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Normalizing Trauma and Humanizing Fear: A Qualitative Assessment of Ebola Survivors and Social Challenges

By

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Degree to be Awarded: Master of Public Health

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By

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2020

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An abstract of
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Abstract

Background

Ebola Virus Disease (EVD) is a devastating disease that leads to many physical and mental effects including vision and eye issues, joint pain, long-term immune dysfunction, inability to concentrate, depression, anxiety, and post-traumatic stress disorder. Survivors of the disease will also experience many social challenges after their recovery. Though negative social effects are recognized in existing literature, much of the current research does not focus on social challenges specifically. Therefore, this study seeks to close the gap in the literature by answering the research question "What social challenges do Ebola survivors in West and Central Africa experience after their recovery?"

Methods

This is a qualitative study utilizing in-depth, semi-structured interviews with health workers to answer the proposed research question. To be included in this study, participants must have been over 18 years of age and had previously worked with EVD survivors in the West or Central Africa Ebola responses in either a direct health care role or through a programmatic scope. From March 2021 to October 2021, 13 interviews were conducted over Zoom, with an average length of 40 minutes. Interviews were transcribed verbatim and analyzed thematically with MAXQDA.

Results

The sample for this study consisted of participants that worked in both direct health care and public health roles, many of them working in at least 5 separate responses. Participants worked in many different countries, including Sierra Leone, Guinea, Democratic Republic of the Congo, and many different organizations, including the World Health Organization, the United States Centers for Disease Control and Prevention, Partners in Health, and Red Cross. Results of this study were organized into four main themes, "Social Challenges Caused by Social Beliefs," "Physical Effects of Disease Compounded by Social Effects," "Uncertainty of Viral Persistence," and "Elements for Future Programs." Each main theme has at least one subtheme. For "Social Challenges Caused by Social Beliefs," the subthemes include stigmatization, ostracization, community resentment, support and reintegration, and loss of identity. "Physical Effects of Disease Compounded by Social Effects" includes Ebola treatment unit experience, and "Uncertainty of Viral Persistence" includes Ebola as a sexually transmitted disease and education and general understanding of Ebola. Lastly, "Elements for Future Programs" included communication, beneficial partnerships, multi-level interventions, elements of existing programs, and current coping mechanisms.

Conclusion

With further understanding of the social challenges survivors experience and the factors that contribute to these challenges, future interventions and research can be focused on specific issues, to hopefully achieve higher success. By utilizing results of this study, steps can be taken to improve survivors' quality of life and help them to truly recover from this horrific disease.

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Chapter 1: Introduction

Ebola Virus History and Characteristics

The first incidence of Ebola Virus Disease (EVD) occurred in 1976, in the Democratic Republic of the Congo near the Ebola River (Zawilińska & Kosz-Vnenchak, 2014). At the same time, the disease was also seen in southern Sudan and northern Zaire, caused by two different species of the virus (Zawilińska & Kosz-Vnenchak, 2014). The disease often resurfaces, generally in spillover from the animal reservoir, and there was an unprecedented epidemic from 2014 to 2016 in West Africa, which left 11,000 people dead and 17,000 survivors (Overholt et al., 2018). EVD is a zoonotic RNA *filovirus,* and is one of the most lethal and virulent pathogens in humans (Marcinkiewicz et al., 2014).

Once a person becomes infected with Ebola, the virus begins by disabling the immune system, making it very difficult for the body to fight off the virus (Marcinkiewicz et al., 2014). Symptoms and manifestations of EVD include fever, vomiting, diarrhea, internal and external bleeding, shock, and multi-organ failure (Marcinkiewicz et al., 2014; Zawilińska & Kosz-Vnenchak, 2014). Generally, symptoms appear after a four to ten day incubation period, with a total range of two to twenty-one days (Zawilińska & Kosz-Vnenchak, 2014). The Ebola virus is transmitted by bodily fluids and secretions, often through direct contact with an infected person by caregiving or sexual intercourse (Zawilińska & Kosz-Vnenchak, 2014). Long-term effects of the disease can be both mental and physical. Possible physical effects include vision and eye issues, joint pain and movement issues, in addition to evidence of long-term immune dysfunction among Ebola survivors (Wiedemann et al., 2020). Mental long-term effects of EVD include

inability to concentrate, trouble sleeping, depression, anxiety, confusion, post-traumatic stress disorder (PTSD), and isolation (Tucci et al., 2017).

Of the viruses in the *Ebolavirus* genus, the highest mortality rate is up to 90%, with rates of other species of the virus being 53% and 25% (Zawilińska & Kosz-Vnenchak, 2014). For almost the entire history of Ebola, there have not been any specific treatment methods or cure, however, there have been developments in monoclonal antibody treatment methods (Tshiani Mbaya et al., 2021). Investigational products and treatments have been used in recent outbreaks with varying degrees of success (Tshiani Mbaya et al., 2021). Recently, there have also been two approved vaccines developed for the Ebola virus, a single-dose, and a two-dose. The two-dose vaccine has been shown to be safe and effective in African and European adults (Barry et al., 2021). Data from trials of the two-dose vaccine support the use of the vaccine as EVD prophylaxis in at-risk adult populations (Barry et al., 2021; Ishola et al., 2021).

Traditional EVD prevention consists of disinfecting measures and barrier personal protective equipment, like condoms, gloves, goggles, and biohazard suits. A 2016 study in Sierra Leone found that general knowledge of EVD was high and comprehensive and attitudes towards prevention were satisfactory (Jiang et al., 2016). However, some of the population still engages in behaviors that can increase incidence of Ebola. These behaviors include traditional burial practices which have shown to lead to increased transmission of the disease and unwillingness to report Ebola symptoms or infection because of mistrust of the health system (Jiang et al., 2016). This indicates that it should still be a priority to further strengthen public education and increase community engagement with Ebola prevention.

Ebola and Mental Health

EVD can lead to many negative mental health effects in both survivors and other members of the affected communities. Specifically with survivors, psychological stress can be induced by experiences in the Ebola treatment units (ETUs), which are the main method of treating those infected with Ebola virus (Ionara Rabelo & Rosa Crestani, 2016). After the epidemics and outbreaks end, survivors and communities have trauma that lingers (Reardon, 2015). Many people have lost loved ones throughout the epidemic, even if they did not contract the disease themselves, and they often struggle to cope with their losses (Reardon, 2015).

The most common mental health effects that Ebola survivors experience are depression and anxiety (Jalloh et al., 2018; Secor et al., 2020). A 2018 cross-sectional study in Sierra Leone showed that 31% of people knew at least one person that died from Ebola, and 34% knew at least one person that was quarantined (Jalloh et al., 2018). Many of these individuals also experienced poor mental health, with 47% of all respondents reporting symptoms of anxiety, depression, and PTSD (Jalloh et al., 2018). Another 2017 cross-sectional study based in Guinea found that 15% of respondents reported levels of depression symptoms, and clinical consultations showed that these symptoms have significant repercussions for social re-integration (Keita et al., 2017). A third cross-sectional study aimed to assess the prevalence of depression and anxiety among Ebola survivors in Liberia, Sierra Leone, and Guinea (Secor et al., 2020). This study concluded that depression and anxiety are common among survivors in all three countries, however, the severity and prevalence level varies by each location (Secor et al., 2020). With the significant mortality and risks associated with contracting EVD, only recently have organizations begun investigating and prioritizing the mental health toll of the disease (Shultz et al., 2015). Major drivers of the mental health effects of the disease are fear and public perception, both founded in

the manifestations and prevention methods of the illness, which need to be addressed in order to help mitigate the issue of mental health in Ebola survivors (Shultz et al., 2015).

Ebola Survivors and Social Effects

Ebola survivors deal with many social effects including employment difficulty, stigma, discrimination, and a lack of social support. Survivors from a study in Guinea reported a lower socioeconomic status (90%), a less favorable work situation (79%), worse psychological status (60%), and more physical health problems (31%) than before their EVD diagnosis (Delamou et al., 2017). Psychosocial challenges such as anxiety, grief, and stigma are known consequences of EVD survival, and drivers of adverse experiences in survivors (James et al., 2020).

A contributor to these social effects and others in Ebola survivors is stigma. Stigma can be defined as "negative attitudes and beliefs... leading to prejudice and societal exclusion" (James et al., 2020). Stigma leads to feelings and experiences of blame, worthlessness, loneliness, isolation, social exclusion, and discrimination (James et al., 2020). Stigma can be external or internal. Stigma of EVD survivors is founded in community fear, and has led to exile, job loss, verbal abuse, divorce, and destruction of property (James et al., 2020). Infectious disease stigma in general can lead to individuals who are infected not adhering to treatment methods, not seeking treatment, and utilizing other informal methods of care that are not as effective (James et al., 2020). Pervasiveness and intensity of EVD survivor stigma is thought to have both emotional and physical consequences (Overholt et al., 2018). A 2018 study in Liberia found that 98% of respondents experienced stigmatization, but those experiences lessened over time (Overholt et al., 2018). In another study, Ebola survivor experiences and emotions were also shown to change over time, from diagnosis to treatment to discharge to the rest of their life (Karafillakis et al., 2016). Survivor empowerment and education can help to reduce the timeline

for relief in this process. A Liberian study showed that communities had levels of discriminatory beliefs towards survivors throughout the epidemics and after, though they do decline a little over time (Kelly et al., 2019).

Survivors experience even more difficulty when it comes to reintegration into their specific communities and society overall. One study in Guinea found that 72% of responding survivors experienced lower levels of reintegration into their workplace, 70% with friends, 69% in general, and 21% with family than before EVD diagnosis (Delamou et al., 2017). Many survivors cope with the challenges of community reintegration by becoming involved with the Ebola response efforts, such as educating the public, contact tracing, and caring for patients in ETUs (Karafillakis et al., 2016).

Once diagnosed or suspected of being ill, survivors' belongings will often be burned or otherwise ruined through disinfection methods with chlorine which, when paired with the social effects associated with EVD survival, can greatly affect survivors' employment and financial status (McTernan, 2016). A specific example of a survivor having financial difficulty is of a woman who had to resort to selling porridge when her husband, who was the breadwinner of the family, died of Ebola. People in the community found out that she was a survivor, and stopped buying her food so she was no longer able to provide for herself (McTernan, 2016).

Survivor programs are often not comprehensive and typically end soon after the immediate outbreak. In the aftermath of each outbreak and epidemic, there are many programs that are designed to help survivors dealing with stigma, discrimination, reintegration, and financial hardships, but as time passes, funding runs out and survivors' needs are no longer a priority to the organizations implementing the programs (McTernan, 2016). There have been some grassroots initiatives designed to help survivors, like the Survivor Dream Project, which is

focused on empowering women with education and community (Wurie, 2016). Community based mental health and psychosocial interventions need to be integrated with the wider health system in order to address the issue of stigma and social issues facing EVD survivors (James et al., 2019). Interventions and programs also need to include mental health specialists, and clinical teams need to be trained to recognize psychological stress in patients (Mohammed et al., 2015). Increased social support can also lead to better outcomes in survivor mental health and less negative social effects (Mohammed et al., 2015).

Research Gaps and Study Purpose

Though there is evidence of the mental and social effects of EVD, there is not a great deal of research specifically looking into the intersection of the two and the root causes of the social effects themselves. With the extreme and deadly nature of Ebola, public health interventions and research focus on the immediate treatment of the disease, not the long-term social effects for those who do survive. There are very few, if any, qualitative studies that utilize in-depth interviews to explain the social challenges that come with EVD survival. Additionally, there are little to no studies directly speaking with public health and healthcare professionals about their observations surrounding this issue. This study exclusively interviewed this population, allowing for a unique perspective on the topic and an opportunity to compile experiences and recommendations from a diverse sample of health professionals that have worked with Ebola survivors. The overarching purpose of this study is to identify and explain the social challenges that Ebola survivors face and compile specific recommendations for future interventions by experts in the field. The study also serves to understand how social challenges can differ by country or region, and how survivors currently cope with the challenges based on the perceptions of health professionals.

Theoretical Framework

This study utilized the Theory of Social Networks and Social Support, the Health Stigma and Discrimination Framework, and the Social Ecological Model in development of the research question, analysis of data, and application of results. These theories were chosen based on their connection with the issue of Ebola survivors' social challenges; the Theory of Social Networks and Social Support being a key assumption on the connection to social support and health status, the Health Stigma and Discrimination Framework explaining stigma's effect on health, and the Social Ecological Model to explore levels of intervention needed.

The Theory of Social Networks and Social Support contains two main elements, networks, and support. A social network can be defined as "the web of social relationships that surround an individual" (Karen Glanz, 2008). The goal of this study as related to the Theory of Social Networks and Social Support is to explore and understand the networks of the communities surrounding Ebola survivors, and the support systems within the networks, to use as a knowledge foundation for future programs helping Ebola survivors with social issues. The theory was used to inform the interview guide (example: "Describe the social networks within the community.") and interpret the results of the study.

The Health Stigma and Discrimination Framework is a relatively new theory that focuses on articulating the stigmatizing process across socio-ecological levels as it relates specifically to health (Stangl et al., 2019). The Health Stigma and Discrimination Framework was used to form conclusions and extrapolate the results of this study into recommendations for future programs and interventions concerning the social challenges of Ebola survivors.

The Social Ecological Model, in current applications, focuses on the individual, interpersonal, community, organizational, and policy/societal levels as they relate to research and

interventions (Poux, 2017). For this study, the model was used in formulation of the interview guide (example: “What level of intervention would be most effective?”), data analysis, and the interpretation of results.

Significance and Rationale

EVD is a serious illness that many people suffer the effects of; and it is a very well-known emerging infectious disease with large global public health significance. EVD has a high likelihood of death with very few standardized and reliable treatment options, which make interventions for the disease difficult. Though it is largely concentrated in Africa, the possibility for global spread of such a deadly disease increases the public health significance of the problem. As treatment methods for EVD are evolving, there are higher numbers of survivors that are suffering from mental health and social effects specific to Ebola survival. Research like this, that delves into the details of the social challenges, where they come from, and ways to solve them is needed to create a solid foundation of knowledge and recommendations for future interventions to help survivors have higher quality of life. Though some survivor programs have been put in place, they are often short lived with many issues in communication and engagement.

Ebola is a major global health problem and improving survivor quality of life is a critical element of the problem. In addition to quality of life, the issues that survivors face can lead to other consequences like risky behaviors, such as not using protective barriers like condoms, and unwillingness to report illness. Assessing the needs of survivors will improve global public health as a whole, through improving the understanding of survivor social challenges and creating more effective interventions.

Formal Statement of the Research Question

This study seeks the answer to the main research question, *"What social challenges have Ebola survivors in Central and West Africa faced after their recovery?"* through interviewing health workers that have had close involvement with Ebola survivors and programs. As well as the sub-questions *"How do survivors cope with these social challenges?"* and *"What are possible methods that can be used in future programs addressing this problem?"*

Seeking the answer to this research question will hopefully increase the foundational knowledge of the issues surrounding Ebola survivors' social challenges. Additionally, this research could encourage and inform future interventions and studies directly addressing or assessing the mental health and social challenges of EVD survivors.

Chapter 2: Literature Review

Introduction

Ebola survivors face many challenges after their recovery, especially in connection to their social wellbeing. Existing research on Ebola survivors, social challenges, and survivor programs was reviewed to inform this research project, specifically the research question and the interview guide. Sources used for the literature review include original research projects, systematic reviews, organizational reports and memos, presentations, news and magazine articles, and peer-reviewed journal articles. Studies from outside of Central and West Africa or programs that did not include a mental health or social focus were only referenced lightly, and not analyzed in depth, as they are not within the scope of this study. Specifically, this review explores existing research relevant to Ebola survivors, social challenges they face, and the survivor programs that have been implemented. The theoretical frameworks used for this particular study are thoroughly reviewed in this chapter.

