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Trust, fear, stigma and disruptions: community perceptions and experiences during periods of low but ongoing transmission of Ebola virus disease in Sierra Leone, 2015

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ABSTRACT

Social mobilisation and risk communication were essential to the 2014–2015 West African Ebola response. By March 2015, >8500 Ebola cases and 3370 Ebola deaths were confirmed in Sierra Leone. Response efforts were focused on 'getting to zero and staying at zero'. A critical component of this plan was to deepen and sustain community engagement. Several national quantitative studies conducted during this time revealed Ebola knowledge, personal prevention practices and traditional burial procedures improved as the outbreak waned, but healthcare system challenges were also noted. Few qualitative studies have examined these combined factors, along with survivor stigma during periods of ongoing transmission. To obtain an in-depth understanding of people's perceptions, attitudes and behaviours associated with Ebola transmission risks, 27 focus groups were conducted between April and May 2015 with adult Sierra Leonean community members on: trust in the healthcare system, interactions with Ebola survivors, impact of Ebola on lives and livelihood, and barriers and facilitators to ending the outbreak. Participants perceived that as healthcare practices and facilities improved, so did community trust. Resource management remained a noted concern. Perceptions of survivors ranged from sympathy and empathy to fear and stigmatisation. Barriers included persistent denial of ongoing Ebola transmission, secret burials and movement across porous borders. Facilitators included personal protective actions, consistent messaging and the inclusion of women and survivors in the response. Understanding community experiences during the devastating Ebola epidemic provides practical lessons for engaging similar communities in risk communication and social mobilisation during future outbreaks and public health emergencies.

Key questions

What is already known?

- The 2014–2015 Ebola epidemic in West Africa devastated individuals, families and communities in the most heavily affected countries—Sierra Leone, Liberia and Guinea.
- Even though widespread transmission had been largely contained by March 2015, several districts in Sierra Leone continued to report new cases of Ebola that were frequently linked to unsafe burials and traditional healing practices.
- Qualitative examinations of community perceptions and experiences related to the Ebola epidemic—especially during periods of low but ongoing transmission—are limited.

What are the new findings?

- Contextualised community understanding of Ebola transmission risks, perceptions of and experiences with Ebola survivors, stigma and fear associated with the disease and trust in the healthcare system.
- In-depth description of the social and economic impact of the prolonged epidemic is described through the diverse perspectives of Sierra Leoneans across the four regions of the country.
- Community perceptions of the healthcare system indicating ways to address mistrust triggered by fear, avoidance and misunderstanding.

INTRODUCTION

Social mobilisation and risk communication were essential features of the response to the unprecedented Ebola epidemic in West Africa. In March 2015, when the present assessment was designed, >8500 Ebola cases and 3370 Ebola deaths had been officially reported in Sierra Leone.[1] The number of survivors in Sierra Leone exceeded 3000 people nationwide.[2] 19 March 2015 marked the first day of no new reports of Ebola cases in the country, and the epidemiological data during this period suggested that the outbreak was on a downward trend.[1 3] Intensified efforts in the national Ebola response were then focused

Key questions

What do the new findings imply?

- Though the Ebola epidemic in West Africa ended, understanding community experiences during the devastation provides practical input for future Ebola or other viral haemorrhagic fever outbreaks.
- There should be targeted social mobilisation and risk communication efforts particularly around safe burial practices and personal protective actions such as hand washing.
- There should be targeted communication with survivors and the community at large to address stigma and safe sexual practices.

on 'getting to zero and staying at zero'. The Ebola response involved numerous interventions including contact tracing, use of specialised medical burial teams, isolation of suspected cases and treatment of confirmed cases.[4] Social mobilisation and community engagement efforts promoted early medical care, acceptance of Ebola survivors and avoidance of contact with bodily fluids of suspected cases.[5–7] These efforts were considered critical components in reducing Ebola transmissions and containing the epidemic.[8–18]

To assess public understanding of and engagement in Ebola prevention, several national knowledge, attitudes and practices (KAP) surveys were conducted by partners in the Ebola response.[19–21] The results of these surveys demonstrated that knowledge of Ebola and self-reported prevention practices improved over time. Intention to accept modifications to traditional burials also improved, but participants reported delays in ambulance services for transporting the sick and deceased.[21] While the household KAP surveys provided quantifiable data on public perceptions, there was a need for more in-depth understanding of perceptions, attitudes and behaviours associated with Ebola transmission risks. Other qualitative studies have individually explored issues related to Ebola response efforts in Sierra Leone, including Ebola transmission risk, survivor stigma and community interactions with the healthcare system.[22–26] However, few qualitative studies have examined these combined factors during periods of ongoing transmission.

Therefore, the objectives of this study were to (a) contextualise communities' understanding of an Ebola-free environment[i] at the household, community and country level; (b) understand perceptions, attitudes and beliefs about Ebola survivors as well as the range of behaviours associated with Ebola stigma and (c) obtain a nuanced understanding of communities' trust in the healthcare system.

