

Adaptation, Experiences, and Support Needs of Survivors of Ebola Virus Disease in Bombali and Kenema Districts of Sierra Leone: **Formative Assessment in Kenema and Bombali Districts**

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Acronym List

CCP	Johns Hopkins Center for Communication Programs
EVD	Ebola Virus Disease
FGD	Focus Group Discussion
IRB	Institutional Review Board
JHSPH	Johns Hopkins Bloomberg School of Public Health
MOHS	Ministry of Health and Sanitation
NGOs	Non-governmental Organization
PIRCSM	Public Information, Risk Communication, and Social Mobilization
SLAES	Sierra Leone Association of Ebola Survivors
SLESRC	Sierra Leone Ethics and Scientific Review Committee
USAID	United States Agency for International Development

Executive Summary

After Sierra Leone's Ebola epidemic, the Government of Sierra Leone, USAID and other partners developed and implemented the Comprehensive Program for Ebola Survivors (CPES) to support access to care and improve livelihoods for survivors of Ebola virus disease (EVD). In spite of these program priorities, EVD survivors in Sierra Leone have reported stigma and discrimination based on their survivor status and fears of transmission of the virus.

A recent outbreak of EVD in Guinea in February 2021 was found to be genetically linked to the 2014–2016 Ebola outbreak and may possibly be linked to a latent or relapsed infection linked to an EVD survivor. This potential outbreak origin was reported in local news outlets and spread through some local communities, heightening EVD survivors' fears of increased stigma and ostracization. Breakthrough ACTION collaborated with the Sierra Leone Public Information, Risk Communication, and Social Mobilization pillar and representatives of the Sierra Leone Association of Ebola Survivors (SLAES) to support Ebola preparedness planning in Sierra Leone.

This qualitative study among EVD survivors in Sierra Leone was based on recommendations from the WHO to increase understanding of how new knowledge about the potential for long-term latent infection and transmission of EVD affects EVD survivors' perceptions of risk, psychosocial needs, concerns around health and stigma, and relationships with others including health workers. Informal discussion groups among EVD survivors were conducted in Kenema and Bombali districts to elicit information about these themes. The study was approved by the Johns Hopkins University Institutional Review Board and the Sierra Leone Ethics and Scientific Review Council. The results may be used to identify information gaps that can be addressed through risk communication interventions to support EVD survivors.

A total of 24 discussion groups were held with six to eight participants per group. The total number of participants was 169, with 90 individuals from Bombali and 79 from Kenema districts, and 64 males and 105 females. The main themes are summarized below.

Context of daily lives

The overall sentiment among participants was that it was not easy living as an EVD survivor. Common issues of concern that affected their daily activities, livelihoods, and overall quality of life revolved around their health status (physical, psychosocial, mental) and community life. The following themes emerged as key in the context of daily lives of EVD survivors.

Perceived health status: All participants had concerns about their physical and psychosocial health. Participants described ill health such as itchy eyes and deteriorating eyesight, body and joint pain, chest pain, heart palpitations, headaches, memory loss, malaise, and changes to their menstrual cycle, libido, and fertility. They perceived their health problems were a result of EVD and the treatment they received for EVD. No participant characterized their health as being good.

All participants described having psychosocial health concerns including being worried about their own health and mortality, and the health of their children, including those not yet born.

Many participants reported having traumatic memories. They frequently thought of family members who had not survived, had disturbing dreams about them, and people and sounds in the community were frequent reminders of those who had died. Some participants experienced psychosomatic ailments on the anniversary of their diagnosis of EVD, or death of a loved one from EVD, EVD survivors also had anxieties about a future outbreak of Ebola in Sierra Leone and how it would affect them and their families. Few mentioned having the coping skills to manage the range of emotions that they were feeling.

EVD survivors also described concerns about livelihoods including economic instability, specifically difficulty paying for food, housing, and other necessities, inability to maintain work, and a dependence on family and friends for support.

Community Life: Community life was explored in the context of relationships with family, community, and the health system. Most participants reported having good relationships with family members, but a few EVD survivors had negative relationships with family members after they recovered from their illness. A few reported that their spouse or partner had abandoned them because of fears of contracting EVD from the survivor. The main negative behavior from family was distancing themselves from any contact, physically or through communication, with the EVD survivor.

Relationships with community members varied from a sense of belonging and inclusiveness to one of harassment, isolation, and exclusion. Some participants reported having good interactions with community members, they actively participated in local activities, and were treated well. Others perceived that they were not accepted as productive or valuable members of their community and had been evicted from their accommodation because the landlord had fears about contracting Ebola. Some described not being able to participate in community activities because of ill health, lack of money, and/or continued harassment about their history of having EVD. A few participants reported that they had relocated to new communities where they were not known, to keep their survival status private.

Primary issues related to experiences with the health system in the context of being an EVD survivor, were a lack of free health care services, poor interactions with health workers, and perceived poor quality of care. All participating EVD survivors were distressed that free health care services for EVD survivors were discontinued in 2018 without any warning or explanation. All participants recounted experiences where they were denied free health care at the health facility and could not afford the consultation fee or the cost of medicines prescribed for treatment. All EVD survivors described negative interactions characterized by rudeness, lack of empathy, and sometimes verbal abuse when interacting with health facility staff. Consequently, several EVD survivors stated that when they are unwell, they opt to use traditional medicines, go directly to the pharmacist, or self-medicate.

Stigma

Participants described experiences with stigma within their communities after their re-integration. While this has decreased over time for some participants, many continue to experience stigma frequently. Participants described being assaulted by strangers, treated rudely

by community members, and separated from others by individuals who were afraid of them. Some lost their businesses due to non-patronage by community members, and others were refused services at businesses, or restricted in their use of community resources such as obtaining water from the well. EVD survivors also described stigma from family, friends, and community that was related to their receipt of support from government and external agencies. More females and those in rural settings, described experiences with stigma related to being an EVD survivor.

Knowledge

EVD survivors confirmed that misinformation about EVD was not uncommon among community members including the belief that EVD was not real and was man made to kill poor people or was a curse or the will of God. These misconceptions were also expressed by a small number of EVD survivors. Common myths among community members that were reported by EVD survivors included beliefs that: EVD survivors had been genetically altered by their illness, and not wholly human; that survival was linked to a blood type; the government was making money from the blood of survivors; and conspiracies to exterminate individuals with specific illnesses including EVD

Perception of Risk

Participants had conflicting perceptions about whether they could get EVD again, and whether they could transmit it to others. Some participants stated health workers informed them that they could not get sick with EVD but could transmit it if they were to touch an infected person. Some believed one could not get sick or transmit the virus to others, while others perceived that it was possible to get sick again. However, the persistent unresolved health issues among EVD survivors were fueling doubts among survivors about the possibility of infecting others with EVD. A few participants stated they were no longer sure whether they truly were protected from EVD. Few participants had heard about the outbreak of EVD in Guinea. Those who were aware of the outbreak in Guinea, and those who heard about it from their colleagues through the FGDs, expressed anxiety about this outbreak including acute fear, dread, and loss of appetite, among other feelings.

Support Systems

All EVD survivors reported that at this time, there was no support provided to them. In the past, they had received food (rice, oil) and other items such as buckets, pots, beds, mattresses and bedsheets, clothes, slippers, monetary payments for blood donations, cash transfers, school fees, books, and pens for children, but these were discontinued without prior warning. Many felt that they had been abandoned. Support from friends and family was often limited as there was a perception that EVD received sufficient help from other government and external sources.

Perceived Needs

EVD survivors characterized their current needs as being related to correct information, access to medical care and support systems for improved health, and support for livelihoods and for EVD orphans. Types of support needed included continuation of free healthcare services, job and

skills training to support income generation, provision of food for those unable to work, support for orphans, and small business loans.

Recommendations based on the results include a multifaceted approach that aims to not only work at the individual EVD survivor level, but also addresses factors evident at the community. At the community level, interventions should be wide ranging in scope and aim to dispel misconceptions and fears around EVD. As many communities in Sierra Leone are rural, mass media could be supplemented with group events such as community engagement and dialogue. Interventions for health providers should include frank discussions about possible personal beliefs and biases that impact ability to provide good quality person-centered and respectful care.

General recommendations based on the results include community dialogues, knowledge-building on EVD, improved relationships with health care system, livelihood support for EVD survivors, development of information resources, and capacity-strengthening for SLAES to better support its members.

Introduction

Ebola virus disease (EVD) is an infectious zoonotic viral disease that is endemic to West and Central Africa, with an average case fatality rate of 50%. EVD has several animal vectors including fruit bats and primates, but the majority of human transmission occurs from direct contact with blood or bodily fluids from infected humans. 2014–2016 saw a regional outbreak of EVD in Sierra Leone, Guinea, and Liberia with a total of 28,616 cases of EVD and 11,310 deaths. In Sierra Leone alone, there were 8,706 laboratory confirmed cases and 3,956 reported deaths (2021). In addition to the death toll, the country faced significant economic, social, and behavioral changes as a result of the epidemic, especially for those who survived the disease. EVD survivors returned to communities that viewed them with increasing suspicion and fear. In the months following the official end to the EVD outbreak, survivors reportedly experienced increased stigma from their families, communities, and medical staff as they tried to return to pre-epidemic normalcy. One of the primary forms of stigma that EVD survivors reported stemmed from communal perceptions that EVD survivors could spread Ebola after recovery from the disease. This resulted in some communities advocating for complete isolation of returning survivors, sometimes for months, before their re-integration into the community (Nuriddin, Jalloh et al. 2018).