Ebola Survivors

Ebola survivors are those who have recovered from Ebola Virus Disease, a community whose numbers are increasing with every outbreak. In 2015, there were an estimated 6,300 to 12,600 survivors living in West Africa, but the 2014 to 2016 outbreak of the disease in West Africa alone left over 17,000 survivors (Qureshi et al., 2015; Subissi et al., 2018). The Ebola Virus Disease Survivor Study, conducted in 2015, distributed a questionnaire to 105 Ebola survivors in Guinea regarding the health consequences of survival (Qureshi et al., 2015). Health problems that were most commonly reported by survivors were anorexia (98%), joint pain (86.7%), and back pain (45.7%) (Qureshi et al., 2015). An emerging issue that negatively affects

survivors is the possibility for transmission for an unknown amount of time after recovery. An analysis conducted in 2018 found evidence to suggest that the Ebola virus can be detected and transmissible through semen for up to 18 months after recovery (Subissi et al., 2018). Analysis of the most recent outbreak from February to June 2021 has found that the origin of the index case is from a survivor of the outbreak 5 years earlier, suggesting that virus can be transmissible long after recovery (Keita et al., 2021). Recrudescence, or relapse, is a known and documented problem among EVD survivors. A case report from 2019 in the Democratic Republic of the Congo found that a patient who was ill with Ebola recovered and tested negative with polymerase-chain-reaction assays but got sick again six months later with no new contact (Mbala-Kingebeni et al., 2021).

Negative psychological and psychosocial manifestations are a common sequela that EVD survivors must face after their recovery. A systematic review conducted in 2018 found three studies that measured overall psychological distress experience by survivors conducted in Nigeria, Sierra Leone, and Liberia (James et al., 2019). In all three studies, survivors experienced higher levels of psychological distress than non-survivors in the same communities (James et al., 2019). The specific forms of psychological distress reported in the studies included depression, anxiety, guilt, flashbacks, worthlessness, substance addiction, and suicidal tendencies (James et al., 2019). Among all reviewed papers for this study, depression emerged as the most common major psychological symptom experienced by Ebola survivors (James et al., 2019). A 2017 study conducted in Guinea assessed depression among a cohort of survivors with the Center for Epidemiologic Studies-Depression Scale (Keita et al., 2017). The study found survivors with severe depression cases, PTSD, hallucinations, as well as suicidal ideation and attempts (Keita et

al., 2017). Multiple studies have found that mental and psychological effects lessen overtime for survivors (Karafillakis et al., 2016; Keita et al., 2017).

Ebola Survivors and Social Challenges

The Ebola Virus Disease Survivor Study found that 96.2% of participants believe that their Ebola diagnosis has impacted their social life negatively (Qureshi et al., 2015). A mixed methods study that was designed to assess survivor experiences and attitudes consisted of 28 in depth interviews and short surveys with survivors in 2015 (Karafillakis et al., 2016). This study found that while many survivors had no social issues upon recovery, there was still a portion of the sample that reported experiencing discrimination, fear, and stigma from members of their community (Karafillakis et al., 2016). Most of the survivors in this study reported losing their jobs, financial difficulties, and being unable to provide for their families after recovery, when they had described their lives before infection as normal and comfortable (Karafillakis et al., 2016). A cross-sectional study conducted in Nigeria to assess social support among EVD survivors and contacts found that poor social support was only an issue for less than 25% of the respondents (Mohammed et al., 2015). However, this study was only able to recruit 4 survivors out of the total 117 participants, so the results are not directly applicable to survivor populations (Mohammed et al., 2015).

Stigma is a well-documented social challenge facing Ebola survivors, and there have been several studies assessing its effect. Entire villages have been stigmatized with large groups of people leaving the village, some never returning even after the end of the outbreak, which leaves villages and their communities vulnerable to financial issues (McTernan, 2016). A longitudinal cohort study conducted in Liberia assessed the perceived stigma that survivors were facing at various intervals post-recovery (Kelly et al., 2019). At baseline, 63% of the 859 total

participants in the study reported at least one item from the stigma index, mostly job loss or forced relocation due to social alienation (Kelly et al., 2019). A similar study was also conducted in Liberia found that 98% of participants experienced at least one type of stigma (Overholt et al., 2018). The most common forms of stigma experienced by survivors who were also health workers included avoidance, rejection, lack of reintegration, and disease denial (Sow et al., 2016). Additionally, survivors that experience enacted stigma, meaning unfair treatment by others, are more likely to utilize informal healthcare methods according to a cross-sectional study conducted in 2018 in Sierra Leone (James et al., 2020). Some studies have found evidence that levels of stigma decline over time, but many survivors find it to be a lasting challenge (Kelly et al., 2019; Overholt et al., 2018). Rises in stigma have been observed in survivor populations when EVD re-emerges and subsequent outbreaks occur (Overholt et al., 2018).

Many survivors cope with their reintegration struggles by assisting with the Ebola response. For example, in the 2015 mixed methods study all survivors reported that they considered it "their role" to help their country end the Ebola outbreak by becoming involved in contact tracing, social mobilization, education, and patient care efforts (Karafillakis et al., 2016). A cross-sectional study in Guinea found that 45% of the sampled survivors became involved with the Ebola response after their recovery (Delamou et al., 2017). The same cross-sectional study assessed overall reintegration of survivors with a semi-structured questionnaire, administered to 121 EVD survivors (Delamou et al., 2017). The majority of survivors in this study reported low levels of reintegration among their place of work, their friends, and the community overall, 72%, 70%, and 69% respectively (Delamou et al., 2017). However, only 21% of survivors reported feeling less integrated with their families after EVD (Delamou et al., 2017). Additionally, 66% of survivors felt rejected by their friends and 55% felt rejected by their

neighborhood (Delamou et al., 2017). Literacy level was found to be an influencing factor in survivors' feelings of acceptance, but being a healthcare worker or being involved in the response were not found to be influencing factors (Delamou et al., 2017).

Survivor Programs

Most survivor programs are implemented by international organizations, such as the World Health Organization, Partners in Health, Red Cross, and United Nations Children's Fund. with support from local partners (Cénat et al., 2020). In 2015, the Sierra Leone government created the Comprehensive Program for Ebola Survivors, or CPES, to improve the wellbeing of survivors in the country (Alva et al., 2020). CPES received financial support from the United States and the United Kingdom as well as other donors (Alva et al., 2020). This program allowed survivors access to health services such as ophthalmology, neurology, mental health, reproductive health, child health, counseling, semen testing, and treatment for other EVD associated health issues at no cost (Alva et al., 2020). A mixed-methods evaluation of the program found that more survivors were seeking care at health facilities, the Sierra Leone health system had increased ability to respond to the needs of survivors, and that the level of survivors experiencing disability dropped (Alva et al., 2020). However, the evaluation also found that quality of care declined over the course of the program (Alva et al., 2020).

In some communities there are local survivor organizations meant to connect survivors with each other and with governments and other implementing partners to advocate for care. One of these organizations is the Sierra Leone Association of Ebola Survivors or SLAES, the members are all survivors who work to connect others with the Sierra Leone government programs (Alva et al., 2020). Organizations like the Red Cross provide relief packages to survivors which include mattresses, clothes, food, money, personal hygiene items, household

items, and condoms (Pattison, 2015). Donation packages like these help to alleviate the financial strain put on survivors, as they often leave the ETU to find that all of their belongings have been destroyed or burned (Pattison, 2015). The Survivor Dream Project is a grassroots organization to support the reintegration of survivors into their communities and build the capacities of women in the program (Wurie, 2016). The community-based organization operates on the idea that "one has to continuously work on their heart and mind to deal with trauma," and accomplishes this through holistic psychosocial, educational, and entrepreneurial spaces (Wurie, 2016). Since 2015, the Survivor Dream Project has helped over 20 women by providing social and financial opportunities for them to grow after their recovery (Wurie, 2016).

Theoretical Framework

With the established connection between social elements and the mental and emotional health of Ebola survivors, this study is primarily founded in the Theory of Social Networks and Social Support. The analysis of data and application of results was informed by the Health Stigma and Discrimination Framework and the Social Ecological Model. These theories were chosen because of their focus on the social elements of health as well as ways to address social problems at different societal levels. The Theory of Social Networks and Social Support guides the study's assumption that there is a connection between social networks and health, while the Health Stigma and Discrimination Framework and the Social Ecological Model identify the ways and levels future interventions can be designed and used to create change.

The Theory of Social Networks and Social Support contains two main elements, networks, and support. A social network can be defined as "the web of social relationships that surround an individual" (Karen Glanz, 2008). Social support is consciously given and can be categorized into four types of behaviors, emotional support, instrumental support, informational

support, and appraisal support (Karen Glanz, 2008). Social networks and social support go hand in hand, because social support is an important function of relationships (Karen Glanz, 2008). Utilizing a focus on both narrower social support and the broader social networks allows research to be more comprehensive. The social network surrounding a person, and in turn, the social support they have, are known to have an effect on their overall health and wellbeing (Karen Glanz, 2008). The goal of this study as related to the Theory of Social Networks and Social Support is to explore and understand the networks in the communities surrounding Ebola survivors, and the support systems within the networks, to use as a foundation for future programs helping Ebola survivors with social issues.

The Health Stigma and Discrimination Framework is a relatively new theory that focuses on articulating the stigmatizing process across socio-ecological levels as it relates specifically to health (Stangl et al., 2019). The framework follows the path of stigma drivers and facilitators, to stigma marking, to stigma manifestations, to outcomes, and finally to health and social impacts (Stangl et al., 2019). A distinguishing feature of the framework is equating the 'stigmatized' and the 'stigmatizer' (Stangl et al., 2019). This is done intentionally to emphasize the "broader social, cultural, political and economic forces that structure stigma" (Stangl et al., 2019). The Health Stigma and Discrimination Framework provides a foundation to explore the stigma and discrimination of Ebola survivors as a causal factor in their mental and emotional health status after recovery. Additionally, this framework was used to provide guidance and context to recommendations and next steps based on results of the study.

The Social Ecological Model focuses on the various levels of the human ecology, the microsystem, mesosystem, and the macrosystem (Bronfenbrenner, 1977). To be more specific in current applications, the Social Ecological Model looks at the individual, interpersonal,

community, organizational, and policy/societal levels as they relate to research and interventions (Poux, 2017). A major emphasis from the Social Ecological Model is that health issues, programs, and interventions are most impactful when spread across multiple human ecological levels (Bronfenbrenner, 1977; Poux, 2017). As mentioned in previous sections, the Social Ecological Model was used in the development of interview guide questions for this study. The model was also used in the analysis and recommendation process, allowing the connection of results and recommendations to different levels of society.

Summary of the Problem

As shown through the literature review and the introduction chapter, there is a breadth of research aimed at explaining EVD survivors' physical and mental health problems post recovery, and some studies focusing on the social difficulties they face after recovery. Though there is evidence of the mental and social effects of EVD, there is not a great deal of research specifically examining the intersection of the two and the causes of the social effects themselves. Additionally, there have been programs aimed at improving survivor wellbeing, but they often focus more on physical rather than social wellbeing, which is just as important for overall health. These programs also dwindle over time due to lack of funding and support. There are few qualitative analyses specifically focusing on the social challenges survivors face, and none from the perspective of health workers. By interviewing health workers about their experiences seeing survivors' social challenges, a new perspective will be brought to the issue, hopefully allowing the opportunity for new knowledge to be gained on the topic. Knowledge that could be used to design and improve future survivor programs focusing specifically on mitigating their social challenges after recovery.

Study Objectives and Relevance

This study seeks to close the research gap and identify the specific social challenges that Ebola survivors face after recovery through in-depth interviews of health workers that have worked directly with Ebola survivors or on the implementation of survivor programs. Ebola is a major health problem facing the world today, making this research extremely relevant. The most recent outbreaks have been linked to survivors from past outbreaks, of over five years ago. As more uncertainty surrounds the transmission of the virus, fear and discrimination of survivors will follow. Continuing discrimination and stigma can make it more likely for survivors to seek informal health care options and even hide their condition completely, creating the opportunity for more transmission of the disease. These make it even more imperative that survivors are supported and accepted socially by their communities. Additionally, it needs to be remembered that health includes a person's social and mental wellbeing as well as their physical wellbeing. Survivors need social support to truly recover, and that will never be achieved as long as stigma, fear, and discrimination are prominent in their communities.

Chapter 3: Student Contribution and Methodology

Student Contribution

This project was first developed as the final "mini study" for my Qualitative Research Methods class, rooted in my long-time interest in Ebola and social determinants of health. Three interviews were conducted as part of this mini study and were included in the dataset for this expanded project. After encouragement from my professor, Dr. Charles Barber, I decided to expand the project into a full thesis research study. The overall goal and design of the study stayed consistent through the transition. Once all of the details were solidified, I found my thesis committee and submitted the protocol and other relative documents to the Emory Institutional Review Board . The entirety of the project was planned, coordinated, and designed by me, including protocol development and IRB submission, with guidance from my thesis committee.

The interview guide was informed by my initial literature review and the chosen theories, written solely by me. All study materials were reviewed and edited by my thesis chair, Dr. Walker, before commencement of the project. Additionally, all interviews were conducted, transcribed, and analyzed by me. Transcription was done through the program Otter.ai, where audio files were uploaded and automatically transcribed by the program. After automated transcription, I read through each transcript while listening to the corresponding recordings to quality check and edit each file before the transcript was finalized. Each finalized transcript was analyzed thematically with MAXQDA. All contact with participants and potential participants was done by me through my Emory Microsoft Outlook email account. I've written and researched each chapter of this thesis, with editing done by my thesis committee, Dr. Walker and Dr. Comeau. I plan to first submit the journal article portion of this manuscript to the *Social*

Science and Medicine journal. Other potential journals for submission include *Global Health: Science and Practice* and the *Journal of Global Infectious Diseases*.

Methodology

Study Design

This study was conducted using in-depth, semi-structured interviews of health professionals that have worked directly with Ebola survivors or with survivor programs. Each interview lasted between twenty minutes to one hour and took place between March and October of 2021. The purpose of the study is to understand the social challenges that Ebola survivors face, mitigation strategies, and ways to improve future programs through the lens of health care workers.

Study Sample and Recruitment

As a Rollins Earn and Learn student, the Principal Investigator (PI) works as an intern in the Division of Global HIV and TB at the Centers for Disease Control and Prevention. Through the PI's CDC network, they identified and contacted health care professionals who worked with Ebola patients or programs purposively based on their field experience. Then, snowball sampling was used to recruit further participants. A total of thirty five potential participants were contacted, with thirteen participating in the study. To be included in this study, participants must have been over eighteen years of age and previously worked with EVD survivors in the West or Central Africa Ebola responses in either a direct health care role or through a programmatic scope. The PI determined that participants met the inclusion criteria for the study through initial email conversations. Once initial participants were contacted, each participant identified two or three people that would also be beneficial for the study. All participants were contacted a

maximum of three times to set up an interview by email. No incentive was provided, financial or otherwise.

Measures

The interview guide was developed from key concepts in existing literature identified during the initial literature review and edited under the guidance of Dr. Barber and Dr. Walker. The guide consisted of a total of seven questions, each with two or three possible probing questions. Questions were organized into three major sections, 1. Field Experiences ("Tell me about your time working on the Ebola response in West or Central Africa," "Explain the social networks within the communities"), 2. Survivor Specifics ("What are the effects of these social challenges on survivors?" "How do survivors cope with social challenges specific to Ebola survival?"), and 3. Possible Solutions ("What are some ways that you think these social challenges faced by Ebola survivors could be mitigated?"). This specific interview structure was designed to build rapport with each participant and lead them into telling their experiences in sections corresponding to elements of the research question. At the close of the interview, participants were given an opportunity to ask any questions of their own or add any information they thought would be meaningful to the study. Participants were also asked about the organization(s) they worked for, the country they worked in, their job title(s) or role(s), their area of expertise, and the number of responses they have worked in.