[i] An Ebola-free environment refers to a country where there is no known active Ebola outbreak.

METHODS

During April and May 2015, 27 focus group discussions (FGDs) were conducted in Sierra Leone with adults from the general population across all four geographic regions (Western Area, Northern Province, Eastern Province and Southern Province) in Sierra Leone in 6 of Sierra Leone's 14 districts: Western Area Urban (n=4), Western Area Rural (n=4), Kambia (n=8), Port Loko (n=4), Kono (n=3) and Moyamba (n=4).[ii] Outside the capital city (Western Area), one urban/peri-urban community and one rural community were selected in each district (figure 1). These districts were selected based on their epidemiological profile during the study's planning phase in March 2015: (i) ongoing transmission of Ebola or (ii) last reported Ebola transmission in respective region (table 1).[2]

Within the selected districts, communities (n=12) were purposefully selected based on ongoing or recent Ebola transmission history to allow for more accurate recall, mitigating recall bias and ensuring that the findings would be relevant to the then-present context of the Ebola response in Sierra Leone (figure 1).

Sampling and selection of participants for FGDs

Within the selected communities, a combination of snowball and venue-based purposive sampling from public places, such as markets, halls and schools, was used to identify a cross section of participants from four

Table 1 Epidemiological profile of selected districts by region, Sierra Leone, March 2015

Region	District	Rationale
West	Urban Rural	Ongoing Ebola transmission Combined, these two districts in the capital of Freetown recorded the highest number of new and cumulative cases of Ebola[51]
North	Kambia	Ongoing Ebola transmission Continued to have hotspot communities mainly along the Forécariah border area with Guinea[2]
	Port Loko	Ongoing Ebola transmission Shares a border district with Kambia and was the second highest number of cumulative cases[2]
East	Kono	Most recent Ebola transmission in the Eastern region Only district in the region with ongoing transmission as of February 2015[2]
South	Moyamba	Most recent Ebola transmission in the Southern region Only district in the region with ongoing transmission as of March 2015[2]

[ii] Two FGDs were conducted in Kambia in order to include participants from the area that borders Guinea, and an FGD with young women was not conducted in Kono due to recruiting constraints.

