

Experiences of Ebola Survivors: Causes of Distress and Sources of Resilience

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Abbreviations:

CFR: case fatality rate
CM: complementary medicine
ETC: Ebola Treatment Center
EVD: Ebola Virus Disease
HCW: health care worker
PHEIC: public health emergency of international concern
PPE: personal protective equipment

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Abstract

Introduction: An appreciation of the experience of Ebola survivors is critical for community engagement and an effective outbreak response. Few qualitative, descriptive studies have been conducted to date that concentrate on the voices of Ebola survivors.

Problem: This study aimed to explore the experiences of Ebola survivors following the West African epidemic of 2014.

Method: An interpretive, qualitative design was selected using semi-structured interviews as the method of data collection. Data were collected in August 2015 by Médecins Sans Frontières (MSF) Belgium, for the purposes of internal evaluation. Data collection occurred at three sites in Liberia and Sierra Leone and involved 25 participants who had recovered from Ebola. Verbal consent was obtained, audio recordings were de-identified, and ethics approval was provided by Monash University (Melbourne, Australia).

Findings: Two major themes emerged from the study: “causes of distress” and “sources of resilience.” Two further sub-themes were identified from each major theme: the “multiplicity of death,” “abandonment,” “self and community protection and care,” and “coping resources and activities.” The two major themes were dominant across all three sample groups, though each survivor experienced infection, treatment, and recovery differently.

Conclusions: By identifying and mobilizing the inherent capacity of communities and acknowledging the importance of incorporating the social model of health into culturally competent outbreak responses, there is an opportunity to transcend the victimization effect of Ebola and empower communities, ultimately strengthening the response.

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Introduction

This study describes the experiences of men and women from communities in Liberia and Sierra Leone who contracted Ebola and survived during the 2014 West African Ebola epidemic. Understanding the experiences of Ebola survivors is critical to the development and improvement of outbreak planning and care coordination. At every phase, a greater understanding of the community's experience is likely to inform risk reduction and clarify the social impact for future epidemics. Importantly, the issue of cultural appropriateness was identified as having one of the greatest impacts on the effectiveness of the response effort. The issue of community engagement also was seen to be critical to successful control of the Ebola outbreak.¹

Background

In December 2013, an unknown febrile, infectious disease with a case fatality rate (CFR) of 90% was reported in Guinea.^{2,3} Initially suspected to be Cholera or Lassa fever, in March 2014 it was confirmed to be the Zaire strain of the Ebola virus.⁴ Despite early and repeated pleas for assistance, predominantly from the international humanitarian organization Médecins Sans Frontières (MSF; Geneva, Switzerland), it wasn't until August 2014 that a public health emergency of international concern (PHEIC) was declared.⁵

In less than 18 months, Sierra Leone, Guinea, and Liberia recorded an estimated 11,147 direct deaths from Ebola, including 507 deaths of health workers.⁵ Indirect deaths due to the collapse of the fragile health systems meant that untreated malaria, tuberculosis, human immunodeficiency virus, complicated deliveries, and trauma far exceeded direct deaths from Ebola.^{4,6} While widely accepted that the international community's response was delayed, the severity of the epidemic was compounded by a complex combination of geographic,

sociocultural, political, host, and pathogen factors rather than a failure of surveillance.⁵ For example, all three countries were emerging from civil wars, resulting in a depleted health workforce. Sub-Saharan Africa accounts for 24% of the global burden of disease and is home to just three percent of the world's available health workforce.⁷

Ebola is a severe hemorrhagic viral disease with a high CFR.⁸ Transmission occurs via direct contact with symptomatic patients and their body fluids.⁵ The signs and symptoms of Ebola are fever, headache, joint and muscle pain, widespread bleeding, and diarrhea.⁹ While supportive treatment such as fluid and electrolyte management, maintaining oxygenation and blood pressure, and treating opportunistic infections can significantly improve the chance of survival, there is no treatment that will cure Ebola Virus Disease (EVD).