Procedures

Semi-structured interviews were conducted and recorded with each participant over Zoom, each one lasting between twenty minutes to an hour with an average length of forty minutes. The interview guide was informed by the theoretical framework of the study, using the Theory of Social Networks and Social Support, the Health Stigma and Discrimination

Framework, and the Social Ecological Model. Participants were read a consent form before the beginning of each interview and provided verbal consent to participate in the study. Written notes were taken by the interviewer during each interview in order to identify interesting or possibly important details for analysis. One participant completed a written questionnaire using the same questions and structure as the spoken interview, because of a language barrier. Prior to completing the questionnaire, this participant was given a written copy of the consent document and provided verbal consented over the phone. In total, thirteen interviews, including one questionnaire, were completed between March 2021 through October 2021. Interview participants were emailed after the interview with a copy of the verbal consent form, and all participants were sent a request to provide further contacts for the study.

At the completion of each interview, the Zoom audio files automatically saved to the PI's computer, and were immediately uploaded into the secure transcription software, Otter.ai. Interviews were transcribed verbatim, then manually edited for clarity and accuracy. This was done to ensure quality of the transcripts and to become familiarized with the data to begin the analysis process according to the Braun and Clarke framework for thematic analysis (Braun & Clarke, 2006). All identifiable information was redacted or changed during the transcription editing process to keep participant privacy and confidentiality. Audio files and final transcripts were stored on the PI's personal, password protected laptop. Upon completion of the study, all audio recordings will be permanently deleted. The written questionnaire was filled out by the participant then scanned and emailed to the PI. The responses to each question were then edited for clarity and compiled into a Word document transcript. The original written copy of the questionnaire will be permanently deleted upon completion of the study.

Analysis

Transcripts were imported into MAXQDA and analyzed thematically. Analysis followed Braun and Clarke's suggested six-phase framework for thematic analysis of qualitative data including familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke, 2006).

In MAXQDA, all transcripts were read in full for familiarity prior to beginning the coding process. After each transcript was read, narrative memos that summarized each participant's experiences were written in order to increase familiarity with the data. Open coding was done with each complete transcript to generate initial codes and to begin the search for themes. Both these inductive codes from the data and deductive codes from the interview guide were used to inform the final code book. Examples of inductive codes include 'Loss of Identity,' 'Disbelief and Skepticism,' and 'Ebola Business.' Written notes taken during each interview contributed to the inductive codes as well. Elements from these notes were identified as inductive codes prior to open coding, with examples including 'Fear,' 'Ostracization,' and Community Resentment.' Deductive codes were identified prior to open coding from each question of the interview guide, with examples being 'Social Beliefs,' 'Mitigation Strategies,' and 'Social Network.' In total there were sixty initial codes, produced from the interview guide, written notes, and the open coding process. These initial codes were grouped into eight main codes and many subcodes, which became the final codebook and eventually informed the identification of themes.

With the final codebook, the transcripts were each recoded, with no changes being made to any code. Within the codebook, each code and subcode were given a definition, instructions on when to use, and an example segment. After the final coding session was complete, coded

segments were read over for each code. Memos were written describing any overlaps or interesting connections between cases. Additionally, memos for each case were written with visual spreads of each code, in order to assess which codes were most common in each individual case. Cross case comparisons were conducted to determine the spread of each code or subcode across the dataset as a whole. The visual tool MAX Maps was used to view all segments for each of the most common codes and to sort them into classes. Next, analysis memos were written identifying themes that stemmed from the most important or prominent codes. Each analysis memo included a definition of the theme, methods for identifying the theme, examples from the data, properties and dimensions, and examples of properties and dimensions. Code co-occurrence models were used to see the interactions between themes and codes. Exact quotes relevant and meaningful to each theme were identified and marked to be included in the write up of the report. Descriptive data of the sample were input into an Excel file and organized into a table graphic to be included in the final report.

Ethical Considerations

IRB approval was obtained through the Emory University Institutional Review Board, as Study 00002828. During initial screening contact and again prior to beginning each interview, participants were informed that the study was part of a master's thesis project. Additionally, all participants were made aware that they could skip any questions or withdraw from the study at any time if they desired. All identifying information, both for participants and any other individuals they mentioned during their interview, was changed, or deleted for privacy and confidentiality during the transcript editing process and through all documentation.

Chapter 4: Journal Article

Normalizing Trauma and Humanizing Fear: A Qualitative Assessment of Ebola Survivors and Social Challenges

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Declarations of Interest: None

Abstract

Ebola is a devastating illness that leads to many physical and mental effects including eye issues, joint pain, long-term immune dysfunction, depression, anxiety, and post-traumatic stress disorder. Survivors of the disease will also experience many social challenges after their recovery. This qualitative research study utilized in-depth, semi-structured interviews with health professionals who have worked with Ebola survivors in West and Central Africa to identify these social challenges. A total of 13 interviews, lasting 40 minutes on average, were conducted over Zoom from March to October of 2021. The sample included participants that worked with the United States Centers for Disease Control and Prevention, the World Health Organization, Partners in Health, and local organizations. Participants worked in Sierra Leone, Guinea, Democratic Republic of the Congo, Liberia, and Uganda. Verbatim transcripts of interviews were analyzed thematically, resulting in four main themes. These four themes are "Social Challenges Caused by Social Beliefs," "Physical Effects of Disease Compounded by Social Effects," "Uncertainty of Viral Persistence," and "Elements for Future Programs." Each main theme has at least one subtheme. For "Social Challenges Caused by Social Beliefs," the subthemes include stigmatization, ostracization, community resentment, support and reintegration, and loss of identity. "Physical Effects of Disease Compounded by Social Effects" includes Ebola treatment unit experience, and "Uncertainty of Viral Persistence" includes Ebola as a sexually transmitted disease and education and general understanding of Ebola. Lastly, "Elements for Future Programs" included communication, beneficial partnerships, multi-level interventions, elements of existing programs, and current coping mechanisms. These results provide foundation and direction for Ebola public health practice and research. Social challenges survivors experience, the interaction between physical and social effects of disease, and viral persistence need to be the focus of future research and programs. Programs need to include effective communication, be locally driven, and address issues at multiple levels.

Key Words: Ebola survivors, qualitative research, social challenges, stigma, West Africa, Central Africa, Ebola, health workers

Introduction

Ebola Virus Disease

Ebola Virus Disease (EVD) is a zoonotic RNA *filovirus,* and is one of the most lethal and virulent pathogens in humans (Marcinkiewicz et al., 2014). The first incidence of EVD occurred in 1976 in the Democratic Republic of the Congo near the Ebola River. Since then, the disease periodically resurfaces in spillover events (Zawilińska & Kosz-Vnenchak, 2014). Symptoms and manifestations of EVD include fever, vomiting, diarrhea, internal and external bleeding, shock, and multi-organ failure; with symptoms generally appearing after a four to ten day incubation period (Marcinkiewicz et al., 2014; Zawilińska & Kosz-Vnenchak, 2014). The virus is transmitted by bodily fluids and secretions, often through direct contact with an infected person by caregiving or sexual intercourse (Zawilińska & Kosz-Vnenchak, 2014). Of the viruses in the *Ebolavirus* genus, the highest mortality rate is up to 90%, with rates of other species of the virus being 53% and 25% (Zawilińska & Kosz-Vnenchak, 2014). For almost the entire history of Ebola, there have not been any specific treatments or cure, however, there have been developments in monoclonal antibody treatment methods (Tshiani Mbaya et al., 2021). Recently, there have also been two approved vaccines developed for the Ebola virus, a single-dose, and a two-dose (Barry et al., 2021; Ishola et al., 2021).

Ebola Survivors

Ebola survivors are those who have recovered from Ebola Virus Disease, a community whose numbers are increasing with every outbreak. In 2015, there were an estimated 6,300 to 12,600 survivors living in West Africa, but the 2014 to 2016 outbreak of the disease in West Africa alone left over 17,000 survivors (Qureshi et al., 2015; Subissi et al., 2018). An emerging issue that negatively affects survivors is the possibility for transmission for an unknown amount

of time after recovery. Prior analyses found evidence to suggest that Ebola virus can be detected and transmissible for up to 18 months after recovery, even without new contact with the virus, however more recent outbreak analyses suggest that the virus can be transmissible as long as 5 years after recovery (Keita et al., 2021; Mbala-Kingebeni et al., 2021; Subissi et al., 2018).

Survivors of EVD experience many physical and mental effects including vision and eye issues, joint pain and movement issues, long-term immune dysfunction, inability to concentrate, depression, anxiety, and post-traumatic stress disorder or PTSD (Tucci et al., 2017; Qureshi et al., 2015; Wiedemann et al., 2020). For many survivors, psychological stress can be induced by experiences in the Ebola treatment units (ETUs), which are the main method of treating those infected with Ebola virus (Ionara Rabelo & Rosa Crestani, 2016). Many people have lost loved ones throughout the epidemic, even if they did not contract the disease themselves, and they often struggle to cope with their losses (Reardon, 2015). Major drivers of the mental health effects of the disease are fear and public perception, both founded in the manifestations and prevention methods of the illness, which need to be addressed in order to help mitigate the issue of mental health in Ebola survivors (Shultz et al., 2015).

Ebola Survivors and Social Challenges

In addition to mental and physical effects, Ebola survivors deal with social effects including employment difficulty, stigma, discrimination, and a lack of social support. Survivors from a study in Guinea reported a lower socioeconomic status (Marcinkiewicz et al., 2014), a less favorable work situation, and worse psychological status than before their EVD diagnosis (Delamou et al., 2017). Stigma is a known psychosocial consequence of EVD survival, and can be defined as "negative attitudes and beliefs... leading to prejudice and societal exclusion" (James et al., 2020). A 2018 study in Liberia found that 98% of respondents experienced

stigmatization, but those experiences lessened over time (Overholt et al., 2018). Other studies have found that 96.2% of survivors believe that their Ebola diagnosis has negatively affected their social life, and many survivors report losing their jobs, experiencing financial difficulties, and are unable to provide for their families after recovery, though they described their previous lives as normal and comfortable (Qureshi et al., 2015; Karafillakis et al., 2016).

Once diagnosed or suspected of being ill, survivors' belongings will often be burned or otherwise ruined through disinfection methods which, when paired with the social effects associated with EVD survival, can greatly affect survivors' employment and financial status (McTernan, 2016). Survivors experience even more difficulty when it comes to reintegration into their specific communities and society overall, including lower levels of integration in to their workplaces and with family and friends than before EVD diagnosis (Delamou et al., 2017). Many survivors cope with the challenges of community reintegration by becoming involved with the Ebola response efforts, such as educating the public, contact tracing, and caring for patients in ETUs (Karafillakis et al., 2016).

Most survivor programs are implemented by international organizations, such as the World Health Organization, Partners in Health, Red Cross, and United Nations Children's Fund, with support from local partners (Cénat et al., 2020). Survivor programs are often not comprehensive and typically end soon after the immediate outbreak. In the aftermath of each outbreak and epidemic, there are many programs that are designed to help survivors with stigma, discrimination, reintegration, and financial hardships, but as time passes, funding runs out and survivors' needs are no longer a priority to the organizations implementing programs (McTernan, 2016). Some grassroots initiatives are designed to help survivors. The Survivor Dream Project is focused on empowering women with education and community (Wurie, 2016).

Community-based mental health and psychosocial interventions need to be integrated with the wider health system in order to address the issue of stigma and social issues facing EVD survivors (James et al., 2019). Interventions and programs also need to include mental health specialists, and clinical teams need to be trained to recognize psychological stress in patients (Mohammed et al., 2015).

Theoretical Framework

This study utilized the Theory of Social Networks and Social Support, the Health Stigma and Discrimination Framework, and the Social Ecological Model as a framework in which to examine the issues of stigma and social challenges experienced by EVD survivors. These theories were chosen based on their connection with the issue of Ebola survivors' social challenges; the Theory of Social Networks and Social Support being a key assumption on the connection to social support and health status, the Health Stigma and Discrimination Framework explaining stigma's effect on health, and the Social Ecological Model to explore levels of intervention needed for possible solutions. The theoretical framework can be seen in ***Figure 1*** below.

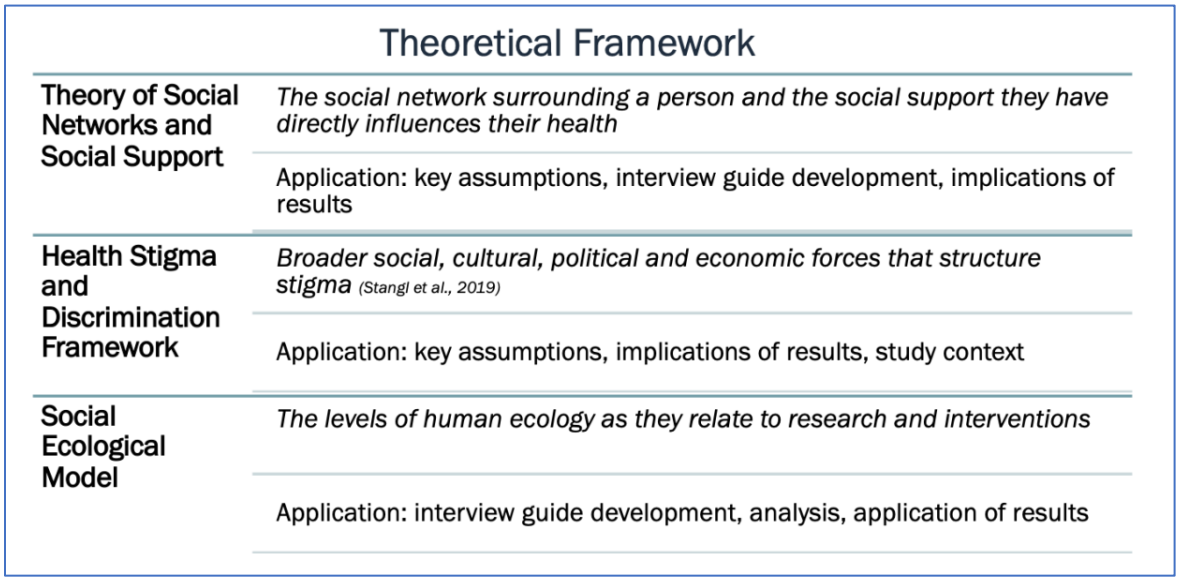


Figure 1: Theoretical Framework

Purpose

This study seeks to identify the specific social challenges that Ebola survivors face after recovery through in-depth interviews of health workers that have worked directly with Ebola survivors or on the implementation of survivor programs. This study seeks the answer to the main research question, *"What social challenges have Ebola survivors in Central and West Africa faced after their recovery?"* through interviewing health workers that have had close involvement with Ebola survivors and programs. As well as the sub-questions *"How do survivors cope with these social challenges?"* and *"What are possible methods that can be used in future programs addressing this problem?"* Seeking answer to this research question will hopefully increase the foundational knowledge of the issues surrounding Ebola survivors' social challenges. Additionally, this research could encourage and inform future interventions and studies directly addressing or assessing the mental health and social challenges of EVD survivors.

Methods

Study Design

This study was conducted using in-depth, semi-structured interviews of health professionals that have worked directly with Ebola survivors or with survivor programs. The purpose of the study was to understand the social challenges that Ebola survivors face, mitigation strategies, and ways to improve future programs through the lens of health care workers. IRB approval was obtained through the Emory University Institutional Review Board, as Study 00002828.

Sample and Recruitment

The Principal Investigator (PI) for this study identified three participants purposively based on their past field experiences. After the purposive sample was selected, snowball

sampling was used to identify and contact other potential participants for the study. A total of thirty five potential participants were contacted, with thirteen participating in the study. To be included in this study, participants must have been over 18 years of age and had previously worked with EVD survivors in the West or Central Africa Ebola responses in either a direct health care role or through a programmatic scope. The PI determined that participants met the inclusion criteria for the study through initial email conversations. Once initial participants were contacted, each participant identified two or three people that would also be beneficial for the study for the PI to contact. Potential participants cited two main reasons for why they chose not to participate in the study, the first being that they were unable to set aside time in their schedule to participate in an interview and the second being that they did not feel their experiences provided them enough information to be useful to the study.