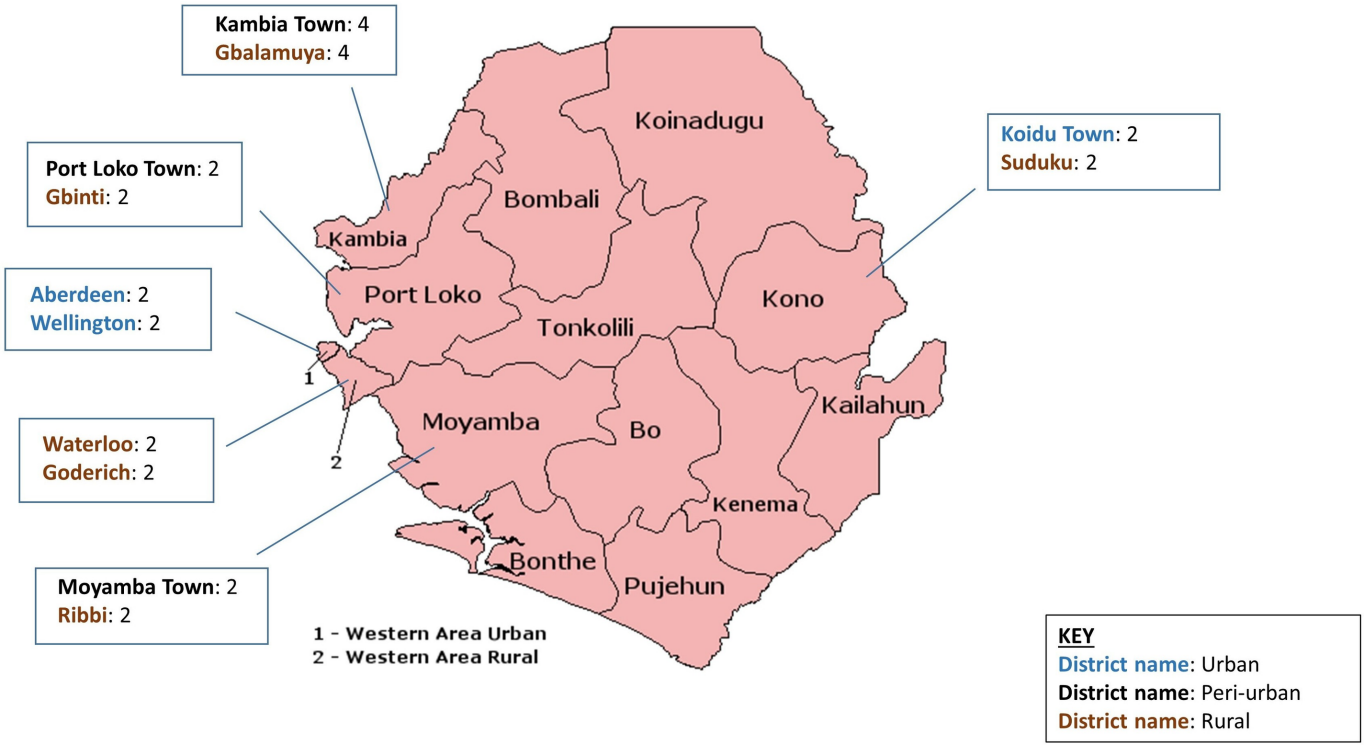

Figure 1 Number of focus group discussions around community perceptions of Ebola survivors conducted in urban and rural communities in six selected districts in Sierra Leone, 2015.

homogeneous categories grouped by age and gender: (i) adult men aged ≥25 years; (ii) adult women aged ≥25 years; (iii) young men aged 18–24 years and (iv) young women aged 18–24 years (table 2). Participants were excluded from the sample if they were younger than 18 years.

Reflective of previous FOCUS 1000-facilitated FGDs, these categories were structured so participants would feel comfortable sharing candid feedback with peers. There were no relationships with participants before the study began, all participants provided written or thumb-printed informed consent and all were free to end their participation in the focus groups at any time—though none did (online supplementary appendix A).

Development of interview guide and protocols

Behavioural scientists and community engagement experts from Sierra Leone's Ebola response efforts developed the semistructured interview guide and protocols, pretested with community members and finalised based on their feedback. Discussion topics were aligned with the three study objectives and included (a) current Ebola environment[iii] and an Ebola-free environment, activities and barriers to achieving and staying at zero infections, as well as perceived possibilities of sexual transmission from Ebola survivors; (b) participants' knowledge of, perceptions of and experiences with Ebola survivors and elicited suggestions to improve the lives of survivors and (c) health-seeking behaviours and attitudes towards healthcare workers (HCWs) and the healthcare system (online supplementary appendix B).

Training of data collection teams

A senior programme manager at FOCUS 1000 (MFJ) and the Centers for Disease Control and Prevention (CDC) health promotion team lead (KH) trained both male and female facilitators and note-takers from the respective districts, who were multilingual in English, Krio and other local languages, on FGD administration during a 3-day workshop in Freetown. The training covered topics such as screening of participants, confidentiality, informed consent, moderation techniques, note-taking and Ebola safety measures. Facilitators were trained on probing for in-depth information and nuances relating to the local context. The teams were also trained on accurate and consistent translation of questions and probes from English to local languages. Teams were matched to their assigned locations based on relevant language skills and familiarity with the corresponding district.

Implementation and administration of FGDs

Though data saturation was reached at 16 FGDs, a total of 27 FGDs were conducted to ensure all regions were included and adequately captured deviant views and experiences. All FGDs were conducted privately at common gathering places within participants' communities. FGDs were primarily conducted in Krio, the country's most widely spoken local language. In some

[iii]Current Ebola environment refers to the time frame within the past month at which participants were interviewed. Interviews were conducted in April 2015. At this time, the Ebola outbreak in Sierra Leone was still active.

Table 2 Characteristics of participants selected from the four types of community focus groups, March 2015

Adult men aged ≥25 years	Adult women aged ≥25 years	Young men aged 18–24 years	Young women aged 18–24 years
► Traditional healers ► Traditional leaders ► Religious leaders ► Male laypersons	► Sowies (female traditional healers) ► Traditional leaders ► Mammy queens (community leaders) ► Women with market shops ► Female laypersons	► Male youth leaders ► Male laypersons	► Female youth leaders ► Female laypersons

instances, participants organically transitioned to other local languages (eg, Mende in Moyamba). When necessary, keywords were translated to local languages by study teams, and participants were given the opportunity to provide their feedback in that language. The facilitator moderated the discussion while the second team member took written notes and documented group dynamics. All FGDs were tape-recorded with the consent of participants and usually lasted about an hour. FGDs were not repeated. However, major discussion points were repeated to participants at the end of each FGD. In addition, the teams held a 30 min debrief to summarise and rapidly document key themes that emerged from the discussion.

Data management

Note-takers, in consultation with the facilitators, transcribed and translated all audio recordings to English. Another study team member reviewed each transcript against the audio recording to ensure accuracy and consistency of translations. In the few incidents where discrepancies were found, a second reviewer discussed and reached consensus on the meaning of the quotation with the first reviewer and note-taker. Continued Ebola transmission in Sierra Leone prevented participants' subsequent review and feedback of completed transcripts.

