In What Ways Did The 2014-2015 Ebola Viral Disease Outbreak in Sierra Leone Affect Women?

An examination of gender and human rights in a major disease outbreak

Research Report presented in partial fulfilment of the requirements

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Dedication

In January 2015, I was standing outside a morgue in a small community hospital in Sierra Leone watching a local NGO funded burial team remove a deceased person from the morgue for burial. Outside the gates of the morgue, some family members of the deceased waited for the white gowned, gloved and hooded team to complete their task. They were sweating in the thirty-five degree heat, fumbling in the layers of thick protective gloves that they worked in. Beside them stood a nervous man equally dressed in protective gear, carrying a backpack sprayer, and the pungent smell of 0.5 percent chlorine drifts across the compound. There would be no riding with the deceased to the cemetery today, just the carful placement of the body in its double thickness plastic body bag into the back of a Toyota Land cruiser, and the rapid drive away from the hospital out onto the dusty roads, leaving behind the man's wife, crying her grief to the assembled crowd.

I lean across to ask a local person I know what she is saying. She is crying at the top of her voice, "my husband, my husband, he is gone, my children, they are gone, how will I live, how will I live" She walks between people loudly calling out her grief, desperate, and tearful. The people around her do not console her, they give her this time to grieve, but they are there nonetheless. It is brought home to me yet again the terrible toll Ebola takes from families in this country, and my thoughts turn later that day to this woman, and other women like her who have endured the effects of Ebola. They have been the caregivers of the sick, buried their families, and who have had to carry on in a society where it seems being a woman means you have less opportunity, less education, and less chance of surviving if things go wrong.

Ebola can kill in a matter of hours, it seems to suck the very life away from people and many do not survive it. Its origin and transmission have at times been mystifying to local people, as has the random nature of the illness and whom it claims. People in Sierra Leone are no strangers to death, childhood mortality rates are high, and the country carries a heavy burden of lethal tropical illness at the best of times, but Ebola is something else entirely.

Ebola affected every aspect of Sierra Leonean society, at every level, in some way. Even the way people greeted each other changed, hugs and handshakes were no longer evident, people stood a respectful distance away from each other; a sore trial for a culture that is known for its warmth and welcome toward others. I wonder where all this will lead, and what it will all mean for the people of Sierra Leone in the future. It is to those people, especially the women, that this research is respectfully dedicated.

Acknowledgements

I would like to thank my supervisor Sharon McLennan, for her very patient advice and support in helping bring these ideas to fruition, despite my global wanderings in the NGO world. Indeed, a big thank you to all the tutors in the Development Studies department at Massey, who have educated, challenged, and inspired. I would also like to thank my wife Rebecca and my two children Danyon and Ursula, they have put up with long hours of me being shut away researching and writing. Finally, a big thank you also to all those who participated and helped in my research, who served with me in Sierra Leone, and put aside the often traumatic memories of that work to assist in my report, you know who you are.

Abstract

Ebola Viral Disease (EBV) is a filovirus with a high mortality rate that ravaged the West African region intensively in the 2014/2015 period, with some cases persisting into 2016. The rapid advance of the illness was characterised by the near collapse of the health system of Sierra Leone, as medical and nursing staff fled or succumbed to the disease. The statistics concerning mortality rates from the illness in West Africa reflect an epidemic in which more women than men have died. These statistics parallel the gendered mortality rates of many natural disasters, and it is clear that epidemics and disasters, when they occur, often reflect pre-existing gender inequalities. This is a fact recognised within the policy structures of many large international NGOs when planning humanitarian response. The reasons for these disproportionate figures are explored within this report using a human rights perspective.

This report draws on academic and grey literature, and a small-scale survey of workers involved in caring for those suffering from Ebola, to explore how a person's level of risk to an event like Ebola and their capacity to respond to or prepare for it, can be affected by a person's gender, level of poverty, social class, age, ethnicity, and the pre-existing human rights landscape. Human rights are intended to be universal, but as this report will demonstrate, there are many factors limiting the implementation of basic human rights in relation to gender and humanitarian action. This study explores some of the reasons why more women than men died from Ebola in Sierra Leone and why, as many of the survey respondents reported, women suffered disproportionately during the outbreak . The reasons for this are outlined within the findings, but include cultural practices around mortality, gender roles within society, a lack of education leading to an inability to take up preventative health messages, and pre-existing bias against women at many levels of society.

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List of Acronyms

EVD – Ebola Viral Disease

WHO – World Health Organisation

UNDP – United Nations Development Programme

UNAMSIL – United Nations Mission Sierra Leone

ECOWAS – Economic Community Of West African States

UN – United Nations

NGO – Non-Government Organisation

IFRC – International Federation of the Red Cross

MSF – Medicine Sans Frontieres

SDG – Sustainable Development Goals

MDG – Millennium Development Goals

ETC – Ebola Treatment Centre

UNPF – United Nations Population Fund

FGM – Female Genital Mutilation

ECOMOG – Economic Community Military Observer Group

YLL – Years of Life Lost

MUHEC – Massey University Human Ethics Committee

IMD – Indian Meteorological Department

UNDAW - United Nations Division for the Advancement of Women

UNISDR - United Nations International Strategy for Disaster Reduction

HGHI - Harvard Global Health Institute

LSHTM - London School of Hygiene and Tropical Medicine

WID – Women in Development

GAD – Gender And Development

Chapter One: Introduction, Background to the Research, and Methodology

Introduction

As of early 2016 the most pervasive epidemic of Ebola Viral Disease (EVD) ever recorded in history has finally faded, although it is not gone completely from all of West Africa. At its peak the illness was most prominent in three West African countries, Guinea, Liberia, and Sierra Leone. This outbreak of EVD in West Africa was associated with significant mortality rates, in some areas in excess of 71% of those effected (Medecins Sans Frontieres, 2014). The knock on effects of EVD have been huge, and in many ways are still unfolding. Certainly, besides the direct mortality figures, EVD at its height stifled development, largely reversed recent hard-won socio-economic gains, intensified poverty, food insecurity, and additionally destroyed the livelihoods of many people (UNDP, 2015; African Development Bank, 2014). Prior to the EVD outbreak, Sierra Leone *was* making steady progress with development goals. Economically, the disease cost the West African region at least six percent of its annual growth in 2015, this figure is projected to climb in 2016, due to ongoing trade restrictions and the knock on effect caused by Ebola globally, (UNDP, 2014).

While the effects of the EVD outbreak are certainly very visible at a macroeconomic level in all the effected countries, it is the effects, both social and economic, that Ebola has had upon the women of Sierra Leone that this report will discuss, in relation to human rights. Sierra Leone has a mixed record on human rights; the country emerged a decade ago from an appalling civil war in which women were often the recipients of violence, and on occasion also combatants (Abdullah, Ibrahim, & King, 2010). Since that time, the country has enjoyed political stability with considerable assistance from overseas agencies.

Ebola has been the biggest challenge to the government of Sierra Leone since the 1990s civil war, and although its efforts to control the disease have overall been courageous and commendable, there have been many examples where the actions of the government have been ineffective. This has led to social breakdown, eroded human rights, furthered corruption, and worsened the plight of the most vulnerable, especially women (Thomas, Phillips, Lovekamp, & Fothergill, 2013).

The government of Sierra Leone turned to the international community and humanitarian organisations to render assistance during the EVD outbreak. It is fair to say that donor-recipient relationships can be fraught with potential complications and pitfalls in aid delivery, as has been evident in many humanitarian operations globally, including on occasion the Sierra Leone EVD response (Boseley, 2015; Beeching, Fenech, & Houlihan, 2014). However, delivery of life saving aid is crucial to the survival and wellbeing of affected populations in disaster, conflict and epidemic, and although the efforts of the World Health Organization (WHO) and others have been criticised in the media, overall they were seen as effective (Boseley, 2015).

Looking at other examples of disaster response and subsequent humanitarian action can provide useful insights into the likely progression of events around outbreaks such as EVD. This Research Report cites the example of the 1991 tropical cyclone in Bangladesh (BOB 01), as a sentinel case study on gender and disaster, and illustrates the link between this event and one of the most noticeable trends in aid delivery today, the drive to deliver gender sensitive interventions. Indeed, following the cyclone it became clear that humanitarian aid should be targeted more effectively towards marginalised groups; and in many countries women fall into this category. As such, NGOs and governments have an obligation to consider gender in aid delivery, in order to meet basic human rights needs at a time of human vulnerability.

As this paper will demonstrate, there are clear linkages between human rights, the status of women, and humanitarian intervention during times of crisis, as well as general progress toward wider development goals and objectives. Simply put, when the basic human rights of over fifty percent of society (women) are met, all of society stands to benefit, and when gender issues are incorporated into humanitarian intervention, this can lead toward better outcomes for women and a society in general (Bradshaw, 2013).

This view now appears nearly uniform among the major actors in the humanitarian and development fields, and is a view supported by the United Nations, and The World Bank, (UN Women, 2014; The World Bank, 2015). In the context of discussions around the post 2015 Sustainable Development Goals agenda, the UNDP noted that "*gender equality, centred in human rights, is recognized both as a development goal on its own, and as vital to accelerating sustainable development"* (UNDP, 2015, p1). As such, gender is likely to feature strongly in the new Sustainable Development Goals, or SDGs (Save The Children UK, 2015).

It is therefore relevant to reflect on gender and the EVD outbreak through a human rights lens. This approach allows examination of wider contextual global issues of humanitarian aid delivery and gender, as well as adding insight into the need for ongoing attention to gender specific issues in tailoring a humanitarian response. Examining the effects of EVD on women will add perspective to the wider issues that are at play within recovery and development efforts in Sierra Leone today.

The later part of this report will describe the findings of the research, which sought to gain insight from the observations of those expatriates who worked on the Ebola response, using a Survey Monkey questionnaire. The link for this questionnaire was passed from one respondent to another, and asked a series of questions regarding participant`s observations, witnessed while working with Ebola sufferers. Although this study is of a small scale and limited in scope, it was able to ethically gain insight into the lives of women in Sierra Leone from the perspective of those there to help. From a human perspective, the subject matter can be grim reading, but it is worthwhile in that it helps the reader to gain insight into the dynamics of gender in emergency and epidemic situations, and how the pre-existing human rights landscape can influence outcomes.

Research Question

The following is the core research question around which this Research Report is based:

In what ways can a major disease outbreak impact on the human rights of women?

Research Aims

In order to address this research question, the following aims were developed in a format suggested by O' Leary (2014):

- To explore the social and economic effects and impact of Ebola Viral Disease (EVD) on women within Sierra Leone, through a human rights lens.
- To better understand the possible gender issues that may occur within humanitarian interventions, more specifically in disasters and epidemics such as Ebola Viral Disease.

Research Objectives

The following specific research objectives will support the stated research aims (O' Leary, 2014):

- To understand the background history and current status of women in Sierra Leone
- To understand how past humanitarian crises have affected women and led to policy change within major NGO organisations active in the humanitarian sector.
- To better understand the role of gender during a major disease outbreak such as EVD within Sierra Leone, in the short to medium term.
- To conduct a small-scale qualitative research study, exploring the experiences of humanitarian workers engaged in responding to the EVD outbreak, in relation to observations around gender.
- To explore the what connections, exist between human rights, gender, and humanitarian action in a major disease outbreak

Methodology and Research Design: Qualitative Research

The methodology employed within this study is qualitative in nature, for the following reasons. Firstly, qualitative methodologies provide a way of gaining an understanding of organisations and situations, from the experiences and observations of people (O'Leary, 2010). This was deemed a to be the best approach, as the effects of Ebola need to be understood from a human perspective; to gain insight into the human experience of EVD, in the context of the social and political situation of Sierra Leone today, for women. This is something that is very difficult to achieve fully using other methodological approaches, a view supported by Davies & Hughes, (2015). Secondly, there are very limited sources of data that may be employed for quantitative purposes in Sierra Leone as, during the EVD epidemic, general health system collapse resulted in very poor statistical data gathering both at a regional and a local level. In addition the small scope and short time frame for this research project did not enable to collection of quantitative data in the field. Thirdly, early on in the initial literature review, it became evident that the voices of those who were affected by EVD were not very visible in the mainstream media, and yet, as this paper will support, it is often the collective personal

accounts of people during times of disaster that have contributed greatly to changing humanitarian policy in the past, (Ariyabandu & Foenseka, 2006; Aoláin, 2011). Finally, I propose that using qualitative research in this way provides a valuable framework within which to tie in wider humanitarian issues such as human rights, and gender, during disasters and epidemics. The chosen method for data collection was a survey rather than directly interviewing respondents. This is a less common approach for qualitative research, and the reasons for this decision will be outlined in the next section.