Measures

The interview guide was developed from key concepts in existing literature identified during the initial literature review and the theoretical frameworks. The Theory of Social Networks and Social Support ("Explain the social networks within the community.") and the Social Ecological Model ("What level of intervention would be most effective?") were used to formulate specific questions in the interview guide. In total, the guide consisted of seven questions, each with two or three possible probing questions. Questions were organized into three major sections that aligned with the research questions: Field Experiences ("Tell me about your time working on the Ebola response in West or Central Africa," "Explain the social networks within the communities"), Survivor Specifics ("What are the effects of these social challenges on survivors?" "How do survivors cope with social challenges specific to Ebola survival?"), and Possible Solutions ("What are some ways that you think these social challenges

faced by Ebola survivors could be mitigated?"). At the close of the interview, participants were given an opportunity to ask any questions of their own or add any information they thought would be meaningful to the study. Participants were also asked about the organization(s) they worked for, the country they worked in, their job title(s) or role(s), their area of expertise, and the number of responses they have worked in.

Procedures

Semi-structured interviews were conducted by the PI and recorded with each participant over Zoom, each one lasting between twenty minutes to an hour (average duration: 40 minutes). The PI read the consent form to participants before the beginning of each interview; participants provided verbal consent that they agreed to participate in the study. Written notes were taken by the interviewer during each interview in order to identify salient details for analysis. One participant completed a written questionnaire using the same questions and structure as the spoken interview, because of a language barrier. Prior to completing the questionnaire, this participant was given a written copy of the consent document and provided verbal consented over the phone. In total, thirteen interviews, including one questionnaire, were completed between March 2021 through October 2021. Interview participants were emailed after the interview with a copy of the verbal consent form.

At the completion of each interview, the Zoom audio files automatically saved to the PI's computer, and were immediately uploaded into the secure transcription software, Otter.ai. Interviews were transcribed verbatim, then manually edited for clarity and accuracy. This was done to ensure quality of the transcripts and to become familiarized with the data to begin the analysis process according to the Braun and Clarke framework for thematic analysis (Braun & Clarke, 2006). All identifiable information was redacted or changed during the transcription

editing process to ensure participant privacy and confidentiality. Audio files, final transcripts, and the written questionnaire were stored on the PI's personal, password protected laptop. Upon completion of the study, all audio recordings were permanently deleted.

Analysis

Transcripts were imported into MAXQDA for data analysis. Analysis followed Braun and Clarke's suggested six-phase framework for thematic analysis of qualitative data including familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke, 2006).

All transcripts were read in full for familiarity prior to beginning the coding process. After each transcript was read, the PI wrote narrative memos that summarized each participant's experiences. Open coding was done with each complete transcript to generate initial codes and to begin the search for themes. Both these inductive codes from the data and deductive codes from the interview guide were used to inform the final code book. Examples of inductive codes include 'Loss of Identity,' 'Disbelief and Skepticism,' and 'Ebola Business.' Written notes taken during each interview contributed to the inductive codes as well. Elements from these notes were identified as inductive codes prior to open coding, with examples including 'Fear,' 'Ostracization,' and Community Resentment.' Deductive codes were identified prior to open coding from each question of the interview guide, with examples being 'Social Beliefs,' 'Mitigation Strategies,' and 'Social Network.' In total there were sixty initial codes, produced from the interview guide, written notes, and the open coding process. These initial codes were grouped into eight main codes, and many subcodes, which became the final codebook and eventually informed the identification of themes. All coding was completed by the PI, there was not a second coder.

After the final coding session was complete, coded segments for each code were reviewed. Memos were written describing patterns and connections between cases. Additionally, memos for each case were written with visual spreads of each code, in order to assess which codes were most common in each individual case. Cross case comparisons were conducted to determine the spread of each code or subcode across the dataset as a whole. Next, analysis memos were written identifying themes that stemmed from the most important or prominent codes. Each analysis memo included a definition of the theme, methods for identifying the theme, examples from the data, properties and dimensions, and examples of properties and dimensions.

In order to ensure rigor and validity of the study, all results were triangulated with sources from the literature review as well as memos, presentations, and reports gathered from study participants. After automated transcription, all transcripts were proofread multiple times at different points in the study process by the PI. Codes were applied consistently based on the predetermined directions within the final codebook in order to ensure non-selectivity in the data. In order to reduce the potential for bias, the PI constantly examined their own positionality as a cultural outsider, non-field worker, and non-survivor and remained reflexive on their own pre-conceived notions and beliefs throughout the research process.

Results

Demographics

The sample for this study included three participants who worked in direct patient care as health providers or physicians and ten who worked in programmatic or public health focused areas in roles such as program coordinator, contact tracer, epidemiologist, behavioral scientist, and health communicator. The most common organization that participants worked for was the

United States Centers for Disease Control and Prevention (CDC), followed by Partners in Health (PIH), the World Health Organization (WHO), Red Cross, GOAL Global, the United Nations Children's Fund (UNICEF), and organizations such as local programs, Ministries of Health (MOHs), or non-governmental organizations. The majority of participants worked in multiple countries, including Sierra Leone, Guinea, Democratic Republic of the Congo, Liberia, and Uganda. Each participant was involved with at least two separate outbreak responses, with the majority being involved with more than five responses. Only one participant was local to the area they worked in. Demographics can be viewed in ***Table 1***.

	N
Organization	
US Centers for Disease Control and Prevention	6
Partners in Health	4
Local Organizations	4
World Health Organization	3
GOAL Global	2
Red Cross	2
United Nations Children's Fund	1
US National Institutes of Health	1
Country	
Sierra Leone	7
Guinea	7
Democratic Republic of the Congo	7
Liberia	3
Uganda	1
Role	
Program Coordinator	3
Physician	2
Epidemiologist	2
Infection Prevention	2
Team Lead	1
Medical Officer	1
Health Communicator	1
Behavioral Scientist	1
Clinician	1
Area of Experience	**13**
Program	10 (76.9%)
Healthcare	3 (23.1%)
Number of Responses	**13**
5+	7 (53.8%)
4	2 (15.4%)
3	2 (15.4%)
2	2 (15.4%)

**Categories for Organization, Country, and Role are not mutually exclusive*

Table 1: Sample Demographics

Themes

The results of this study are categorized into four distinct themes, ***seen in Figure 2***, two developed from the research question or sub-questions and two developed inductively from the data. Themes are organized from the broader element of "Social Challenges Caused by Social Beliefs," to specific challenges "Physical Effects of Disease Compounded by Social Effects" and "Uncertainty of Viral Persistence," to specific recommendations for the future in "Elements for Future Programs." Names used in this section are pseudonyms and have no relation to any individual participant.

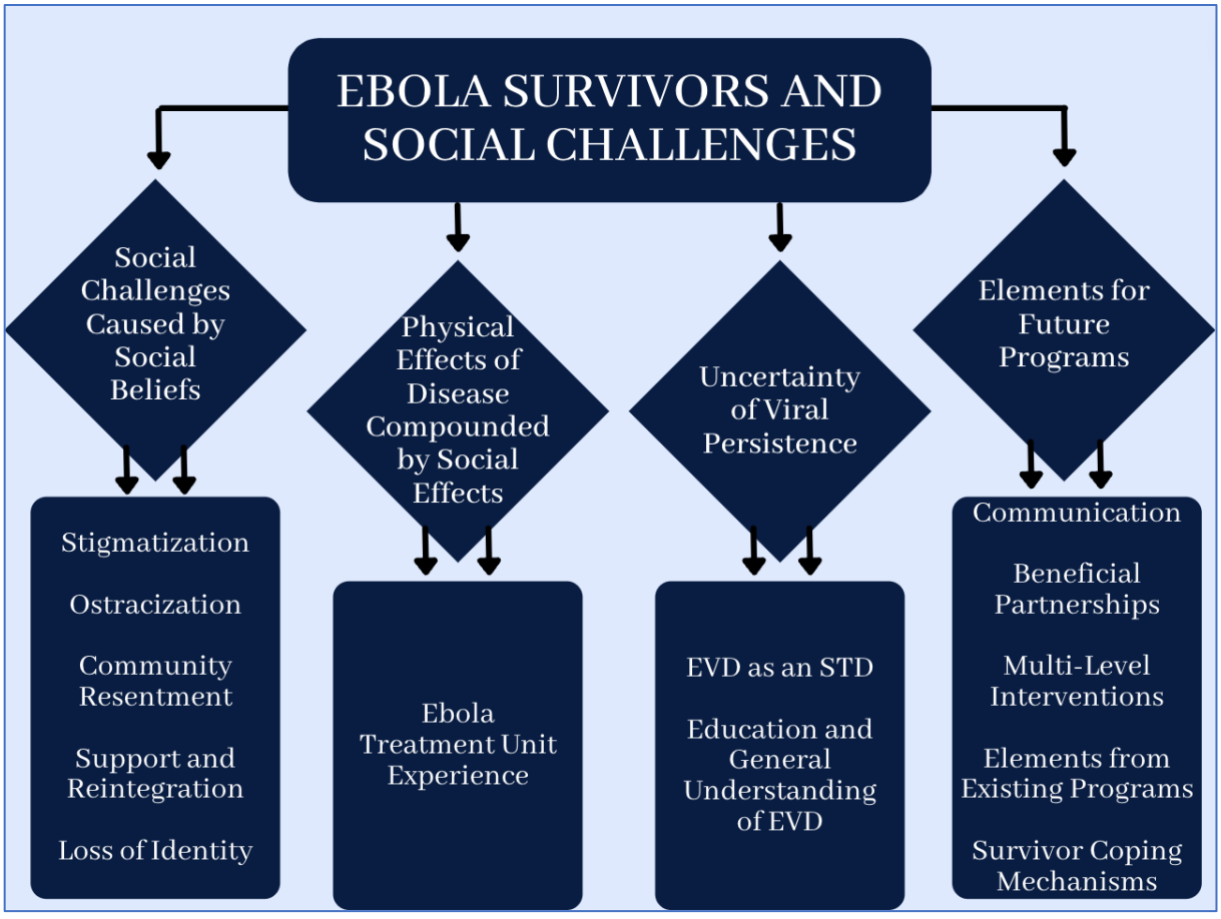


Figure 2: Conceptual Model of Results

Social Challenges Caused by Social Beliefs

Participants describe the social challenges that survivors experience, as well as the social beliefs and other factors that contribute to the challenges. There was agreement among participants that the social challenges that survivors experience are directly influenced by the social beliefs surrounding the disease as well as other contributing factors such as distrust of governments and organizations, fear, misunderstandings of disease, and viral persistence of the disease. One participant, Daniel, exemplified the intersections between all of these contributors and the social challenges and beliefs:

> But of course, I think you'll find when you when you turn over these rocks, in terms of the stigma, or social challenges, barriers are driven by fear. Right? And that fear is related to fear of anyone who's connected to that disease, which has always had this sort of mythical nature to it... So, it's understandable that that fear would exist, but now add to that fear, the possibility that you could be harboring a virus and, and that that could be lasting for a long period of time.

The issue of EVD survivors and social challenges is a complicated one. Contributors to social beliefs and challenges often interacted with each other in the data, occurring in the same segments, for example, stigma and ostracization often being linked by participants. The most prominent social challenges reported by participants were stigmatization, ostracization, community resentment, support and reintegration, and loss of identity.

The single most common social challenge in the data was stigmatization. Annie, as well as other participants, asserted that every survivor will experience stigma. She explained, "*what is really striking, is yes, any survivor will experience, to an extent, some type of stigmatization, but this greatly varies from one person to another*." Stigma for EVD survivors comes from various

places and people, though each survivor's experience is different, they are all bound to have some sort of effect on their social wellbeing. Julie identified an effect that many survivors will experience from stigma: loss of financial stability. She said:

> One example is the stigma has caused them to lose their ability to make a living, because say, they might have been, you know, had a food stand or something, or, you know, had a little restaurant or something, and people don't want to eat food prepared by them anymore, because they're afraid of becoming infected. So, um, it makes returning to their daily lives really hard.

In this quote, and multiple other points during her interview, Julie also connected the source of much of the stigma experienced by survivors as fear from others in the community.

Ostracization is another social challenge that was experienced in many cases, often intersecting with stigma. Connie explained this intersection well, "*there's often celebration over them recovering, but there's still that stigma that sits attached to them right away from the start just because they've had this illness that kills people, and so they get ostracized*." In this instance, stigma could be seen as a cause for ostracization. In other instances, rather than being a cause, ostracization could be associated with stigma. Causes of ostracization are similar to those of stigmatization, a compound of fear and knowledge of the disease. Many participants were able to provide specific instances or examples of ostracization in EVD survivors, but Christopher was able to sum the issue very succinctly in this quote:

> But I do know, that when survivors returned to their communities, they were often refused access to their communities or drastically ostracized. Yeah, so to the effect that like, I heard the story of one having to use, you know, being given he had his own his

> own plate and fork. Like that was his and he had to sit in the corner to eat away from the rest of the family and, you know, was just completely ostracized.

There are levels of ostracization for survivors, they are not necessarily always completely barred from returning their communities. Sometimes it could be on a smaller scale, such as what is described above, where they are brought back in but kept at a physical and social distance from the rest of the community. Both of these dimensions have the potential to negatively affect social and mental wellbeing.

Based on participants' descriptions, community resentment as a social challenge can be defined as the community having negative feelings or jealousy of survivors because of the goods and services they receive. It was introduced by Maria in this quote:

> But what they'll do is for survivors, they'll provide like, you know, free health care, because they know that they'll have, you know, mental health issues potentially afterwards and other physical problems. And then you have this problem where then the community resents them, because they are getting something that they don't have access to, you know, I don't have free healthcare, my family doesn't have free healthcare, but you have the healthcare. And that's because you're a survivor.

Resentment from the community caused many issues for survivors, in reinvigorating stigma, ostracization, and isolation from their communities as well as lack of support. In some cases, violence has even come out of community resentment, shown in this experience shared by Annie:

> I went to discuss with one community in particular where the voices were very violent against EVD survivors... the person that was most against EVD survivors, asking them to be locked down and so on... [the problem] was that this guy was not in favor of

> [providing condoms to survivors], he was requesting to get access also to condoms for the use in his communities, and that he didn't understand why we were giving only condoms to EVD survivors.

In this case, something as small as providing condoms to survivors caused a major issue within the community that was potentially dangerous for survivors themselves.

Support and reintegration are challenges that came up quite often across all cases. This subtheme focuses on reintegration in relation to family and community support, or lack thereof. Common types of interactions and support described by participants include survivors being accepted by their own family or another and being rejected by their family or community. Julie explains the issue of family very well. She said:

> Well, I think that varies a lot. I mean, I think some families are very supportive and encouraging. And, you know, for example... but some of the survivors are orphans. So, you know, in the best of circumstances, extended families support them and provide a loving environment. I think, in other cases, there's so much fear that, that they're kind of shut out from families. And so that's a real question.

There is a spectrum of support, and when the level falls to the negative side of that spectrum, survivors will have a more difficult time reintegrating back into their communities. Additionally, as Julie mentions in this quote, many survivors lose their entire family to Ebola. In these cases, it isn't that survivors are being ostracized or specifically excluded, it's that their support system is completely gone. Another participant, Alyssa, also explains this issue well. She explained:

> Even if somebody survived Ebola, a lot of times, their families didn't, like so you might have had one person who was the only survivor, of a family of 5 or 10, and did not have the social support that you would normally have in those situations, even if you're feeling

> you know, supported by other parts of the community, you don't necessarily have that one person you used to go to, like your grandmother who used to always be there for you. So, when you are feeling pressured, or you're not feeling accepted by community, the people who would be there to accept you most, aren't there anymore because they've passed away.

Another dimension of this subtheme is the differences in experiences by gender. Annie shared how women were rejected by their families, "*this puts women at higher risk, obviously, especially if the women have lost a husband or kids and is being rejected by the in-laws."* Gender differences were mentioned by a few participants but was not directly asked about in every interview.