In public health terms, EVD has a relatively low force of transmission (R0: 1.5-2.0). The goal of the response was to contain the epidemic by reducing R0 below 1.0 and six strategies were used to achieve this: (1) isolation and medical care; (2) safe burial; (3) health promotion; (4) surveillance; (5) contact tracing; and (6) health care access for non-Ebola cases.⁴ On the 29th of March, 2016, the PHEIC in West Africa was lifted. At this time, there was a total of 28,616 probable, suspected, and confirmed cases and 11,310 deaths.¹⁰ Now that the epidemic is over, affected countries are re-orienting their efforts from containment and treatment to addressing the needs of an unprecedented number of survivors, some of whom face long-term physical, psychological, and social sequelae to their illness and to learning from survivors in preparation for future epidemics. The research question for this study was: "What is the experience of Ebola survivors following the West African epidemic in Liberia and Sierra Leone?"

Justification for Study

Ebola epidemic research has traditionally concentrated on epidemiological aspects¹¹ and clinical manifestations while neglecting psychosocial aspects.¹² An understanding of the psychological aspects is vital because behavioral and emotional responses to outbreaks contribute significantly to disease perception, epidemic spread, and the effectiveness of control and preventative strategies.¹³⁻¹⁵ Health care providers also will benefit from the perspective of the recipients of their care.¹⁶

Methods

Research Design

A qualitative, interpretive study design was developed. Qualitative methodology was chosen because it suited the research question which intended to explore the experience of Ebola survivors. The interpretive paradigm was chosen because it is founded in the theoretical belief that reality is socially constructed and negotiated with social settings, cultures, and relationships with other people. Three group interviews were conducted in three different settings and questioning was semi-structured. Group interviewing is a data collection technique that uses group sessions to represent psychological, sociological, and cultural expressions and characteristics.¹⁷ The group interviews were conducted face-to-face in a conversational style in community settings using open-ended questions (Table 1). The interviews were captured digitally and transcribed verbatim.

Setting and Sample

The study took place in three communities in two countries in West Africa which hosted the largest national Ebola Treatment

Key Questions:
1. What was your experience of Ebola in your community?
2. What was your experience as a patient in an ETC?
3. What health messages did you receive?
4. How could the Ebola response be improved?
5. Tell me your story.
Further questions followed the flow of the discussion/conversation and sought to further clarify the meaning of the participant's accounts.

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Table 1. Group Semi-Structured Interview Questions

Abbreviation: ETC, Ebola Treatment Center.

Centers (ETCs). One setting was in Monrovia, Liberia and the other two settings were in Bo, Sierra Leone. Recruitment took place in August 2015. Inclusion criteria included adult males and females, who contracted Ebola, became sick, and survived between 2014 and 2015, who were treated in an ETC, and who were willing to provide an account of their experience. Exclusion criteria included children or survivors who were not treated in ETCs, or who were infected outside the reference period.

Convenience sampling was used to invite participants. Group 1 included six participants from Sierra Leone (n = 6), Group 2 included 12 participants from Sierra Leone (n = 12), and Group 3 included seven (n = 7) participants from Liberia, which cumulated to a total sample of 25 participants (N = 25). No participants were qualified health care professionals; however, some volunteered or became caretakers within ETCs post-recovery. Group 1 were members of a rural community who set up an Ebola survivor self-help group which ran from an empty health care center where the interviews were conducted. Group 2 were members of a small rural village that suffered a loss of 10% of the village population due to the outbreak. In this setting initially, data collectors were approached by the majority of the villagers keen to tell their story; however, for the purpose of group interviews, the group size was kept small. Group 3 were from a more urban setting and most were admitted around the peak of the outbreak between July and September 2014.

Data Collection

Three semi-structured group interview discussions took place, one for each group. All three interviews were facilitated by one of the authors, and a local translator was present to assist. Participants were encouraged to speak their preferred language, which was either English or other Liberian and Sierra Leonean national languages including Krio and Liberian Kreyol. Privacy was ensured and confidentiality within group discussions was agreed upon by the participants, the data collector, and the translator. Ethics approval was provided by Monash University (Melbourne, Australia): CF16/218-2016000100. No ethical issues arose during the conduct of the study.