Data analysis

Plain text versions of the verified transcripts were uploaded into *Dedoose*, a web-based qualitative analysis software. Two study team members (one from CDC's Sierra Leone's Ebola response team and one from FOCUS 1000) used a deductive coding process to develop and reach consensus on a parent codebook. To develop the parent codebook, the analysts identified nodes from thematic areas of the FGD guide as well as other emergent themes from each FGD debrief. To develop a final codebook, they separately coded one transcript through a structured thematic approach using the parent codebook. They then derived and reached consensus on additional subcodes from this first transcript through an inductive process. The two analysts consistently coded all transcripts from the 27 FGDs using the finalised codebook. Phenomenological inquiry was the methodological orientation for the study.

RESULTS

Overall, 183 participants participated in FGDs across six districts. Group size ranged from five to nine participants; with an almost equal distribution of adult men, adult women and young men. However, there were fewer young women in the total sample compared with the other participant categories (table 3). Each district comprised between 11% and 16% of participants. Four recurrent topics were discussed within each of the FGDs from which themes emerged (table 4).

Trust in the healthcare system

Participants described shifting perceptions of the healthcare system as the Ebola epidemic peaked and then declined in the country and discussed perceived benefits and challenges of the healthcare system. Three main themes emerged: interactions with HCWs, accountability in health resources management and training, and the physical conditions of health facilities.

Varied levels of trust in HCWs reflected participants' perceived quality of patient–provider interactions. Participants felt the Ebola outbreak disrupted their 'normal' interactions with service providers. Several participants shared that some HCWs were afraid to physically interact with patients and distanced themselves to prevent possible Ebola infection: 'Things have changed so much … before [the Ebola outbreak] if a pregnant woman went to the hospital, the medical personnel would thoroughly check the pregnant woman but that is not happening anymore because of Ebola. Now when one is sick and goes to the hospital, hardly do medical people touch them; instead they will just issue out drugs' (Port Loko—adult woman).

Other participants felt that HCWs were generally more responsive to patients as the outbreak declined: 'We have started receiving attention from nurses at hospital when we are sick. Before, we feared going to the hospital and when we did, the nurses were also afraid to treat the patients' (Western Area—adult woman). Many participants also expressed appreciation for the altruism and dedication of HCWs in addressing patient needs: 'For the health workers working at both the Holding and Treatment centers, we love them and appreciate their efforts greatly because of the sacrifice they are doing to save lives' (Western Area Rural—young man).

Participants' perceptions of health resource management (ie, allocation, implementation and oversight of health resources such as medications and other medical supplies) during the response also reflected overall trust in the healthcare system. Generally, participants felt that

Table 3 Ebola focus group discussion participants by gender/age category and district, Sierra Leone, April 2015

District	Adult men aged ≥25 years	Adult women aged ≥ 25 years	Young men aged 18–24 years	Young women aged 18–24 years	Total (n=183)
Western Area Urban	6	7	6	6	14% (25)
Western Area Rural	8	8	7	7	16% (30)
Kambia Site 1	6	6	5	5	12% (22)
Kambia Site 2	8	8	9	5	16% (30)
Port Loko	7	7	7	6	15% (27)
Kono	8	7	6	0	11% (21)
Moyamba	7	8	7	6	15% (28)
Total (n=183)	27% (50)	28% (51)	26% (47)	19% (35)	

the provision of health resources improved during the course of the outbreak. However, a minority commented on issues of mismanagement and the desire for increased accountability: 'The government should employ auditors who would check on nurses, the way they carry out their duties and audit them on the utilization of the drugs, especially that of the free healthcare scheme[iv]. If government enforces these [accountability measures] and continues to act on the Ebola preventive messages, it will help to push the country forward' (Western Area Rural—young woman).

Noted across all discussion groups, particularly from Port Loko, Moyamba and Western Area Rural, was the need for the increased allocation of medications to patients at health facilities and associated training of HCWs: 'They [healthcare workers] should be trained on how to give special care to their patient and let more drug be provided because there are many a time when you are sick they complain that there is no drug except you have to get expensive ones' (Moyamba—adult woman).

Participants also shared their perceptions of and experiences with health service facilities, particularly ambulances, Ebola holding centres, Ebola treatment units (ETUs) and hospitals. Participants feared ambulances due to chlorine smells, sirens, emergency vehicle lights and fast driving: 'We have access to ambulances, but we don't like the sound of the ambulance and the way it speeds' (Kambia 1—young man). However, as more survivors returned to their communities from the ETUs and shared their experiences, perceptions of the healthcare system shifted: 'At first, they were calling it "death center" because all those who were taken there died. But now we are seeing them going there and coming out alive. Only those that are taken there late and in serious condition will lose their life' (Kambia—adult man).

Interactions with Ebola survivors

Participants' attitudes and perceptions of survivors were complex and varied widely. Nearly everyone expressed empathy and sympathy for survivors, and reported overall acceptance of them into their communities: 'The community people including the authorities sympathized with the survivors and encouraged them to feel at home. Survivors are treated well as we did not isolate them. They are part of the community and do things in common as we used to do …' (Western Area Rural—young man).