Methods: The Survey Tool

A Survey Monkey survey tool was created to canvas respondents for their observations around the care of people suffering from EVD, and to gain insight into wider gender related issues that may be present, and contributing to the survival and wellbeing of women (See appendix 1 for the questions used). A survey was chosen because it facilitated contact with respondents in a way that allowed people to express their observations in written form in their own time, in response to a series of questions on the subject matter. Additionally, the survey could be passed to a number of respondents simultaneously without the need for direct interviews which, given the international nature of the Ebola response, would have been very challenging. Utilising an online survey also had additional advantages, as it gave access to a unique group of respondents in a cost effective, timely, and efficient manner, a view supported by Wright, (2006). The survey questions were chosen carefully so as to not define a person's response, but to promote an open ended individual narrative of observations concerning EVD. Finally, logistical and ethical challenges precluded direct data gathering; fieldwork in Sierra Leone was not a viable option, and would be beyond the scope of this paper, in addition, ethical considerations reasoned against direct interviews with survivors.

What particularly differentiates this survey tool from other more quantitative survey methods is the thematic analysis employed to understand the narrative; key comments, and commonalities were drawn from the text, this in turn was contrasted with findings from the literature (Grbich, 2012). The survey link itself was emailed to a number of contacts known to the author within the humanitarian field, from three main NGOs operating within Sierra Leone in the international Ebola response. The data collection relied upon respondents answering the survey questions, and then sending the questionnaire on to other possible respondents, a method called the 'snowball' method of data collection (Salganik & Heckathorn, 2004). This

method is very effective for accessing difficult to access respondents, in this case respondents who may be in geographically diverse locations or on assignment in the humanitarian field elsewhere in the world. Thematic analysis of the respondent's answers followed data collection, as well as collation of the non-qualitative data in graph form from the first two questions. These responses were then mapped out for each question, and conclusions drawn, a method of analysis described and supported by O' Leary, (2014).

Methods: Social Media

Social media such as Twitter and Facebook were also canvassed for survivor groups and individuals posting content related to EVD. Individual social media posts were reviewed by searching for content using key words such as Ebola survivor, Ebola, Women and Ebola, and selected for content that was connected or directly related to the research questions. It is evident that even in less developed countries, the internet and social media websites such as Facebook and Twitter have a large and growing presence, and survivor groups on these social media websites are relatively easy to find. Additionally, many organisations such as the World Health Organization (WHO) and United Nations International Children's Emergency Fund (UNICEF) have recorded the accounts of survivors and posted them on their own websites and social media pages (La Rose, 2014, Hessou, 2015, WHO, 2015).

These accounts help to highlight the humanitarian aspect of the illness and personalise what is occurring, or the use of social media may in turn garner support or funding for a particular NGO, additionally, often people just wish to tell their own story (Nahikian, 2012, Yates & Paquette, 2011, Landwehr & Carley, 2014). These sources were used mainly as an adjunct to the main body of research listed above, quotes from individuals relating to EVD were noted and provided an interesting extra resource of personal information. Social media content is largely in the public domain and requires no special permission to use, but there are significant limitations to this as a source of data (Weller & Strohmaier, 2014). Firstly, undertaking a full study of social media content relating to Ebola would be a very large undertaking and falls outside the scope of this report. Secondly, the content and actual accuracy of the information is difficult to verify fully as a data source and as such must be used with caution (Westerman, Spence, & Van Der Heide, 2013). Thirdly, the use of Social Media for research is an emerging field and ethical issues concerning the use of social media content must still be addressed (McKee, 2013).

The biological progression of the disease is relatively well understood from a scientific perspective, but the personal and societal aspects of the illness much less so. As stated previously, research that directly canvases people affected by EVD would be challenging and require a huge commitment of resources that would be well beyond the scope of this report, as well as raising many possible ethical questions. In the interests of exploring the effects of EVD in an effective manner that complies with Massey University ethical standards, (Massey University, 2010) exploring the effects of EVD on people by proxy, via those who had worked with and cared for them is by far the best option.

Limitations of the research

The research is primarily limited by the small scale of the study, and the fact that it does not gather data directly from survivors, as research that directly canvases people affected by EVD would be challenging and require a huge commitment of resources that would be well beyond the scope of this report, as well as raising many possible ethical questions. In the interests of exploring the effects of EVD in a safe and non-maleficent manner that complies with Massey University ethical standards, (Massey University, 2010) exploring the effects of EVD on people by proxy, via those who had worked with and cared for them is by far the best option.

Additional limitations could be possible around any potential cultural bias that may colour the observations of respondents. However, within this study, perceptions and opinions around human rights and gender from respondents are very much generally assumed to be in line with what is accepted internationally, as working for an international NGO usually means adopting their respective codes of conduct in the field, and support for the wider ethical stance of the organisation (Beigbeder, 1991).

Ethical and Contextual Considerations

There are three main areas within the research process that need to be addressed, in the case of the study recorded here these are summarised as; informed consent, harm minimisation, and issues of confidentiality (O' Leary, 2014). These were addressed through Massey University's Human Ethics Committee (MUHEC) requirements. As part of this, I completed the Development Studies in-house ethics process, which included completing an ethics form and

discussion with both my supervisors and one other academic from the Development Studies Department. As a result of this meeting the research was considered to be low-risk, and a low risk notification was sent to MUHEC.

Respondents were provided with general information regarding the purpose of the study, where and how the information would be used, stored, and presented, (see Appendix 2). In addition, the study was designed to ensure the anonymity of respondents. Participation in the study would be at the discretion of the individual. It is especially important for the author to do no harm, and the author is cognizant of the power issues that can be present between researchers and respondents when working in sub-Saharan Africa. This was a core principal when deciding to work with clinicians ethically in Sub Saharan Africa rather than survivors (Emanual, Wendler, Killen, & Grady, (2004).

Summary and chapter overview

This Research Report consists of six chapters overall. Chapter One introduced the research, looking at the research aims, objectives, question, and the methodology. The research methodology differs from the more common interpretations of qualitative research in that it utilises a survey tool, rather than direct interviews with respondents. This way of canvasing respondents was essentially chosen to fit within the limitations of the scope of this research report, and yet still allow the exploring of meaningful observations, without directly contacting and interviewing respondents, a task made extremely difficult by the presence of the Ebola illness itself. The second part of Chapter One chapter focused upon the process of Massey University ethical approval.

Chapter Two will discuss gender, human rights, and disaster response, specifically human rights as a theoretical framework for this paper. Chapter Two will additionally discuss EVD as a global health emergency, and as an event that also has many of the hallmarks of a natural disaster as well. A tropical cyclone in Bangladesh will then presented as a sentinel case study of the impact of gender in disaster, and following on from this is a critique of the international response to Ebola.

Chapter Three will focus on Sierra Leone itself, providing an overview of the country and the ethnic groups living there. Chapter Three will also look into the history of human rights in Sierra

Leone, and begin to narrow down the focus of the research report, looking at the health status of women in Sierra Leone, in addition to their economic, cultural, and political status.

In Chapter Four will discuss the Ebola virus, examining the virus physiologically, the progression and effects of the disease. Chapter Four will also analyse the similarities with other viruses such as Human Immunodeficiency Virus, or HIV, in the way they have impacted upon affected individuals and communities.

Chapter Five is one of the key chapters of this report and will present the research and thematically analyse the findings from each research question. Chapter Five will include the observed impacts of EVD as recorded by research participants, specifically observations around how the disease has affected women, communities, and survivors.

Chapter Six presents and critically discusses the findings of the research report in relation to current literature on the subject, as well as bringing together the threads of EVD, gender, and humanitarian response in Sierra Leone under the umbrella of human rights. Following on from the conclusion will be Annex 1 and 2, which list the research questions and the information sheet given to participants in the small scale study undertaken for this report.

Chapter Two: Human Rights, Gender, and Disaster Response

Introduction

The first part of this chapter introduces human rights as an overarching theoretical framework for this study, and in addition to describing the background of the concept of international human rights, illustrates the strong links that exist between basic human rights, gender, and humanitarian response. The chapter finishes with a section on gender and development, and how this has evolved to become a major driving force in NGO policies during humanitarian intervention.

The second part of this chapter will explore the background to gender and development, and gender in the context of humanitarian disasters, before exploring the similarities between the EVD outbreak and the gendered impacts of natural disasters. Although the EVD outbreak is not generally considered a natural disaster, there are many similarities between Ebola and a natural disaster that are obvious in comparison, particularly in relation to gender issues. The size and magnitude of the current EVD outbreak itself is unique in recent times, and unparalleled in relation to any other disease outbreak, although some comparisons can be drawn with some of the socio-political effects of HIV, which will be discussed in Chapter Four.

Human Rights as a Theoretical Framework for this study

On face value the subjects of Ebola Viral Disease, humanitarian intervention, and gender may appear to be somewhat separate entities in themselves, however human rights can be seen to occupy the common ground shared between them, as illustrated by Figure 1. To explore this further, the relationships between the various headings depicted in Figure 1 are complex, and they relate to each other on many levels. For example, humanitarian intervention can be seen to address any one of a number of identified humanitarian or development related goals, but one of the major objectives of humanitarian intervention is to essentially support the *intrinsic human right to life* and the best obtainable level of health where it is threatened (Foreign & Commonwealth Office, 2015). Human rights then become a cross cutting issue, and a lens through which not just international humanitarian intervention can be viewed, but also the response measures taken by a government. Further to this, the measures implemented by

governments during crisis periods will, as this assignment will demonstrate, often reflect the accepted status quo in relation to gender.

This report aims to incorporate human rights as a theoretical framework, as human rights and human welfare are essentially the rasion d' etre for any humanitarian intervention. In the opinion of the author, it is only through supporting human rights, and its associated concepts such as good governance, can true progress toward wider development goals occur, and the effects of disease, natural disaster, and conflict be sustainably mitigated.

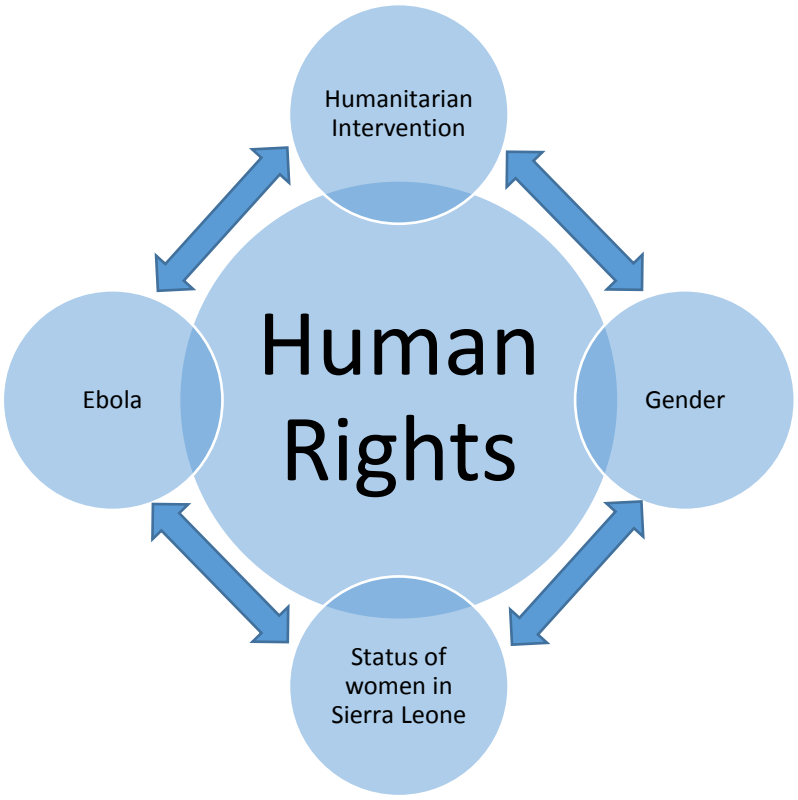

Figure 1. Human Rights occupies the common ground between humanitarian intervention, gender, the status of women and EVD

A Brief History of Human Rights

Basic human rights can be seen as reflecting acceptable, ethical, standards of behaviour in relation to how human beings are treated (Nickel, 2014). Historically there have been a number

of laws and documents relating to human rights, but the most quoted in recent history is the Universal Declaration of Human Rights (UDHR), signed in Paris in 1948 (UN, 2015). From the 1948 text:

> *Human rights are rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible* (OHCHR, 2014).