Data Analysis

Data from 25 participants were transcribed verbatim and cross-checked for accuracy. Thematic analysis was chosen as the method of data analysis, which is congruent with the interpretive paradigm. Thematic analysis is compatible with both realist/essentialist and constructionist paradigms and is fitting of the research question.

Data Set	Location	Characteristics	Data Form	Participants
1	Bo, Sierra Leone	Rural: Self-Care Group	Audio: 101 mins	6
2	Bo, Sierra Leone	Rural: Heavily-Affected Village	Audio: 54 mins	12
3	Monrovia, Liberia	Urban: Admitted during Outbreak Peak	Audio: 105 mins	7
Total			260 mins	25

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Table 2. Participants Profile

Thematic analysis is a flexible and useful research tool, which can potentially provide a rich, detailed, and complex account of data.¹⁸ Furthermore, thematic analysis can highlight similarities and differences across the data set and allows for both psychological and social interpretations of data.¹⁸

Data analysis progressed through six phases of thematic analysis, including data preparation and familiarization, generating initial codes, searching for themes, reviewing themes, and defining and naming themes.¹⁸ Researchers sought both semantic and latent themes.¹⁸ Cross-checking between the data collector and the chief investigator occurred in all phases. Analysis took a data-driven approach as the researchers were not attempting to fit the data into a framework.

Findings

Two major themes, “causes of distress” and “sources of resilience” emerged from the thematic analysis of the survivor’s experience of Ebola. Under these major themes, four sub-themes emerged: “multiplicity of death” and “abandonment,” and “self and community protection and care” and “coping resources and activities.” Under these four sub-themes, 78 codes were identified. The two major themes were dominant across all three sample groups, even though each survivor experienced infection, treatment, and recovery differently. Certain sub-themes and codes were more dominant in particular groups depending on the journey and nature of the interviews. The nuances of each testimony are outlined below. The composition and characteristics of each group are outlined in Table 2.

Causes of Distress

Multiplicity of Death—This sub-theme refers to the phenomenon of experiencing death, loss, and grief to an overwhelming degree and at multiple levels. Multiplicity of death is a theme distinct to the unique experience of being embroiled in a PHEIC involving a deadly infectious agent. This sub-theme emerged from testimony of participants witnessing death of both individuals and groups, loved ones and strangers. Multiplicity of death also represents the symbolic death participants experienced in terms of their way of life, cultural practices, and identity.

Participants recounted witnessing large-scale death and suffering: “Just like my brother is saying, we used to die there like 10, 15, 20 bodies per day” (Survivor, Group 1). Participants were particularly distressed by the manner in which some bodies were handled post-mortem:

“I just thought I would be left with the other victims to be rot in that plastic... euh that body bag. If one would die in that, I died another 20-30 times, because each time someone died,

that moment I was totally off ... I was not myself, thinking that the next time I would be the next one they would be taking” (Survivor, Group 2).

And this:

“The bodies I remember, when we came out to take some fresh air and when you look there, the bodies were stocked up like bags of charcoal on the truck” (Survivor, Group 3).

The experience of witnessing death while in care clearly distressed and outraged participants to the point that some recounted striking until corpses were removed:

“That night, four persons died and I was in between and so then I was trying to really quarrel with the authorities because there were dead bodies ... and people who had not died were staying in the room ...” (Survivor, Group 3).

In terms of symbolic death, there was acknowledgement that the way of life had changed. Ebola’s mode of transmission was particularly damaging to participant’s cultural identity, including caring compassionately for the sick: “In [this country], we love our family. That’s when many of us contact the sick. Just because we love us” (Survivor, Group 2).

Abandonment—Abandonment included experiences prior to and during care and upon returning home post-recovery. Abandonment occurred on three levels: (1) abandonment by health care workers (HCWs); (2) abandonment by health care services, collectively, that closed as an outbreak response measure to prevent nosocomial infection; and (3) abandonment by communities expressed by participants through their experience of ostracism and stigmatization. In terms of abandonment by HCWs:

“And then so he [participant’s brother] went to the... hospital for blood test and they said No! because they started having rumors that there was a disease around and they don’t want to admit anyone with that disease. So, he came back and he got worse then [clap] he finally died” (Survivor, Group 1).