Most participants discussed the need for improved conditions and supplemental services for, including the provision of free healthcare, education and employment opportunities. Some survivor populations such as orphans and widows were particularly seen as needing stronger government support and protection: 'Government should provide livelihood support to them especially the widows … the orphans should be taken care of by the Government … those in higher institutions should be given scholarships to further their education' (Kambia—adult man). Participants also expressed similar concerns for survivors' health after discharge from the ETU (table 4).

Participants also acknowledged that survivors experienced stigma and discrimination on return from ETUs: 'Some people still have some negative perceptions about the survivors and so they are finger pointing them whenever they see them passing by' (Kambia—adult man). Reportedly, even the most vulnerable survivors (ie, orphans and widows) experienced similar results (table 4).

In addition to perceived social stigma, there was an overwhelming belief among participants that survivors, both male and female, can possibly transmit Ebola to their partners through sexual intercourse: 'Ebola can transfer easily through unprotected sex with an infected person' (Kambia 2—adult woman). In alignment with national messaging at the time of data collection, a recurring subtheme was that survivors should abstain from sex or use a condom for at least 90 days after discharge from an ETU.

A minority of participants expressed that survivors should abstain or use condoms for longer than 90 days: 'If I am their girl or boyfriend, to be on a safer side, you add two more months to the three months given to them making five months before having sex' (Kambia—adult

[iv] The free healthcare scheme references the government's healthcare initiative to provide cost-free services and drugs to pregnant women, lactating mothers and children under the age of five.

Table 4 Emerging themes and key quotes from Ebola focus group discussion (FGD) participants, Sierra Leone, 2015

	Emerging themes	Key quotes from participants
Trust in the healthcare system	Treatment of healthcare worker	'People are not treated well at the holding centers and hospitals. My father was sick and when he was taken to the hospital, he was isolated by the health workers. No "attention was given to him", except the security officer who came to his aid and advised that we take him to Emergency hospital [ETU] where he was later transferred.' (Western Area Rural—young woman)
	Confidence in facilities	'It is only now that we realized that we were lack of hospitals in this country, the Ebola outbreak manifest it clearly. Only now they are building hospitals.' (Western Area Urban—young man)
	Fear of infection control measures	'The people think that, the too much chlorine sprayed in the ambulance before collecting the patients contributed to the death of many people because the ambulance is sealed.' (Western Area Rural—young woman)
Interactions with Ebola survivors	Integrating survivors back into the community	'Ebola survivors should be put together in a particular place for a period of their first three months.' (Port Loko—young men) 'A child who survives will find life very difficult after Ebola because the child will face so much stigma and shame, and discrimination from friends as most parents will warn their children not to go closer to them.' (Port Loko—young woman)
	Perceptions of possible sexual transmission	'Some survivors do not carry condoms with them anywhere they go, it can happen to people who are not survivors. Sometime you may feel at risk of STI when you want to have sex but if condoms are not available at the moment you have no option you just have to.' (Moyamba—young woman)
	Improving the survivor situation	'Government should provide a periodic health checkup for the Ebola survivors as most of them have health problems and do not have money to see doctors for further treatment.' (Western Area Rural—young woman)
Impact of Ebola on lives and livelihood	Economic hardship	'We are all farmers and traders before Ebola … my sister who was a trader lost all of her business when she was under quarantine … they later ended their quarantined period and things are hard for her now. She has no one to refund all she has lost. She barely survived [Ebola] with her children. So this is one example of the crisis that Ebola has brought to us.' (Kambia—adult man)
	Social impact	'Ebola has affected the way we used to interact with friends … like we used to play football but now that cannot happen because of Ebola. It has also affected religious practices for both Muslims and Christians. Like the Christians when we pray there is a particular song we used to sing which is "Hold somebody." When singing it we used to hug each other but we can no longer do that. Also for the Muslims they cannot shake hands [after prayers] like they used to do before.' (FGD—Port Loko—young man) 'Some of the actions I want government to be doing so that Ebola will never come to Sierra Leone again is continuous cleaning of the communities so that the country as a whole because Ebola is associated with dirt.' (Moyamba—adult woman)
Barriers and facilitators to ending the outbreak	Barriers to an Ebola-free environment	'Those working at the check points are doing selective checking especially if you are in a private vehicle they would not even stop you on the way or even at the check point but will check all public transport.' (Port Loko—young woman)
	Facilitators of an Ebola-free environment	'The only way we can get Sierra Leone an Ebola free environment is to abide by the rules and regulations that has been put in place meaning we must use preventive measures until the country attain 42 days 0 Ebola case.' (Kono—young man) 'It is only now that we realized that we were lack of hospitals in this country, the Ebola outbreak manifest it clearly. Only now they are building hospitals.' (Western Area Urban—young man) 'We want government to involve the women in the fight against Ebola. The women are the caregivers at home; they care for the husband, children and the rest of the family members at home.' (Kambia—adult man) 'People like to see real things before they believe if these people champion the Ebola fight they can win. At the initial stage of the virus there was lot of denial that makes thing very difficult to control the virus so if these survivors champion the fight against Ebola we must surely get to zero. Which is everyone concern now.' (Moyamba—young woman)
	Protective health behaviours	'I strongly believe that if only we continue to practice the hand washing activity, avoid body contact and all the things that we should not do then Ebola will never come back into our community.' (Port Loko—young man)