In 1948, the Universal Declaration of Human Rights (UDHR) brought human rights into the realm of international law (UN, 2015). The UDHR also led to the establishment of the High Commissioner for Human Rights, the Human Rights Council, and also a number of human rights treaty bodies. A fundamental principle of the UDHR and the United Nations Charter, which was embraced by world leaders in 1945, states that men and women are equal in regard to human rights and further to this, protecting and promoting the rights of women is the responsibility of all governments and states (UN, 2015).

Regarding the right to health, article 25 of the UDHR states that:

> *Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services*" (UN, 2015).

This is further backed up by additional conventions such as International Convention on the Elimination of All Forms of Racial Discrimination, which was adopted by UN member states in 1965, which also mention (briefly) health, and the International Covenant on Economic, Social and Cultural Rights (1966). This states that it is the "*right of everyone to the enjoyment of the highest attainable standard of physical and mental health"* (UN, 2015).

Additionally, the World Health Organization publishes the following in relation to health: *The WHO Constitution enshrines the highest attainable standard of health as a fundamental right of every human being* (WHO, 2015), as well as the following, "v*ulnerable and marginalized groups in societies tend to bear an undue proportion of health problems".* The same principles concerning the ethical pursuit of human rights govern NGO organisations in their actions, a view supported by Beigbeder, (1991), Nelson & Dorsey, (2003), Ghere, (2013), Pease, (2012), and Gourevitch, Lake, & Stein, (2012), among many other authors and publications.

From this we can see that not only is it the responsibility of governments to provide an acceptable level of health care to its citizens, which is a fundamental human rights issue, but it is also within the mandate of international non-governmental organisations to act ethically, to support and promote human rights in their activities abroad.

Gender and Development

Consideration for the roles and value of women in development evolved only slowly in development theory until the 1970s, and was not seen to any great extent in development administration and planning until the 1990s (UNDP, 2001). However, there is now much more recognition of gender issues and the importance of women's empowerment, by international development agencies and many governments. Much of the credit for this is given to the UN, who sponsored a number of conferences on women, gender, and development over the last three decades, which have been collectively influential in furthering gender issues globally. Of special note is the concept of gender mainstreaming, which was established as a term for the global strategy for promoting gender equality through the United Nations Fourth World Conference on Women in Beijing in 1995 (UNDP, 2001). Gender mainstreaming can be defined as "the process of assessing the implications for women and men of any planned action, including legislation, policies or programmes, in all areas and at all levels" (UN Women, 2014).

Trends within development theory relating to women, such as the movement described as Gender And Development (GAD), and also Women In Development (WID)[1] have also been instrumental in helping to shape legislation and gender mainstreaming as a major focus within NGOs (Bradshaw, 2013). They have also led to the concept of `gender mainstreaming` in emergency response, where the gender specific needs of women and other marginalised groups are taken into account at every level of planning and executing a disaster response action (Morrow, 1998; Hines, 2007; MacDonald, 2005). This will be discussed further later in this chapter.

1 WID (or Women in Development) is a term used to describe the policy of integrating women more prominently into development policy and practice, (Reeves & Baden, 2000).
The GAD (or Gender and Development) approach emphasizes the socially constructed basis of differences between men and women and focuses on challenging existing gender roles and relationships (Reeves & Baden, 2000).

An Overview of Vulnerability in Humanitarian Response

Vulnerability is a term often used in relation to disaster management and gender, and is also a term used in a great deal of literature relating to humanitarian action (Manyena, 2006). Vulnerability can be defined as "*the characteristics of a person or group and their situation that influence their ability to anticipate, cope with, resist, and recover from the impact of a natural hazard"* (Blaikie, et al., 2004, p11). It is frequently implied in the literature that a person's level of vulnerability, and their ability to survive and recover from disasters, epidemics, wars, or events where human life wellbeing, and dignity are put at risk, can be subject to many variables.

Examples from the literature, of factors influencing vulnerability, include:

A person's age: People who are elderly often have decreased mobility, lower income, higher levels of disability, and are often more isolated than younger people. Additionally, older people tend to underutilise available aid resources in an emergency (Thomas, et al., 2013). Children have lower rates of survival in disasters than adults, and are at much higher risk of illness post disaster (Sebellos, Tanner, Tarazona, & Gallegos, 2011) and depending on age, and children respond differently to stressors depending on developmental level and the presence of a supportive environment (Osofsky & Osofsky, 2013).

In the case of EVD in West Africa, disproportionately high mortality rates among working-age adults have been noted, this is the age group who are also the most likely to have young children (Evans & Popova, 2015). The high mortality rates of EVD has created high number of orphans; as of February 2015, in Sierra Leone there are 3300 Ebola related orphan children (Evans & Popova, 2015). Although these figures represent only apportion of the total number of orphan children in Sierra Leone, according to Evans and Popova (2015, p946) there are also possible issues of stigmatisation, "*A related concern is that stigma might lead to rejection of orphans by households that would traditionally have fostered them"* a view supported by Deacon & Stephney, (2007). These children are almost certainly likely to have adverse cognitive, developmental, and emotional effects lasting into adulthood (Beegle, De Weerdt, & Dercon, 2010). Of those children that themselves contract Ebola, the outcome is generally poor, especially if they are under 5 years of age (Remy & Chertow, 2015). More on stigma will be discussed in the research findings section.

Socio-economic status: Income and socio-economic status have a huge impact upon vulnerability, and can be a major deciding factor in disaster outcomes (Kim, 2012). For example, disasters in the less developed world tend to have higher mortality rates and longer lasting sequelae (Blaikie, Cannon, Davis, & Wisner, 2004). However, being poor is *not* a decisive indicator for a lack of resilience in disaster or epidemic. According to a study by Aktera & Mallick (2013) centred on the outcomes of the 1991 Bangladesh Tropical Cyclone, those of lower socioeconomic status were more vulnerable in that they suffered higher levels of economic, physical and structural damage from the cyclone. However, the statistics around vulnerability did not necessarily equate to low resilience, as "these individuals exhibited a greater ability to withstand the shock compared to their non-poor neighbours" (Aktera & Mallick, 2013, p114).

Ethnicity: Ethnic grouping can contribute significantly to the outcome of disasters in several main ways. Due to multiple historical issues, ethnicity can be linked to poverty and socio-economic status, as well as geographic location, all factors that can increase vulnerability. For example, there may be political or power imbalances, which reduce an individual's resilience to disaster, or communication difficulties that prevent the uptake of prevention and recovery initiatives (Morrow, 1998; Kim, 2012; Vasta, 2004).

Disability: People with a disability whether physical, behavioural, cognitive, or sensory are significantly more vulnerable during a disaster to death or injury than a more able bodied person, as was shown by studies around Hurricane Katrina, and the 2004 Asian Tsunami (Hemingway & Priestley, 2014). This also applies to disaster preparation and recovery measures, few of which are designed to be easily utilised by people with disabilities (Ariyabandu & Foenseka, 2006).

Culture: This can be roughly interpreted as shared patterns of belief and behaviour in a particular society (Barker, 2004), and it may also influence disaster resilience by governing ways in which people cope with and respond to disaster events, (Blaikie, et al., 2004).

Sexual Orientation: Research relating to disaster response, recovery, and vulnerability among people identifying as gay, lesbian, transgendered, or bisexual has become more visible in the last decade (Dominey-Howes, Gorman-Murray, & McKinnon, 2014), although there is currently little information relating specifically to these groupings of people in disaster response. However it seems reasonable to suggest that if marginalisation and victimisation occurred prior

to a disaster event, then it will be likely to occur during and post disaster as well (Mitrovic, 2015).

Gender: A great deal of the literature from major organisations reviewed suggests that men and women respond in different ways to a disaster or emergency (IFRC, 2015; WHO, 2005; Enarson, et al., 2007). The World Health Organization suggests "there is a pattern of gender differentiation at all levels of the disaster process: exposure to risk, risk perception, preparedness, response, physical impact, psychological impact, recovery, and reconstruction (WHO, 2005). Some of these responses are clearly governed by societal gender roles for both sexes, roles which also often leave women disadvantaged in many aspects of day to day life generally (Bradshaw, 2015; Ariyabandu & Foenseka, 2006; IFRC, 2015). Indeed, complex cultural gender issues can be present in a society, and can be active and visible in everyday life "*at the level of the individual, family, community, and society at large, and reflected institutionally as well as in social and cultural norms*" (Ariyabandu, 2012, p5).

Societal gender roles aside, Holbrook, Hoyt, & Anderson, (2001, p 1) suggest psychologically there may be differences to the way men and women process traumatic events, with women being at risk of "markedly worse functional and psychological outcomes after major trauma than men, independent of injury severity and mechanism". This surprising assertion has been echoed in a number of other studies to a greater or lesser extent, and is certainly associated with stress and traumatic events, a view supported by Vogt, Pless, King, & King, (2005), Chen, et al., (1999), Dell'Osso, et al., (2013), Freedman, et al., (2002), and Stein, Walker, & Forde, (2000). However, these studies are not based around the developing world and do not delve into cultural differences, in dealing with trauma related to disaster.

Existing legislative and political environment. The political environment plays a huge part in influencing a person's vulnerability, as we are very much governed and occasionally limited in our opportunities by legislation, and what political freedoms we may be able to enjoy, as well as the degree in which government adheres to universal human rights, especially in relation to women (Friel & Marmot, 2011).

EVD, A Global Health Emergency, and as a Natural Disaster

EVD is officially entitled a Global Health Emergency according to the World Health Organization, (WHO, 2014). However, as stated in the introduction to this chapter, EVD also

shares many of the hallmarks of a significant natural disaster as well (Barton, 2005). For example, the disease spans national borders, and affects a considerable cross section of the community, and has a very high mortality rate, has deeply affected day to day life in the countries where it is present and, at the time of writing, is still not fully eradicated in West Africa. Additionally, EVD has similarities to HIV, or other haemorrhagic fevers such as Lassa fever, in the way it has affected large groups of people. However, its high lethality and more rapid onset set it aside from HIV and Lassa to some degree.

Previous occurrences of EVD have been limited to smaller geographical areas, the lethality of the disease preventing its spread, however the current outbreak is multinational. Thus, many parallels can be drawn from human responses around natural disasters and human reaction to the trauma of EVD, because EVD has so obviously changed day to day life in affected countries at every level (Beeching, Fenech, & Houlihan, 2014).

Additionally, outbreaks of communicable diseases are common following the occurrence of natural disasters, population displacement, and when health infrastructure and systems stop functioning effectively, (WHO, 2006). The health system in Sierra Leone has come under tremendous pressure, many of the country's top doctors have died of EVD, and many other health care personnel have also perished, or abandoned their workplaces. In this situation, other diseases normally latent, or poorly managed, quickly become resurgent and all figures around the common indicators for population health such as childhood mortality, and vaccination preventable illnesses worsen (Takahashi, et al., 2015).

Bangladesh: a Case Study in Gender and Humanitarian Response

There is one particular sentinel study that features prominently in literature on gender policy from the world's major humanitarian organisations. This study has been cited in many cases as influential in shaping gender policies today. This case study is BOB 01, the April 1991 Tropical Cyclone in Bangladesh (Shrader & Delaney, 2000).

In the aftermath of the cyclone it was evident that, women had a far higher mortality rate than men (Mazurana, Benelli, & Walker, 2012). Therefore, disaster planning and response must take into account the obvious gender disparities that are evident in the studies listed below, and ensure that the needs and human rights of women are being met. Further to this, gender

inequality can be seen as a violation of global Human Rights declarations, obligating NGOs to tailor their interventions to support and maintain the rights of women.