The final subtheme under social challenges and effects is the loss of identity that survivors experience. Participants explained that loss of identity was very powerful and strongly influential on survivors' mental and social wellbeing. One participant, who was also a survivor themselves, explained the feeling very well:

> What I found listening over time, is that you know, if you could have a conversation, you know, and ask them, who are you? 'Well, I'm an Ebola survivor.' It's important to engage that right? But it cannot be the only thing that defines them. So, one of the struggles that I think is under talked about is the return to their lives cannot just be I'm an Ebola survivor. And I found myself as opposed to the initial steps of getting people to engage with looking in the eye, what they've just been through, right, which is it really defines you for a little while. It really does and still got us in some ways.

This feeling of only being an Ebola survivor signifies the idea that survivors have lost their previous lives and identities. At the same time, this loss of identity can appear on a spectrum. For example, Annie explains:

> And I recall one interview where the survivor said ‘yes, I'm called names like, they are using the Ebola.’ I mean, some people in the communities are referring to people only by Ebola. And he was like, ‘yeah, it's okay, I made it a joke, and I don't take it personally.’ But at the contrary some people will have difficulties to cope with that.

Loss of identity can be rooted in internal feelings or in external perceptions of community members. In both scenarios, survivors have the added challenge of coming to terms with their new identity as an Ebola survivor and with the loss of their personal identity.

Physical Effects of Disease Compounded by Social Effects

The cyclical nature of Ebola effects was reported in many interviews and in many different ways. This theme is shown when participants state that physical and social effects of EVD interact with each other to detriment of the survivor. For example, financial hardship is caused by physical and social difficulties, and connected to family support. Overall health is affected by social and mental health as well, inhibiting survivor recovery. Isaac explained the compound of effects in relation to Ebola difficulties:

> Because people who get Ebola, had on average, I'd say 10 to 12 family members that had died while they were sick. And because the culture there is just so dependent on these extended family networks of providing resources and sharing, that they would come out, and they wouldn't have any auntie's, or uncle's or their mom or their grandma, everybody was dead. And then on top of that, they were often very emaciated, they were super sick

> and ill, and so they couldn't really work, because they just were still sick. They didn't have a huge viral load, but their bodies still, you know, still needed to recover.

Again, the importance of the connection between physical health and emotional health is clear. With the loss of a social network, survivors are left on their own and physically unable to support themselves, deepening their hardships. The subtheme for this main theme is "Ebola Treatment Unit (ETU) Experience," an element that contributes to the cycle of Ebola survivor challenges.

Ebola treatment units, or ETUs, are known to be very harsh environments. This is explained by Christopher in this statement:

> Going into an Ebola treatment center, seeing a load of people walking around in spacesuits, whilst you're told to lie in a bed that you'd never normally do because you know, you will sleep on the floor mattress on the floor when you're at home. And watching your loved ones get wheeled out, is extremely traumatizing. It's traumatizing enough for the staff and what it must be like for the patients.

Ebola patients are put into a very strange and scary environment, where they are continually traumatized by visuals of this devastating disease and the deaths of their friends and family. This experience in the ETU is very traumatizing to Ebola survivors, and once they leave that traumatic space they face social challenges and physical challenges that come along with the disease. Survivors are continuously being re-traumatized, even after their recovery. Maria further elaborates on this point:

> Just being in an Ebola treatment center, which...it was a little bit of a horrific experience, because basically, you're in a room filled with beds with other really sick people. And they die, and no one knows that they die because they only come in periodically until you're basically in a room with a dead body for like hours on end... So, just from that

> experience, they can have a cluster of [mental health effects] further compounded by, they go back to the communities, and all of a sudden, your husband or your wife doesn't want to be around you, or your family doesn't want to be around you.

Mental, physical, social, and emotional health are all intertwined. Ebola survivors experience challenges in all areas of their health, and without further intervention and better methods of mitigation, they won't be able to fully recover.

Uncertainty of Viral Persistence

Participants discussed the uncertainty of viral persistence as an issue that effects survivors. This is exemplified with Julie's statement:

> Up until the most recent outbreak, the thinking was, that once you survive Ebola, you're immune. But now in this most recent outbreak, well the one in Guinea in particular, it's believed that it was infection from somebody from the 2014-2016 outbreak, which suggests that people are infectious for much longer period of time.

This theme includes two subthemes, first focuses on the cause of panic around viral persistence, "EVD as a Sexually Transmitted Disease" and second focuses on the effects of viral persistence, "General Understanding of EVD."

The fact that Ebola is a sexually transmitted disease adds layers to the uncertainty around viral persistence. From Catherine:

> We have a lot of messaging of like, survivors can't transmit Ebola, which has to kind of be amended with sexual transmission. And I think that is going to be a huge challenge that we have moving forward. And I know, there's lots of discussions of how we need to kind of look at HIV, to better understand how we can approach stigma, but also approach prevention.

This realization contributes to the social effects and challenges that survivors face in general, so there is a lot of fear in the Ebola community that new uncertainty among EVD as a persistent STD will reinvigorate a lot of the stigma that survivors have experienced. Viewing EVD as an STD shows how the uncertainty of viral persistence can cause panic and fear among survivors and others in Ebola-affected communities.

When exploring the effects of uncertainty in Ebola viral persistence, it is clear that education campaigns and general understanding of EVD in the population will be negatively impacted. In an example from Maria:

> I think part of it is trying to understand the phenomena, and the risk factors, then we can counsel the patient. But then also the community can understand, it can persist, but only for this time period, or these are the people who are at risk. And so, we're going to follow them every you know, whenever, like if there's something that you can give them because it's fears, like absence of knowledge. And honestly, there is an absence of knowledge here, because we don't really know the full extent of Ebola virus persistence in survivors.

The unknown and uncertainty around viral persistence adds to fear and misunderstanding.

Elements for Future Programs

Participants suggest elements that would be beneficial for future programs, either directly or indirectly by explaining things that have not worked in past programs. Elements of this theme also include participant references to current coping strategies that survivors utilize, such as relocating or joining the outbreak response, that could possibly be expanded. General education, comprehensive care, strategic methods, humanizing survivors, and clear communication with those affected are all key elements of this theme. Daniel exemplified these key elements with this statement:

> So general education, that is strategic and that humanizes real stories and allows to the average man to connect, connect survivors, experiences to that to their own background experiences of difficulty and challenge which humans resonate with, you know, so I think it could be good that way, I think enabling what we know already about survivors, enabling their care, and understanding what care they need.

Each of the key topics -- "Communication," "Beneficial Partnerships," "Multi-Level Interventions," "Elements from Existing Programs," and "Current Survivor Coping Methods" – are further described below.

Communication was explored as an important element for future interventions. Annie summed the need for communication with survivors and survivor associations through explaining a past program that worked very well. She said, "*So one of the practices we put in place in the DRC was really to support the local survivor association, so that we can have regular meetings and could listen to their needs, and also to the questions they may have*." Annie emphasized the need to listen to survivors and hear their needs and experiences in order to create better programs and interventions to support them. In the same vein, other participants identified the need for outside organizations to better communicate with local partners in order to reduce miscommunications that have been detrimental to past programs and harmful to survivors. Christopher used a specific situation to show the dangers of miscommunication:

> And if they're told they're going to get something, and then they don't get it. There's also issues with communication of things. The WHO called CPES, the comprehensive program for Ebola survivors, just the health care program, they started by calling it the comprehensive package for Ebola survivors, because it's a package of healthcare that people were gonna get. And the government said they were going to get free health care.

> And then in one meeting, a survivor representative just goes, where's our package? We're waiting for our packages, where are they?

This was a specific situation where a simple miscommunication that could have been avoided by consulting community members before it became an issue for survivors.

Participants, most of whom were not local to the areas they worked in, identified the benefits of developing partnerships with local and international organizations and health systems. In connection with the previous subtheme of communication, the main partnership identified was with the local Ministries of Health and survivor associations. One participant, Julie, wanted to emphasize the need for local partners:

> To the extent possible, let's let the local in country organizations, like Red Cross, and churches, and local governments, and even locally based NGOs, you know, and other agencies that actually have in country offices, let them lead, and let the international community provide the sort of financial support and some of the oversight, but to the extent possible, but you know, the face of this should be local.

In addition to the overwhelming support for local partnerships, participants also identified many international organizations that have established a connection within countries affected by Ebola. These include Doctors Without Borders, WHO, CDC, UNICEF, GOAL Global, and Red Cross. Another dimension of this subtheme is the idea of partnering with existing health systems, as Maria put it, "*not recreating the wheel*" and working on "*capacity building and strengthening existing health systems*." The purpose of working within existing health systems, hospitals, and clinics, is to enable communities to empower themselves and strengthen their own ability to respond to Ebola outbreaks and survivor challenges. This ties back to local being best; if the

local system is effectively supported and expanded, there will be less need for international intervention.

Participants identified the level at which interventions would be most effective, with twelve out of thirteen cases identifying a level of importance spanning across the spectrum of the Social Ecological Model. Most commonly, participants suggested the community, individual, and societal levels. An example being Dave suggesting the individual level, "*But at least what we've seen work time and time again are these highly individualized and specific, on the ground, kind of grassroots work, where you can't just create a plan that sees a large community or sees a region as, as all kind of homogeneous*." Or Daniel suggesting the societal level in this statement, "*So I don't mean just broad educational, social program, social education, but I mean, specific and strategic. So that's one thing I would say at a high level.*" Though participants suggested specific levels that were most important to target, many also recognized the importance of utilizing multiple levels in interventions for maximum effectiveness.

Many participants identified elements of existing programs that have been successful and should be integrated into future programs, such as social and behavioral task forces, community engagement, survivor packages, and recovery ceremonies. An example of this is from John:

> In fact, in the current outbreak that I'm running now, we do have an SBS [social behavioral science] taskforce... everything that's involved in the response, you gotta have community engagement, and acceptance, right? Yes, there's a lot of social behavior of science engagement, and a lot of engagement with the community.

A dimension of this subtheme is the idea of physical support in addition to social support and community engagement. Margaret identifies the challenges that survivors experience financially, and how they've been successfully mitigated here:

> When sometimes we would discharge people and they'd go home to their village, and their house had been burned down, or their, all of their belongings had been burned, or sort of this deep sense of, they weren't welcomed back... So, at some point, we actually started doing sort of like a survivor package to help them go home and read get reestablished, so your oil, food, clothing, just the basics that when they first came into the Ebola unit we had to get rid of, and so wanting to give them sort of culturally appropriate materials that would help them get reaccustomed, re acclimated to their daily life, as it was before Ebola.

Supplying survivors with physical supplies can be beneficial in their reintegration to their communities, as well as helping them to financially recover from their illness.

Across five cases, a coping method that survivors use to help with their social challenges is helping others in the community that have gotten sick with Ebola. Many survivors cope with their challenges by helping others, through volunteering the treatment centers, or conducting community engagement. Catherine, who worked in Ebola treatment units, said:

> They're in there for like 12 hours in the ETUs taking care of these kids. And then one of the physicians in the in one of the responses I worked with, was a survivor. And they do their part on that. And another one I knew was the one who would alert us to cases in the hospital where she got Ebola, she'd be the first one to call and make sure someone got sent to the ETU. So, they were doing their part as much as they could.

There are opportunities for future interventions in utilizing survivors as response workforce. Many survivors become involved with the response, through volunteering or as a paying job. International organizations could facilitate that action in order to help more survivors recover

financially and socially as well as aiding the response efforts. This would also increase the level of localized involvement in each response.

Discussion

Study Purpose

The goal of this study was to answer the research question, "*What social challenges do Ebola survivors face after their recovery*?" in order to close the gap in current research surrounding survivor social challenges. These data describe the general beliefs, feelings, and experiences from health workers surrounding Ebola survivors and social challenges. The sample population for this study is a diverse group of individuals with different backgrounds and experiences in many countries and organizations that are all distinct from one another. Key findings of this study include social challenges caused by social beliefs, elements for future programs, explanation of the uncertainty around viral persistence, and exploration of physical effects of the disease being compounded by the social effects of the disease. This research can be used to encourage and inform future interventions and studies directly addressing the social challenges of survivors.

Social Challenges Caused by Social Beliefs

Elements important to social challenges found in the data included stigma, ostracization, community resentment, support and reintegration, and loss of identity. Many of these elements were found across multiple transcripts and were consistent with prior research (Delamou et al., 2017; James et al., 2020; Karafillakis et al., 2016; Qureshi et al., 2015). Two of these elements, loss of identity and community resentment, were not present in existing literature. Both elements were identified as major challenges for survivors through this study, but not recognized in the literature, identifying a gap that should be further investigated. There have been proposed

solutions to the problem of reintegration, such as reintroduction ceremonies or recovery certificates, but according to participants, they have had varying degrees of success in different areas and communities. As for gender differences in reintegration and support, they were mentioned by participants but were only present in the literature as demographic information (Delamou et al., 2017). Families being accepting of survivors after they recover is very influential to their ability to reintegrate into their communities. This is a complex issue that becomes even more complex when examining the dimensions of family loss and gender differences among survivors.

Physical Effects of Disease Compounded by Social Effects

As for the idea that physical effects of the disease are compounded by the social effects, there is no direct connection between the two in existing research. Both of these elements are recognized as existing challenges for survivors, but their relationship has not been explored in much, if any, scientific research. This particular study shows that connection in a cyclical, bi-directional way, meaning all effects continually influence each other. This knowledge can be used to provide a basis for more research into the phenomenon in the future. Specifically, more qualitative research can be done to explore survivor experiences concerning the physical and social challenges they face after recovery, possibly identifying a stronger connection between the two elements.

Uncertainty of Viral Persistence

Many existing studies have examined viral persistence in EVD survivors , however, during the data collection period of this study, those sources were being upended by new developments in the issue in current outbreaks (Keita et al., 2021; Mbala-Kingebeni et al., 2021; Subissi et al., 2018). Throughout the year of 2021, Ebola outbreaks were found to be caused by

viral persistence in survivors (Keita et al., 2021), which completely changed the timeline experts in the field had previously established (Subissi et al., 2018). This is an element that is becoming very important and needs to be researched and examined more from all angles. The best way to combat both fear and misunderstandings of Ebola is with educational campaigns, but those are more difficult to implement when those who lead the campaigns do not have the information. Countries and communities have been terrorized by Ebola for years, and thought they had a good understanding of the disease. With that being flipped, there is now less understanding among the general population, and no clear way to provide education to mitigate that problem.

Elements for Future Programs

In recommendations for future programs and interventions, important elements across cases included communication, beneficial partnerships, multi-level interventions, existing programs, and current survivor coping strategies. Similar to the previous theme, many of these elements were present in existing literature (James et al., 2019). However, participants in this study were able to identify specific elements of existing programs that have been effective, identify beneficial organizational partners, and provide relevant experiences that back-up these conclusions. To the researcher's knowledge, no prior studies have focused on the perspectives of health workers. Participants recommended that programs should be approved by a community advisory board, or at least a community leader, in order to ensure proper communication between outside organizations and locals. In reference to the Social Ecological Model, it can be surmised from the data that the ideal program or intervention should be multi-level. Programs should be designed to address individual and interpersonal level concerns, community level concerns, and national or societal concerns. Participants recommended engaging with survivor organizations and leaders at the community level in order to plan and implement more successful programs. At

the individual level, participants identified providing packages of needed items and health care to survivors would improve their circumstances. Societally, the entire health systems in affected areas need to be improved and supported to better local efforts and programs. These recommendations intersect with previous and current response efforts (James et al., 2019; McTernan, 2016; Wurie, 2016), participants recognize this and suggest they be expanded in the future. With specific but broad and strategic programs, social challenges of Ebola survivors could be better mitigated.

Strengths and Limitations

A major strength of this study is the experience and diversity of the sample. Thirteen interviews were conducted for this study, and each one represents a unique perspective and experience because of their differing combinations of country, organization, role, and number of responses they've worked on. Diversity in the sample but consistency in the data is an important way to show validity of the research study. The data for this study was very rich and provided a lot of opportunity to extract themes. A secondary strength of this study is the use of a solid framework, the framework for thematic analysis by Braun and Clarke, to guide the analysis process. Additionally, a codebook was created with both inductive and deductive codes and used for the creation of themes. The results are strengthened by this codebook, as it included clear and concrete definitions and instructions to ensure consistency of coding. Lastly, the study explores a topic that, to the knowledge of the researcher, has not been investigated from this particular perspective.

