-old woman

> "I want my children and I to go to schools, also money to help me with money to sell for us to get food." – 28-year-old woman

There is no significant difference between fathers worrying about how to pay for their children's school fees compared to EVD-survivor mothers ($\chi = 0.65$, $p < 0.10$); it is a shared concern across genders. Parents and guardians who cannot afford schooling for some or all of their children appear more likely to have higher PSS levels, including experiencing withdrawal ($r = 0.66$) and anxiety ($r = 0.43$). Over half of the EVD survivors expressed being willing to learn new skills in hopes of gaining employment and the desire to be financially empowered. Yet as the next section examines, many programs for vocational and educational support of EVD-affected households promised in the National EVD Resettlement Program were not implemented.

Experiences With GOL EVD-Related Service Provision, 2015–2022

Survivors were asked to rate (1 low to 5 high) their overall satisfaction with governmental services they received, mainly related to the National EVD Resettlement Plan. The correlation analysis (Table 2) implies that survivor PSS levels are negatively correlated with receiving immediate assistance after ETU discharge (r = -0.41), particularly sadness (r = -0.44). However, a survivor's satisfaction level with governmental support services appears to have little relationship to long-haul PSS. Higher satisfaction rates of service provision do appear negatively correlated with negative QOL factors, including experiencing contemporary stigma (r = -0.55), issues of eviction (r = -0.45), and the inability to pay school fees (r = -0.33).

Of the 19 survivors, 17 (89.5%) agreed that, in general, the government's policies did not help Ebola survivors in the long run. Of the 19 participants, 18 (94.7%) felt that international donors no longer provided sufficient support for EVD survivors, and, more tragically, that the world had forgotten about them. Most survivors shared that in the years after recovery, they lived in dire poverty and often survived day-to-day on depleted resources. All of them (100%) see themselves as heroes for surviving EVD and helping to combat EVD during the crisis. But their disease status also continued to make them vulnerable in various ways. Thus the inequitable distribution of EVD-related benefits and services, the lack of provisions by the GOL, or the lack of support pledged by international development stakeholders, often appear in their narratives as emotional disillusionment.

> "We had a promised policies that was not offered. We still stand here to suffer from a lot of things." – 37-year-old woman

> "The government of Liberia promise us resettlement and stay awaiting their promise." – 40-year-old man

> "The government made a promise of resettlement to survivors, up to present no avail, even about survivors' kids going to school free was all lies." – 31-year-old woman

Of the 19 participants, 18 (94.7%) expressed dissatisfaction with the National Resettlement Plan's failure to come to fruition, as detailed in formal materials disseminated and during ESNL meetings.

> "Still waiting on that promise [GOL resettlement promise], because the promise [h]as cause us so much, where we live others think that we are rich because the government promise to us resettlement." – 28-year-old woman

> "Promise was to resettle us but did not live up to their promise, after all our belongings got burn because of Ebola … [assistance could] help to survive on." – 40-year-old woman

> "Resettlement from the government of Liberia didn't [happen] … I need funding for my kids and [my] education and also support for business to sustain my family." – 38 year-old man

Overall, disappointment with general QOL provisions, such as vocational training, employment, resettlement, and scholarships seems to have been a shared experience for nearly all survivors. In contrast, their experiences with medical programming and research vary.

Experiences With Internationally Funded EVD-Related Medical Programs

There were various short-term grant projects after the crisis in Liberia, funded by bilateral agencies such as USAID and various foundations, which were meant to facilitate improving medical care and mental health services for survivors and close contacts. There were fewer long-term health initiatives offered. However, one of the largest was PREVAIL, which offered ongoing medical screenings and consultations linked to clinical trials on mitigating the effects of Ebola (Browne et al., 2018; Dodd et al., 2016; Eghrari et al., 2021; Faley, 2022).

Our 2022 study asked participants about their PREVAIL experiences. All 19 participants report joining between 2014–2016, yet their PREVAIL experiences greatly vary. Five (26%) elected to drop out early from the study, often due to negative experiences as study participants. Ten (52.3%) report experiencing inequitable, poor, or discriminatory treatment by PREVAIL staff in at least one instance. Survivors who report experiencing poor treatment by PREVAIL tend to demonstrate significantly higher PSS rates ($r = 0.56$), including poor sleep ($r = 0.48$) and poor eating habits ($r = 0.40$). At the same time, early participant dropout is significantly correlated with lower PSS ($r = -0.45$). While implementation quality ratings by EVD participants in PREVAIL are not significantly associated with PSS, overall participant satisfaction appears generally poor: 42% reporting being extremely unsatisfied with services.