On the 29th of April 1991, a category 4 tropical cyclone classified by the Indian Meteorological Department (IMD) as BOB 01 made landfall from the Bay of Bengal in Bangladesh. This was one of the most destructive cyclonic events on record at that time, bringing with it very strong winds and a six-meter tidal surge that quickly inundated the socio-economically disadvantaged and densely populated coastal land. Over 138, 000 people lost their lives, and the number of those affected ran into the millions.

Studies by Bern, et al., (1993) and Chowdhury, et al., (1993) conclude that considerably more women and children than men died from this event. As such, the Bangladesh tropical cyclone can be seen as a sentinel event, in that it was one of the first major disasters with a high death toll to have reliable sex disaggregated data to draw from. Further to this, the disaster has been examined both from the perspective of both disaster preparedness and response as well as from an anthropological perspective. These viewpoints have enabled researchers to examine many different human aspects of the disaster that hitherto may not have been visible.

Although grim reading, a plethora of possible reasons for the gender imbalance in the mortality figures have been proposed, and have been subsequently investigated by researchers. To begin with, problems were found with the early warning systems, as the message to evacuate did not reach all of the affected population in a timely fashion, and therefore people had inadequate warning of the oncoming cyclone. In particular, women often missed the cyclone warnings as these had been communicated mainly in public areas, some of which women did not customarily have access to (Ikeda, 1995; D'Cunha, 1997; UNDAW and UNISDR, 2001). In addition, many women were in their homes and elected to stay there, some felt unsafe leaving their homes and going to the cyclone shelters (Chowdhury, Bhuyia, & R, 1993). Additionally, there were too few concrete cyclone shelters to accommodate all the people at risk, and of these, a good number were flooded anyway, rendering them unusable (Bern et al., 1993).

Most of the deaths were from drowning, as a result of the storm surge coupled with high tide that covered many areas. In Bangladesh it is not common for women to learn to swim, and the female dress code makes swimming more difficult. It has also been suggested women may have needed to find their children before departing their houses for safer lodging, and leaving home without being permitted or accompanied by their male relatives, especially at night

during the worst of the cyclone, was seen as culturally inappropriate (Eklund & Tellier, 2012, p589).

The data relating to this disaster event was at the time cited by a number of humanitarian organisations as prima facia empirical evidence that disaster preparedness and response should be more tailored to meet the needs of women, and other disadvantaged groups in society (IFRC, 2015; UNDAW, 2015; and UNISDR, n.d; WHO, 2005; Ikeda, 1995). As such, gender has become 'mainstreamed into humanitarian aid at many levels for example, the Government of Bangladesh has since drafted a guidebook intended as a roadmap to designing gender specific disaster preparedness and response measures in Bangladesh. This guide specifically recognised women as an at risk group due to their socio-cultural position in society, and stated that any disaster preparedness measures must take this into account and meet their needs accordingly (Shafie & Rashid, 2009).

To conclude, disasters can have gender specific effects due to the socio- cultural and socio-economic status of women, which need to be accounted for in disaster preparedness activities. As can be clearly seen from the above case study, the cultural position of women is key to their outcomes and often the outcomes of dependants who may be with them. Additionally, the post disaster phase can be very unsafe for women as social disruption can bring with it increased rates of substance abuse and crime. In the decades following the Bangladesh cyclone as well as other well recorded disasters such as Hurricane Mitch, the literature concerning disaster response has grown significantly, and certainly contains a great deal more reference material around gender, and gender mainstreaming, as well as gender specific interventions in disaster response (Ariyabandu, 2012; Shrader & Delaney, 2000).

A Critique of the Impact of the Tropical Cyclone in Bangladesh on Post Disaster Humanitarian Intervention and Gender Mainstreaming.

While the gender-specific needs of women are now routinely considered in humanitarian action, there are authors who have criticized this generalist approach to gender and disasters, and presented a convincing argument that the current thrust toward gender specific response to emergencies is not fully evidenced by enough robust research or statistics, and that there is a lack of depth in the available evidence around gender specific issues in emergency situations (Ariyabandu, 2012).

It is clear that it is inherently difficult to gather reliable data in the middle of a disaster response where there are other more pressing humanitarian needs; this is especially true of sex disaggregated data (Eklund & Tellier, 2012). It has been suggested, according to Enarson, Fothergill, & Peak, (2007), that too much has been made of the data from single studies such as the Bangladesh tropical cyclone, and that the terms relating to gender from this and other studies have taken up by many NGOs have become often repeated, becoming a 'truism', without further exploration. As such, it is evident in the literature on gender and disaster response that the extent to which our gender really makes us vulnerable in disaster outcomes is still open to some debate, and would certainly benefit from further ongoing research (Mazurana, et al., 2012; Bradshaw, 2015).

Some authors go further than this and descry the image present in much of the literature that seems to paint women as helpless victims of disaster, including Childs, (2006) and Bradshaw, (2013). Bradshaw (2013) in particular recognises that gender roles at a time of a disaster or humanitarian crisis can be very different to normal. Traditional gender roles may be overturned; women become the decision makers, far from hapless victims. Women are able to field "*valuable knowledge and experience in managing and coping with disasters, often formed by living with regular, seasonal disaster cycles and managing the associated risk*s" (IFRC, 2015); casting them purely as victims does the injustice of failing to recognise the extent of their contribution to disaster management and resilience where they have been able to do so. Additionally, women are on the front lines of disaster management, in professional roles, and as leaders, in every capacity.

However, it is fair to say overall that the limitations around gender and what is culturally acceptable behaviour for women in less developed countries is very much a complex reality. Bradshaw (2013), also goes on to suggest that although women's voice may certainly be more audible in a post disaster scenario, patriarchal behaviours may still dominate even in fielding assistance; and in this context the NGO can become the provider of aid and development, and the dominant voice for women. In this picture, not much changes for women.

Other viewpoints in reviewed literature paint a further picture around vulnerability and resilience. These seem to be more encompassing terms than just using the term 'gender' (Sudmeier-Rieux, 2014), and as mentioned previously, there is acknowledgement that there are other factors present that mitigate the impact of disasters beyond just cultural behaviours, such as asset ownership, family, or other socio-cultural supports, (Vasta, 2004). Added to this,

as the discussion on vulnerability showed, there are also other elements to consider such as a person's ethnicity, race, social class and nationality, and how much control they are able to exercise over these things and decision making generally (Enarson et al., 2007).

Gender and the International Humanitarian Response to Ebola

There is evidence that the frequency and the extremity of disasters is increasing globally (Whybark, 2015). Causes for this trend include climate change and an increasing number of destructive weather events, increasing population density, human settlement moving into marginal more disaster prone areas, increasing occurrences of crop failure and famine (Enarson, Fothergill, & Peak, 2007).

Along with this trend is an increasing trend toward a new era of global emergency governance in response to crisis. Crisis management, in a traditional view, was primarily the responsibility of national governments, with international humanitarian agencies providing expertise where necessary (Heath, 2015). However, in the case of EVD, the disease quickly took on transnational dimensions and, as later discussions in this thesis will show, the health system in Sierra Leone effectively stopped functioning in many areas, leading a number of NGOs to fill the treatment gap left by the government in treating people with Ebola.

The EVD outbreak is certainly a very significant event, and it has galvanised NGOs from across the globe to action, including most of the major players in the humanitarian disaster response field. In practice, all of the major humanitarian organisations involved in relief and aid work have policies promoting the inclusion of vulnerable groups in disaster response such as children, people with disabilities, and women. This is especially true of those groups utilising the United Nations Cluster System, and those utilising the associated SPHERE minimum standards for humanitarian intervention (IFRC, 2015; UNOCHA, 2015) in which the term 'Gender Mainstreaming' has become a common phrase. The humanitarian response in Sierra Leone did not fall under the auspices of the UN cluster approach, but was rather a semi coordinated, health focused relief effort.

Having seen the background to gender mainstreaming and how it has become important on a global level, to what extent did NGOs and other groups actually implement gender specific policies in the field? The author has not been able to uncover any identifiable examples of gender specific interventions in Sierra Leone, despite the very well-publicised status of Sierra

Leone being near the bottom of the UN and WHO gender index, and the WHO having a prominent part in managing the outbreak (Boseley, 2015). When conducting activities directed toward monitoring and evaluation, as well as impact assessment, NGOs and the government departments alike will have to ask themselves the question, could their health promotion and disease management activities have been better tailored to women, and if so would this have saved lives?

Conclusion

The first part of this chapter introduced human rights as a theoretical framework for this study, and presented a brief history of human rights, gender and development. The chapter went on to look at EVD as both a global health emergency and as a natural disaster, due to the commonalities that exist with both, evidenced by the similar social, gendered, and economic, effects that have occurred.

This chapter also looked at gender and vulnerability in humanitarian response using a well-known sentinel disaster event; a tropical cyclone in Bangladesh, and finished with a critique of gender in humanitarian intervention. The next chapter will focus in on Sierra Leone specifically, starting with a country description, which covers ethnic composition, and human rights in Sierra Leone.

Chapter Three: A Country Profile of Sierra Leone, and Gender in Sierra Leone

Introduction

This chapter will explore the history of Sierra Leone in order to illustrate the historical context in which the EVD epidemic has occurred, and how the socio-cultural, and economic story of Sierra Leone has contributed to the current situation. Sierra Leone has a rich and varied cultural past which women have played a very prominent role in shaping. The country is associated with the trans-Atlantic trade in slaves, whereby thousands of people were shipped to the New World from the coasts of Sierra Leone. Colonialism has been a constant factor, with a close association with the United Kingdom for many decades. However, the most salient event in recent history has been the Sierra Leonean civil war, which continued from 1991 to 2002. Ethnic and political divisions were major contributing factors to the conflict, and although the differing ethnic groups are still very visible today, hostility between them appears rare.

Sierra Leone Country Profile

Geographically, The Republic of Sierra Leone is located in West Africa, Guinea is located to the northeast, Liberia in the southeast, and the Atlantic Ocean forms the south-west border. The country is separated into four geographical regions: The Northern Province, Eastern Province, Southern Province and the Western Area, which are then also divided into fourteen districts. Freetown is the capital and the largest city. The overall population of Sierra Leone sits at around 6.1 million (UNDP, 2015). Climatically, Sierra Leone has a very hot tropical climate, with essentially two seasons, a summer rainy season, which runs from May to December, and a winter dry season from December to April.

Economically, Sierra Leone is one of the world's poorest countries, ranking 180th out of 187 countries in the United Nations Human Development Index in 2011 (UNDP, 2015). The country relies heavily upon the extractives industry, and small-scale manufacturing. More than 60% of the population are recorded as surviving on less than United States (US) $ 1.25 a day (African Development Bank, 2013; USAID, 2013). The currency of Sierra Leone is the Leone, which exchanges for about 5000 Leones to one US dollar at the time of writing.

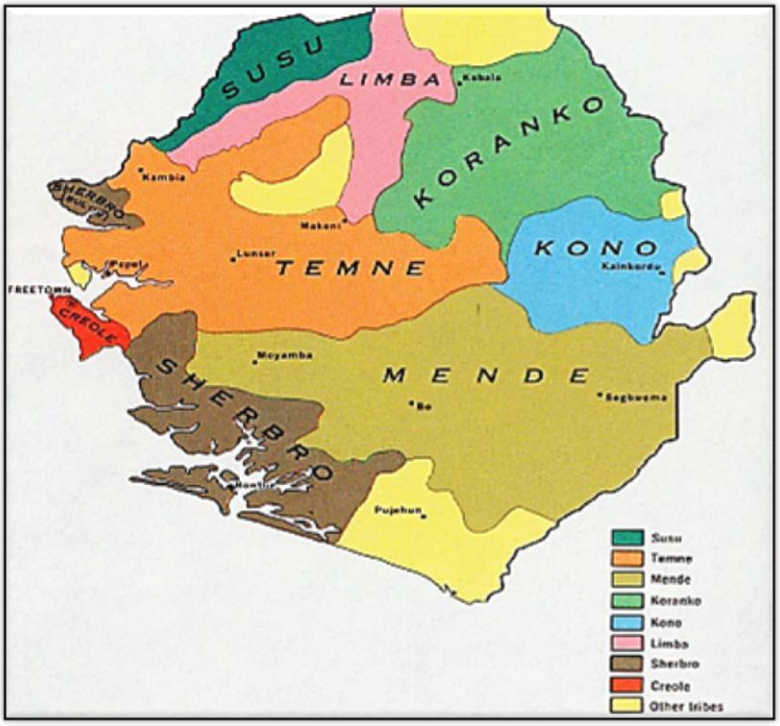

Figure 2. The approximate geographic location of the major ethnic groupings of Sierra Leone

Source: Woldt, Cadrin, & Jalloh, 2009

Ethnic Groupings

As represented in *Figure 2,* Sierra Leone is mostly comprised of two major ethnic groupings, the Temne, (35%) and the Mende (31%). The remaining population is comprised of a number of smaller ethnic groupings such as the Limba 8%, and the Kono 5%, Mandingo 2%, and the Loko 2%. Additionally, there are also the Kriole (2%) who are the descendants of freed North American slaves that settled in the Freetown area in the late-18th century. There are also small numbers of other expatriate groups such as Europeans, Lebanese, Pakistanis, and Indians, making up the rest (UNDP, 2015). The cultural identity of people in Sierra Leone is often centred around family, clan, tribe, and which ethnic grouping one might belong to, especially in the rural areas. Politically, the ethnic grouping of the majority of government has caused concerns for people who feel their ethnicity may not be fairly represented in power (Abdullah, Ibrahim, & King, 2010).