A limitation of the study could be that the study was designed to focus the secondary experiences of health workers rather than survivors themselves. With this, results of the study could be different than what they may have been if survivors themselves were interviewed.

Survivors may have different perceptions of their struggles, or they could add to what can be provided by health professionals. Even so, the study was designed this way to capture the unique perspective of health workers. The sample is also limited because there are many organizations and countries that were not represented. Though there was one local Sierra Leonean participant, more local perspectives from health workers who are from the affected areas could have been included in the study. Lastly, all portions of this study were completed by a single person, the PI. Though elements were reviewed and edited by faculty advisors, there is possibility for researcher bias with only one person conducting analyses and synthesizing results.

Reflexivity

The PI and the participants for this study remained reflexive of their positionality through the course of this research. The PI acknowledged their standing as an outsider, with no direct experience with Ebola or Ebola survivors prior to the conduct of the study. As for participants, all recognized during their interviews that they do not have the same knowledge as a survivor or a local would have. They were mindful of their limitations in experience and indicated when they did not know enough to discuss the topic. It was also important to note that various circumstances could influence their perceptions, whether that be war or political violence or the outbreak itself. Their perception of the community may not be reflective of how the community is in non-crisis times.

Implications

There are many potential implications to the future of public health practice and research as it connects to Ebola survivors and social challenges from this study. There is now a collection of expert opinions which can be expanded upon and used for future programs and interventions. The results of this study both confirm existing research and add new facets of known elements

within the literature. Specific social challenges and their causes have been identified through this study, as have important elements for future programs. These can directly influence the planning of future programs and guide future research in different directions. Communication, beneficial partnerships, and multi-level interventions can be included in future programs through the evidence provided from this study. Future research can focus on the cycle of physical and social effects of Ebola infection. This study also comes at a unique time, where questions concerning viral persistence are becoming very prominent in the field. Results of the study confirm that this issue is on the minds of those working in the field. This particular result can be expanded upon in future research, both in public health worker's perceptions of the problem and more clinical research into why it is happening. Similarly, as cited by many participants, the work is beginning to focus on the social wellbeing of survivors rather than just physical outcomes. Social behavioral task forces and social scientists are being included in current responses, and this work should be continued. Lastly, this study can be expanded upon for future iterations. Data collected for this study could be re-analyzed for different themes or expansion of current themes. The sample population could be expanded to include more locals or survivors themselves.

Conclusion

Exploring the social challenges that Ebola survivors face through the lens of health workers provides a very unique perspective on the issue. It also allows for exploration without detriment to survivors' mental wellbeing through rehashing their experiences. Future interventions addressing the social challenges of survivors need to be locally involved, focus on communication with survivors and community members, and approach the issue at multiple levels. With further understanding of the social challenges survivors experience and the factors that contribute to these challenges, future interventions and research can be focused on specific

issues, to hopefully achieve higher success. Viral persistence in survivors and the compounding effect of physical and social challenges of Ebola need to be investigated and targeted in future programs and interventions. By utilizing results of this study, steps can be taken to improve survivors' quality of life and help them to truly recover from this horrific disease.

Tables and Figures

Figure 1:

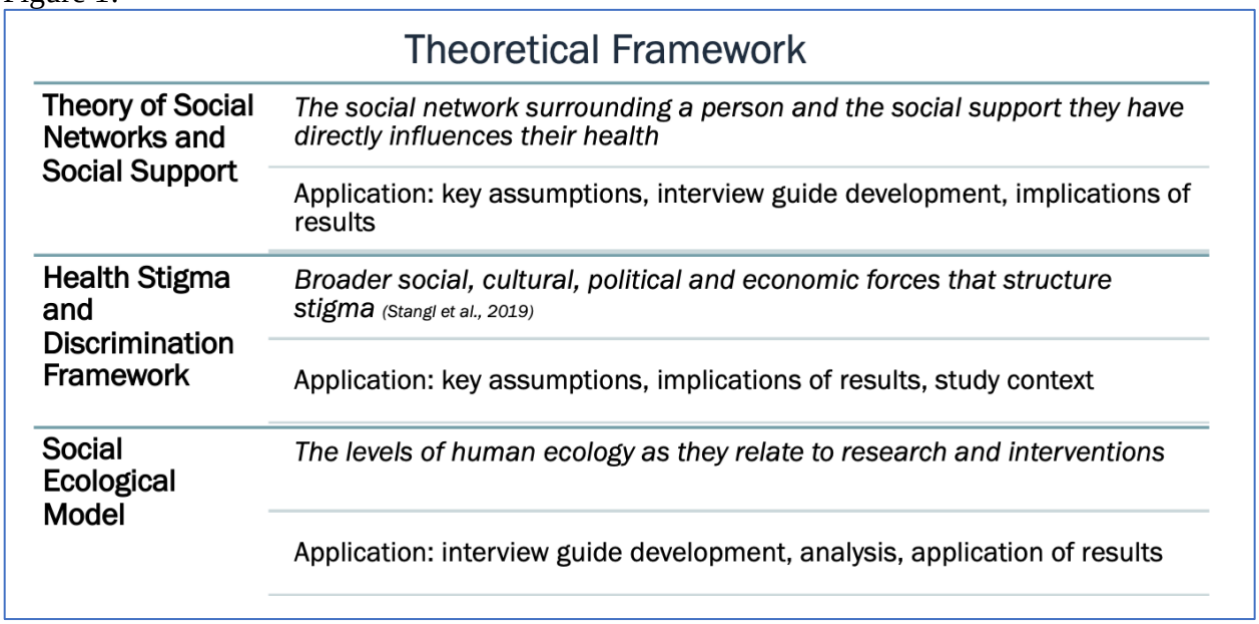
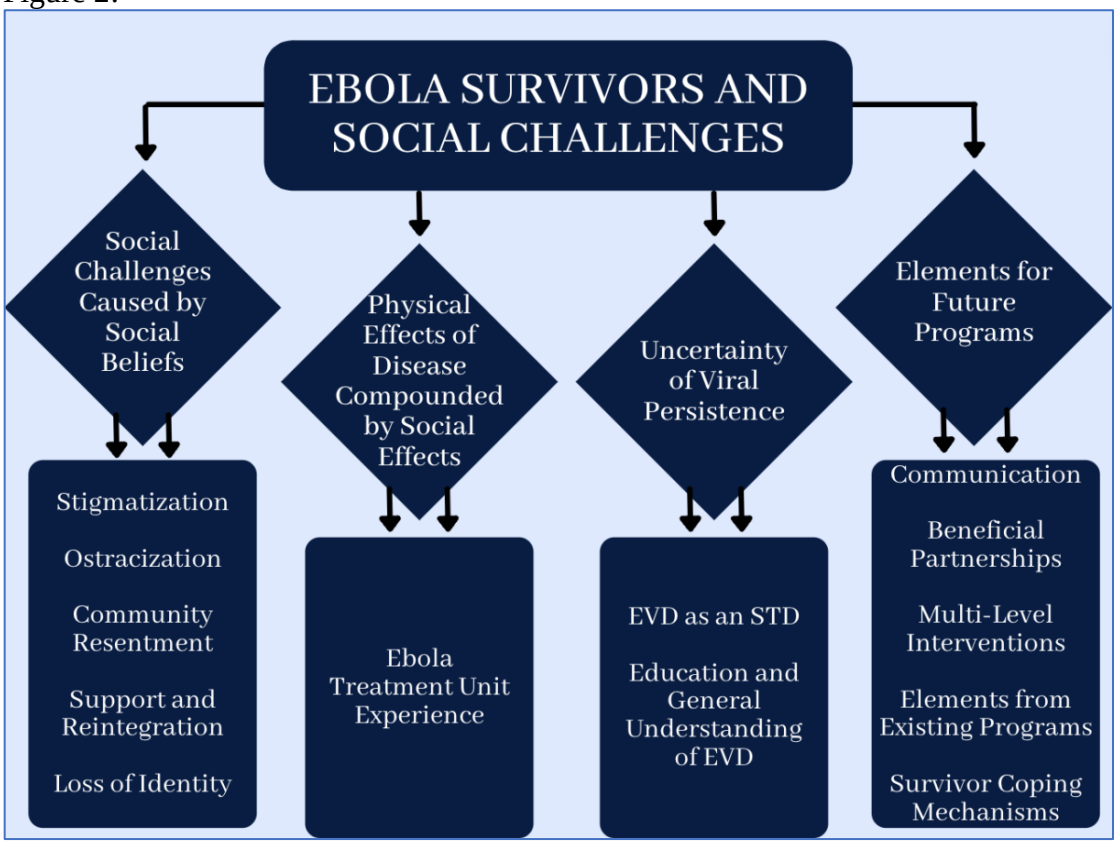


Table 1:

	N
Organization	
US Centers for Disease Control and Prevention	6
Partners in Health	4
Local Organizations	4
World Health Organization	3
GOAL Global	2
Red Cross	2
United Nations Children's Fund	1
US National Institutes of Health	1
Country	
Sierra Leone	7
Guinea	7
Democratic Republic of the Congo	7
Liberia	3
Uganda	1
Role	
Program Coordinator	3
Physician	2
Epidemiologist	2
Infection Prevention	2
Team Lead	1
Medical Officer	1
Health Communicator	1
Behavioral Scientist	1
Clinician	1
Area of Experience	**13**
Program	10 (76.9%)
Healthcare	3 (23.1%)
Number of Responses	**13**
5+	7 (53.8%)
4	2 (15.4%)
3	2 (15.4%)
2	2 (15.4%)

**Categories for Organization, Country, and Role are not mutually exclusive*

Figure 2:


EBOLA SURVIVORS AND SOCIAL CHALLENGES
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Chapter 5: Public Health Implications

Summary

This study explored the social challenges that Ebola survivors face after their recovery through the perspective of health workers. Prior research has not examined this issue from the perspective of health workers, and this study uses that as a way to improve upon the existing knowledge foundation. Results were organized into four main themes, "Social Challenges Caused by Social Beliefs," "Physical Effects of Disease Compounded by Social Effects," "Uncertainty of Viral Persistence," and "Elements for Future Programs." Knowledge gained from this study will be beneficial in future public health research, programs, and interventions.

Implications for Research and Practice

Future research surrounding Ebola survivors needs to address two main issues, viral persistence of the disease and the compounding physical, mental, and social effects of the disease. This study comes at a unique time, where questions concerning viral persistence are becoming very prominent in relation to Ebola survivors. Results of the study confirm that this issue is on the minds of those working in the field. This particular result can be expanded upon in future research, both in public health worker's perceptions of the problem and more clinical research into why it is happening. As for the cycle or compounding of effects, specific social effects have been identified through this study. These results can be used as the basis for future research on these effects specifically, and their connection to the physical effects of Ebola. This study can also be expanded in future iterations. The data collected in this study could be re-analyzed for further theme identification and expansion of current themes or with a different analysis technique all together. Alternatively, the study could be expanded by including more

survivors and locals in the sample population or focusing solely on survivors and locals. Participants in this study emphasized the importance of involving survivors and locals in programs, and it is equally important that they are included in the research surrounding Ebola. There are many opportunities for the work begun by this study to continue.

As for public health practice, specific social challenges and their causes, as well as important elements for future programs have been identified through this study. Evidence from the results of this study can directly influence the planning of future programs with the inclusion of communication, beneficial partnerships, and multi-level interventions. Future interventions and programs can use the results of this study as support for focusing on specific areas, such as stigma and ostracization, reintegration, loss of identity, and community resentment. The work surrounding Ebola survivors is beginning to focus on social wellbeing rather than just physical outcomes. Social behavioral task forces and social scientists are being included in current responses, and this work should be continued. Through more targeted programs, that also utilize beneficial program elements found in this study, survivor health and wellbeing can be improved.

Strengths and Limitations

A major strength of this study is the experience and diversity of the sample. Thirteen interviews were conducted for this study, and each one represents a unique perspective and experience because of their differing combinations of country, organization, role, and number of responses they've worked on. Diversity in the sample but consistency in the data is an important way to show validity of the research study. The data for this study was very rich and provided a lot of opportunity to extract themes. A secondary strength of this study is the use of a solid framework, the framework for thematic analysis by Braun and Clarke, to guide the analysis process. Additionally, a codebook was created with both inductive and deductive codes and used

for the creation of themes. The results are strengthened by this codebook, as it included clear and concrete definitions and instructions to ensure consistency of coding. Lastly, the study explores a topic that, to the knowledge of the researcher, has not been investigated from this particular perspective, improving the greater body of research on Ebola survivor social challenges.

A limitation of the study could be that the study was designed to focus the secondary experiences of health workers rather than survivors themselves. With this, results of the study could be different than what they may have been if survivors themselves were interviewed. Survivors may have different perceptions of their struggles, or they could add to what can be provided by health professionals. Even so, the study was designed this way to capture the unique perspective of health workers. The sample is also limited because there are many organizations and countries that were not represented. Though there was one local Sierra Leonean participant, more local perspectives from health workers who are from the affected areas could have been included in the study. Another limitation of this study is the short timeframe and lack of funding, as it was completed within a year as a master thesis project. With a longer timeframe and funding, more participants could have been gathered, including more locals and survivors in order to get an even more diverse sample. Lastly, all portions of this study were completed by me alone. Though elements were reviewed and edited by faculty advisors, there is possibility for researcher bias with only one person conducting analyses and synthesizing results.

Reflexivity

The participants and I remained reflexive of our positionality through the course of this research. I acknowledged their standing as an outsider, with no direct experience with Ebola or Ebola survivors prior to the conduct of the study. Additionally, I recognized my background knowledge of Ebola allowed me to better understand the content of the interviews, while also

acknowledging any preconceived notions that may have an influence on the research process. As for participants, all recognized during their interviews that they do not have the same knowledge as a survivor or a local would have. They were mindful of their limitations in experience and always identified when they did not know enough to discuss the topic. It was also important to note that various circumstances could influence their perceptions, whether that be war or political violence or the outbreak itself. Their perception of the community may not be reflective of how the community is in non-crisis times.

Conclusion

Exploring the social challenges that Ebola survivors face through the lens of health workers provides a very unique perspective on the issue. It also allows for exploration without detriment to survivors' mental wellbeing through rehashing their experiences. Future interventions addressing the social challenges of survivors need to be locally involved, focus on communication with survivors and community members, and approach the issue at multiple levels. With further understanding of the social challenges survivors experience and the factors that contribute to these challenges, future interventions and research can be focused on specific issues, to hopefully achieve higher success. Viral persistence in survivors and the compounding effect of physical and social challenges of Ebola need to be investigated and targeted in future programs and interventions. By utilizing results of this study, steps can be taken to improve survivors' quality of life and help them to truly recover from this horrific disease.

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Appendices

Recruitment Email

Hello!

I am Caitlin Plumb, a current second year MPH student in the Behavioral, Social, and Health Education Sciences department of Rollins School of Public Health at Emory University. [Insert how contact info was found.] From your experiences, I was hoping you would be interested in participating in a study I am conducting.

For my thesis project, I am conducting a qualitative research study focusing on the social challenges that Ebola survivors face. The purpose of this study is to identify and examine the specific social issues that Ebola Virus Disease survivors face after recovery, possibly answering whether or not the issues differ by country of residence and how survivors cope with the issues. In order to explore this topic, I am conducting in-depth interviews with people that have worked in the field response to recent (within the past 10 years) EVD outbreaks and epidemics in West and Central Africa. The interview should last between 30 and 45 minutes depending on the discussion and will be done and recorded over zoom. Results of this study will be disseminated through a final manuscript and thesis defense, and possibly through publication. In all of these cases, no identifiable information will be included, you will be kept completely anonymous.

I would love to interview you to get your perspective and expertise on the topic, and also to possibly find others you may know that meet the criteria for my study and would be willing to participate. I would greatly appreciate if you could pass this along to/share contact information of others you know that may qualify and be interested.

The interview will ideally be conducted in [set specific timeline]. Wednesdays, Thursdays, and Fridays are best for me, but my schedule is very flexible, so I am happy to work around your availability.