Some participants went to great lengths and sacrifice to deliver unwell family members to health care facilities; however, many recount being turned away on arrival and described the impact that had on their situation:

“... The hospital, the staff, the nurses and doctors, they ran away from them ... so we take them back to their community. But then no medication, no caring... so there they would stay dying” (Survivor, Group 1).

And this:

“...because even the nurses whom they rely on to take care of the sick... they don’t know Ebola... the moment they see in hospital a patient with signs of Ebola, they all run away because they also fear for their lives” (Survivor, Group 1).

Abandonment was also felt through the closure of health care facilities: “The doctors were afraid, so the government told them to close the hospitals” (Survivor, Group 3).

The sub-theme of abandonment was present across all groups and also was used in reference to a lack of contact with HCW while in care. Patient contact time was limited as one strategy to reduce nosocomial infection of HCWs. One participant interpreted the abandonment to be due to the lack of hope, referring to the “death sentence” that many participants believed Ebola to be:

“... I told my friends maybe they [HCWs] are not paying attention to us because they know we are going to die. That’s why they did not care for us, I thought at that time” (Survivor, Group 3).

And this:

“...They catch him and took him to hospital... he was not attended to. He was not given food, people used to put food in plastic and kicked towards him. Finally, he died. From that time, they lost trust People were scared to come out” (Survivor, Group 1).

Abandonment was described as a distance between patients and HCWs due to personal protective equipment (PPE):

“The white lady, I don’t know her name. Because you just see people, through this mesh, or they have some kind of eye glass on their face, you only see a small part of a body” (Survivor, Group 3).

Abandonment was also evident in the testimony as ostracism from the community, stigmatization: “Mockery, mockery, they mock us ... because we have had contact, that is the only reason” (Survivor, Group 2); and “They mock us, you are sick... I have no friends. I am always by myself... You have to change your location because of Ebola” (Survivor, Group 2).

Sources of Resilience

Self and Community Preservation: Protection and Care—While participants described causes of distress, they also described ways in which external and internal stress was managed, adapted to, or acted upon. These were cognitive and behavioral efforts used to manage stressful demands related to the outbreak.¹⁹

Despite a lack of familiarity with the disease and the response,²⁰ there was evidence that participants suspected Ebola early in the outbreak, which resulted in instinctive self-isolation and actions with the intent to protect others and limit the spread of the outbreak:

“So, I thought and said to myself if I would die, my wife will die and my children will die. It would be a great loss to my entire family. So, I said, let me go and die alone so they can live” (Survivor, Group 3).

Participants also isolated themselves from HCWs exposed to the virus, demonstrative of an act of self-preservation: “I used to have some malaria and will go to this man to treat me. But

I never [knew] he was treating the Ebola patient. If I knew that I didn’t go” (Survivor, Group 3).

Apart from making great sacrifices and demonstrating remarkable resilience, there was also evidence that people used their existing scarce resources to protect others:

“... they told me I don’t have Ebola... But I was not satisfied with myself. Later I got in a car and told the man driving that I wasn’t satisfy with myself. So, I wore long sleeves, socks on my hand and feet. When I got at the ETC, I told the people there to spray his car and also the shirt he was wearing...” (Survivor, Group 3).

Similarly while in care, when resources were limited and contact was restricted, some participants cared for other patients who were family members, acquaintances, or strangers:

“Yes, I was sick, but I used to wear gloves and help to take care of positive babies... and I had a baby there I was taking care of. Not my baby, but someone else’s baby, I think the mother died... but he [the baby] later died because a lady went and vomited on him” (Survivor, Group 3).

Some participants described satisfaction through caring for others:

“When I was recovering... I was encouraging other patients to take their medicine, to walk around. I encourage them, when they were not able to use the bathroom I helped them” (Survivor, Group 3)

Coping Resources and Activities—Participant’s adaptation to the fear, stress, and uncertainty was illustrated by various coping resources and activities. Some participants mentioned strength found in religious belief: “It was because of God that we came out” (Survivor, Group 3). Sometimes this belief was interpreted broadly to include magic and superstition:

“People get affected by this kind of disease and then afterwards they survive... by the hands of God or magic” (Survivor, Group 3).