A Brief Overview of the Social and Political History of Sierra Leone

The area that would become Sierra Leone has been inhabited by indigenous African tribes for around 2500 years. The Portuguese initially traded along the coast in the 15th Century, later, other European powers such as the Dutch and the British became involved in Sierra Leone, especially in the slave trade. Slavery became a defining feature of Sierra Leone, with Europeans buying or trading for slaves collected by powerful local chiefs.

From 1600 onward Portuguese authority waned in favour of England. The English crown established several forts and trading posts along the coast, and until slavery became abolished in English law in the early 1800s, shipped millions of Africans across the Atlantic to colonies in America and the Caribbean. The interior of Sierra Leone continued to be the provenance of mainly indigenous peoples. Following the American Revolution, former slaves, many of whom had sought help from Britain, were given their freedom, and were transported to Sierra Leone to begin a new settlement there around the area now known as Freetown.

The next period in Sierra Leonean history saw Britain expand its influence inland; supressing any indigenous tribes not already won over through treaty, and securing the borders of the country with French Guinea to the North. However, although the British maintained a considerable colonial administrative apparatus in Serra Leone, they often ruled and collected taxes by proxy, through the establishment of friendly or compliant local chiefs. In 1961 Sierra Leone peacefully gained independence from Britain (UNAMSIL, 2005).

The 1991-2002 Sierra Leone Civil War

The Sierra Leonean civil war had huge impacts upon the country and its people, and became widely known for its barbaric brutality and graphic violence, inspiring films such as 'Blood Diamond' staring actor Leonardo Di'Caprio, named for the trade in diamonds that was used by many participants to fund the conflict.

The conflict began in Sierra Leone in March 1991, when combatants from the Revolutionary United Front (RUF) began an action from the east of the country near the border with Liberia, directed at deposing the government. With aid from the United Nations (UN) aligned Military Observer Group (ECOMOG) of the Economic Community of West African States (ECOWAS), the Army of Sierra Leone initially tried to protect the government, but later army factions launched

a coup d'état and overthrew, and removed the government. The next decade in Sierra Leone was one of anarchy as various salient political figures vied for power, fighting against and at times aligning with other factions. There were accounts of the involvement of foreign mercenaries, arms dealers, and widespread corruption (UNAMSIL, 2005).

The conflict lasted until 2002 when a UN peacekeeping force began disarming fighters from all sides. At this time, the British Army began training and deploying a new Sierra Leonean army, which proved militarily decisive. This combined with international sanctions and pressure finally brought all the warring factions to the negotiating table. The UN portrays the UNAMSIL mission as a template for successful peacekeeping, conflict resolution, reintegration of ex combatants into society, and state building (UNAMSIL, 2005; Torjesen, 2013). However despite social and political progress from the days of lawlessness and anarchy, according to UNAMSIL (2005) Sierra Leone as a country still needed to take "*concrete steps to address the root causes of the conflict and cultivate a culture of human rights."*

During the civil war, there are many accounts of atrocities directed toward non-combatants, especially women. There are accounts of abduction, torture, rape, and women being forced to serve as soldiers, leaving many women with lasting physical and emotional trauma (Friedman-Rudovsky, 2013; Coulter, 2009; Holland & Saidu, 2012).

Sierra Leone today

In the time since the civil war, a fragile peace has been maintained, and progress has been made economically, politically, and with human rights legislation (International Monetary Fund, 2014; The World Bank, 2014). Despite this progress Sierra Leone is still sits as one of the world's poorest and least developed countries, where an abundance of natural resources has not translated into any form of real wealth for most Sierra Leonean people (Sudmeier-Rieux, 2014). Unfortunately the current EVD outbreak has impacted upon Sierra Leone at most every level of society in some way, and has halted economic advancement causing widespread concern among banks and financial institutions (Jalloh, 2014). It remains to be seen if the economy of Sierra Leone will be able to return to something approximating the pre Ebola period.

Human Rights and Gender in Sierra Leone

Human rights are an ongoing concern in Sierra Leone. The Government of Sierra Leone has been subject to the following criticisms in relation to general human rights abuses in Sierra Leone, as noted by the US Department of State in 2015:

> *Major human rights problems included security force abuse and use of excessive force with detainees, including juveniles; harsh conditions in prisons and jails; official impunity; arbitrary arrest and detention; prolonged detention, excessive bail, and insufficient legal representation; interference with freedom of speech and press; forcible dispersion of demonstrators; widespread official corruption; societal discrimination and violence against women, discrimination based on sexual orientation; female genital mutilation (FGM); child abuse; trafficking in persons, including children; and forced and child labour* (United States Department of State, 2015).

However, in relation to gender, the government of Sierra Leone is signatory to a number of human rights accords and conventions such as the Convention on the Elimination of all forms of Discrimination against Women (CEDAW), the African Charter on Human and Peoples Rights, the Maputo Protocol, among others (UNCHR, 2015). Despite the signing in recent years of many of these accords, the perception on the ground by many women's groups suggests it will be a long time before these political gestures shift the patriocentric culture of Sierra Leone (Bendu, 2011).

In order to understand in what ways Ebola has disproportionately affected women in Sierra Leone, it is hugely important to understand the socio-political and cultural status women currently hold in Sierra Leonean society. Equally useful is how the status of women in Sierra Leone sits comparatively to contemporary African states, as well as globally.

Statistically, Sierra Leone has a Gender Inequality Index Value of 0.662. The Gender Index Value, according to the United Nations Development Programme (UNDP), is a measure of the loss of achievement within a country due to gender inequality, as well as providing *"empirical foundations for policy analysis and advocacy efforts"* (Women's United Nations Report Network, 2014, p1). The index uses three main indices of measurement, reproductive health, empowerment, and labour market participation (see Figure 3) (UNDP, 2015).

As previously stated, an index rating of 0.662 indicates *significant* gender based inequality across all the indicators and dimensions shown in Fig. 3, ranking Sierra Leone at a 183 out of 185 countries on which there is data. By comparison, New Zealand ranks 0.185, or seventh, out of 185 countries in the world, according to the United Nations Development Programme Human Development Report data (UNDP, 2013). Additionally, from further UNDP (2013) data, out of other neighbouring African states, Liberia sits higher at 0.655, or 175th, Côte d'Ivoire sits marginally higher still at 0.645, or, 171st out of 185 placings.

Data indicators for the Gender Inequality Index in Sierra Leone

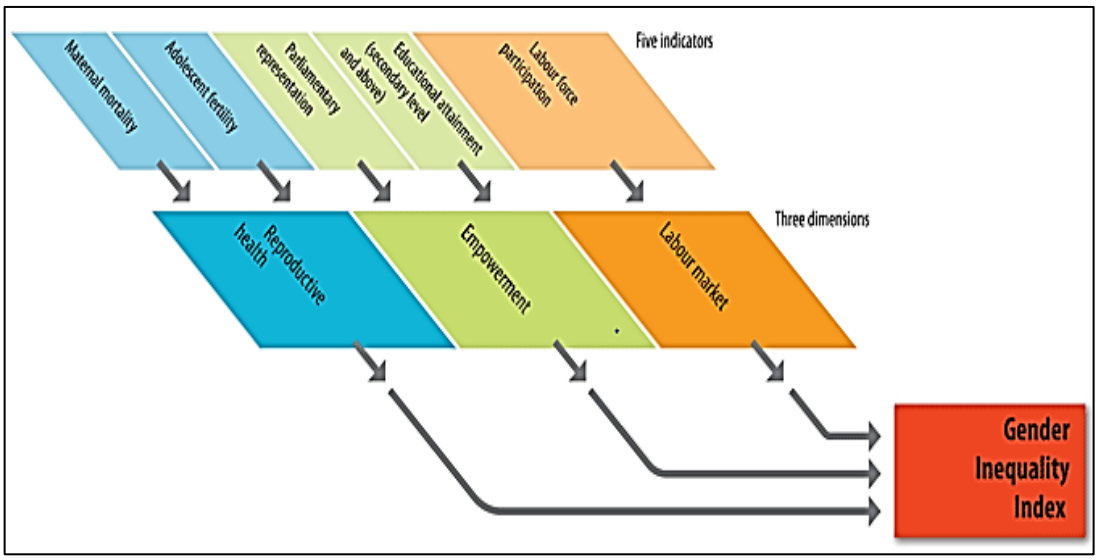

Figure 3. The five indicators and three dimensions creating the composite Gender Inequality Index

Source: Women's United Nations Report Network, 2014

The Socio-Political Status of Women in Sierra Leone

Politically, women have held power and leadership positions including chiefly roles within Sierra Leonean society on occasion (Day, 2012), however it is fair to say that traditionally this was an exception rather than a norm; currently women make up around, 18.9% of local politicians, and 13.4% of politicians at a national level, below the average for contemporary neighbouring countries in Africa (Abdullah, 2012). Historically, positions of power or influence held by women have often been more noticeable among the urbanised and better-educated Krio, and less so the more rural or patriarchal ethnic groupings, a trend that persists to the current period

(McFerson, 2012). Advances have been made in meeting the rights of women to fair political representation in recent years, but this appears to have been a difficult and protracted process (Castillejo, 2008).

When women are included in decision making and are better represented, then human rights obligations and conventions are met, as well as "people report the highest levels of life satisfaction" (York & Bell, 2014, p48). The opposite is also true; "*women's exclusion from decision making results in state institutions and policies that do not address gender inequalities and are not accountable or responsive to women citizens, thereby perpetuating women's political, social and economic marginalisation*" (Castillejo, 2009, p1). Which, as this research report will demonstrate, leads to poorer outcomes for women in humanitarian crisis, a view supported by Aoláin, (2011).

Cultural Female Roles in Sierra Leone: Secret Societies, Marriage, Family, and Kinship

Although, as noted above, it is not unknown for women to hold power as chiefs, even paramount chiefs, although this was never as common as with men (Day, 2012; Castillejo, 2008). For the most part female roles within the clan or family grouping still revolve around family, children, and a division of labour that sees women more involved in activities such as "planting, harvesting, weeding, gathering wood, cooking, cleaning, marketing, and child care" (Ember & Ember, 2001).

It is a milestone of adulthood to be married, and marriage brings considerable prestige to both men and women, with many marriages arranged between families sometimes while the girl was still very young (Girls Not Brides, 2015). Children are seen as an investment in the future of the family and parents, both to provide for the parents in old age, and participate in household labour activities, but also to be able to foster relationships with other families and clans through strategic marriages and dowry (Ember & Ember, 2001). Kinship networks then become central to life; individuals are obliged to assist other family members throughout life. For this reason, when married a couple often choose to reside in proximity to their own kin as this can bestow social and economic benefits (Falola & Amponsah, 2012).

Women's secret societies are an interesting cultural phenomenon in Sierra Leone and indeed throughout West Africa in one form or another. They provide many functions, such as instruction to younger initiates in cultural women's activities, providing social and financial

support, and guidance on esoteric matters. It is also of note that there is a strong connection with women's societies and the practice of Female Genital Mutilation (FGM) practices, (UN Women, 2015; Bosire, 2013).