After Sierra Leone's Ebola epidemic, the Government of Sierra Leone, USAID and other partners developed and implemented the Comprehensive Program for Ebola Survivors (CPES) to support access to care and improve livelihoods for survivors of EVD. This included access to specialty services for EVD survivors and interventions aimed at stigma reduction at community and health facility levels. In spite of these program priorities, EVD survivors in Sierra Leone have reported stigma and discrimination based on their survivor status (Hugo, et al. 2015) as well as internalized stigma and fear related to care seeking at health facilities (Secor, et al. 2020; Overfelt et al. 2018). This makes them prone to isolation which could delay surveillance efforts and care seeking behavior and exacerbate mental health issues among this population.

While the EVD outbreak of 2014–2016 has been over for years, survivors still face medical and social repercussions. Another outbreak of EVD in Guinea on February 17, 2021 was found to be genetically linked to the 2014–2016 Ebola outbreak and may possibly be linked to a latent or relapsed infection linked to an EVD survivor (Fairhead, et al. 2021; Keita et al, 2021). This potential outbreak origin was reported in local news outlets and spread through some local communities, heightening EVD survivors' fears of increased stigma and ostracization. In light of this, Breakthrough ACTION collaborated with the Sierra Leone Public Information, Risk Communication, and Social Mobilization (PIRCSM) pillar and representatives of the Sierra Leone Association of Ebola Survivors (SLAES) to support Ebola preparedness planning in Sierra Leone.

In a February 17, 2021 WHO Disease Outbreak News publication on EVD in Guinea, WHO emphasized the need to provide risk reduction measures and various supports to EVD survivors to reduce EVD transmission, in light of recent resurgence of the disease in Guinea. Specifically, WHO states, "To reduce the risk of possible transmission from virus persistence in some body fluids of survivors, WHO recommends providing medical care, psychosocial support, and

biological testing ... through an EVD survivors care program.” Discussions with the SLAES staff indicated that EVD survivors have faced increased stigma in their community based on information related to possible latent infections among EVD survivors. In addition, the association staff discussed concerns about how EVD survivors can protect themselves, their partners, and other family members from the risk of transmission. Stulpin et al’s. (2020) summary of studies on the long-term health consequences of EVD confirmed that EVD survivors have significant physical and mental health disorders that persist long after their recovery, including uveitis, kidney problems, headaches, muscle aches, memory loss, joint pain, and abdominal, chest and neurological findings. Studies have reported a reduced life expectancy, specifically a five-fold increase in mortality compared to the general population (Fausther-Bovendo H, et al., 2019). Psycho-social and mental health issues are also rife in the lives of EVD survivors and include experiences with loss of employment and social difficulties for not just the survivor but their families (Stulpin, 2020). Many EVD survivors report difficulties resuming work and normal life and overall poor quality of life. In addition, “stigma is a crippling problem” that is common among EVD survivors and results in rejection, isolation, and hardships in all areas of their lives, and difficulties assimilating back to normal life (Stulpin, 2020).

The research in Sierra Leone was based on the aforementioned WHO recommendation and aimed to increase understanding of how new knowledge about the potential for long-term latent infection and transmission of EVD affects EVD survivors’ perceptions of risk and behaviors, psychosocial needs, concerns around health and stigma, and relationships and interactions with others including health workers. Informal discussion groups among EVD survivors elicited information about these themes and will be used to identify information gaps that can be addressed through risk communication interventions.

The findings provide context around the unique needs of EVD survivors that is useful for the development of risk communication strategies for EVD preparedness and emergency management, including components of an EVD survivor care and support program. The research also identified myths, misinformation, and fake news that could potentially undermine trust and participation in emergency preparedness programs. This information can inform the development of communication materials that provide accurate information about the potential for long-term latent infection and transmission, answer questions of importance to survivors (and the public), and increase awareness of, and access to, existing medical, biological testing, and psychosocial resources for Ebola survivors. Johns Hopkins Center for Communication Programs (CCP), who leads the Breakthrough ACTION project, also may use the results to provide technical input into the future development of information resources to mitigate fears and misinformation about risk post-infection with EVD.

Study Aims and Objectives

The study aimed to explore EVD survivors’ knowledge and perceptions of EVD transmission and risk, support systems and interventions, and experiences interacting with individuals in their community. Specific objectives included exploring and understanding:

1. Individual and community knowledge around long-term latent infections and EVD
2. Awareness of and participation in on-going interventions and messaging about EVD and care services among EVD survivors

3. The community context in which EVD survivors live
4. Individual and community perceptions around risk of EVD and its transmission, health, and interpersonal relationships, especially myths and misinformation
5. EVD survivors' personal experiences with stigma and access to health services
6. Individual behaviors of EVD survivors around relationships and access to care
7. Psychological health and concerns – the impact of EVD on survivors' mental health including perceptions of stigma and ill-treatment.

The study aims also may support:

8. Development of credible sources of information about risk and transmission of the EVD virus
9. Generate findings to serve as reference point for One Health sectors including the Ministry of Health and Sanitation (MoHS), Environmental Protection Agency, and Ministry of Agriculture and Forestry and other health agencies to strengthen sensitization and health management in the country.
10. Mitigation of potential rumors and misinformation about EVD and EVD survivors

This report summarizes key findings on the impact, behavior, and stigma associated with individuals living as EVD survivors in two districts of Sierra Leone.

Methods

Study Design

The study used qualitative methods to collect information on EVD survivor knowledge, perceptions, and behaviors. The study population included adult men and women 18 years of age and older living in Bombali and Kenema districts of Sierra Leone.

Study sites and population

The study targeted the two districts (Bombali and Kenema) that had a high number of EVD cases during the 2014–2016 epidemic. Based on records, Bombali district had the third highest concentration of EVD survivors in Sierra Leone and borders Guinea where there was an Ebola outbreak in 2021. Kenema district also has a high concentration of survivors and borders Liberia, another location of the earlier EVD outbreak. Bombali and Kenema districts are culturally, economically, and geographically distinct, and this provides opportunity to understand differences in cultural norms and stigma to better tailor behavior change campaigns and risk messaging. The study population were adult survivors of EVD living in the study districts.

Sample size and sampling

The study included 24 focus group discussions (FGD), 12 from each district, as illustrated in Table 1. Six to eight participants were recruited for each FGD.

Table 1: Sample distribution of FGDs and participants in Bombali and Kenema, Sierra Leone.

	Urban			Rural			N
	Male	Female	n	Male	Female	n	
Tonkolili	3	3	6	3	3	6	12
Kenema	3	3	6	3	3	6	12
Total	6	6	12	6	6	12	24

The research used purposeful sampling to identify and recruit participants into groups stratified by sex and urban/rural localities for variation in experiences. Participants were identified through collaboration with the SLAES staff, district health management team, and community-based health workers. Participants were randomly selected from the registration list of the SLAES organization in each district.

Study participants

Study participants were eligible to participate in the study if they met all of the following inclusion criteria:

1. Is 18 years of age or older at the time of the survey
2. Is a member of SLAES or identified as an EVD survivor by SLAES
3. Has resided in one of the study districts for at least 1 year
4. Provided voluntary informed consent

5. Understands and speaks English and/or Krio, Temne, Mende.
6. Consents to and passes COVID-19 screening¹ prior to the discussion
7. Agrees to follow COVID-19 prevention precautions during the discussion

Potential participants were not eligible to participate in the study based on the following criteria:

1. Less than 18 years of age at the time of the survey
2. Does not provide voluntary informed consent
3. Exhibits respiratory symptoms, is sick, or does not pass COVID-19 screening
4. Unwilling to adhere to COVID-19 precautions prior to and during the interview
5. Is not available for an interview during the time period for data collection

The research team

The research team consisted of CCP research staff and a local contractor that conducted field work with a team of local data collectors (including public health officers from the Government of Sierra Leone), supervisors, and support staff. CCP research staff trained the team on the study purpose and methods, including sampling, recruitment, tools, field work, quality assurance, interviewing techniques, and database development and management. Training content included information on research ethics in the field, rights of human subjects during research, obtaining informed consent, and implementing safety precautions for COVID-19 during community entry and field work.

A key component of the training was opportunities to practice using the study methods and the forms and tools in English as well as their local language versions. The local project manager, research leads, and field team coordinator received additional training on the protocol, supervision, quality assurance, communication, and reporting requirements for the study.

Data collection tools

A qualitative discussion guide was used to facilitate and guide group discussions. The focus of the discussion was on the perceived individual and community-related factors surrounding their status as survivors. Main themes explored included but were not limited to: knowledge about latent infection and risk of transmission; perceived community behaviors and overall response to re-integration of survivors including personal experiences in community and with health system; fears and concerns for self and family; stigma-related experiences; awareness of support services; and knowledge and information needs.

The data collected were anonymous and no personal identifiers were included in the notes taken or the electronic database. Participants were assigned unique study identification numbers which were used on the data collection forms.

¹ Screening included a temperature check, questions about currently having symptoms of COVID-19 disease, recent exposure to someone diagnosed with or having symptoms of COVID-19 disease, travel out of the community in the last two weeks.