> "PREVAIL had a good start, welcome us with smile and great respect, snacks as breakfast and later lunch, as [time goes by] no, snacks was out and we started to overstay … . The rumors was about after the five years study we could have benefit … . My concern is PREVAIL ended with no benefit for survivors after five years of study." – 40-year-old man

> "I participate in the study and the beginning was fine but later the staffs started using harsh words on us, their interest for survivors decrease and cause dissatisfaction for me." – 35 year-old-man

> "[My children] face stigmatization because they come from an Ebola-affected home, and some of them are child survivors … . [As a participant in the PREVAIL study], my concern is our benefit, because some of us have eyes problem, where we going to get treatment from?" – 37-year-old woman

> "The study started with snacks morning hours and little lunch follow noon hours, but all changes, we arrive by 8:00 am and stay 'til 4:00 for only lunch, [then] change of attitude of PREVAIL staff towards survivors, became too harsh." – 45-year-old woman

Most of their statements indicate that PREVAIL service quality at first was strong but began to falter as time went on. Chief complaints about PREVAIL include a) requirement burdens for participants, such as time and cost implications; b) insufficient financial compensation; c) inequitable distribution of service quality or poor explanation of the random-selection process for critical disability services, such as partial or full blindness caused by EVD; and d) potential ethical violations on the part of staff, such as discrimination and abuse. Various survivors used the word "harsh," the colloquial use of which in Liberia can indicate the use of foul language, name-calling, hurtful impatience, and intolerance. Most survivors noted feeling misled by PREVAIL staff that survivors who consented to be human participants would receive medical treatment for their disabilities, in addition to the regular medical diagnoses all survivors received.

> "PREVAIL has been good … help us to know our health status; my issue is PREVAIL ended the study without any [medical or financial] benefit for survivors." – 28-year-old woman

> "The [PREVAIL] study didn't favor us survivors even when [we went] to protest … since [then] no action … My eyes are having problems and I told the study but no solution had been taking towards that [when promised]." – 40-year-old male

Similar statements by survivors criticize other international programs, such as the John Snow Inc. Ebola Transmission Prevention & Survivor Services program, a two-year (2016–2018) USAID-funded initiative.

> "JSI survivors care policy program. Failed and they went with impunity." – 43-year-old man

Documentation related to the resettlement plan by the GOL and internationally funded interventions such as PREVAIL indicates their intent was to alleviate many of the hardships that were lowering QOL for survivors (Dodd et al., 2016; Hanson-DeFusco et al., 2022; IREX, 2015; Office of the Inspector General, 2018; UNICEF, 2015). Yet both the initial qualitative and quantitative analyses validate all study hypotheses. The study's

small sample size limits the generalizability of findings to larger populations; thus we bolstered the quantitative analysis using bootstrap regression modeling.

Multivariate Modeling

We conducted nonparametric bootstrapping that involves randomized sampling with replacement (see Table 3). This method excludes any assumptions concerning underlying population distribution. It serves as an alternative for hypothesis testing in small-*N* studies. By conducting bootstrap regression modeling, we may assess the model parameters' variability and, more so, the extent of random variation within each coefficient related to incremental changes in data values (Cheng et al., 2016; Dwivedi et al., 2017; Munoz et al., 2018).

Table 3: *Bootstrapped Regression Modeling of 2022 Liberian EVD Survivors' Aggregate PSS Level*

	Coefficient			
	Constant	No funds for school fees (1-yes; 0-no)	Level of satisfaction with service provisions (1-5 strongly agree)	Poor treatment by PREVAIL staff (1-yes; 2-no)
Avg. bootstrap estimate	2.08	2.96***	-0.12	1.27**
Bootstrap SE	1.33	0.46	0.31	0.63
Bias	-0.11	0.08	0.00	0.10
Normal CI	(-0.52–4.68)	(2.05–3.87)	(-0.73–0.50)	(0.05–2.50)
Percentile CI	(-0.96–3.80)	(2.29–4.00)	(-0.69–0.57)	(0.28–2.48)
Bias-corrected CI	(-0.53–3.85)	(2.03–3.69)	(-0.69–0.50)	(0.12–2.30)

Notes: Two bootstrap confidence intervals (CI) are shown for each coefficient. SE = standard error.
*** $p < 0.01$, ** $p < 0.05$, * $p < 0.1$. Number of observations = 13, replications = 632. Adj. R^2 = 0.59, Wald $\chi2$ = 66.48, p = 0.00.