I am happy to answer any questions you may have, and I look forward to hearing from you!

Caitlin Plumb

Verbal Consent Form

Emory University
Oral Consent Script
For a Research Study

Study Title: Social Challenges that Ebola Survivors Face According to Health Workers
Principal Investigator: Caitlin Plumb, Rollins School of Public Health: Department of Behavioral, Social, and Health Education Sciences

Introduction and Study Overview

Thank you for your interest in our Ebola survivor research study. We would like to tell you everything you need to think about before you decide whether or not to join the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.

The purpose of this study is to identify the social issues that Ebola survivors deal with, causes and effects associated with them, and identify elements needed for successful future interventions. This study will take about 30 to 45 minutes to complete.

If you join, you will be asked to participate in a single, recorded, in-depth interview over Zoom.

There are two risks associated with this study. First is breach of confidentiality. This is not very likely, as we are taking all necessary precautions to ensure privacy and confidentiality. Second is the possibility of emotional distress. Due to the nature of Ebola Virus Disease and your role in the response, some elements of the interview may be uncomfortable for you. You are free to skip any questions you do not wish to answer, as well as end the interview completely if any emotional discomfort occurs.

This study is not intended to benefit you directly, but we hope this research will benefit Ebola survivors in the future by informing future research and interventions.

Study records can be opened by court order. They also may be provided in response to a subpoena or a request for the production of documents. Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Office for Human Research Protections, the Emory Institutional Review Board, and the Emory Office of Research Compliance. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

We will disclose your information when required to do so by law in the case of reporting child abuse or elder abuse, in addition to subpoenas or court orders.

Contact Information

If you have questions about this study, your part in it, your rights as a research participant, or if you have questions, concerns, or complaints about the research you may contact the following:

Caitlin Plumb, Principal Investigator: 251-752-2389 or by email at cplumb@emory.edu
Emory Institutional Review Board: 404-712-0720 or toll-free at 877-503-9797 or by email at irb@emory.edu

Consent

Do you have any questions about anything I just said? Were there any parts that seemed unclear?

Do you agree to take part in the study?

Participant agrees to participate: Yes No

If Yes:

_____
Participant ID Number/Pseudonym

_____ _____
Signature of Person Conducting Informed Consent Discussion Date Time

_____
Name of Person Conducting Informed Consent Discussion

Interview Guide

Study Title: Social Challenges that Ebola Survivors Face According to Health Workers
Study Number: 00002828
PI Name: Caitlin Plumb

Interview #:_____
Date:_____

Questions
First, let's begin by talking about your experiences in the field.

1. Tell me about your time working on the Ebola response in West or Central Africa.
    - What country(ies) did you work in? How long were you there? Please describe each separate outbreak response.

2. Describe the community or communities that you worked in.
    - Explain the social networks within the community. What organizations did you work with?

3. Explain the social beliefs surrounding the disease in these communities.
    - How prevalent are these beliefs? How did these beliefs influence community behavior during the outbreak?

Now, we can transition to talking about the survivors specifically.

4. What are the effects of these social beliefs on Ebola survivors?
    - What barriers did they face in returning to their everyday life? Describe any mental health effects of the beliefs have on survivors.

5. Explain what the onset of these effects looks like for the survivors.
    - How soon after recovery do they set in? Describe how long these effects last for survivors.

6. How do survivors cope with social challenges specific to Ebola survival?
    - What tools are available to them within the community? In what ways, if any, are they supported by their family?

To close out the interview, let's discuss possible solutions.

7. What are some ways that you think these social challenges faced by Ebola survivors could be mitigated?
    - What organizations would be most beneficial for partnerships? Which community leaders would be most influential? What level of intervention would be most effective?

That concludes my prepared questions. Is there anything else related to EVD survivors' social challenges you would like to talk about or that might be useful?
I can also answer any questions you may have for me.

Again, thank you very much for your participation, it is very appreciated. Have a great day!

IRB Approval

IRB EXEMPT REVIEW

June 28, 2021
Caitlin Plumb, BA
cplumb@emory.edu

Title:	Social Challenges that Ebola Survivors Face According to Health Workers
Principal Investigator:	Caitlin Plumb
IRB ID:	STUDY00002828
Funding:	None
Documents Reviewed:	• Ebola Study HIPAA Waiver, Category: Other; • Ebola Survivor Study Interview Guide, Category: Surveys, Questionnaires, Interview Guides; • Ebola Survivor Study Protocol, Category: IRB Protocol; • Ebola Survivor Study Recruitment Email, Category: Recruitment Materials; • Ebola Survivor Study Verbal Consent, Category: Consent Form;

Dear Ms. Caitlin Plumb:

Thank you for submitting an application to the Emory IRB for the above-referenced project. Based on the information you have provided, we have determined on 6/21/2021 that although it is human subjects research, it is exempt from further IRB review and approval. This project meets the criteria for exemption under 45 CFR 46.104(d)(**D2ii**). Specifically, you will survey ground responders observations on social issues that Ebola survivors endure.

Please note the following in association with this exemption:

- Ebola Survivor Study Protocol(1.1)
- Ebola Survivor Study Verbal Consent(1.0)
- Ebola Survivor Study Interview Guide(1.0)
- Ebola Survivor Study Recruitment Email(1.0)

This determination is good indefinitely unless substantive revisions to the study design (e.g., population or type of data to be obtained) occur which alter our analysis. Please consult the Emory IRB for clarification in case of such a change. Exempt projects do not require continuing renewal applications.

Please note that the Belmont Report principles apply to this research: respect for persons, beneficence, and justice. You should use the informed consent materials reviewed by the IRB, if applicable. Similarly, if HIPAA applies to this project, you should use the HIPAA patient authorization and revocation materials reviewed by the IRB unless a waiver was granted. CITI certification is required of all personnel conducting this research.

Unanticipated problems involving risk to subjects or others or violations of the HIPAA Privacy Rule must be reported promptly to the Emory IRB and the sponsoring agency (if any).

Sincerely,

Ashton Hughes
IRB Analyst
Now that your submission has been approved, please take a few moments to complete the Emory IRB Satisfaction Survey. We will use your responses to improve our service to the Emory research community. We appreciate your feedback!

Codebook

Code System	Memo	Frequency
Code System		867
Contributors to Social Beliefs	Definition: Elements that contribute to the social beliefs about Ebola held in the community. Deductive. Use When: Something is suggested to contribute to social beliefs. Double code with all subcodes. Make note of segments that do not fit into existing subcodes. Example: "I think, number one, a lot of them didn't believe that it was real. That's pretty pervasive, and all the outbreaks, they feel that it is a scam perpetrated by their government, their federal government, as well as NGOs and WHO and other outsiders and pharmaceutical companies who are basically bringing Ebola to these countries so that they can experiment on them."	66
Contributors to Social Beliefs\Viral Persistence	Definition: Viral persistence of Ebola contributing to the social beliefs held in the community. Inductive. Use When: It is suggested that viral persistence contributes to social beliefs. Double code with main code. Example: "So yeah, there's lots of, I think, lots of stigmatization, and ostracism. And, of course, it doesn't that's not helped by the uncertainty around viral persistence."	27
Contributors to Social Beliefs\EVD as an STD	Definition: EVD as an STD contributing to the social beliefs held in the community. Inductive. Use When: It is suggested that EVD's perception as an STD or EVD being treated as an STD contributes to social beliefs, especially with reference to other STDs or STD prevention methods. Double code with main code. Example: "Recalling that any of the survivor were well supported with being tested regularly until the test, but also that we would support EVD survivors and their partners in power to implement what has been called safer sex practices. So this is really based on what was done for HIV and other STI disease. And also, obviously, we would provide condoms to survivors."	10
Contributors to Social Beliefs\Visuals of Prevention	Definition: Visuals of prevention, such as PPE, ambulances, etc., contribute to the social beliefs in the community. Inductive. Use When: It is suggested that visuals of prevention contribute to the social beliefs. Double code with main code. Example: "But a lot of it's driven by, you know, all the people that we were, you know, all the gear that you wear when you're taking care of patients. In the isolation wards, or even in the laboratory, and so it's a very foreign concept, you know, personal protective equipment."	7
Contributors to Social Beliefs\Ebola Business	Definition: Ebola Business, the money-making aspect of the responses or intentions of governments, contributes to the social beliefs in the community. Inductive. Use When: Ebola business is suggested to contribute to the social beliefs. Double code with main code. Example: "And again, at least for DRC, it's not so much the case, I would say, in West Africa, but in DRC, because Ebola was a business that I've seen a lot of issues with the use of funds, corruption and so on, which really complicated any action we wanted to take at a local level. And this is true, also for survivors program."	4
Contributors to Social Beliefs\Distrust of Orgs and Govts	Definition: Distrust of organizations and governments, whether they be local or international, contributes to the social beliefs held in the community. Inductive. Use When: It is suggested that distrust of governments and organizations contributes to social beliefs. Double	21

	code with main code. Example: "There were narratives about the Ebola didn't exist, and it was being used as a means and mechanisms to build government power. There was the myths and beliefs that it was brought by foreign nations to continue kind of killing off people of color. There are also the mystification of the religious and sin. So that it was something that was brought on by wickedness and sin. And yeah, it was, there was a lot of disbelief and myth that was surrounded in fear."	
Contributors to Social Beliefs\Fear	Definition: Fear as a contributor to social beliefs surrounding Ebola. Inductive. Use When: It is suggested that fear contributes to social beliefs in the community. Double code with main code. Example: "And often, just, again, people were fearful, and they didn't understand. And so my sense is that many survivors felt really pretty isolated."	16
Contributors to Social Beliefs\ETU and ETC Perceptions	Definition: ETU and ETC perceptions contribute to the social beliefs in the community. Inductive. Use When: It is suggested that the people's perception of ETUs and ETCs or the facts of the ETUs contribute to social beliefs. Example: "We definitely heard people say, you know, the ETU is where you go to die because people go in and they never come out. And in many ways, that's true for a good portion of people. They don't see their loved ones again. And then that's, it's a really scary thing. And so it, it makes a lot of sense."	6
Social Beliefs	Definition: The beliefs held in the community about Ebola. Especially when considering how Ebola would be seen socially. Deductive. Use When: Something is suggested to be a belief amont the community that may affect social interactions surrounding Ebola. Make note of segments that do not fit under existing subcodes. Example: " And they basically are being perceived as like walking time bombs, that you know, harbor this deadly virus that can come out at any time and then kill everybody."	56
Social Beliefs\Fear of EVD or Survivors	Definition: Fear as a social belief surrounding Ebola. Inductive. Use When: It is suggested that a social belief held in the community is fear of Ebola or of Survivors themselves. Double code with main code. Example: "And often, just, again, people were fearful, and they didn't understand. And so my sense is that many survivors felt really pretty isolated."	21
Social Beliefs\Community Behavior	Definition: Community behavior being influenced by social beliefs. Inductive. Use When: It is suggested that a social belief directly influences community behaviors, especially in consideration to behaviors towards survivors. Double code with the main code. Example: "For example, we often heard about someone who was sick in a village but that our outreach workers couldn't find or that the community was hiding them."	14
Social Beliefs\Disbelief and Skepticism	Definition: Disbelief and skepticism of the existence of Ebola as a social belief in the community. Inductive. Use When: Disbelief and skepticism are suggested as being beliefs in the community. Double code with the main code. Example: "The people in the said community did not believe the disease is real."	19
Social Beliefs\Culture and Traditions	Definition: Cultures and traditions being important elements of social beliefs in the community. Inductive. Use When: It is suggested that social beliefs in the community revolve around or incorporate culture and tradition. Double code with main code. Example: "I will say the one other thing as well is that in terms of burial practices, that was a huge one, because particularly in Sierra Leone, which is a heavily	13

	Muslim country, there's a lot to be said about the honors that go into like washing somebady's body and preparing them for burial and things like that. Obviously, with Ebola you couldn't do that. So again, if somebody would die, you know, taking that ability away and saying everybody had to have a safe and dignified burial. But it couldn't be the one that they were used to. Um was a lot for people to sort of adjust to and obvious reasons why people would not want to do that, because that, as we see, you know, in Coronavirus, as well, you take away somebody's ability to grieve in the way that they want. And that impacts like the you know, it causes level of trauma to an individual and to a community to have to go through that."	
Challenges from Social Beliefs	Definition: Social challenges that survivors experience because of the social beliefs held in the community. Deductive. Use When: Something is described as a challenge suvivors face after their recovery. Make note of any segments that do not fit with established subcodes. Example: "And I mean, we still see that, that now, you know, that if somebody was a survivor, they can be treated differently, is what we're hearing from, you know, when when the social behavior analysts go out and do some of these surveys and find out that there's been a lot of that still lingers even after people survive"	75
Challenges from Social Beliefs\Onset and Length of Challenges	Definition: Onset and length of time survivors might experience these challenges. Deductive. Use When: The participant explains how soon challenges set in or how long they may last. Double code with main code. Example: "I think it probably It does get better over time. But I think people in the community know who had been sick and recovered. I think maybe it does lessen over time. But they they still know because when we've had investigations going on, and trying to determine, say, the source of a particular outbreak, and they will know, oh, you know, oh, so and so over there, he was sick in the last outbreak. So they know it's not forgotten."	6
Challenges from Social Beliefs\Community Resentment	Definition: Community resentment is a challenge that survivors experience. Inductive. Use When: It is suggested that community resentment is a challenge for Ebola survivors. Double code with main code. Example: "And then you have this problem where then the community almost kind of resents them, because they are getting something that they don't have access to, you know, I don't have free healthcare, my family doesn't have free healthcare, but you have the healthcare. And that's because you're a survivor."	9
Challenges from Social Beliefs\Stigma	Definition: Stigma is a challenge that survivors experience. Inductive. Use When: Stigma is identified as a challenge Ebola survivors face. Double code with main code. Example: "I think people will get ostracized or there's certainly, you know, a stigma associated with being an Ebola case, or having an Ebola case in your home or your family."	24
Challenges from Social Beliefs\Loss of Identity	Definition: Loss of identity is a challenge that survivors face. Could also be that being a survivor is has become their identity. Inductive. Use When: It is suggested that identity is a challenge survivors experience. Double code with main code. Example: "I mean, some people in the communities are referring to people only by Ebola to the one who have been, we have survived by Ebola or whatever. And he was like, yeah, it's okay, I made a made it a joke, and I don't take it personally. But at the contrary some people will be, will be, will have difficulties to cope with that."	4

	Challenges from Social Beliefs\Ostracization	Definition: Survivors face the challenge of being ostracized by their community. Inductive. Use When: It is suggested that ostracization is a challenge survivors face after recovery. Double code with main code. Example: "You know, and so, there's a it's, it's always a little sad, because people, people know exactly where the people who are sick are or came from. And there is quickly being you can quickly be shunned from the rest of the community."	13
	Challenges from Social Beliefs\Family Support	Definition: Lack of family support is a challenge that survivors face. Caused by loss of family or by rejection of family. Inductive. Use When: Family support is mentioned as a challenge survivors experience. Double code with main code. Example: "you know, some people come out and their families don't want them or sometimes they don't have a family anymore. I had a colleague in Sierra Leone who was now taking care of some children because their parents had died during Ebola. So sometimes you've lost a good portion of your family and you're coming out and and people are scared."	17
	Challenges from Social Beliefs\Resistance to Treatment	Definition: Community members being resistant to treament or interventions as a challenge survivors face. Directly caused by social beliefs surrounding Ebola and Ebola survival. Inductive. Use When: It is mentioned that community members are resistant to treatment or other intervention methods. Double code with main code. Example: "I think when with certain actions, because on the other side, you have the actions of people knowing that if someone has Ebola they're going to come and they're going to clean out their house with bleach, they're going to burn their belongings. And that's a really scary thing to see. And so it can cause a lot of resistance, but also like you've taken our things and burned them and you didn't replace them. Yeah, so there can be a lot of a lot of issues, balled up into one, whether it's you believe it's Ebola or not, or whether you're scared of the authorities."	6
	Challenges from Social Beliefs\Isolation	Definition: Isolation either within the community or outside of the community is a challenge survivors experience. Inductive. Use When: It is suggested that isolation is a challenge survivors experience. Double code with main code. Example: "Yeah, so again, I think often, when we first had folks who were surviving, they weren't always welcomed back into their community. And often, just, again, people were fearful, and they didn't understand. And so my sense is that many survivors felt really pretty isolated."	7
	Challenges from Social Beliefs\Hiding Cases	Definition: Suspected or possible cases of Ebola being hidden. Directly caused by social beliefs surrounding Ebola or survivors themselves. Inductive. Use When: It is suggested that hiding possible cases is a challenge affecting survivors or caused by beliefs around survivors. Double code with main code. Example: "For example, we often heard about someone who was sick in a village but that our outreach workers couldn't find or that the community was hiding them."	7
	Challenges from Social Beliefs\Finances	Definition: Financial challenges being experience by survivors. Inductive. Use When: Financial challenges caused by survivors' experiences with Ebola is something they face. Double code with main code. Example: " So people will say, you know, I'm a vendor and I sell things. And after I came back, surviving Ebola, I went back to, you know, my same business and no one is buying for me anymore.They go buy from the other guy, but they won't buy from me."	8