Data management

Data were collected on paper forms by up to three note takers. After each discussion, the notetakers shared and discussed their notes on the dialogue during the discussion and validated and consolidated the responses for each question in the tool. A final transcript of the discussion and findings was developed. Each finalized consolidated transcript was uploaded to an electronic tool with capabilities to collate the data into a database of cases, for analysis. The data were analyzed using content analysis and manual thematic coding.

Permissions and Ethics

The study protocol was reviewed and approved by the Sierra Leone Ethics and Scientific Review Committee (SLESRC) at the Sierra Leone MOHS and the Johns Hopkins Bloomberg School of Public Health (JHSPH) Institutional Review Board (IRB) in Baltimore.

Permissions for the research were obtained from the Chief Medical Officer at the MOHS, and study approvals were obtained from JHSPH IRB and SLESRC. Approval letters were presented to each District Medical Officer and district health management team, local councils, chieftain heads, and community leaders. The study was explained, questions were answered, and the research team was introduced to leaders.

Results

The results yielded meaningful and actionable information about the context of EVD survivors' lives. A description of the sample and major themes from the discussions are described below.

Description of the Sample

Overall, there was high interest to participate in the discussions among EVD survivors. A total of 24 FGDs were held with six to eight participants per group. The total number of participants was 169, with 90 individuals from Bombali and 79 from Kenema districts, and 64 males and 105 females.

Context of Daily Lives

The overall sentiment among participants was that it was not easy living as an EVD survivor. Common issues of concern among the group that affected their daily activities, livelihoods, and overall quality of life revolved around their health status and relationships with others. Better understanding of EVD survivors' perceptions of their health status in turn identifies specific priority health and information needs for this group. EVD survivors described their physical and psychosocial health, including mental health.

Perceived health status

Information about how they were feeling was a priority topic for participants. All participants repeatedly focused the discussion on concerns about their physical and psychosocial health. One participant stated that persistent ill health was common among all survivors, as illustrated below:

“All survivors are not feeling well, if any survivor said he or she is feeling well then that particular [person] is lying, just like others were saying, we are experiencing complications after complications and we are going through a lot as survivors.” (Kenema, Urban, Female)

“Since I was infected with the virus, my health condition has never been in a good state. My concerns are my health. Since I came from treatment center, my health has been deteriorating every day. I have been experiencing general body pains and weaknesses all over my body. I'm becoming weaker and weaker every day.” (Bombali, Rural, Female)

Participants described specific physical, mental, and social health issues that impacted their daily lives. These issues are summarized below.

Physical Health

Overall, participants described being in poor health using words and phrases such as “*not feeling fine*”, “*suffering*”, “*not good*”, and “*discouraged and sick*”, and “*not physically strong*”. Indeed, no participant characterized their health as being good, and every discussion group had several

participants describe health issues that they perceived to negatively affect their overall quality of life.

Participants mentioned symptoms of ill health such as itchy eyes and deteriorating eyesight, body and joint pain, chest pain, heart palpitations, headaches, memory loss, malaise, and changes to their menstrual cycle, libido, and fertility. They seemed to perceive all of their health problems as a result of having had EVD in the past. Many believed that the health problems they currently have were a result of the treatment they received for Ebola, and several mentioned they have issues with their sight because they were repeatedly sprayed with chlorine at Ebola treatment facilities when they were sick. Others believed that their immune system was compromised as a result of EVD.

“Am not feeling fine because I have persistent headache, cough, chest pain, general body pain. And in the evening, I will start feeling increase in the body temperature and this will continue throughout the night.” (Kenema, Urban, Male).

“Also, since I was discharged from the treatment center, I have not been able to impregnate my wife though we had four kids before. Long as I am with my wife unto this time no pregnancy. That has been my worry I don’t know if I will be able to make a woman pregnant.” (Bombali, Urban, Male)

Since I discharged from treatment centers, I normally come in contact with infections most times, and it’s from one infection to the other. Is like my immune system has been compromised during the sickness and there is no proper treatment for me.” (Bombali, Urban, Male)

Psychosocial Health

All participants described having psychosocial health concerns including anxieties and constant worry. They reported seeing other EVD survivors die or “go mad” and so they are worried about their own health and mortality, and the health of their children, including those not yet born. EVD survivors described being “worried”, “embittered”, “sad”, “stressed”, “angry”, “disturbed” and “frustrated”. Few mentioned having the coping skills to manage the range of emotions that they were feeling.

A major mental health issue among EVD survivors was how EVD would affect their lifespan and ability to produce children.

“I am mentally disturbed. I don’t know my correct health status and how long I can continue like this, putting my life at more risk, this is one of my concerns I am very worried about what will happen to me in the future, and also my life span whether I will live long. And also thinking about the virus in my system, if it will be transferred to my unborn children. I also have concern about my mental health because I do forget a lot.” (Kenema, Urban, Male)

“I am concern about my health status because some of my colleagues are dying. I am worried about my health and life span as I heard that EVD survivors won’t live for more

than five years. I am concerned and worried about the years I am going to live for in this world.” (Kenema, Urban, Female)

Many participants had unanswered questions about their health status and the reasons behind their ill health, and this heightened their anxieties concerning their health.

In addition to having anxieties about their health, many participants reported being sad and weepy about memories that were difficult to forget, somewhat similar to behaviors of a post-traumatic stress response. Participants reported that any discussion about EVD reminded them of the past, and that it was difficult for them to forget what they had experienced when they had been sick with EVD infection. They frequently thought of their family members who had not survived and also had disturbing dreams about them.

“Members of my family were infected and only 11 of us survived. It has not been a good memory for me to lose my entire family, so I have lost all hopes.” (Bombali, Rural, Female)

“I had a dream of my child, the thing is that when I was sleeping last night, I saw my child in my dream and when I woke up I was not feeling fine, and I did not feel like eating. The dream made me sad. My baby died during the Ebola outbreak, and it was the Ebola virus that killed the child.” (Bombali, Rural, Female)

People and sounds in the community also were frequent reminders of those who had died and triggered intense feelings about what they were missing. These were memories that caused sadness and anxiety among survivors.

“Whenever I walk in the street and see children at the same level of my deceased child, it does send signals to me and makes me shed tears.” (Kenema, Urban, Female)

“We have talked about the sound of the ambulance, which sounds like ‘goodbye’ in the Temne language.” (Bombali, Rural, Female)

“If I hear Ebola song playing my heart will start palpitating and I will begin to cry.” (Kenema, Urban, Male)

Some participants seemed to have psychosomatic ailments on the anniversary of their diagnosis of EVD, or death of a loved one from EVD, such as not being able to see, headaches, sleeplessness, dreams, and feelings of sadness.

“I am not seeing properly with my eyes; my eye usually runs water even when you are sleeping. Whenever that day comes, the day I contacted the virus, I don’t normally see on that day.” (Bombali, Rural, Female)

EVD survivors also reported extreme mental health issues and stated that *“we also have some of our colleagues who sometimes behave as if they are mad”*. Some of them described how their friends had *“gone mad”*, resorted to the use of drugs, and in the example below, how they themselves had occasionally acted abnormally or out of character.

“I am really sad because of my situation I sometime do things which are not of my knowledge, unconsciously I even run mad sometime, I can remember the last time I picked up a knife for my brother who is also a survivor telling him that I will kill him. Another time my brother said I was at the cemetery digging and he said that I told him that I was looking for survival.” (Kenema, Urban, Male)

“Some of my colleagues have gone mad by involving in drugs addict[ion]” (Kenema, Urban, Male)

Some EVD survivors described how everything they do is attributed to their survival status, and they have to fight to not lose their identity and sense of self from being constantly labeled as “survivor”.

“People usually say to me ‘you are a survivor’. But sometimes I told them that I did not buy the sickness so you should stop describing me and identifying me as a survivor.” (Bombali, Rural, Female)

In addition to anxieties about their current health status, EVD survivors also had anxieties about a future outbreak of Ebola in Sierra Leone and how it would affect them and their families. A few participants who were aware of the outbreak of EVD in Guinea, and those hearing about it for the first time through the discussion, described stress and anxiety related to this knowledge. Some reported having worry, anger, crying fits, palpitations, loss of appetite, diarrhea, sweats, and fear. A few reported being calm because they believe they are immune to EVD, but they did worry about others who may be at risk, including their family.

“Whenever I heard of Ebola I will become emotionally and psychologically stressed up. I will think endlessly about what Ebola did to my family. Am suffering today because of Ebola ... When I heard about Ebola in Guinea, I concluded that a lot of people are going to die and a lot of family will perish as it happens to us.” (Kenema, Urban, Female)

“When I heard the news, I said to myself we are finished! My sister was in Guinea I was calling them every day and night. She told me that they were safe where they are but I was so worried. I was [feeling] unrest and I was not feeling fine.” (Bombali, Rural, Female)

“When I heard the news in Guinea there was fear in me that health workers will start using undiluted chlorine on Ebola suspects. There is fear in me that people will start urinating blood which was one of my worst moments while I was admitted at the Ebola treatment center.” (Kenema, Urban, Male)

“I was in class when I heard that EVD is in Guinea. I felt like having diarrhea, feeling upset and persistent sweating.” (Kenema, Urban, Male)

An extreme example of mental anguish precipitated by fear of a repeat experience with EVD, is illustrated in the following illustration from just one participant:

“When I heard that Ebola is in Guinea, I felt bad and said to myself, if by any means it comes to Sierra Leone, I will drink poison and die because I don’t want to see people die again.”
(Kenema, Urban, Female)

Livelihoods

Other concerns raised by participants included economic instability, specifically difficulties in paying for food, housing, and other necessities, inability to maintain work, and a dependence on family and friends for support.