The coefficients for survivors having insufficient funds to send their children to school and experiencing poor or discriminatory treatment during the PREVAIL project (2015–2019) are significant. The level of overall satisfaction with the services that were provided since Ebola appears limited. We note that the modeling appears significant (replications = 632). In Table 3, if a survivor lacks the money to pay their children's school fees, they will predictably experience 43 percent higher (2.96 points of a possible 7) PSS than peers who can pay. Additionally, all survivor participants in this study confirmed that they served as human participants in the PREVAIL clinical trials. Those who stated that they were treated poorly or were discriminated against by PREVAIL staff appear to have an 18 percent (1.27 points) higher rate of PSS.

Discussion

Disease-affected people are made more vulnerable by their health status, especially when it is compounded by marginalization and poverty. Often, infected patients suffer added issues of financial hardship, stigmatization, health complications that require extra medical care, and the need for mental health services and tailored social services to support their healing and social reintegration. When these needed policies and programs fail or are inadequate, patient vulnerability can increase to catastrophic levels. Poor access to needed health care and poor quality of care increase the chances of medical complications, death, and poor mental health (Banati & Idele, 2021; Kola et al., 2021; Moreno et al., 2020). Additionally, the failure of promised services due to corruption, mismanagement, or improper implementation can have a notable impact on disease-affected people's physical and mental health (Anabwani & Navario, 2005; Banati & Idele, 2021; Campbell, 2003; Courtright, 2018; Davis, 2022; Faley, 2022; Foster, 2005; Moreno et al., 2020).

In keeping with the above, social determinant frameworks and social gradient theory posit that people from lower socioeconomic backgrounds may face greater health risks and lower life expectancy, and the impact of their social status can be exacerbated by experiences over time without proper intervention (Alegría et al., 2018; Allen et al., 2014; Marmot, 2005). "Social determinants of health play an important role in the epidemiology and transmission of Ebola. … Poverty, cultural beliefs and practices and prior ineffective public health messages have all played a role in the emergence of Ebola" (LaBrunda & Amin, 2020, p. 103). From a social determinant perspective, most Liberians in general have higher rates of mental health issues related to poverty, malnutrition, high rates of sexual violence, and surviving the war (Kirsch et al., 2017; Marsh et al., 2021; Medecins san Frontieres, 2009; Tayler-Smith et al., 2012; WHO, 2017).

Ebola further complicated EVD survivors' psychosocial health. First, the results of our 2022 study indicate that Liberian EVD adult survivors report moderately high levels of PSS, as a result of long-haul effects of the disease. Many survivors appear to be affected by long-term stress, mainly anger, flashbacks, and anxiety, which they link directly to their disease status. Their levels of stress appear comparable, if not higher than, reported aggregated PSS levels and individual stress levels among survivor data captured in 2015 (Decosimo et al., 2019; Glayweon & Hanson, 2015; Hanson et al., 2016; MOH/IMS, 2014). Nevertheless, in the wake of the EVD recovery, access to mental health and psychosocial services dwindled. Only one in 100 Liberians have regular access to MHPSS treatment, outside of religious and spiritual support (Kirsch et al., 2017; WHO, 2017).

Second, the study shows that survivor PSS (aggregate and disaggregated items) is positively correlated with diminished QOL factors. People made vulnerable by disease experience different levels of community or familial support over time. During the crisis, when survivors returned home, they were regularly shunned by their communities, often out of fear of their disease status. Additionally, EVD-affected people were often viewed as cursed, often linked to cultural concepts of voodoo, in which illness falls upon a person based on a hex or bad luck, all of which can spread to others through proximity (CDC, 2015; Decosimo et al., 2019; Faley, 2022; Hanson et al., 2016; Nurhussein, 2016; United Nations Development Programme, 2014; Schwartz, 2019). Most survivors made statements reflecting the ongoing issues in 2022 of disease-related stigmatization, but there are some indications that stigma against EVD-affected children may have declined over time. This policy achievement may be in part due to the notable effort by the Ministry of Education, the MOH, and the MOG starting in 2015 and continuing over the long term to build awareness, promote inclusion, and mitigate stigma against EVD-affected peoples, especially children in schools (Decosimo et al., 2019; Kirsch et al., 2017; Miller et al., 2018; MOH/IMS, 2014; UNICEF, 2015).