man). Some participants proposed isolation of survivors from the community for 90 days or more was necessary to prevent further transmission: 'The community should have written a project, to keep all Ebola survivors together until after 90 days, to prevent Ebola transmission through sex. The Ebola survivors should not have been allowed to stay or sleep in the same room with their partners. They should have their separate rooms because, you can't be at the stream and wash your hands with your spit' (Western Rural—young woman). Suggestions to isolate survivors from the community were expressed across all districts, but more so in Port Loko, Moyamba and Western Area Rural (table 4).

Impact of Ebola on lives and livelihood

Participants discussed the interruptions to their daily activities and community interactions because of government-imposed bans on public gatherings.[27] Economic, sociocultural and religious disruptions were particularly perceived as caused by the Ebola outbreak. Nearly every participant shared that the outbreak had a negative toll on his or her household economy, primarily due to loss of income during the prolonged epidemic. Many were farmers and traders, and limitations in community interactions hindered their ability to exchange goods and services. Adult participants frequently mentioned their inability to meet basic household needs (table 4). Consequently, some participants expressed the desire to return to pre-outbreak business practices to improve their current economic conditions: 'After the Ebola, things will be normal and everybody will be going back to their regular business' (Port Loko—adult man). Others felt it was the government's responsibility to aid in economic recovery with special support for those directly affected, such as survivors: 'The government should support the Ebola survivors with business capital or provide bikes for the youth who are Okada riders [motorcycle taxis], as most of them are struggling to get food' (Western Rural—young man).

Participants further shared that a breakdown in sociocultural systems disrupted community development activities, reflecting bans on social gathering, including school closures (table 4).[27] Perceived social consequences of the outbreak included decreased motivation towards education and increased teenage pregnancy: 'There has been a setback in the educational system and this has affected us, the young school going girls, as most of us have deteriorated. Others became pregnant and others have lost the passion for education … There are other children in the community who do not have support [for schooling] due to death of parents through Ebola and some have lost confidence in school' (Western Rural—young woman).

A break in the daily rituals of community members was also perceived as an interruption in religious norms. Congregating for daily prayer or services on the religious Sabbath also hindered common practices among community members: 'It has also affected religious practices for both Muslims and Christians. Like the Christians when we pray, there is a particular song we used to sing which is "Hold somebody." When singing it we used to hug each other but we can no longer do that. Also for the Muslims they cannot shake hands [after prayers] like they used to do before' (Port Loko—young man).

Another recurring theme among participants was the banning of traditional burial practices (often involving the washing or touching of the corpse) and restrictions in funeral participation. While the majority of participants acknowledged the need for such alterations, they voiced initial dissatisfaction with the specialised Ebola burial teams put in place by the government. Some participants cited instances when deceased family members were not buried respectfully: 'Before Ebola we used to bury our dead and give them our last respect but now we cannot. They bury our dead in disrespectful manner; they drag them away in bags as if they are logs. They take them to unknown places for burial. The disease is the devil's own. We pray for it to end now' (Kambia—adult male). Although Ebola burial teams may have improved timeliness and quality of services provided to families, participants recurrently expressed a strong desire to return to traditional burial practices.

Barriers and facilitators to ending the outbreak

As Ebola cases decreased across the country, participants generally celebrated the news: 'Ebola is free in my area or community as we now have common interaction amongst one another as before' (Port Loko—young man). Some participants expressed caution: 'Ebola cases are going down unlike the previous months and I can say that our community is a safe zone and our people are vigilant and ready to help identify suspected Ebola cases …' (Port Loko—adult man). The conflation between having no cases of Ebola in an area and the potential end of the outbreak interrupted established prevention-related attitudes and practices.

Though many were optimistic about the end of the outbreak, perceived barriers to an Ebola-free environment included denial of Ebola's continued and prolonged existence; belief that sexual transmission of Ebola by survivors was occurring; continuation of prohibited cultural practices such as secret burials and traditional healings; and large migration flows through porous borders between Kambia and Guinea. 'The barriers that still prevail among the community people are stubbornness and the ego to follow tradition … People still practice washing, dressing and burying dead loved ones, all in the name of giving last respect. This is the major reason why we still have new cases as people say 'we met the tradition' (Western Rural—adult woman). Participants also noted inconsistent actions among Ebola responders—contradictory to promoted messages—as barriers to ending the outbreak: 'The check points that are available now on the roads are not practicing the hand washing and also they are now not doing any proper checking' (Port Loko—young woman). A minority commented on issues of corruption and mismanagement of medications in the

healthcare system as additional barriers: 'Pharmaceutical board needs to do thorough searches in order to control the proliferation of counterfeit drugs and expired drugs' (Port Loko—adult man).