“Life for Ebola survivors is not really easy in this community. As my brother was saying, farming is our main source of livelihood, and this involves a lot of physical activities. We don’t have strength to work like others in the farm. We don’t have money to pay people to work in our farms, at the end of the day we rely on other little food we get from others. We are not getting enough food and that is why you are seeing our physical appearance like this.” (Kenema, Rural, Male)

In summary, EVD survivors described having many anxieties and concerns in the area of their physical and psychosocial health, the health of their families and children, livelihoods, their ability to care for themselves and dependents, and fear of another EVD outbreak in Sierra Leone. Programs that increase access to physical and mental health for survivors, and those that provide opportunities for re-training and entrepreneurship may be helpful in addressing the health and livelihood needs of EVD survivors.

Community Life and Engagement

Interpersonal interactions are key to inclusiveness within the family and community. The extreme nature of the EVD epidemic in Sierra Leone and the persistent fears and misunderstanding about the disease has potential to marginalize those who were affected by it. EVD survivors responded to questions about their relationships with family and community members.

Experiences with family

Most participants reported having good relationships with family members. Some had enjoyed supportive relationships since they had recovered from their illness, while others had family that were initially distanced from them, but who had rekindled relationships over time.

“Our family members have been good to us since the onset of the sick until this moment. Our families have been caring and loving to us.” (Kenema, Urban, Female)

“I have never experienced negative treatment from my family members. They are kind and hospitable. They gave me all the supports I want and I’m grateful for that. There was never a time that I experienced any maltreatment from family members. They are doing their best to [give] support to their best of ability.” (Bombali, Rural, Female)

Conversely, some EVD survivors had negative relationships with family members after they recovered from their illness. A few reported that their spouse or partner had abandoned them because of fears of contracting EVD from the survivor. The main negative behavior from family was distancing themselves from any contact, physically or through communication, with the EVD survivor. This was done by evicting the EVD survivor or relegating them to the fringes of the household compound where they do not have contact with other family members.

“My family treats me like an outcast just because I am a survivor. In fact, they asked me out of the house, and I am paying rent for me and my sister.” (Bombali, Rural, Female)

“We have been treated unfairly by our extended family members fearing that we would give them Ebola. On several occasions, they have tried to drive me out of the house, but I always stood my ground. However, they succeeded in isolating me to a single room at the back house.” (Bombali, Rural, Female)

A few participants described that their family members left them because they could not provide them the basics for survival. One former head of household described how his family unit and their unity had been affected by his illness; members were scattered and no longer together and he had no knowledge of where they were.

“It is very bad for me, even my children have left me and gone different ways, my family has now gone apart as I cannot provide for them, I cannot finance them, all have disappeared in different ways and in different directions.” (Kenema, Urban, Male)

Experiences with community

Most participants mentioned that it was publicly known in their communities that they were EVD survivors. A few participants reported that they had relocated to new communities where they were not known, to keep their survival status private. Many EVD survivors described how they were formally re-introduced to their communities after their recovery through integration ceremonies that were held by health workers and community leaders.

Relationships with community members varied from a sense of belonging and inclusiveness to one of harassment, isolation, and exclusion. Some participants reported that they had good interactions with community members, they actively participated in local activities, and were treated with *“respect, peace, and love.”* A few also stated that they had leadership roles in community affairs; some of these individuals had these roles prior to getting sick and others were newly elected.

“As for community participation, I’m very much involved. As a matter of fact, I’m part of the local court system ... I take part in all the community activities. They call me whenever there is a meeting or family discussions. I also summon them to family meetings often and they would attend.” (Bombali, Rural, Male)

“People in this community are aware of our status, they all know that we are survivors, and they are aware of the facts that we are their relatives, we are not worried as we feel part of

the community. I am one of the tribal authorities in this community, I was before I got sick and still I maintained. I do take part in community activities, and nobody has ever asked me a question concerning EVD.” (Kenema, Rural, Male)

“My family and community are not hostile towards me, they are very caring and supportive to me. Could you imagine that I was even appointed as youth leader in my community.” (Bombali, Rural, Female)

Some EVD survivors stated they were okay where they lived because they moved to an area where their status as an EVD survivor was not publicly known within the community.

“Personally, where I used to stay was not easy for me to live as there were a lot of provocations, but since I moved to a new environment where no one knows that I am a survivor, I can live well now.” (Kenema, Urban, Female)

“Presently where we stay people don’t know we are survivors as we refuse to tell anyone in other to avoid provocation.” (Kenema, Urban, Female)

However, some EVD survivors perceived that they were not accepted as productive or valuable members of their community. Some reported that they were evicted from their accommodation because the landlord had fears about contracting Ebola. Other participants reported that they were limited in community participation by their ill health, lack of money, and/or continued harassment about their history of having had EVD. Consequently, they had no or limited contact with childhood friends, co-workers, and even their favorite vendors and service providers (for example, hairdressers).

EVD survivors reported that some community members did not consider them to be normal or respected individuals, and they were labeled as being “*crazy people*” who “*don’t think straight*” and will “*never get back to normal*” as a result of the infection and the treatment they received for EVD. In some cases, EVD survivors were perceived to be lower in hierarchy than an insane individual.

“People think that we are not yet free from the virus and they make bad statements about us: ‘Bifo ar kip Ebola survivor mek ar kip insane posin’ [Before I date an Ebola survivor, I prefer dating a mad person].” (Kenema, Urban, Female)

“People usually say the chlorine has climbed up my head which mean the chlorine has made me lose my senses, so they are saying people should not argue with me.” (Bombali, Rural, Female)

“Friends called me ‘Ebola candidate’. Some family members called me ‘mad man’. Some community members called me ‘big fool’ or say ‘I do not blame you, it is the Ebola madness’”. (Kenema, Urban, Female)

Other negative reactions towards EVD survivors were perceived to stem from fears that that the survivor, and their children to be born, can transmit the virus to others. This belief has destroyed

friendships, separated families and friends, ended marriages, and deterred new social relationships.

“Some community people still believe that we are capable of transmitting the Ebola virus. Look at the way people were afraid to buy my food, just because I’m a survivor. Some even believe that our children will have traces of the virus. The husband of my colleague, [my colleague who is] a survivor, ran away from her because he still feared that any children they bear will have the Ebola virus. So, he abandoned her. Even I, since I lost my husband, no man has ever come my way and they are afraid even to come closer to me.” (Bombali, Rural, Female)

“My interaction with people is not good in the community, I used to play with my friends before contacting Ebola, but ever since I was discharged from the treatment center we play no more, we don’t do things like before.” (Kenema, Urban, Male)

“I visited my sister who just gave birth. She had to separate the chairs and did not allow me to touch her baby because she was afraid that I will transfer the virus to her child. Even my children were not allowed to fetch water from the well. The landlord preferred to fetch the water for us with her own bucket and turn it for us to our own bucket and was very careful not to touch our bucket.” (Kenema, Urban, Female)

While poor relationships with community members were present in both districts and among both sexes, EVD survivors from Kenema and females described having more negative experiences. The results also show that beliefs and fear among community members that EVD survivors were still able to transfer the virus to others existed prior to the 2021 EVD outbreak in Guinea. Programs to eliminate stigma and improve community relations with EVD survivors may consider including information about transmission of EVD, to better manage rumors, misinformation, and the fears that underlie negative community behaviors towards EVD survivors.

Experiences with the health system

Health workers played an active and important role in introducing EVD survivors back to their communities, however they were implicated in negative encounters and experiences with EVD survivors who sought health care services at health facilities. Poor relationships with health care workers were described as a reason for non-use of services at health facilities.

Primary issues related to experiences with the health system in the context of being an EVD survivor, were a lack of free health care services, poor interactions with health workers, and perceived poor quality of care.

Lack of free health care

All participating EVD survivors were distressed that free health care services for EVD survivors were discontinued in 2018 without any warning or explanation. Some described how health workers had scolded them for requesting free medicines after the government’s free medical

program for EVD survivors had ended. All of them recounted situations where they had been denied free health care at the health facility and could not afford the consultation fee or the cost of medicines prescribed for treatment.

“The only bad experience I have had was from our community health center. I went there for treatment and the In-Charge told me that the center is not for Ebola survivors.” (Bombali, Rural, Female)

“They treated us badly and unfairly. I went to hospital on one occasion and when I produced my certificate, the nurses just ignored me and told me that this is not an Ebola treatment center where free treatment is available for survivors.” (Bombali, Rural, Male)

Poor interpersonal relationships

All EVD survivors described negative interactions characterized by rudeness, lack of empathy, shouting, and sometimes verbal abuse when health workers spoke to them about free medical care. One participant from Bombali district stated he had *“never been treated well”* by the health system. Many participants stated that their survivor certificates were thrown away or at them, and they were ignored and not provided a consultation service.