Despite the billions in funding to support EVD mitigation and recovery and the pledges by the GOL and international community to support survivors over the long term, Liberia still appears to suffer the lack of resourcing it needs to meet the needs of the survivors and their close contacts. Most survivors were hopeful that the National Resettlement Plan would help secure desperately needed services, mainly education and vocational training support, MHPSS, and equitable rights against discrimination. The largest grievance among survivors appears to be the failed promise to be resettled in communities where they could find strength and support.

Third, our analysis reveals that higher satisfaction with service provisions is negatively correlated with negative QOL factors. Survivors who ranked governmental provisions as good were less likely to report eviction, inability to pay for their children's schooling, and contemporary issues of stigma due to their disease status. However, most survivors ranked their satisfaction with service provisions as low, indicating a disappointment in anticipated and needed support. Fourth, the correlation analysis and bootstrapping indicate that higher satisfaction with internationally funded service provisions (governmental and PREVAIL) is not statistically associated with survivors' PSS (aggregate and disaggregate). Satisfaction levels with provision support may not be a robust indicator related to stress. However, specific experiences that were common among survivors' testimonies are significantly related to stress, mainly being able to provide for

children financially and how they were treated when participating in medical studies.

Ebola came with increased financial hardships for the overall Liberian population, but more so for EVD-affected households. Financial hardships added to their psychosocial burden (Department of Global Communications, 2020; Rogers & Dixon, 2015; Schwartz, 2019; Transparency International, 2015). Even after Ebola ended, survivors often had ongoing post-Ebola physical complications, as well as "lack of finances due to loss of their possessions or jobs during the Ebola outbreak [as] … major reasons for their current low socio-economic position" (James et al., 2019, p. 675). While the Liberian economy improved after 2016, including a rise in gross national income (Kuperman, 2023; Pilling, 2018), all 19 participants in the study report suffering from long-term financial hardships as a direct result of their disease status. The inability to fund their children's schooling is related to statistically higher levels of PSS, according to the bootstrap analysis. A qualitative analysis of their statements reflects an internalized sense of failure related to not providing for the educational welfare of their children. Most of these statements evince sentiments of helplessness, desperation, and failure as providers. Research indicates that parental anxiety is often internalized as negative attitudes toward self and low morale. Anxiety also can be passed down to children (Brumariu & Kerns, 2010; Dollberg et al., 2021).

In the short term, most INGO-led and internationally funded EVD programs supported survivors and their families with immediate needs assistance. All 19 survivors received healthcare access, temporary financial support, and employment with EVD-related programming, which is correlated to lower long-haul stress. Many international partners, such as USAID, pledged ongoing EVD survivor support in the 2015 Partner Coordination Workshop for the Support of Survivors. However, as new international crises, such as the Nepalese earthquake, took center stage, funding for EVD survivors dwindled (Davis, 2022; Hanson et al., 2017; MOH/IMS, 2014). Some long-term initiatives were fulfilled, such as PREVAIL and the Ebola Transmission Prevention & Survivor Services program, but participants' testimony suggests these programs likely experienced diminished levels of quality, along with instances of implementation failure over time. Other investigations and testimonies corroborate participants' statements (Browne et al., 2018; Davis, 2022; Dodd et al., 2016; Faley, 2022; Office of the Inspector General, 2018; PCWSS, 2015).

Importantly, negative interactions (mainly harsh or discriminatory treatment) by medical and administrative staff during the PREVAIL study appear linked to higher rates of PSS and specific stressors, such as anger. Comparatively, if participants dropped out early from PREVAIL, they had lower PSS. These findings may indicate a larger problem that may need further formal investigation by the GOL and the U.S. National Institute of Allergy and Infectious Diseases, about the extent to which vulnerable EVD survivors experienced instances of "too harsh" behavior on the part of PREVAIL staff and diminishing quality of program implementation over time. Moreover, an investigation should also determine whether these negative experiences are symptoms of a larger ethical issue with the integrity of the PREVAIL study in general and how it treated its research participants.