The Economic Status of Women in Sierra Leone

Women have traditionally played a huge and often overlooked part in the Sierra Leonean economy, and overall within the workforce there are more women working than men (Abdullah et al., 2010). However, they tend to be more visible in the informal economic sector, and the agricultural sectors such as small scale growing and trading, as well as manufacturing items for sale in an economy that at a macroeconomic level relies most heavily upon the extractive industry and agriculture (CIA World Factbook Sierra Leone, 2015).

Economically, the role of women in Sierra Leone is acknowledged by some authors as being under researched (Solomon, 2006), and the full economic effects of EVD upon Sierra Leone and women even more so, however, what is clear is that women as a matter of survival have adapted to adverse circumstances before. The Sierra Leonean civil war impacted hugely upon the economic status of women, but during the course of the conflict there was clear evidence of adaptation to the changing economic situation and exploitation of opportunity as, and if, it became available (Solomon, 2006).

The Health Status of Women in Sierra Leone, and Demographic Country Data

Overall health outcomes for men and women in Sierra Leone are poor, with a mean life expectancy for women of 48, and of 46 years for men (African Development Bank, 2013). The World Health Organisation data on the maternal burden of disease is displayed in *Figure 1*, this data was gathered in 2004, so therefore cannot be termed as being absolutely currently relevant. As figures 5 and 6 demonstrate, across the age spectrum of the population there are more women than men, especially in the older age groups, where the gap becomes much more significant. Data around the burden of mortality in Sierra Leone prior to the EVD outbreak shows that, pre-term birth complications account for 5% of total female mortality, and the overall infant mortality rate sits at 128 deaths per 1000 live births, a figure worse than most neighbouring countries (Center for Disease Control and Prevention, 2015). Much of the rest of

the available mortality and morbidity data for Sierra Leone is either not available or is not sex disaggregated. However, subsequent to this, health data concerning Sierra Leone, commissioned by the University of Washington in the United States, has become available, published in 2010. This shows trends in mortality rates for gender, and statistics around Years of Life Lost, or YLL, to disease (University of Washington, 2010).

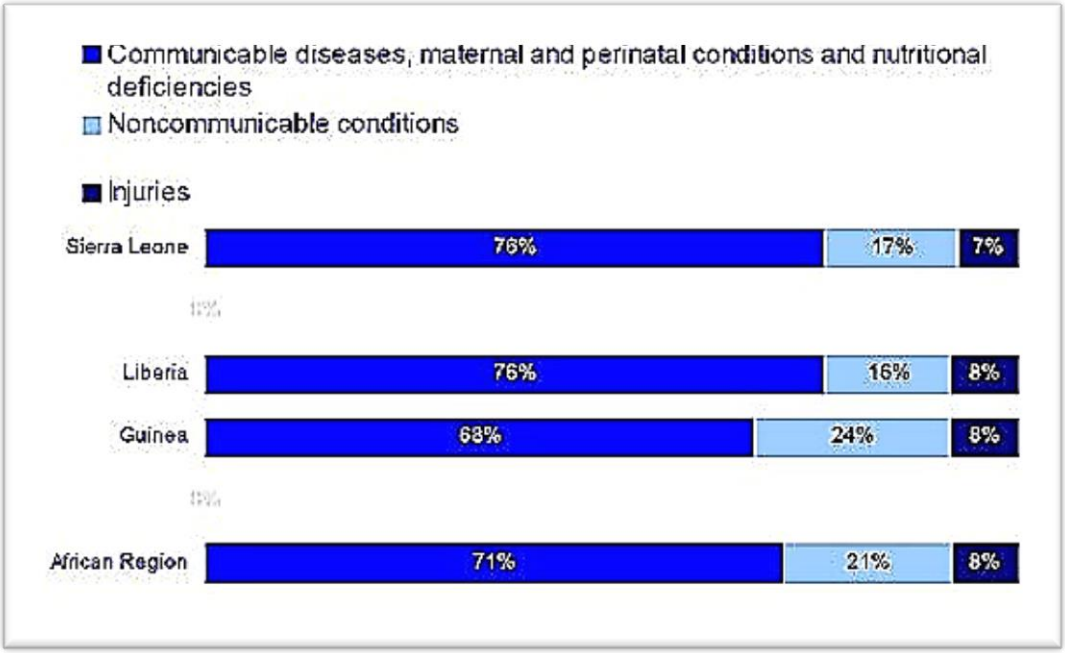

Figure 4, Distribution of the maternal burden of disease, as a percentage, by broader causes in Sierra Leone comparative to neighbouring countries

Source: World Health Organisation, 2004

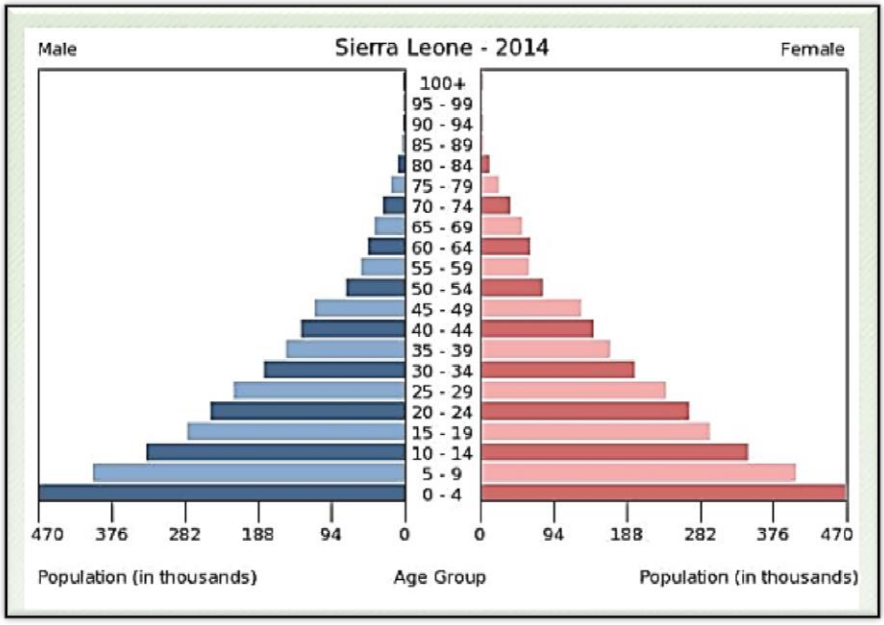

Figure 5. Gender composition of Sierra Leone

Source: CIA World Factbook: Sierra Leone, 2015

Age in years	Percentage of the overall population	Male	Female	Population difference for women
0-14	41.9	1,198,553	1,208,775	+ 10,222
15-24	18.8	524,819	557,142	+32,323
25-54	31.6	872,284	943,626	+71,342
55-64	3.9	101,856	123,164	+21,308
65 and up	3.7	91,198	122,308	+31,110

Figure 6. Gendered demographic data

Source: CIA World Factbook: Sierra Leone, 2015

This study compares and contrasts data from 1990 to 2010, which falls outside of the current Ebola outbreak in Sierra Leone, however it can be seen that the burden of gender related mortality is significant, and appears increasing for females, even prior to the current EVD outbreak. For example, illnesses related to maternity, including some communicable diseases, increased in the period 1990 to 2004 (University of Washington, 2010). This is significant, as the current EVD outbreak has essentially severely reduced access to, and the availability of, healthcare for many women in Sierra Leone. As will be discussed later in this paper, the impact of EVD on the health system of the country was significant, and included general curfews on movement, loss of medical, nursing, and midwifery professionals. Additionally there has been a real reluctance to present for treatment at a hospital where there is the very real possibility one may be cohabitating on a hospital ward in close proximity to people suffering from Ebola (Jallow & Nathe, 2015; Hayden, 2014).

This situation can only further exacerbate the burden of communicable disease across the age, and gender related spectrum, the results are likely to be statistically visible in health related data for Sierra Leone in the future (Centers for Disease Control and Prevention, 2015).

Conclusion

Sierra Leone is an ethnically diverse country situated on the West coast of Africa, with a hot and humid climate. In the past Sierra Leone has had to contend with colonisation, political upheaval, ethnic tension, civil war and currently the Ebola outbreak. Economically, Sierra Leone was growing a relatively steady pace prior to the EVD outbreak; this growth has slowed dramatically over the last 12 months. Sierra Leone has made some solid progress on human rights issues and reconciliation since the destructive civil war, however much remains to be done.

The later part of Chapter Three examined the socio-political status of women in Sierra Leone; this was discussed, as were cultural female roles in Sierra Leonean society. Overall it can be seen that the socio political, health and economic status of women in Sierra Leone fares poorly compared to statistics from other countries globally, and even neighbouring states. This socio-political landscape, as will be seen in the findings chapter, would very much influence the

course of the Ebola viral illness. The next chapter will focus on the Ebola viral illness itself, what it is, and the physical progression of the disease.

Chapter Four: Ebola Viral Disease, and its Effects upon the Health System of Sierra Leone

Introduction

This chapter begins by exploring Ebola Viral Disease, or EVD, how it is transmitted, its clinical manifestations and treatment options. The progression of the disease will be discussed and in addition, this chapter will begin to look at the effects that EVD has had more generally on Sierra Leone and its health systems. Finally, this chapter will examine EVD in relation to other viral diseases such as Human Immunodeficiency Virus (HIV).

Ebola Viral Disease

Ebola, is a viral illness, sometimes called Ebola Haemorrhagic Fever, is a disease from the viral family Filoviridae (Davidson, Brent, & Seale, 2014). The family Filoviridae includes three sub-groups: Cuevavirus, Marburgvirus, and Ebolavirus. The sub-group Ebolavirus contains five types that have been recognised and named from the geographic areas of their origin where they were first identified. These are Zaire, Bundibugyo, Sudan, Reston and Tai Forest. The first three, Bundibugyo Ebolavirus, Zaire Ebolavirus, and Sudan Ebolavirus have historically been associated with large outbreaks in Africa. However, the virus causing the 2014-2015 West African outbreak belongs to the Zaire type (WHO, 2014; Beeching, Fenech, & Houlihan, 2014).

The incubation period for Ebola is most usually from 2 - 21 days, (Center for Disease Control and Prevention, 2015). Clinically, people with Ebola can present with a high fever, fatigue, muscle pain, sore throat and headache. This is progressively followed by vomiting, diarrhoea, rash, symptoms of reduced kidney and liver function, and in some cases, both internal and external bleeding, for example bleeding from the gums, and melena (blood in stool) (Medecins Sans Frontieres, 2014). Death from EVD, when it occurs, usually comes from a massive systemic inflammatory response leading to hypovolaemia, and organ hypo-perfusion, and subsequent shock. This typically occurs around day 7-9 (Medecins Sans Frontieres, 2014). Secondary bacterial infection, and other associated complications may play a part as well (Beeching, Fenech, & Houlihan, 2014).

A person is generally not infectious, nor is the virus able to be detected in a blood test, until they present with symptoms (Medecins Sans Frontieres, 2014). The symptoms of Ebola in the initial stages of the disease can be confused with a large number of other tropical illnesses, including Malaria, due to a similar clinical presentation. This is a factor that significantly complicates the triage of patients, diagnosis, and treatment, especially in countries with poor diagnostic infrastructure. Additionally, the West African EVD outbreak appears to be an extremely virulent strain of the disease, with rates of transmission higher than previously seen in central African outbreaks (UNDP, 2015; WHO, 2014).

Treatment is supportive as there is no known curative treatment at present, however, at the time of writing, several pharmaceutical companies have produced and are field trialling a number of EVD vaccines, and the initial reports from these vaccines are very positive (CDC, 2015; Henao-Restrepo, et al., 2015). The respective vaccines have passed phase one clinical trials, and phase two clinical trials are underway in West Africa. Although the initial results appear promising, a great deal of work in this area remains to be done (WHO, 2015; Semalulu, Wong, Kobinger, & Huston, 2014).