“On one occasion, I went to government hospital to seek medical treatment. As soon as I showed them my survivors’ certificate, they asked me to sit aside. I waited there for over two hours while they are seeing other people. They never responded to me. When I was tired waiting and asked the nurses, anyone I asked would just ignore me and I went away.” (Bombali, Rural, Female)

“Whenever we went to the government hospital or health centers, they would not treat us even when we showed them our survivors’ certificate. The nurses would allow us to sit and wait for them for the rest of the day and at the end they would vanish without saying anything to us.” (Bombali, Urban, Male)

“I went to the health center for treatment, as soon as my card was given to the nurse, she uttered a statement “Den free tin dem” meaning I am cheap and I depend on free treatment, not knowing that I was standing at the door. After that incident, I have not been to the hospital for the past two years, I prefer to go to the pharmacy when I feel sick or use traditional medicine.” (Kenema, Urban, Female)

Consequently, several EVD survivors stated that the *“don’t feel comfortable”* going for care, and some opt to use traditional medicines, go directly to the pharmacist, or self-medicate. One stated that she does not identify herself as an EVD survivor so that she can be physically examined by a health worker.

Poor quality of health care

Some EVD survivors believed that some health workers were afraid to provide them treatment services when they realized that they were EVD survivors, and they were treated differently from

other clients. They described workers at the health facility as “hostile”, “not polite”, “afraid to come near”, and who treat EVD survivors “as if they are not human beings.” Some EVD survivors stated that health workers were afraid to examine them. Consequently, they had little confidence in the treatment they received at the health facility and had resorted to the use of pharmacies or traditional medicine.

“I do not feel fine using the health facility as a survivor. They treat me differently when I identify myself as a survivor. I do not usually go now as a survivor. ... I will not identify myself as a survivor because they will not treat me fairly.” (Bombali, Rural, Female)

“Using the health care service based on the way we are treated, and this has made some of us not to use the health care service again.” (Kenema, Urban, Female)

“I went to the health care center. I got there very early. The health care worker inserted my card under so I would be the last patient to see the doctor. I felt bad. And even when I saw the doctor, he did not touch me but rather distanced himself from me even when examining me.” (Kenema, Urban, Female)

“When I started feeling my eyes, I went to the eye clinic health service. The doctor never touched my eye to actually know what the problem is, instead he only stood over me a distance away and said I should be the one to open my eyes for myself. He just prescribed medicine and I should go. No examination was done on my eyes.” (Kenema, Urban, Female)

Stigma

Participants described experiences with stigma within their communities after their re-integration. While this has decreased over time for some participants, many mentioned that they continue to experience stigma. Some experiences with stigma were resolved with intervention of community leaders, but for many EVD survivors, being stigmatized occurs regularly in their lives. Many individual stories of harassment and abuse were shared. Participants described being assaulted by strangers, treated rudely by community members, and separated from others, by individuals who were afraid of them. Even the sight of a stranger holding the large certificate given to survivors was enough to make others move away. More females and those in rural settings, described experiences with stigma related to being an EVD survivor.

Stigma from fear of transmission of EVD

Stigmatizing behaviors were fueled by the belief that EVD could still be transmitted by survivors. Community members were careful not to have any physical contact with EVD survivors including sharing or touching items that the survivor had used. Children were also instructed not to interact with survivors of EVD, thereby socializing them to stigmatizing behaviors. Attempts by EVD survivors to have closer interactions with community members were often rejected.

“Even the compound where I stay all my neighbors keep off from me and say I am an EVD survivor. I was treated so badly during a time when I was passing around my neighbor’s compound, they use chlorine to clean the compound after me.” (Kenema, Urban, Female)

“Children who used to come to us before Ebola now if you call them they will not respond to you and if you give them food, they will not accept it. Not even asking them to launder your clothes they will not do it, just because I am a survivor. Even the cup that we use to drink from they will not drink from it at all. Even when you happen to sleep in the same place, they will push far away from you so you will not touch them. Just after the Ebola, I lost my husband and people said I must have transferred the sickness to my husband, and he has passed away now. People have been asking me to leave out of their places.” (Bombali, Rural, Female)

“Up till now in my community when I want to share food with people, as long as I have partaken of it, they will not accept it. My friend whom I used to eat with, eat with me no more after I discharged. I was treated badly when I attended a burial ceremony, as soon as I sat next to a friend, she stood up and left.” (Kenema, Urban, Female)

Some community members also changed their routines, habits, and preferences, to limit their interactions with EVD survivors. Consequently, survivors lost their customers and their business, and also lost opportunity to receive services from others.

“The community people used to fetch water from my compound. Since I became a survivor, they have stopped coming to my compound to fetch water. My lecturer whom we also use to interact with stopped his children from going into our compound and also put a stop that we should do likewise.” (Kenema, Urban, Female)

“When I was discharged and returned to my people, it was difficult for me to start selling cookery again. I borrowed some money and started to sell. Unfortunately, I was surprised to find out that I didn’t have as many customers as before. One day a young man came to me and explained to me that people are afraid to buy my food because I may transfer the virus to them. I felt discouraged and frustrated.” (Bombali, Rural, Female)

“Before I used to cook and all of us eat together but since I became a survivor when I cooked, they will not eat my food and they also prefer not to use my pot. The one who used to help me, after knowing that I am a survivor they stopped helping me. And the salon which I used to do my hair, they rejected me with my money They used to move away from me when I go to the mosque for prayers, so I decided to pray at home, whenever someone comes to visit me they will refer me to as “na da survivor u dae ask for” [“Are you asking for that survivor?”] (Kenema, Urban, Female)

In some cases, other family members such as children, grandparents, and partners experienced instances of stigma because of the EVD survivor in their family.

“When I came back from the treatment center, I got pregnant, and the baby I gave birth to have a mark in the face. Could you imagine people claimed that it is the Ebola virus in me

that has affected the baby. They usually call her “Ebola child”. The child is ashamed of the name, and I am also ashamed.” (Bombali, Rural, Female)

“On one occasion my child was excluded to eat with his paternal brothers. When I asked why they said he had a wound on his hand which may lead to some form of transmission. Then I asked them what kind of transmission, they just laughed and went away. As for me, I’m not allowed to eat with my mates fearing that I may infect them with the Ebola virus.” (Bombali, Female, Rural)

“It is difficult for me to be involved in the community activity as I have never been invited to any community program. My family have also found it difficult to be involved in the community activities because of me. My mother was asked to stop going to the mosque for prayers and selling fish in the market, all because I am a survivor.” (Kenema, Urban, Female)

Some participants described how stigma was reduced in their communities with the help of community leaders. Sensitization meetings were conducted to address stigma, and by-laws were enacted to punish those who demonstrated stigmatizing behaviors.

“Initially when we were back from the treatment center, stigmatization was experienced in my community. People were afraid to get close to us, share things with us, but after community engagement with stakeholders and community, people’s stigma was reduced.” (Kenema, Urban, Female)

“The issue of stigma in this community was not too much because we have by-laws that protected Ebola survivor from stigmatization. If you were caught stigmatizing any Ebola survivor, you will pay a fine of five hundred thousand Leones that is one. Another fine is to take the complaint to the police station, another measure is not to take part in any community activities.” (Kenema, Rural Male)

Stigma from support services

Community level stigma had roots in several misconceptions, including the belief that EVD survivors had accumulated wealth from substantial benefits they received from non-governmental organizations (NGOs) and the government. In this sense, the response to support survivors has in some way contributed to stigmatizing behaviors of community members. Survivors described how friends and family had denied their requests for assistance because they believed that the government was taking care of all their needs financially and materially. EVD survivors say they are mocked for receiving aid from others, and that community members do not believe that they are capable of obtaining anything based on their own merits.

“Even family members are refusing to support us, because they are thinking that we are having support from the government.” (Bombali, Rural, Female)

“The people were mocking me when I was getting support from the government and NGOs saying, they wish they had got Ebola and survived, so that they too can have [government] supply.” (Bombali, Rural, Female).

“I was treated badly by my aunty six months after I discharged. Each time my children went to her for food, she uttered a statement saying; “una mama e Ebola money don don sef?” [how come your mother finished all the money she has derived from the Ebola program?]. Before coming to this meeting, I had no money, so I went to my neighbor to borrow transportation and he said, “have you finish all your Ebola money?” (Kenema, Urban, Female)

Stigma remains a pressing issue for many EVD survivors and may need to be reprioritized in the scheme of interventions for survivors. Programs also should explore how to limit their footprint when interacting with survivors in order to manage social stigma from community members around EVD survivor campaigns and benefits.

Knowledge

EVD survivors confirmed that misinformation about EVD was not uncommon among community members including the belief that EVD was not real and was man made to kill poor people or was a curse or the will of God. These misconceptions were also expressed by a small number of EVD survivors. A perception that EVD survivors had mental issues was also commonly described, however perceptions about whether it was the disease or treatment that caused this, varied.

Common myths among community members that were reported by EVD survivors included beliefs that: EVD survivors had been genetically altered by their illness, and not wholly human; that survival was linked to a blood type; the government was making money from the blood of survivors; and conspiracies to exterminate individuals with specific illnesses including EVD. The following illustrations summarize some of the misconceptions about EVD.