According to Kim et al. (2013), one of the "biggest obstacles facing global health is a failure of delivery. The gritty business of actually delivering health care in developing countries has not attracted much academic interest" (p. 1060). Research on the implications of healthcare delivery and global health policies for impoverished populations, in relation to global initiative funding and program designs implemented ad hoc in any country, is fragmented, often looking through an insular lens at the general impact on a health-affected population in need (Braithwaite, 2018; Farmer et al., 2013; Kim et al., 2013; Kruk et al., 2016; Office of the Inspector General, 2018; Waage et al., 2015). "What scant attention to research and teaching of health-care delivery exists is focused on specific questions about particular interventions (e.g., the feasibility of administration of a vaccine and its cost-effectiveness) rather than on the broader systems and conditions" (Gostin & Friedman, 2014, p. 1061; Kim et al., 2013). Health policy outcomes can be adequately assessed only by researching the experiences of disease-affected people after they receive treatment, determining whether

the medical and ongoing public services remain accessible, and measuring the quality of the care and support afforded to patients in the long run (Kruk et al., 2016). A social determinant framework can more robustly capture external factors related to quality care.

Research suggests that a social gradient can exist where positive healthcare experiences and outcomes are related to socioeconomic status (Zlotnick et al., 2018) as with rates of education/literacy (Hill-Briggs et al., 2020). Identifying who is more likely to be affected by external factors, such as socio-economic hardship, disabilities, level of education, and social status, is crucial to informing any future efforts taken for equitable global health policymaking for disease-affected populations. Presently, information on policy decisions targeting adverse social conditions can be limited. Patient care strategies may be improved with more robust data on the specific social risks that the target population faces so that needed adaptations can be made to their healthcare treatment (Gottlieb et al., 2019; Hill-Briggs et al., 2020; Zlotnick et al., 2018). Likewise, community-level strategies for patients can be adopted in order to target "improving the broader health and well-being of the local population through a mix of direct investments in communities and collaboration through multisector partnerships" (Gottlieb et al., 2019, p. 243).

Limitations

We used a mixed methods approach, blending quantitative analysis with the qualitative exploration of survivors' experiences and the intrinsic meaning behind them in relation to social determinants of health and mental health. Our main objective in collecting open-ended answers was to explore narratives that reveal the essence of participants' individual EVD-related experiences (Cook et al., 2008; Dunn, 2017; Shadish et al., 2002). The generalizability of the statistical findings is limited by the small sample size. This study, like other small *N* studies, can only present simplified statistical analyses, establishing correlation patterns but not necessarily causal mechanisms beyond associated relationships. Bootstrap modeling can better inform generalizability but in itself has limitations (Cheng et al., 2016; Cook et al., 2008; Dwivedi et al., 2017; Shadish, 2010; Shadish et al., 2002). Future larger-scale and/or randomized control trial studies may better inform the generalizability of these results to the general EVD population.

There are pros and cons for surveys to include either a 5-point Likert scale for survey items or 2-point answer options (Chyung et al., 2017; Dunn, 2017; Shadish et al., 2002; Voutilainen et al., 2016). Likert scales can better assess the magnitude to which participants are experiencing different PSS stressors (Chyung et al., 2017; Decosimo et al., 2019; Voutilainen et al., 2016; WHO, 2017). The PSS Likert-based survey has been implemented in various mental health studies of Liberian survivors (Decosimo et al., 2019; Hanson et al., 2016; WHO, 2017). We did not scale the levels of PSS due to concerns about the length of the study and the user-friendliness of online surveying. Several Liberian experts recommended at the time that we avoid complicating the survey with additional scaling. Future research may also benefit from pilot-testing both Likert and binary scales when investigating PSS among survivors.

Conclusions

The purpose of this study was to learn directly from EVD survivors what they experienced in the more than half a decade after the crisis. When we examine the EVD crisis and support for survivors through their eyes, we can better understand the context for their belief that the world has forgotten about them. Even though they may no longer carry the virus, its physical, financial, and social burdens often have not diminished with time. Survivors report continuing to face high rates of stress, comparable to, if not higher than, rates reported during the 2014–2016 crisis. The long-haul psychosocial well-being of survivors over time is linked to diminished QOL factors, as well as the quality of pledged service provisions.