And this:

“You know the people outside were saying that it was witchcraft in this village and that is why people were dying in numbers” (Survivor Group 1).

Given the extraordinarily challenging circumstances, some activities, which would not typically be recognized as coping activities, demonstrated strategies for coping with distress in the context of no treatment, scarce resources, and collapsed health systems. These included running away: “There is no treatment ... my elder sister she run away from Freetown, she came here and died” (Survivor Group 2); seeking complementary medicine (CM): “My sister gave me a country medicine [herbs];” and treating patients at home when health care services were not accessible: “She came [my niece] brought medicine for me, a drip on me, injection and took care of me at home.... I was extremely lucky” (Survivor Group 3) and:

“So, when I took him there was no hospital that was open. So, I thought how will I manage when there is no hospital? So, I take him from hospital to hospital. No way. So, he was home, I used to bath him ... feed him and my wife will cook. That’s what we were doing till later he died” (Survivor Group 3).

Discussion

In ETCs, participants witnessed death in great numbers and distress erupted from the management of corpses, including stacking bodies in view of patients and leaving the dead amongst the living. This finding corroborates an earlier study in Kikwit, Democratic Republic of Congo where survivors identified the most discouraging experience to be witnessing the death of others.¹⁸ The West African culture insists on compassionate care for the ill and ceremonial care for bodies.²⁰ In this cultural setting, a corpse is still a living being to be nurtured, cared for, and prepared for a dignified transition to the next life.²¹ Participants authenticated these values through their distress and outrage related to corpse management. While the official outbreak response effort largely viewed traditional burial practices as irrational, unnecessary, and high-risk, the treatment of corpses and burial practices incorporate important procedures to distribute inheritance and are believed to ensure the deceased an afterlife.²² While facilities were overwhelmed and safe burial practices (including cremation) were central to the response, it is also vital to respect the social and spiritual implications of changing deeply entrenched social practices. Such consideration may improve community engagement. Concerns about the treatment of corpses can supersede unfamiliar health considerations which may seem less likely or tangible than familiar social consequences.²²

Ancestral funeral and burial rights which are deeply entrenched in cultural identity were extremely challenging to maintain during the peak of the outbreak. In the eyes of participants, taking this away comprised a symbolic death of an important component of their identity. While high-risk practices can fuel an outbreak, strong evidence suggests that when technical interventions cross purposes with entrenched cultural practices, culture always wins and therefore response efforts must work within culture, not against it.²² Disregarding cultural concerns is not only counterproductive because it risks inciting community resistance, but it also demonstrates a lack of respect and empathy for the individual's or community's situation and raises ethical dilemmas about prioritizing public health over individual needs.

Abandonment was described by participants in a number of ways, including abandonment by HCWs, closure of health care facilities, and abandonment by the community in the form of stigmatization. Participants explained their abandonment by HCWs in different ways, including due to a lack of knowledge, fear, and being instructed to do so. On another level, abandonment was felt due to reduced contact time with HCWs. In West Africa, personal care is usually provided by family members; however, Ebola presented a unique situation that made this cultural practice impossible. Participants adapted to abandonment by caring for themselves and others who were family, acquaintances, and even strangers of the opposite sex.

Participants interpreted closure of health care facilities as abandonment and constituted an important cause of distress which led to shopping around for care and home care. Home care without appropriate resources amplified risk of transmission and led to poor patient outcomes. Little evidence exists on the impact of closing health care facilities as a strategy to reduce nosocomial Ebola infection; however, estimated indirect deaths due to health system collapse were thought to significantly exceed direct deaths due to Ebola.^{6,20} In the past, health facilities were implicit in Ebola outbreak amplification and were identified as the principal cause of the initial explosive spread.¹² However, during the recent West African outbreak, community transmission was identified as a principal driver,²⁰ bringing into question the harm versus

benefit effect of closing health care facilities and requires further research.