Origins and causes of Ebola

“I don’t think Ebola is something natural. It is a man-made disease intended to reduce the population of the poor especially the Africans. They achieved this by inflicting the virus upon the people with the use of chlorine being sprayed on suspects.” (Bombali, Rural, Female)

“People still do not believe that Ebola is real. They said, they wanted blood that was why they brought the Ebola sickness. We need to tell people what Ebola is, since they do not believe that the sickness is real.” (Bombali, Rural, Female)

“People in my own community believe that people who have survived Ebola, it’s not really Ebola but rather malaria. Also, they told us that Ebola rules are specific type of blood group that is the “O” type, if you belong to that group, you will not survive the Ebola virus.” (Kenema, Urban, Male)

Consequences of EVD

“They said we the survivors can never give birth again neither can we have relationship.”
(Kenema, Urban, Female)

“Some people said all Ebola survivors will lose their sense of hearing after 5 years.”
(Bombali, Urban, Male)

“People believe that I am between life and death because I am a survivor, people say that I am half human and that I will die at any time because I am a survivor.” (Kenema, Urban, Male)

“One news they say about EVD survivors is that they will go blind one day when the medicine in their body expires in fifteen years’ time. They also said that survivors’ children will have the traces of EVD virus. That they will transmit the disease any time they started doing sexual intercourse. These are some of the reasons my husband may have abandoned me.” (Bombali, Rural, Female)

“Some people believed that after ten years, all Ebola survivors will go mad. Some say the medicines in our blood will make us mad when it expires in ten years’ time. Some people said we will never bear children again and if we do, our children will have the trace of Ebola in their blood. They said our senses will never be equal again and that is why they said we are hot-tempered and aggressive.” (Bombali, Rural, Male)

Conspiracy Theory

“They say we have been programmed at the treatment center such that whenever they need to perform some experiments, they would just alert the vaccines in our body, and they would get from us what they want. They said we are an experimental being for the White man.”
(Bombali, Urban, Male)

“I also heard from someone that says all infected patient of Ebola that has Lassa fever and HIV/AIDS infection will be killed in order to reduce HIV/AIDS in the country.” (Kenema, Urban, Male)

Rumors, myths, and misinformation information persist around Ebola, its origins, and its effect on individuals. There is a clear need for credible factual information about EVD among EVD survivors and among the general population. Providing correct information may help mitigate fear and promote better relationships between EVD survivors and their communities. Programs should consider the wide range of categories of misinformation that exists when they develop message campaigns and information resources about EVD.

Perceptions of Risk

Participants had conflicting perceptions about whether they could get EVD again, and whether they could transmit it to others. Some stated one could not get sick with EVD but could transmit

it if they were to touch an infected person, while others felt one could not get sick or transmit the virus to others. Conversely, some perceived that it was possible to get sick again.

Some participants did not perceive that they could get infected with Ebola again and spread it, and many participants referenced their certificate provided at discharge from a treatment facility as proof of this. Participants reported that they were informed by health care workers that they could never contract EVD again and were protected from it because of immunity gained from their previous infection. Most participants conveyed that they were only at risk of spreading Ebola if they did not abstain from sexual activity for three months after they had recovered from their illness, or if they touched an infected person and then a non-survivor.

“The doctor said as long as you have contracted the EVD and you have survived, there is no way you can have the virus again. We cannot get EVD again neither can we transmit it again.” (Kenema, Urban, Female)

“Because we were told while at the treatment center that as long as you are an Ebola survivor, there is no way you can contract the virus again. ...In fact, when they had wanted to manufacture Ebola vaccine, they used our blood sample for that purpose.” (Kenema, Urban, Female)

Others believed they were not at risk of transmitting it because since they recovered, they had not passed the virus on to others they were in close contact with.

“No because if I can give another person Ebola infection, I would have given it to my children and all my neighbors but none of them have ever complained of Ebola. No, I cannot because they said Ebola infection can be transferred when you touch someone, and I have lived and played with friends and family members.” (Kenema, Urban, Female)

Knowledge that they were protected from future EVD infection prompted some EVD survivors to decline to be vaccinated with the Ebola vaccine

“No, I don’t feel at risk of contracting the virus, because they said as long as I am a survivor my system is immune to virus. I even declined to take the EVD vaccine as they said we can’t get the sick again.” (Kenema, Urban, Female)

“I absolutely have no risk and no fear in getting the sick again because I was discharged from the treatment center.” (Bombali, Urban, Male)

Some participants also made it clear that risk of getting EVD again was not a priority for them, but the risk of early death from persistent ill health was their concern.

“No, we are not at risk of getting the Ebola again, but we are risk of dying early because of our health complications we are going through.” (Kenema, Urban, Female)

“I’m not at any risk of getting Ebola. My concerns are my health. Since I came from treatment center, my health has been deteriorating every day.” (Bombali, Rural, Female)

Few participants had heard about the outbreak of EVD in Guinea. Those who were aware of the outbreak in Guinea, and those who heard about it from their colleagues through the FGDs, stated they were not happy that EVD had resurfaced in Guinea. Some described anxieties about this outbreak including acute fear, dread, and loss of appetite, among other feelings. They also expressed sorrow and empathy for those affected by the new outbreak.

“I’m not worried about getting Ebola because the medical doctors at the treatment center told me that I will never get infected with Ebola. I can only transmit Ebola by touching someone with Ebola and then pass it on to non survivors. This is the only way we as survivors can transmit Ebola. I was not worried when I heard of Ebola in Guinea because I’m immunized against Ebola. Ebola nor go ever catch me again me na embam body for Ebola. [Ebola will not ever catch me again. My body is protected from getting Ebola.]” (Bombali, Rural, Male)

“I have no fear when I heard about Ebola in the next country, because I was told that, I will never contract the virus again.” (Bombali, Rural, Female)

“From what we heard in Guinea, they said a male EVD survivor transmitted the virus so meaning there are ways that a survivor can transmit the virus.” (Kenema, Urban, Female)

“When I heard about the disease in neighboring country I reflect to my past and that made me to become worried because EVD is a killer disease and I don’t want to hear anything about it not even in any African country, if not, it is possible that it will transfer to our country, so that is my main worry.” (Bombali, Urban, Male)

The outbreak in Guinea also may have rekindled fears among community members who had begun to accept EVD survivors as being risk-free, as illustrated below.

“Quite recently my landlord asked me to leave the house for no payment of rent. But when we find out what really happen, money was not the issue. The issue was the emergence of Ebola in Guinea. He was afraid that if Ebola emerge in Sierra Leone, I will likely be infected and I will end up infecting his family. We are currently searching for a place to live.” (Kenema, Urban, Female)

However, because of persistent unresolved health issues, doubts about the possibility of infecting others with EVD are beginning to surface among EVD survivors. A few participants stated they were no longer sure whether they truly were protected from EVD.

“I am worried now if I would be infecting others though I was informed before discharge that there are no tendencies I would reinfect anybody, that’s my worry.” (Bombali, Urban, Male)

“Yes, they said we cannot get the virus again but I’m not 100% guaranteed about it that we cannot get the same Ebola again.” (Kenema, Urban, Male)

“I don’t actually know if I may or may not be affected by Ebola virus. Though doctors have assured me, I’m not sure if that will be the case.” (Bombali, Rural, Female)

Their persistent ill health worries participants, influences their beliefs that they are not immune to sicknesses, and questions their belief about immunity to EVD. Knowledge of a fellow EVD survivor who contracted the coronavirus infection also made one EVD survivor question his belief that he was protected from viral illness.

“Yes, I think I can get sick again because, since I recovered, I have been experiencing so many health issues like chest pain, fever etc. that is why I am still thinking that I can get the sick and transmit it to others.” (Bombali, Urban, Female)

“One of our colleagues who survived Ebola was diagnosed with corona and we were told by doctors that we will not get any viral disease as we have recovered. So it worries me why he was diagnosed of corona. So, we are at risk of getting Ebola virus.” (Kenema, Urban, Male)

In addition, instructions to abstain from sex for some months after recovery, and their inability to be a blood donor for family, raised suspicions about their immune status among some participants.

“Yes, I think so when my granddaughter was sick, they were supposed to give her blood and while they were looking for a donor, I volunteered so that they can get my blood for her. But they refused to take my blood and my daughters’ blood because we were survivors. So, I thought I may have the virus, or I have got the chance of getting the virus again or the virus is in my blood. So, we were told to go find someone else.” (Bombali, Rural, Female)

A few participants noted that there are different strains of EVD, and the survivors in Sierra Leone may be susceptible to other strains that were not present in the country during the last epidemic. Coupled with ill health and a weak immune system, they consider themselves at risk of EVD.

“Yes, I think I am at risk of contracting the Ebola again. The medical practitioner said there are four types of EVD strain, so I might get the sick if the other strain of virus comes. Secondly, I am not fully treated to improve my immune system and I don’t eat the required food that the body needs. As a result of that I am at risk of contracting the virus again.” (Kenema, Urban, Female)

A few participants also mentioned they were told that they would only have immunity to EVD for about ten years. This may have been interpreted to mean that EVD survivors will die in about ten years after recovery or will get sick again.

Risk perception varies among EVD survivors, and they have unanswered questions that further perpetuates uncertainty about their vulnerabilities to EVD and other illnesses. Correct information about individual risk of EVD among those recovered from the disease and among those in contact with EVD survivors is needed. Information about risk of EVD should be provided in a way that does not cause panic or increase stigma but emphasizes the safety measures that are needed to keep all individuals, including EVD survivors and their families and contacts, safe.