Ebola is for reasons of its lethality, approached with great caution by researchers, even in western virology research labs, where at least two scientists have contracted EVD and died when handling the virus (Sydney Morning Herald, 2004; Pinedo & Morris, 2014). Additional concern exists when conducting research in the field that may bring medical researchers into contact in any way with the illness or those who may carry it. However, the humanitarian need and sheer size of the outbreak has prompted a major increase in the amount of study and scientific enquiry into the illness. As such, several studies are worth noting at this point, such as Bellan, et al., (2014) and Scarpino, et al., (2014) who theorise that there may be asymptomatic community carriers of the disease, if this is so, then the scale of the outbreak maybe considered to be severely under estimated. Additionally, recent research indicates that the disease may be carried particularly within areas of the body that have a reduced exposure to the immune system, such as the testes, the placenta, and the inner portion of the eye, possibly creating a reservoir for further infection (Kupferschmidt, 2015).

The Progression of EVD and the Effects on the Health System of Sierra Leone

The first reported cases of EVD emerged in Guinea in March 2014, after health authorities reported a number of fatalities from an un-identified virus, later confirmed to be Ebola (Beeching, Fenech, & Houlihan, 2014). The border regions of West Africa are reasonably porous with trade and the movement of people, consequently the disease did not remain in the area of origin. As such, the first cases in Sierra Leone occurred in May 2014, in the Kailahun district, and were attributed to the funeral of a traditional healer who had been working across the border with Ebola patients in neighbouring Guinea (WHO, 2014). The deceased from this event, notably, were 14 local women (McNeil, 2014).

In early June 2014 Sierra Leone closed its borders after 158 new cases were confirmed in several districts. Government containment measures proved ineffective, with troops brought in to try to maintain a curfew in affected districts in an effort to reduce the person-to-person spread of the illness (Semalulu, Wong, Kobinger, & Huston, 2014). In July the first cases were reported in Freetown, the capital. Also in July 2014, Dr. Sheik Umar Khan, the foremost infectious diseases expert in Sierra Leone died of Ebola in Kenema district hospital. His loss was a severe blow to containment and management efforts, as he was an internationally noted virologist (Bauscha et al., 2014). His loss was followed by that of a number of other prominent doctors and virologists who were also colleagues of Dr. Kahn, further robbing Sierra Leone of expertise in managing the outbreak (McNeil, 2014; Bauscha, et al., 2014). In August of 2014 EVD was declared a Global Health Emergency by the World Health Organization (WHO, 2014).

By early October 2014 every district in Sierra Leone was reporting cases. Reported cases continued to climb throughout the remaining months of 2014 (Parsons & Ahmad, 2015; (WHO, 2014). Concurrently there were reports of rioting in some districts, and numerous reports of deceased persons lying un-retrieved in the streets (Boseley, 2014). Burial teams went unpaid, and often were not supplied with the correct Personal Protective Equipment (PPE) to do their jobs safely. Subsequently many went on strike and refused to work, further exacerbating the spread of the illness (Semalulu, Wong, Kobinger, & Huston, 2014).

This situation was further complicated by problems with the healthcare system in Sierra Leone. Healthcare is provided by the public sector, religious missions, local and international NGOs, traditional birth attendants, traditional healers, and a small private sector. Fees are charged depending on what treatment and drugs may be needed (UNDP, 2014)., Medical services work

to a more centralised health care model, with tertiary level services available only in the biggest centres (World Health Organization, 2004), which means that for many women in rural areas, traditional birth attendants (TBAs) are the only option for perinatal care.

During the EVD crisis, hospitals shut down or ran on minimal staff as many workers abandoned their stations and refused to come to work, or were sick themselves. For example, some hospitals such as rural Kono Government Hospital, had deceased and sick persons lying unattended throughout the hospital compound, as well as in the hospital wards themselves. Used contaminated medical equipment, needles, and PPE littered the hospital grounds (see figure 7) (ABC News, 2014). These and other personal and professional accounts illustrate the degree of breakdown in health services as a result of EVD throughout much of the middle and later part of 2014 in Sierra Leone (Kieny, et al., 2014; Farrar & Piot, 2014). The situation was summarised by The World Health Organization:: "*there were inadequate numbers of qualified health workers, and infrastructure, logistics, poor health information; surveillance, governance, and drug supply systems were weak"* (WHO, 2014).

Figure 7. Medical equipment and waste in a hospital ward abandoned during the EVD outbreak, prior to cleaning and disinfection, Photo: Dr. D. Rijken, 2014.

The effects described above were not only felt in rural areas but also in larger, better-resourced centres such as Freetown. One study revealed a huge decline in hospital admissions, and surgery being performed, due to the presence of Ebola patients within hospitals and the highly contagious nature of the illness; other patients did not want to access health services while Ebola patients were present (UNDP, 2015). The lack of timely screening for the illness also played a part, as people were either mis-diagnosed, or not able to access services quickly enough (Bolkin, Bash-Taqi, Samai, Gerdin, & Von Schreeb, 2014).

Additionally, the movement of people suspected of having EVD was also problematic, as many ambulance drivers died or would not come to work the military was drafted in to provide transport for the sick from outlying areas to Ebola treatment facilities, over very rough roads. Once again, minimal PPE was available for these workers, and the long journey was often fatal for people who are already very weak and unwell (Wonacott, 2014; Carrick, 2014).

In December 2014, the Government of Sierra Leone banned all public Christmas celebrations and initiated a further nationwide curfew and lockdown. Lockdowns and curfews continued into the first part of 2015, during which health surveillance teams went door to door in many areas looking for new cases. The number of new cases underwent several spikes and dips over early 2015, but by late 2015 the number of recorded new cases had fallen significantly, with few new cases now the national norm (National Ebola Response Centre, 2015).

The epidemiological picture of the outbreak is complex; it has occurred in both smaller rural areas as well as larger urban centres (UNDP, 2015). This caused significant issues with control of the illness, as rural health facilities quickly became overwhelmed with cases in a short space of time. Additionally, the progression of the disease is such that just one unsafe burial or sick person in a community can result in a significant number of fatalities (McNeil, 2014; Medecins Sans Frontieres, 2014; Hayden, 2014).

In addition, it is especially difficult for clinicians, let alone lay people, to differentiate between differing tropical illness such as early onset Malaria, which is very common, and Ebola, particularly in the home. Ebola has a similar clinical presentation to many other tropical diseases. This means it can even be challenging, even for healthcare staff, to triage cases of Ebola in the initial stages of the illness, especially if the patient is a poor historian, does not speak the same language as the interviewer, is too young, unable to communicate information about possible contacts, or too unwell to do so. This means that many Ebola sufferers were

diagnosed too late and remained at home for too long, and as a result, women may have found themselves obligated to exercise their accepted role as carers within the home, and thus be exposed to the illness (Boseley, 2014). The implications of this are discussed further in the final two chapters of this report.

Figure 8. Health workers removing deceased persons for safe burial, Kenema, Sierra Leone, Photo: Dr. D. Rijken, 2014.

The EVD Outbreak and Parallels with Human Immunodeficiency Virus (HIV)

A number of authors have noted parallels between HIV and Ebola, especially with comparison to the public perception of HIV in its first decade of global prominence (Wainberg et al., 2014). EVD and HIV both share a pedigree of stigma towards sufferers, survivors, and even those health care workers who are working with those affected. By comparison, HIV has had a lengthy time in which there has been considerable effort put into the development of anti-retroviral medications, so much so that where such drugs are available people with HIV can now expect a lifespan comparable to a non-HIV positive person, if they can source the medication (Wainberg et al., 2014). With EVD, no such legacy of research and investigation

exists, despite the illness being known about well prior to the discovery of HIV in 1983 (De Cock & El-Sadr, 2015). Now, with thousands of people affected by EVD and the associated collapse of the health systems of many countries, pharmaceutical companies are scrambling to address this, and produce a viable vaccine (CDC, 2015).

Another noteworthy comparison that can be drawn from HIV, is the amount of additional labour put in by women in countries where HIV is endemic; this is very much under recognised by policy makers and health professionals alike, according to Makina, (2011). Women are obligated to address roles of caring for the sick and the infirm in accordance with cultural norms, and this work is essential to the functioning of society, even though there is no financial remuneration involved, (Budlender, 2004). There are many examples where carers have acquired EVD by attempting to look after sick and infirm members of their family, in addition to the ongoing care requirements needed by people who have survived EVD (Downes, 2015).

The ongoing health problems associated with surviving Ebola are only starting to be explored, but have been reported as very serious for some people. In taking on caring roles, women pay a price in economic opportunity lost elsewhere, as well as lost hours that could also be directed toward education or other economic activities (Makina, 2011). As most economic opportunities also occur outside of the home and cannot easily be balanced with caring work, this can be a significant setback for those women who find themselves in this situation (Budlender, 2004). One final comparison from HIV can be seen in the numbers of women infected with HIV in Sub Saharan Africa, the rates of infection among women are higher, at around 58 percent, compared to men. This is similar to EVD as it stands in Sierra Leone over the 2014 to 2015-time period (Semalulu, Wong, Kobinger, & Huston, 2014; Budlender, 2004). Finally, there have been other viral outbreaks that have dwarfed EVD, such as the 1918 Influenza pandemic which was responsible for the deaths of millions, however these occurred in a time devoid of the understanding of virology that we now have.

Conclusion

EVD is a viral illness with a high degree of lethality that in 2014/15 has caused a major outbreak in West Africa, with thousands of people affected. The disease spreads rapidly through contact with blood and other bodily fluids, death where it occurs, is usually caused by shock and a systemic inflammatory response leading to organ hypo perfusion, in addition to opportunistic

bacterial infection. EVD progressed rapidly through three West African nations in particular, Guinea, Liberia, and Sierra Leone, although at varying stages of the progression of the illness other countries were affected as well. Similarities exist with the social effects of other viral illnesses such as HIV. The next chapter will introduce the research and research questions, and begin to list and analyse findings.

Chapter Five: Analysing Themes within the Research in Relation to Gender, EVD, and Human Rights

Introduction

This section of the research report will present and analyse the results of the primary data collection, which was undertaken using the survey (see Appendix 1 for the tool used). The questions used within the questionnaire were designed to provide an opportunity for participants involved in the EVD response to list their observations around gender, and the effects of EVD on the general population of Sierra Leone.

A multidisciplinary and multinational response

In order to understand the findings it is useful to look at the respondents to the survey. Therefore, the first couple of questions in the survey asked respondents about their role in the Ebola response, and how long they had worked in Sierra Leone. This was to give and some context to the written responses, from which professions did they originate, and some insight into the roles they performed. For example, medicine is mostly concerned with diagnostics, nursing, with direct patient care.

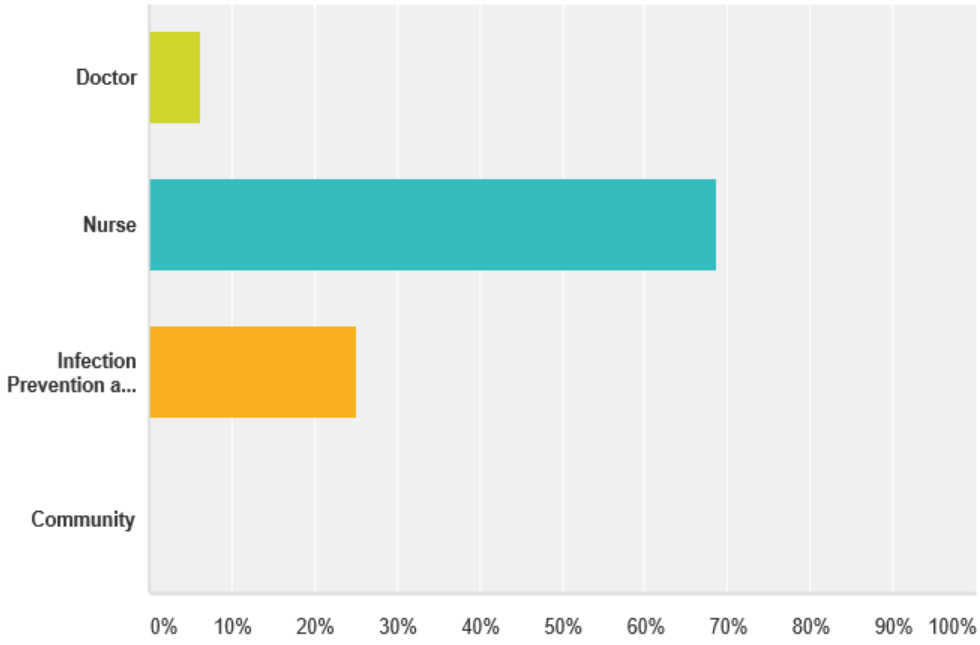

Figure 9. Percentages of survey responses by profession

Interestingly, all respondents listed themselves as doctor, nurse, or as working in infection prevention roles; no respondents described their role as community based. As can be seen from figure 9, nursing as a profession was by far the most recorded role. Question one led on to question two, which examined the respondent's country of origin, this presented a very ethnically diverse group of people; useful to determine if respondents were from Western nations or of African origin. Countries of origin were listed as New Zealand, United Kingdom, Finland, Australia, Canada, Norway, Netherlands, Ireland, Switzerland, United States, Austria, and Kenya.