Several suggestions were identified as positive contributions to ending the outbreak. These facilitators included improved/expanded health facilities, consistent and coordinated messaging, and the expanded roles of women and survivors within response efforts. Improvements in and the development of new hospitals were noted by participants as contributors to improving the healthcare system (table 4). Participants also expressed that if response messaging and actions were consistent between national and local levels this would be an important booster in getting to a resilient Ebola-free Sierra Leone: 'I believe if all the information gathered from the field reaches the appropriate authorities and actions followed and implemented, it will help Sierra Leone to an Ebola-free environment' (Port Loko—young man). Recommendations for greater inclusion of women in the national response was recommended due to women's societal role as caregivers and ability to influence household decision-making around health (table 4). Similarly, the overwhelming majority of participants also expressed strong support for the inclusion of survivors in the fight against Ebola and saw them as trusted motivators to help their communities understand transmission, prevention and medical treatment messages. Survivors were particularly viewed as effective communicators in addressing the range of fears, misperceptions and denial surrounding the disease due to their direct experiences with Ebola: 'People like to see real things before they believe if these people champion the Ebola fight they can win. At the initial stage of the virus there was lot of denial that makes things very difficult to control the virus so if these survivors champion the fight against Ebola we must surely get to zero …' (Moyamba—young woman).

Protective health behaviours were identified as beneficial outcomes of the epidemic. Participants indicated that various disruptions in community relations, practices and traditions (ie, a 'pre-Ebola' lifestyle) also resulted in more cautious personal actions (such as frequent hand washing and no touching) among community members during the outbreak, and may reflect the government-mandated rules and regulations enacted: 'Rules like avoiding body contact, touching, washing, and burying the dead are all working here. We don't want to undergo another quarantine where armed men will guide our movement. We want to continue our normal business, so we don't want Ebola to continue …' (Moyamba—young woman). As these protective behaviours were incorporated into community norms, some felt they should remain even after the outbreak to keep them safe (table 4).

Participants also noted that proactive government interventions may provide additional protection to reduce the likelihood of future emerging infectious disease threats: 'Some of the actions I want government to be doing so that Ebola will never come to Sierra Leone again are continuous cleaning of this city, Freetown, because this city is very dirty and Ebola is associated to dirty …' (Western Urban—adult woman).

DISCUSSION

As transmission began to wane more than a year into Sierra Leone's Ebola outbreak, our findings reveal complex community-level perceptions of and experiences with the nation's healthcare system. Attitudes towards Ebola survivors were mixed and sometimes polarised: FGDs reflected empathy and acceptance, as well as fear and stigmatisation. The economic and social impact of the epidemic on lives and livelihoods was evident as the country struggled to transition to an Ebola-free environment. Collective insights gleaned from these discussions offer a deeper understanding of community-based experiences during the Ebola outbreak and provide useful feedback for Sierra Leone's ongoing preparedness efforts and future response strategies, especially around emergency risk communication under the Global Health Security Agenda.

Overall, our findings suggest that trust in the healthcare system increased for many participants as the outbreak waned, mirroring findings from a separate national household assessment.[28] Trusting HCWs was largely influenced by their perceptions of the quality of patient–provider interactions. Both fear of transmission and infection prevention and control (IPC) measures taken by HCWs may have contributed to misunderstanding among many community members, particularly early on in the outbreak.[29] Additional concerns around accountability, oversight and training of HCWs may have also negatively influenced community perceptions of the healthcare system.[30–33] This convergence of fear, avoidance and misunderstanding has been shown to contribute to community mistrust in healthcare systems.[24 30 34] As the outbreak shifted, HCWs became more responsive (likely due to training and additional resources) and community members returned from ETUs.[29 35] Though these changes may have improved community perceptions over time, rebuilding full community trust requires a positive, consistent and holistic approach to service delivery. Risk communication efforts can enable better community and HCW understanding of and trust in IPC measures. Additionally, understanding potential confounders that are beyond the HCWs control, such as understaffing and funding constraints, may also help community members be more sensitive to HCW challenges and minimise distrust in health staff and the system overall.[32 35]

Another qualitative assessment of Ebola survivors experiences in Sierra Leone conducted within the same time frame and districts found that nearly all participating survivors had positive experiences in ETUs—largely because of the positive interactions with HCWs.[26] Applying this finding to our study suggests that improved interpersonal communication skills of HCWs may also contribute to increased community trust in the healthcare

system. Creating patient–provider feedback mechanisms to identify gaps in the quality of services and supporting survivors to share their positive experiences in ETUs with community members may further strengthen trust in the healthcare system.