Support Systems

All EVD survivors reported that at this time, there was no support provided to EVD survivors. In the past, they had received food (rice, oil) and other items such as buckets, pots, beds, mattresses and bedsheets, clothes, slippers, monetary payments for blood donations, cash transfers, school fees, books, and pens for children, but these were discontinued without prior warning. Every August, participants from both districts stated that they receive a bag of rice from an Asian individual who provides them support. The promise of start-up grants and support for small business development did not progress. A participant stated EVD survivors feel they have been “*marginalized and abandoned by the government.*”

“Before we were getting [help] from several organizations including the government, but all has stopped and there is no one to give explanation.” (Kenema, Urban, Female)

“A lot of organizations have taken our names and promised to give us support at the end of the day we will not receive call from them to tell us our position.” (Kenema, Urban, Female)

“We had a business development training, and the essence was to give all EVD survivors capital to start business. Only a few EVD survivors benefited at the end, and when we ask our head office, no explanation was given.” (Kenema, Urban, Male)

Programs that are transparent about who they are and their intentions, and that feed information back to survivors about how they plan to assist and involve survivors in program development, are more likely to be well received.

EVD survivors reported receiving limited help from friends and family because they believed that survivors received sufficient help from other government and external sources.

“Whenever I ask for help from someone in the community, they refused to give me as they have the perceptions that EVD survivors are rich.” (Kenema, Urban, Female)

Last, a few participants felt their organization was not doing enough to help them and that they were not being treated fairly.

“Even our so-called organization has never come to our aid when we are provoked.”
(Bombali, Rural, Female)

“We are not treating each other fairly as we have a central body or association that can unite us. Our leaders are not trying to unite us. I don’t know why they are doing this. They want us not to talk to you and I don’t know what they are hiding from us. But it is a big blessing that you have asked us to know our plights.” (Bombali, Rural, Female)

Including more of the voices of member survivors in decisions related to programs implemented through their organization would be important to ensure that their priorities and needs are met.

Perceived Needs

EVD survivors characterized their current needs as being related to correct information, access to medical care and support systems for improved health, and support for livelihoods and for EVD orphans. Types of support needed included continuation of free healthcare services, job and skills training to support income generation, provision of food for those unable to work, support for orphans, and small business loans.

Knowledge and information needs

EVD survivors confirmed that rumors and misinformation about EVD were rife in their communities. They stated that they do not regularly receive any information about Ebola from authorities and usually get their information from rumors. They were particularly interested in learning more about the outbreak in Guinea and whether it posed a risk to them.

“I didn’t get any information. That worries me because we hear everything through rumors. Neither the government nor the Ebola survivors association called us to a meeting to discuss or to even inform us about what is happening in Guinea.” (Kenema, Urban, Female)

“What is responsible for the recent outbreak of the Guinea Ebola case because we are not getting clear information about it?” (Bombali, Rural, Female)

A few participants knew that there was another Ebola outbreak in neighboring Guinea, but did not describe it accurately. Descriptions ranged from hundreds of deaths and locked borders to misinformation regarding the cause. One participant was angry that the blood of EVD survivors was used to make the Guinea Ebola vaccine. There were many participants who had not heard that there was another EVD outbreak in a neighboring country, and many participants overall complained about the lack of credible information on this topic.

Participants reported that they would like communities to receive information that EVD survivors are not capable of transmitting the virus and that it is safe to have a relationship with them, that they are not insane, and are not accumulating wealth from the government and community organizations but are suffering. They suggested that this information be shared via radio, newspaper, brochures, social media, and sensitization campaigns featuring survivors.

The majority of participants agreed that there was misinformation about EVD survivors and negative perceptions about them among community members. They described being frustrated that they were not viewed as humans, but as EVD survivors. They described how they did not want to be defined by a disease and believed this contributed to experiences with community- and healthcare-related stigmas. Misinformation commonly went along either health or economic lines. Health information included misconceptions on how survivors became infected, their current infectivity, and their current mental health, while economic misconceptions usually revolved around the aid they received in response to the Ebola crisis.

Specific questions that participants wanted answered included:

Origins of EVD

- What is Ebola? What is the true cause of Ebola? Where did Ebola come from?
- They said Ebola was brought by people, is this true?

EVD outbreak in Guinea

- How did the EVD outbreak start in Guinea?
- How is the current Ebola situation in Guinea? Which type of EVD happened in Guinea? Is it the same one [strain] that surfaced in Sierra Leone?
- Some people said that Ebola emerged again in Guinea because a survivor passed it to people by sexual intercourse and also by blood vomits of a survivor. Is this true?
- They said Ebola is in Guinea. How can we protect ourselves as survivors?

Impacts of EVD

- Will all EVD survivors die after ten years?
- Is it true that EVD survivors are not going to be able to have children, especially as many young girls are having problems with their menstrual cycle?
- Is it true that survivors can transmit Ebola virus after abstaining from sex for six months?
- Why are we experiencing so many side effects? Are the medicine and vaccines in our bodies causing these side effects?

Resources and support for EVD survivors

- What has the Government of Sierra Leone put in place for EVD survivors?
- Why did the Government of Sierra Leone forget about survivor children and widows?
- Why can't the government provide drugs for EVD survivors under the free health care?
- Why are we not getting enough medicine? Food? Or the promises not fulfilled?
- What direct benefits shall we expect after this interview?
- Please ask our so called SLAES executive what are they doing for us and why they don't usually want people to talk to us to know our deplorable conditions?

Access to Information about EVD

- Why are the radio stations not talking about EVD and EVD in Guinea?

Other

- Why have Ebola survivors not been recruited for the fight against COVID-19 prevention?
- Would this research be different from other research where would never know feedback or benefits?
- Why was the Ebola vaccine tested in Guinea first when it was the blood of EVD survivors from Sierra Leone that was taken to make the vaccine?

Access to health services

Many EVD survivors agreed that “*access to health services is key*” to their peace of mind and survival. Participants discussed their need for health services. They reported that they would like the government to prioritize and reinstate the program for free medical care.

“One of the concerns of all EVD survivors is the arrangement which concerns our health status, especially access to free health care. GOAL initially was the one providing health care service for all EVD survivors in the district. We were happy at that time as we were having access to medication at all times irrespective of the complication you have. Things started getting worse only when the government took over our welfare and health issues and we were transferred to the government hospitals and PHUs. As I speak, there is no free health care for EVD survivors, you have to pay for drugs even if you don’t have money.” (Kenema, Urban, Female)

“We also have concern about the way and manner our health issues had been discussed and arranged at health facility level. We were given cards by the ministry that will allow us to use health care services as long as we have the survivor I.D. card, irrespective of the illness we have. Recently, the doctors and the health care workers at PHU say that the survivors I.D. card has expired.” (Kenema, Urban, Female)

In spite of much discussion about mental health problems and anxiety, few EVD participants identified a need for mental health counseling. There is a clear need for support services that diagnose mental health issues and build coping and support mechanisms for EVD survivors and their families.

Support for EVD orphans

The program for EVD orphans implemented by the Ministry of Social Welfare has ended and currently there is no support for orphans of EVD. EVD survivors discussed how young orphans who are not able to pay for their education made decisions to get married at an early age or join gangs.

“One of the greatest concerns is the EVD orphans and those survivors who are not going to school. From the data we have it shows that plenty of the Ebola orphans and Ebola survivors have dropped out of school because of lack of support. Initially, Street Child [an NGO] was giving support to EVD orphans and survivors below age 18 years, but that support has stopped. As a result of this, most of the orphans and the teenage survivors, especially girls, engage in early marriage, and the boys join gang groups. Some boys are members of groups that sell and smoke marijuana and Kush. This is happening because there is no one to support the education of the EVD survivors and orphans.” (Kenema, Urban, Female)

Other needs mentioned by EVD survivors were skills-building and vocational training, adult education for sustainable livelihoods, support for small business development and for farmers (e.g., seeds, tools), food donations for those who are not able to work, and accommodation for those who are not accepted by communities and who cannot afford to work. Several EVD survivors felt that as their illness had damaged their prior businesses, and sapped their strength,

they needed government or external support to re-establish themselves in society, so that they do not continually rely on aid to survive.

In summary, EVD survivors had many needs across multiple sectors including health, education, skills building and livelihoods, social welfare, and access to information. Approaches that are integrated across development sectors, that harmonize goals and share resources, may be more effective in reaching EVD survivors with necessary interventions.

Recommendations

EVD survivors are a vulnerable group that still face a myriad of perceived challenges in their everyday lives. In order to alleviate and address some of these barriers, a multifaceted approach that aims to not only work at the individual EVD survivor level, but community level is needed. At the community level, interventions should be wide ranging in scope and aim to dispel misconceptions and fears around EVD. As many communities in Sierra Leone are rural, mass media could be supplemented with group events such as community engagement and dialogue. Interventions for health providers should include frank discussions about possible personal beliefs and biases that impact ability to provide good quality person-centered care.