Based on the results of this 2022 study, we recommend that more MHPSS programs specifically targeting the

long-haul PSS needs of survivors be developed and made accessible. This must be done with the clear intention of providing more ethical, patient-sensitive treatment on the part of medical staff, based on survivors' reports of negative experiences with initiatives such as PREVAIL. However, providing improved MHPSS services alone is not enough to address the social gradients that challenge survivors' health and quality of life. International funding commitments previously made can be secured through networking INGOs and multilateral donors. The GOL can again focus on prioritizing members of the ESNL and their families for educational scholarships and vocational training, an initiative with proven benefits that is strongly desired by survivors who want to become actors of change in their own lives and communities. Moreover, the GOL and stakeholder partners may reassess the potential of resettling survivors, as initially laid out in the National Resettlement Plan, prioritizing relocating survivors to live closer to one another and EVD-related healthcare services.

There is still an opportunity to make a difference in the lives of one of the world's most vulnerable disease-affected populations. This study takes a first step in considering the long-term social factors that threaten survivors' well-being. Future studies can help better identify survivors' negative experiences and their continuing needs for service provisions. Through such research, global health policy may be better able to select and even combine various patient-care strategies and community-based strategies to address the social adversity still faced by EVD survivors. First and foremost, we must be willing to learn from the past by listening to survivors. May their words be our guide.

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Appendix

Survey

1. Do you consent to participate in this study? Yes, I consent (1); No, I do not consent (0)

2. Have you ever had Ebola? Yes (1) No (0)

3. How old are you? (Participants must be between the ages of 16 and 65.)

4. Where do you currently live? (County name)

5. What is your gender? Male (1) Female (2) Other (3)

6. When did you have (first get infected with) Ebola? What month and year? (example August 2014)

7. Do you continue to suffer today from any of the following symptoms or negative experiences because of surviving (having) Ebola? Click on Yes (1) or No (0) for all below, please.
   Anger
   Withdrawal
   Sleeping issues
   Eating problems (eating too much or too little)
   Anxiety
   Sadness (sad most days of the week)
   Flashbacks
   Stigma from others
   Eviction
   Financial issues or not enough work

8. Did you receive assistance (stipend, foodstuffs, etc.) after being discharged from the ETU? Yes (1) No (0)

9. What years did you receive this assistance? Select all that apply: 2014–2016 (1), 2017–2019 (2), 2020–2021 (3), Today (4).

10. How satisfied were you with this assistance, on a scale of ☹ (not at all, 1) to ☺ (extremely satisfied, 5)?

11. Did you and/or a family member in your household participate in the PREVAIL (Partnership for Research on Ebola Vaccines in Liberia) study?
    a) If so, during what years? 2014 (1), 2015 (2), 2016 (3), 2017 (4).
    b) If so, did you ever stop participating? Yes (1) No (0)
    c) Why? (Please explain your experiences with the study, the program, the quality of care, and any issues you had.)

12. Did you hear any rumors about PREVAIL that concerned you? Yes (1) No (0) If so, what were the rumors?

13. Do you have any other concerns or comments about the PREVAIL study? Yes (1) No (0) Explain.

14. How much have the government policies supporting Ebola survivors helped you or not?
    Did not help at all (1), Somewhat helped (2), Helped a lot (3). Explain.

15. Were there any promised policies or programs promised to Ebola survivors that were not offered, or the quality was very poor? Please explain.

16. What assistance do you need most today because of being an Ebola survivor?

17. Click on the statements that you agree with:
    I feel like the world has forgotten about Ebola survivors. (1)
    Ebola has changed my life forever. (2)
    Being an Ebola survivor makes me a hero. (3)

18. Do you have any biological/born or adopted children you care for? Yes (1) No (0)

19. If you have children you are responsible for, do they currently go to school? Yes (1) No (0)

20. If yes, is the student welcomed and treated fairly, or do they face issues of stigmatization because they come from an Ebola-affected home?

21. If you have children that are not going to school, what are the reasons they are not in school?

22. Were you working before you got sick with Ebola? Yes (1) No (0)

23. Have you had any trouble finding work since, because you are an Ebola survivor? Yes (1) No (0)

24. Please explain your work experience since Ebola ended.