Community perceptions were also influenced by the physical environment of healthcare facilities (both mobile and stationary) and the resources used to stock these facilities (ie, medications, cleaning supplies, etc). Fear of ambulances was often linked to chlorine smells, loud siren sounds and fast driving, suggesting community members may not seek immediate professional healthcare services if their only option was to ride in an ambulance. Similarly, a national household-based survey found that nearly one-third of participants did not intend to ride in an ambulance if sick.[28] To boost public confidence and alleviate fears, an ambulance exhibition was implemented in Port Loko and Kambia.[36] This provided community members—including respected leaders—the opportunity to observe that the ambulances were safe, clean and operated by caring professionals who wanted to save lives. It may be helpful to consider community engagement experiences like this when designing and implementing future preparedness efforts. The conditions of healthcare facilities (ie, Ebola holding centres, ETUs, hospitals) also contributed to community perceptions. Many participants saw these environments as sources of death initially, rather than sources of recovery. As facilities were improved and new facilities were built, trust in these increased.[28] However, additional concerns regarding mismanagement of medications may have contributed to community mistrust.

Following containment of the Ebola epidemic, the three heavily affected countries—Sierra Leone, Liberia and Guinea—took numerous steps to address the health needs of Ebola survivors through provision of specialised health services, counselling and semen testing to help prevent flare-up of new cases linked to viral persistence.[25 26 37–42] A sizeable number of FGD participants called for prolonged isolation of survivors due to fear of possible sexual transmission, which may unintentionally discourage the public from accepting survivors into communities. Given the challenges of communicating virology with lay audiences without inadvertently stigmatising Sierra Leone's >4000 survivors, these findings call for carefully targeted risk communication around the sexual transmission of Ebola by focusing on protective sexual practices aimed at survivors and their partners as new data on viral persistence emerges.[37–42] Additionally, any messaging targeted to the general public should use culturally and regionally appropriate strategies, such as communicating through radio programmes and/or audio visual media, to expand reach and engage community members in preventing discrimination of survivors and their families.[16 22 26 28 43–47] Collaborations between local, national and international partners, such as the Social Rehabilitation and Payment to Ebola Survivors Project, can synchronise social mobilisation efforts and facilitate consistent messaging among community members.[6 26 43]

The negative economic impact of Ebola discussed by participants could be connected to the prolonged nature of the epidemic coupled with restrictions in movement and commerce, such as the shortened trading hours for public markets. Participants recognised that some survivors could not return to their normal livelihoods due to health challenges and/or stigma, potentially leading to health, economic and social implications that can ripple out to their families and communities. In a post-Ebola setting, survivors' needs should be prioritised and include community engagement efforts that promote social inclusion.

Extensive and prolonged disruptions of social, religious and cultural norms throughout the epidemic, along with perceptions of decreased Ebola transmission risk as the epidemic waned, may have fuelled a desire to return to normalcy. Participants' ability to recognise complacency in hand hygiene and safe burials illustrates their knowledge of 'what is supposed to happen' versus 'what was actually happening' in their communities. Such complacency demonstrates the possibility of reversal in protective behaviours during periods of low Ebola transmission. Previous flare-ups of Ebola cases in the subregion are reminders of the Ebola threat and the need for continued vigilance in detecting possible new outbreaks.[48 49] Ongoing community-based surveillance of priority diseases including Ebola remains important and will require sustained community engagement that includes women and survivors in leadership roles.[50]

Limitations

Our findings are subject to several limitations. First, it is possible that community perceptions were influenced by the stage and nature of their outbreak experiences. Fear may have been more prevalent in recently hard-hit communities, while negative perceptions of HCWs may have been more prevalent in communities that were hardest hit early in the outbreak, before treatment and prevention services were well-organised. Fortunately, data collection for this study took place towards the end of the outbreak in Sierra Leone, so participants' perceptions may reflect the length of the outbreak and associated variations over time, rather than isolated incidences. Resource and time constraints limited the number of FGDs with young women, resulting in a less than ideal sample among this target population. Also, the qualitative data are self-reported by community members in peer settings. Consequently, individuals may have provided some favourable responses so as not to stand out among their peers or to be reflective of recommendations provided by the government and local leaders. Finally, social desirability and facilitator influence may have also inhibited participants from sharing their own experiences that may have countered official prevention messages. These limitations were mitigated by having trained facilitators who posed broad and non-leading

questions. Though level of education and socioeconomic status were not included within the demographic information collected, the discussion groups were homogeneously designed to ensure gender or age dynamics did not influence level of participation.

CONCLUSION

Though the Ebola epidemic in Sierra Leone has been declared over, understanding community experiences during the devastating epidemic provides practical input for engaging similar communities should Ebola, other viral haemorrhagic fever outbreaks or other public health emergencies occur in the future.[18] Our findings revealed in-depth, community-level perspectives of barriers and enabling factors associated with reducing transmission risks towards the end of a prolonged Ebola epidemic in Sierra Leone. Findings from this assessment were used to inform more targeted social mobilisation efforts especially in addressing possible complacency in maintaining safe burial practices, understanding social stigma and other challenges related to Ebola survivors, and improving community trust in Ebola health services.

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