Self and community preservation was illustrated through examples of survivors taking initiatives to isolate, protect, and care for themselves and others. Inherent in the transcripts are examples of survivors demonstrating great resilience and self-sacrifice to achieve self-care and community care in overwhelmingly desperate circumstances.

As contact time between HCWs and patients was restricted due to PPE limitations, and because it was not always possible to maintain family contact during the peak of the epidemic, the patient population adapted by caring for each other. Participants, while patients, cared for other more critical patients and cared for children who were not their own. This highlights how humanity can prevail in crisis and demonstrates an inherent strength of communities to deal with catastrophic events. This finding was similar to those of Matua et al²³ who documented survivors and caregivers engaged in processes and actions to "immunize," "preserve," and "protect" against the traumatizing effects of Ebola.

Embracing the social model of health and incorporating it early in response efforts is likely to lead to community engagement which is crucial in responding to an outbreak that has profound psychosocial effects at individual, community, and international levels.⁹ Buseh et al¹ also advocate for a bottom-up, empowerment model when approaching Ebola epidemic responses, utilizing a community-based participatory approach. Buseh et al¹ argue such an approach creates opportunities for frontline health workers to engage leaders and members of local communities to discuss factors surrounding the epidemic.

Self-care and community preservation can be increased by supporting "coping resources and activities." This may be an opportunity to engage communities, ultimately strengthening the response. Coping resources and activities identified in this study include CM, religious belief, and the provision of care from home.

While the official Ebola outbreak response discouraged medical pluralism, traditional medicine has a long history in Africa. Poor access to chronically under-resourced government health facilities made care by traditional healers and self-medication through pharmacies a preferred and predominant option.²⁰ Dominant outbreak response messages that clinical biomedicine is the only effective way to understand and respond to Ebola were contrasted by the population's understanding that there was no treatment nor cure and it was at odds with their experience of abandonment. The Ebola Response Anthropology Platform supports this perspective by recommending flexible protocols to communicate problems and encourage calling on community resources to develop local solutions.²²

This study revealed that survivors found strength in religious belief, which has been interpreted broadly to include both modern and traditional religions. This finding reinforced a previous study in Uganda that found all Ebola survivors identified a belief in God or a spiritual connection as being important during the outbreak.¹² Marshall and Smith²⁴ build on the concept of religion as a resource in PHEIC and make recommendations to engage religious leaders to strengthen future outbreak responses.

Finally, the study revealed care at home as a coping activity. This was an adaptive response to health facility closure and the abandonment by health workers in a culture that values respectful care of the sick. Care at home was perhaps interpreted as hiding the sick, yet could be considered a positive response to overcome challenges. Care at home aligns with Sanjuan et al's²⁵ affirmation that recommends people experiencing traumatic events engage in

processes that assist them to overcome threats, and in doing so “normalize” their lives, at least temporarily.

Limitations

This study was limited by convenience sampling. While participants were encouraged to join the study voluntarily, they may not be representative of the population. During group interviews, anonymity could not be guaranteed, but confidentiality was assured and verbally agreed to by those present. The results are not generalizable to other populations with other conditions.

Conclusion

This study conducted a qualitative investigation based on the experience of Ebola survivors. The first emerging major theme was “causes of distress” and includes the sub-themes “multiplicity of death” and “abandonment.” These indicate opportunities to reduce the distress caused by an Ebola outbreak and may illuminate strategies to improve outbreak response acceptability. The second major theme was “sources of resilience” and included the sub-themes

“self and community preservation” and “coping resources and activities.” These highlight opportunities to enable community participation and deter community resistance. The elements of distress and resilience remind actors to consider the unique psychosocial effects of an Ebola outbreak at individual, community, and international levels. Focusing on factors exacerbating the outbreak and weaknesses in communities rather than strengths compounds marginalization, stigmatization, and inhibits success by failing to integrate existing resources.⁹ By identifying and mobilizing the inherent capacity of communities and acknowledging the importance of incorporating the social model of health into culturally competent outbreak responses, there is an opportunity to empower communities, ultimately strengthening the Ebola response.²⁴

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