Challenges from Social Beliefs\Barriers to Normalcy	Definition: Elements that could be barriers to returning to normal life for survivors. Either directly influenced by social beliefs or exacerbated by social beliefs. Deductive. Use When: Elements not mentioned in other subcodes could affect survivors returning to normalcy. Double code with main code. Example: "Or after, you know, when we did have survivors, often we would send them back to their community and they were healed. They were not contagious, that infectious. Frankly, they had, you know, just survived an ordeal and we're pretty amazing in our eyes, but often communities were scared about them nervous to interact. Just lots of anxiety about transmission and understanding. Once someone came home and had recovered that they were no longer infectious."	9
Challenges from Social Beliefs\Reintegration	Definition: Reintegration into their community being a difficult challenge that survivors experience. Inductive. Use When: Reintegration is identified as being a challenge survivors face. Double code with main code. Example: "They do their dip typically, or as monetary support for survivors, basically, get them back on their feet, and to also improve acceptance back into the community. So a lot of times, there's also, you know, monetary or some other incentive back to the community, to accept the survivors back into their community as well."	12
Challenges from Social Beliefs\Trauma	Definition: Trauma being a challenge survivors face. Either caused by the social beliefs or exacerbated by them. Inductive. Use When: Trauma is identified as being a challenge for survivors. Example: "And watching your loved ones you came in, get wheeled out, is extremely traumatizing. It's traumatizing enough for the staff and what it must be like for the patients."	4
Mental Health	Definition: Effects on survivors directly related to mental health diagnoses or symptoms. Deductive. Use When: Mental health is mentioned either verbatim or through other disorders/diagnoses. Make note of segments that do not align with existing subcodes. Example: "So, just from that experience, they have a lot of, they can have a cluster of stress disorder and depression, anxiety, but then, you know, is further compounded by, you know, they go back to the committee's, and all of a sudden, you know, your husband or your wife doesn't want to be around you or your family doesn't want to be around you. So they they talk about depression. And they talk about feeling isolated."	7
Mental Health\Depression	Definition: Depression being an effect survivors experience. Inductive. Use When: Depression is mentioned specifically as a challenge survivors experience. Double code with main code. Example: "It's not surprising but understudied, you'd be surprised how little we actually know about how much and what type of PTSD, we would expect and anxiety and depression, and just the grief reaction that would be expected and almost all of that."	2
Mental Health\Anxiety	Definition: Anxiety being an effect survivors experience. Inductive. Use When: Anxiety is mentioned specifically as a challenge survivors experience. Double code with main code. Example: "It's not surprising but understudied, you'd be surprised how little we actually know about how much and what type of PTSD, we would expect and anxiety and depression, and just the grief reaction that would be expected and almost all of that."	1

Mental Health\PTSD	Definition: PTSD being an effect survivors experience. Inductive. Use When: PTSD is mentioned specifically as a challenge survivors experience. Double code with main code. Example: "And you see your family members dying, but it's next to you and you know, so Just that effect itself, you know, causes a lot of people to have like PTSD. And so like, after they leave, they can never, you know, they say that they like, they can't go to that place where that ETU used to be. Even that space, like, even after the tents are taken down, that they really can't, you know, visit that space. There was, I think, at one point, they were like, they wanted some, like something physically done to the land that was used, you know, to kind of erase all these kind of memories."	4
Mental Health\Cycle of Effects	Definition: Mental health being a cycle for Ebola survivors. Inductive. Use When: Mental health is identified as being a cyclical experience or the effects are cyclical. Double code with main code. Example: "Mental health effects, I think, I'm not sure if that's the belief, or if the disease or if it's only a vise, this what we say in french, vices, vicious circle, like you lose your employment. So are you wherever you earning, are you your family support, or you whatever support you had, then it becomes difficult for you to, to go to the community or to to to have a normal life. This impacts also your health status. And so it goes, it goes again like that, if nothing is being done."	4
Coping Strategies	Definition: Coping strategies that survivors use to deal with the social challenges and effects they experience after their recovery. Deductive. Use When: Something is identified as being a way survivors cope with the difficulties they experience. Make note of segments that do not align with existing subcodes. Example: "I think coping is mainly just trying to just trying to continue on trying to stay alive and trying to make a living and, you know, suffering through the exclusion that they often experience. I think there have been some survivors organizations, and some have some survivors have become advocates and leaders there. So I think that's been helpful, but, um, beyond sort of the organizing, either from these organizations or advocacy support groups, I don't think there has been a lot besides that."	22
Coping Strategies\Community Tools	Definition: Community tools available for survivors to help them cope with their challenges. Deductive. Use When: An existing feature of the community is identified as being a way survivors cope. Or something is being mentioned as an important tool to be integrated into the community. Double code with main code. Example: "I think they really rely on the community, the local health center or the local traditional healers, to, you know, help them. But I don't I don't think it really goes on long after the outbreak is over, because that's when the partners pull out. And I don't think the local health health system has the resources to provide that kind of support."	10
Coping Strategies\Relocation	Definition: Relocation is a way survivors cope with the challenges they experience. Inductive. Use When: Relocation is mentioned as a way for survivors to cope. Double code with main code. Example: "As a way of cooping, I think, was for some people to move away. So to move in a new community where they wouldn't be known."	5
Coping Strategies\Coping Through Helping Others	Definition: Helping others, often through joining the Ebola response efforts, is a way survivors cope with their challenges. Inductive. Use When: It is mentioned that survivors cope by helping others. Could be direct care, educating the community, etc. Double code with main code. Example: "know for Partners in Health, we actually ended up	8

	hiring a lot of our survivors to be our community outreach workers, because they had experienced this themselves and so we're sort of best position to communicate the situation and explain what would happen in the treatment unit to other community members. And I think there was something very powerful about folks who survived, then also kind of giving back to the broader goodwill community and helping treat others."	
Elements for Future Programs	Definition: Elements that are beneficial to use or keep in mind for future programs. Could be something that has worked in the past or a new idea based on the participant's experiences. Deductive. Use When: Something is identified as a possible mitigation strategy. Make note of segments that do not align with existing subcodes. Example: "So general education, that strategic and that humanizes real stories and allows to the average man to connect, connect survivors, experiences to that to their own background experiences of difficulty and challenge which humans resonate with, you know, so I think it could be good that way, I think enabling what we know already about survivors, enabling their care, and understanding what care they need, their research needed is still very, very true."	67
Elements for Future Programs\Comprehensive Care	Definition: Comprehensive care is an important element for future program development. Inductive. Use When: Comprehensive care is identified as a mitigation strategy for future programs. Double code with main code. Example: "And so, its been interesting, because what they told me was, uh, you know, yeah, we're talking to them about all that stuff. But, you know, we let them talk to us about anything that's bothering them. And a lot of times, they were talking about trauma they experienced during the Liberian Civil War, you know, which is something that happened to them when they're a kid, you know, and it just because that they just don't have access to mental health services in general. And so this was an opportunity to kind of work through those issues as well."	16
Elements for Future Programs\Funding	Definition: Funding is an important element for future programs. Inductive. Use When: Funding is identified as important for future programs or has been identified as a reason a previous program may have failed. Double code with main code. Example: "So that was tough, but, I mean, yeah, they got some good stuff during the time. But then, you know, a few years afterwards, everything's gone."	14
Elements for Future Programs\Humanizing	Definition: Humanizing of Ebola survivors is an important element for future programs. Inductive. Use When: Humanizing is identified as being a mitigation strategy. Double code with main code. Example: "Everyone has an experience of trauma, for example, in North Kivu, that population has been terrorized for decades. So putting I think, putting faces to, to sort of humanize some of the some of the fear that undergirds people's sources, their stigma is a big thing."	9
Elements for Future Programs\Communication	Definition: Effective communication is a key element for future programs. Inductive. Use When: Communication is identified as important for mitigating challenges or examples of poor communication in previous programs. Double code with main code. Example: "I mean, yeah definitely there was an acceptance and understanding you know, there were a lot of messages, you know, that did circulate in communities. You know, basic messages, messages like Ebola is real, because there was also some thought it could be evil spirits or disease was brought by foreigners, which is not	27

	uncommon, actually, for Ebola outbreaks, it's actually a pretty common thing."	
Elements for Future Programs\Education	Definition: Education on Ebola or survivors is an element for future programs. Inductive. Use When: Education is identified as being important or lack of education is identified as being an issue. Double code with main code. Example: "Yeah, I would say a lot of education, but also sort of providing the resources to ensure that people could change their behaviors. appropriately."	12
Elements for Future Programs\Beneficial Partnerships	Definition: Partnerships with specific people or organizations are important for future programs. Deductive. Use When: Partnerships with specific organizations or people are identified as being beneficial for future programs. Could also be organizations that are deemed most influential or most prevalent. Double code with main code. Example: "I mean, local is better, but there are a lot of really good non governmental organizations that are active and in our support of some of these organizations, where we always try to get them to partner with the local ministries of health and local public health agencies as well. So don't go around local government, but try to help them develop capacity as well."	25
Elements for Future Programs\Level of Intervention	Definition: Level of the Social Ecological Model where intervention would be most effective in future programs. Deductive. Use When: A specific level of the SEM is identified as being where programs and interventions need to take place. Double code with main code. Example: "So when you ask what level of intervention would be most effective, it's at community level, that's definitely for sure. "	23
Existing Programs	Definition: Programs or interventions that are currently in place or have been implemented in the past. Inductive. Use When: An existing program is mentioned as being effective or ineffective. Could also simply be a description of an existing program or system. Make note of segments that do not align with existing subcodes. Example: "For everyone, they were aimed at everyone who were helping the Ebola survivors, there was a lot of Ebola survivor specific programs, um NGOs with those kinds of programs. And so yes, they were they were kind of plugged into those strung up after during the outbreak."	30
Existing Programs\Survivor Support Entities	Definition: Existing programs with the specific purpose or goal of survivor support. Could be official or casual partnerships and gatherings. Inductive. Use When: An existing program is mentioned to provide survivor support. Could also be an organization. Double code with main code. Example: "And then also building up the Association of Ebola survivors in Sierra Leone that was their own group that was led and completely controlled by people who survived Ebola. And I think at our peak, we had, I want to say over 950 Ebola survivors who are working in communities, doing health education and promotion, so going to people in their community, talking to them about their experience with disease, their challenges, and really encouraging them to stop performing cultural practices which are associated with, you know, high risk of infection. And that was super successful."	14
Existing Programs\Existing Systems	Definition: Elements of the existing health systems that have been or could be utilized. Inductive. Use When: The existing health system is mentioned. Could be negative or positive. Double code with main code. Example: "Like if you're gonna have a survivor program, we want you to integrate it into a hospital that already exists. So we don't	13

		want them go to separate buildings made specifically and built specifically for that. We want them to go to the hospital, we want them to be treated by the normal doctors that exists in the healthcare system."	
	Existing Programs\Grassroots Responses	Definition: Existing programs that began as a grassroots effort from the community. Could be mention of the importance of grassroots responses in general. Inductive. Use When: Grassroots responses are identified as important or explained in general. Double code with main code. Example: "And so we saw an opportunity to actually build up some adult health literacy programs in schools by working in the schools that were in all these communities and, you know, channeling some funds in there to stand up the schools to be better places for everybody to get education, and then also paid teachers who were in adult education. And I think, at our at our peak, we had about 22, adult literacy schools going on all across Sierra Leone,"	6
	Existing Programs\Local Intervention	Definition: Exisitng programs that were implemented or designed by local organizations or entities. Inductive. Use When: Existing programs are identified as being local or localized interventions. Double code with main code. Example: "But there was definitely a very active group called SLAES, the Sierra Leone association of Ebola survivors. That was incredibly vocal about advocating for ongoing care, you know, eye care. Food and nutritional support, you know, they were very, very outspoken about making sure that folks who had survived Ebola continued to get the care and and kind of wraparound services that they needed. Whether that, like, penetrated and reached everyone across the country? I don't really know. But I Yes, certainly, there were groups, that that was their their priority and main mission."	6
Social Network		Definition: The social network of the community being described or identfied as important for the topic. Gathered from Theory of Social Networks. Deductive. Use When: The social network of the community is explained. Make note of segments that do not align with existing subcodes. Example: "Highly socially networked either through ethnic bonds or religious bonds or other social, you know, networks that way."	21
	Social Network\Social Heirarchies	Definition: Social heirarchies are an important piece of the overall social network in the community. Inductive. Use When: Social heirarchies are identified as important to understand the social network, or key to the social structure of the community. Double code with main code. Example: "I guess, hierarchies in the in a, I don't mean that in 2021 negative way. That there there are social social hierarchies in place that people are very intertwined with them very, and pay a lot of attention to and that, I guess I would call it similar community, that can be political and government but also has to do depending on where you are on that could be tribal sometimes. Could be I would say there's a very, very tight interdigitation with religious And church relationships."	12
	Social Network\Family	Definition: Family is an element of the community's social network. Inductive. Use When: Family is identified as being important to the social network. Could also be a description or explanation of the family idea. Double code with main code. Example: "And so I think, again, even if people didn't have the diagnosis themselves, often there were sort of ripple effects in terms of the family unit. And yeah,	9

	I think just a lot of I mean, understanding, but also sort of recognizing that. "	
Social Network\Religion	Definition: Religion is an element of the community's social network. Inductive. Use When: Religion is identified as being important to the social network of the community. Also when religion is identified and/or explained. Double code with main code. Example: "I mean, local leaders, it could be religion, a lot of people say that the church or the mosque was really useful in welcoming them back and helping them to reintegrate the communities, on the contrary, it was said that they wouldn't dare to, to go back to their original normal church or mosque or wherever they were going to, because they were ashamed. So it really depends"	7
Social Network\Competition	Definition: Competition is an element that can affect the social network. Inductive. Use When: Competition is identified as being an element that can affect the social network or social perceptions among the community. Double code with main code. Example: "And people definitely felt like one of the big challenges I've saw in both countries, but I think I it seemed a bit more acute in DRC was, I do a lot of training. And a lot of people would come to me for help. And I teach them how to do something on the computer somehow, analysis. And then I would finally train up someone who's local who, who knew what he was doing, he could do some of these basic things. And when people would come and ask me to help them do this basic thing. I'd say, Well, why don't you Why don't you ask Yannick? Why don't you ask one of them, they know how to do it. Um, but they often didn't necessarily want to share their knowledge and share their experience. And some of that is all jockeying around for being indispensable and having positions. If you are the only one who knows how to do this in Excel, then they can't fire you. Yeah, um, and so I found that to be one definitely challenging part of some of those social connections of them, not always helping each other out. And I saw that sometimes with the WHO staff as well as they, they don't want to work them their way out of a job. And a lot of what I did was trying to work my way out of a job. So it was always really interesting to see even people who were friends socially, didn't always help each other out. Because there was a bit of competition for a limited number of positions."	1