1. Community dialogues

More intensive community sensitization may be beneficial among communities where EVD survivors live, and ultimately also among the general population. Planning for such interventions should consider including health professionals, trained dialogue facilitators, community mobilizers, community leaders (teachers, religious leaders, council members, chiefs, etc.), and should be conducted in a manner that encourages full participation of community members and free speech. The dialogue should be broader than an introduction of EVD survivors to the community and should promote an in-depth exploration of members' fears and underlying drivers of stigmatizing behaviors in a safe environment. Community sensitizations should also focus on EVD and not the survivors, as to not increase stigma and label them.

Relevant topics for community sensitization may include information on: EVD (what it is, origins, how it impacts lives, risk of and prevention behaviors including availability of vaccines, etc.); living safely and comfortably with EVD survivors; stigma and discrimination; and myths, misinformation, and rumors. Special developmentally appropriate approaches may be considered for sensitizing children about EVD and stigma in their communities. A school-based approach may help to cut the cycle of stigma to which some children may have been socialized.

If EVD vaccination is offered again in the future, sensitization events could be conducted in conjunction with or before EVD vaccine events in order to increase vaccine acceptance and uptake.

2. Knowledge-building on EVD

There was a general lack of information on EVD especially regarding the most recent outbreak of EVD in Guinea. In that vacuum of knowledge, misinformation can quickly spread. Lack of

correct information may fuel fear and biases, so it is important to include interventions that ensure a consistent source of credible information about EVD. Knowledge-building activities are best planned in tandem with community sensitization activities. These activities are necessary for survivors and for community members, with a focus on providing correct information from credible sources to dispel myths, rumors, misinformation, and also allay anxieties about the unknown among EVD survivors. Correct information is also needed about what is known about the sequela from having EVD versus or in combination with other health ailments, and also about EVD treatment and the use of chlorine. This information should be conveyed in a sensitive and optimistic approach that does not cause panic or increase stigma and feelings of hopelessness.

Given that there are outbreaks emerging from survivors, careful thought needs to be put into planning knowledge-building activities so as not to perpetuate fear, misinformation, and also stigma among the general population. Knowledge building and information-sharing approaches need to be explored further with different audiences including survivors, family members of survivors, facility- and community-based health workers, and community leaders in communities that have survivors living in them, to understand how to best share new and involving information so it doesn't undermine trust or increase stigma.

It was also clear throughout the FGDs that EVD survivors still have many questions pertaining to EVD in general, and the communities most likely would as well. Transparent dialogue with opportunities for thorough question-and-answer sessions with content experts may build knowledge of EVD and dispel active rumors.

3. Improved relationships with health care system

Being connected to their families and communities is an important part of the support system for EVD survivors. Program interventions that promote supportive relationships among EVD survivors, their families, communities, and health workers may contribute to better mental and psychosocial health for EVD survivors. These interventions should not be designed as a single event but should be a continuous and sustained community activity over time. Community- and school-based interventions that focus on building trusting relationships with EVD survivors, addressing the fear, myths, and misinformation that inhibit healthy interactions, and reducing sources of stigma to promote inclusiveness may strengthen the support network and a sense of belonging among EVD survivors. Involvement of locally credible and trustworthy influencers such as chieftom chiefs, religious leaders, doctors, and nurses, in activities to address rumors and myths about EVD may help establish trust and acceptance of behavior change messages. Including topic experts such as the health workers and staff of the Kenema Lassa clinic and research center, who have expertise and experience with other hemorrhagic fevers and community response to similar situations may be beneficial for addressing fears and needs of health workers.

There also is a clear need for programs with specific aims to improve interpersonal relationships between health workers and EVD survivors. Social and behavior change interventions that aim to understand and address community- and facility-based health workers' fears and biases regarding EVD survivors, improve interpersonal communication skills of health workers, and build capacity for empathetic care from health workers, will support EVD survivors to access

needed health care services from credible sources. CHWs and CAHWs (from OneHealth) could be a valuable resource for these interventions. Promoting increased attention and access to mental health and counseling services are additional aspects of care that may benefit EVD survivors. Facilitating access of EVD survivors to EVD health specialists (doctors, counselors etc.) may be a consideration to improve relationships with the health system.

Sharing the results related to concerns around EVD survivors and fertility and changes in menstruation with local partners implementing reproductive health programs such as Marie Stopes, Plan International, and others working with women, youth, and the health care system, may help to synergize efforts to address these issues in different programs.

The technical guidance for EVD survivor care in Sierra Leone may need to be updated, as there are new scientific revelations about EVD that may generate new recommendations for survivors. The EVD vaccines may also in the future be promoted as a way to ensure that partners/spouses and families of EVD survivors feel safe and not at risk of disease.

4. Livelihood support for EVD survivors

EVD survivors consistently communicated that their known survivor status influenced fears and stigma among community members, and their status and health complications contributed to loss of income. Fostering sustainable support through linkages to skills-building opportunities, vocational training, and other community programs providing economic and other support could improve their overall livelihoods. These programs could include links to networks for job training and skills-building, support groups for EVD survivors, and community events sponsored by SLAES.

SLAES leadership could be supported with training and resources to work with organization members to apply for small business support and funding or program opportunities. This may improve relationships within the organizations and show members that the leadership has concern for member needs.

5. Development of Information resources

Related to knowledge-building is the need for information resources on EVD for key groups and the general population. These could provide accurate information from credible sources that are accepted by the community and be designed in various formats ensuring they are accessible for all survivors, including those with visual impairment or who have not learned to read due to leaving school early. Involving EVD survivors, health workers, and community leaders in developing and testing EVD- and survivor-related materials can help ensure messages and behaviors are appropriate and accepted by others within their communities and networks. Any resources for EVD and EVD survivors should be stored and accessible through the Health Education Online Library and other information sources familiar to EVD survivors. The resources may form the basis for future interventions and act as a reservoir for information should there be future outbreaks. These resources could also be used in other events or campaigns such as EVD vaccinations and general community outreach. Examples of useful information resources may include: frequently asked questions and responses; factsheets;

debunking myths and misinformation; success stories about health workers and communities supporting the needs of survivors, and resources for support services for EVD survivors.

6. **Capacity-strengthening for SLAES** to better support its members

Given the importance of community support systems for EVD survivors, and as SLAES is one of the strongest channels for reaching and supporting EVD survivors, it may be beneficial to explore ways for SLAES and the One Health Risk Communication Technical Working Group to work together to increase access to timely information on future outbreaks and information resources to address the needs outlined through this research. This could include integrating Ebola survivors into the One Health Risk Communication Technical Working Group's existing system for reporting rumors, misinformation, and concerns and using a WhatsApp group for SLAES members to share updates on outbreaks, respond to rumors, and answer questions.

Interventions with SLAES should however be completely participatory and transparent, as some discussions mentioned difficulties with SLAES leadership and a general sense of distrust among SLAES members. It will be beneficial to give EVD survivors a voice within the management of the organization including problem identification, decision-making on priorities, and planning of events.

Ebola survivor associations across the neighboring countries that had EVD epidemics (Guinea, Liberia, Sierra Leone) may be useful sources of information about programs for managing challenges experienced by EVD survivors. For instance, these associations can share information about their experiences, challenges, and successes in operating as an association. Support for study tours (physically or virtually) for EVD association leaders to learn about what other groups are doing, what works well, and how resources are leveraged to support EVD survivors may yield insights to strengthen local EVD association operations, effectiveness, and overall credibility.

Networking with other organizations with similar mandates in Sierra Leone, such as the Persons with Disability Union, People Living with Human Immunodeficiency Virus Association, and other groups focused on services for the welfare of the aged that may have similar experiences and challenges. These organizations may share information about how they operate and mobilize partners and resources, and also on coping mechanisms and strategies for dealing with health care, community members, and family members. They may also be appropriate leadership mentors for the fairly new organizations working with EVD survivors.

Conclusions

Breakthrough ACTION Sierra Leone with support from the Sierra Leone Ministry of Health and Sanitation hosted 24 group discussions with EVD Survivor in Bombali and Kenema districts to gain insights on survivor experiences and needs.

EVD survivors perceived a plethora of personal challenges regarding their health including physical, mental, and psychosocial issues that they attributed to EVD infection and treatments. Health issues were their most important topics to discuss and included anxiety, chest pain,

eyesight issues, and other problems. Community and family life varied among survivors and some continue to have difficulty integrating into their communities and families while others felt a part of the community. EVD survivors also reported issues with accessing healthcare as they no longer receive free healthcare. They also felt mistreated by health workers. Most EVD survivors reported experiencing stigma and they described instances where community members feared getting EVD from them or their family.

Up-to-date information and quality sources on EVD were scant and misinformation seemed to be commonplace. Rumors related to the origins and side effects of EVD, and conspiracy theories were mentioned. Few participants were aware of the 2021 EVD outbreak in Guinea. Most participants also believed they were currently immune to EVD, however others were beginning to think that they might not be immune to re-infection. Participants felt they had no support systems; they could not get the medicines they needed, they faced economic strain, and some were frustrated with the SLAES organization. To improve their lives and communities, survivors felt they needed better access to quality information, access to opportunities for improved livelihood, free health services and better relationships with health workers.

Recommendations to support EVD survivors in Sierra Leone include transparent community dialogues and sensitization about EVD-related information including risk and transmission, providing information and increasing correct knowledge about EVD to eliminate fear of EVD survivors and break the cycle of fear passed on through families, interventions to improve relationships with health workers, opportunities for livelihood support and new careers, development of information resources, and capacity-strengthening for the SLAES organization.

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