The survey responses reflect the fact that international NGOs are typically very multi-national in their make-up; however, the representation here appears weighted very much towards more developed western countries. The views expressed within this study may therefore be considered more western-centric. Given this, it is important to note that country of origin does not necessarily define culture, or ethnicity, merely place of residence, a view supported by People & Bailey, (2010), as well as Spencer, (2014). Furthermore, a degree of objectivity was achievable by recording expatriate observations, and evaluating them in view of accepted international conventions regarding human rights, and the treatment of people, as well as literature on the subject. The responses also reflect the use of a snowball method of data collection mong assistance focused NGOs, and as the responses in Question 1 suggest, the majority were health professionals, a subject group that would be expected to be aware of humanitarian issues.

The third question asked respondents how long they had worked on the Ebola response (0-3 months, 3-6 months, 6-9 months, longer than 9 months). The answers for this question indicated that most respondents were involved in the EVD response for around 0 to 3 months, with a smaller percentage staying up to six months (see figure 10). No respondents reported a field assignment any longer than six months. In many cases, the respondents were deployed from their home countries for a shorter duration due to the high inherent risks in clinical work with EVD patients, and the intensely emotive and challenging nature of the work. Additionally, according to WHO, regular breaks are recommended for the safety of workers during epidemics such as EVD, long term missions are not advisable (WHO, 2006).

The amount of time spent working within the EVD response

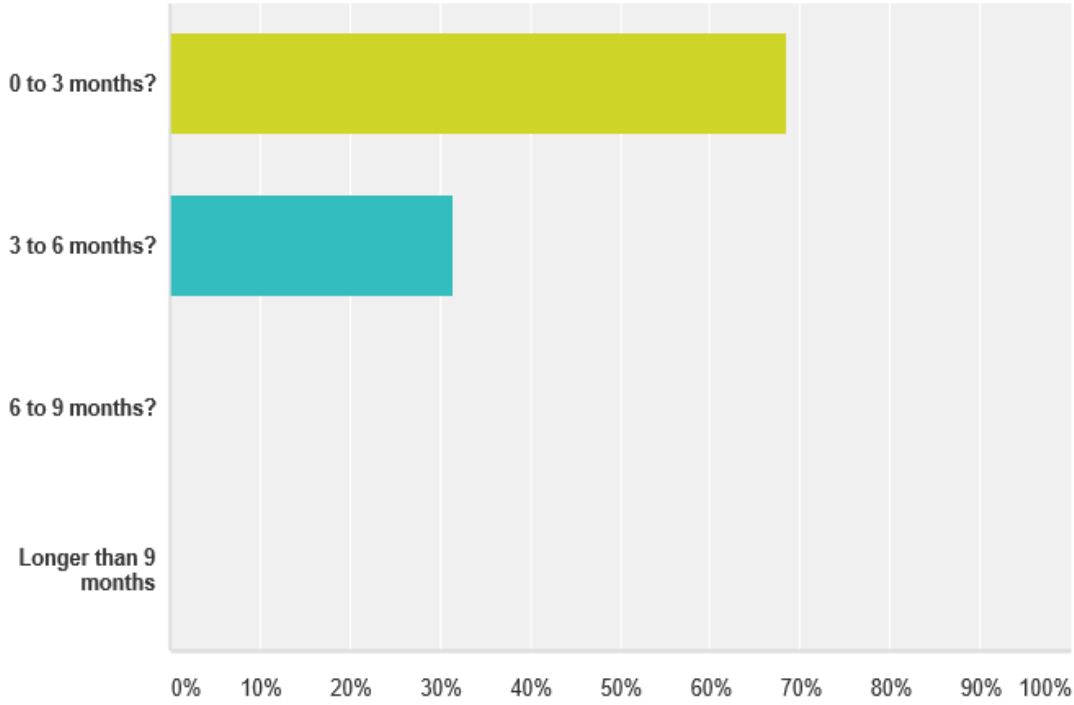

Figure 10. The length of time respondents reported working on the EVD response

The observed impacts of EVD within the community

The survey also asked what respondents thought were some of the general challenges faced by people, or a community affected by Ebola. This was intended to be a broad question designed not to be gender specific, but to capture the overarching themes and cross cutting issues that have emerged, or been exacerbated by the EVD outbreak. Thematic analysis for this part of the report consisted of identifying and summarising key points from the answers and then mapping them according to different headings, as per figure 11.

To begin with, the loss of traditional cultural customs and practices was described as a significant occurrence during the EVD period. This was described as occurring in several ways including the changes to traditional cultural practices, issues of faith and belief and the larger than normal presence of INGOs and foreign personnel within the country.

The most significant cultural change was the curtailment of traditional burial practices. As mentioned earlier in this report, this has strong links with the transmission of the virus.

However, this issue goes beyond burial practices; many other cultural practices that have involved physical contact with others have been altered or suspended during the EVD outbreak as well, such as ceremonies and gatherings.

Secondly, some respondents voiced issues related to faith and belief in the supernatural. For example, there were recorded examples of Ebola being blamed upon witchcraft or other supernatural explanations. The witnessing of beliefs such as these surrounding EVD was noted by two respondents, with one respondent going on to mention the impact upon faith and religious beliefs that EVD has caused. According to respondents, many people were heard to state that they believed the disease had divine origins, or would have a divine cure, or thanking of God for being spared. It is clear that this particular social phenomenon could benefit from further social science research, however, this is once again consistent within the context of a population utilising intrinsic belief systems to explain and assist understanding of a catastrophic event such as Ebola.

Thirdly, mentioned in the context of cultural observations, was the larger than normal presence of INGOs and foreign personnel within the country, including the media. The presence of foreign personnel was noted to have caused cultural clashes on a number of occasions, even with NGO personnel who had been briefed on Sierra Leonean culture prior to departure. Many of these misunderstandings were reported to be at a personal level during the course of day to day work in the Ebola response treatment centres. Most were able to be resolved or were inconsequential, however several respondents noted a deterioration in relationships between some expatriate staff and their local counterparts toward the later part of the EVD response.

Further to this, the presence of a larger than normal cadre of INGO personnel in Sierra Leone also was noted to have caused friction around the division of work, gender roles, and leadership. The EVD response, particularly within the ETCs was geared around a very western model of care with little space for indigenous cultural expression with regard to patient care. This links back to the section of this paper describing how interventions in the field by INGOs must be cognizant of, and respect local cultural beliefs.

The next theme within the responses described concerns around low pay and difficult working conditions for national staff. Appalling conditions, long hours, low pay, and danger, faced by some of the local staff in carrying out their duties within the Ebola response were described, particularly among the community Safe and Dignified Burial teams. For example, one

respondent discussed government burial teams requesting basic PPE on occasion as this had either not been provided, and in many cases no training had been provided in the correct use of PPE. Another respondent described how local staff were torn by wanting to gain paid employment in a very flat economy, and at the same time shouldering fear and stigma around working in the Ebola response.

Additionally, regular breaks were not always available; ETC staff were reported by several respondents as working long hours, months at a time without any significant time off, during the height of the outbreak. During this time, they were daily confronted with traumatic sights of the dead and dying. It is not known if there was any significant psychosocial support for such individuals following these events, but it is likely there is not.

Nearly all respondents cited the general collapse of the health system as being a major challenge. The absence of regular health services was reported to be a huge issue; respondents were able to describe deaths particularly from Malaria as well as a host of other tropical diseases, all of whom would normally have been treated in the government health service hospitals. People avoided the hospitals in many areas due to the presence of Ebola patients even if services were available. Further to this, another common thread was the lack of education regarding Ebola. This was manifested in many noticeable ways, even among professional people in health care settings. For example, it is easy in any situation to for routine to cause potential complacency. One respondent noted examples of severe complacency among hospital laboratory staff, to the extent that PPE was not warn when handling samples of EVD infected blood.

Government failures and inefficiency regarding the Ebola response were also cited in a large number of questionnaire responses. Examples mentioned included the roadblocks placed up both officially and unofficially by the government, military, and by groups that were not obviously affiliated to anyone. On occasion money was charged by those operating the roadblocks to allow people to pass; this was particularly onerous on small business owners trying to move goods from one area to another, or people moving from one area to another for work. The roadblocks were criticised as being harsh and ineffective in controlling the spread of Ebola within the community.

The distance to available treatment centres was discussed as a challenge, related to the general lack of functioning infrastructure in some areas. Lengthy delays traveling would often mean

people arrived at a hospital sicklier, and more dehydrated, lessening their chances of survival. This in turn was seen to add to the perception among some people in the community that the Ebola Treatment Centres were places that 'you only went to die'. This perception began to change with considerable community outreach activities and increased ambulance resources in some village areas.

From a local and community perspective the suspension of the education system, due to the government decision to shut down the schools as a quarantine measure, was cited as significant. This has created a gap in schooling of nearly a year in length for some children and young people, although at the time of writing schools have largely reopened. Other community issues included complaints around the lack of existing infrastructure hampering the Ebola response, for example, the lack of rubbish disposal systems, poor roading, lack of running water, and unreliable communications. Within the hospital setting, this has included multiple systemic failings, for example, respondents cited lack of adequate disposal of used medical equipment and PPE, lack of an adequately sized morgue to store the deceased safely prior to burial.

From an individual perspective, a number of issues were cited by questionnaire respondents. These were; the ongoing physical health effects on survivors, collateral comorbidities not being addressed due to collapse of health system (such as Malaria, or lack of skilled birth attendants for women), not seeing families for a long time for national staff expected to deploy to neighbouring provinces, lack of psychosocial support, isolation when sick, loss of dignity, loss of intimacy with others as NGO employers employed a 'no touch' policy, and stigmatisation of individuals by others, even family. In addition, fatigue among local responders and health care personnel was cited as a huge issue.

The following table, figure 11, collates these themes taken from the and presents them in relation to cultural, international, national, local and community, and individual themes.

Cultural themes	International themes	National themes	Local and community themes	Individual themes
Human Rights issues				
Loss of traditional customs Presence of foreign personnel, foreign cultural values vs Sierra Leonean Non-acceptance of the reality of Ebola	Presence of foreign personnel Cultural clashes	Workers' rights Relationship with government Inter-ethnic suspicions regarding EVD National pride and focus on combatting EVD Religious themes around EVD EVD Orphaned children Pre EVD situation for women	Beliefs around the division of work, gender roles, and leadership in EVD response Disruption of patterns of work and education Break down of health system Lack of knowledge regarding EVD	Stigmatisation Greater vulnerability of women to EVD Cessation of education Possible increase in teenage marriage Lack of health care Grief over loss of family and significant others

Figure 11. Mapping themes from respondent's observations

Gender differences in the impact of Ebola

The final two questions, and the most important in terms of the aims of this research, and are focussed on the relationship between gender and Ebola. Question Five asked about the different ways Ebola impacted women and men, and what challenges might Sierra Leoneans faced that were particular to their gender. This question is one of the key questions in the survey upon which this research report rests. In this question can be seen answers that reflect the respondent's observations around gender, and EVD, many of which overlap into human rights issues.

To begin with, a constant theme throughout this work has been that of grief and loss. This permeates the narrative of survivors, and is a constant throughout the responses to the survey questionnaire. Because of their gender roles in Sierra Leonean society, including as carers of the sick and raising children, many respondents recorded the grief associated with losing a family as being particularly devastating for women. This grief has not just come from losing family to EVD, but also from the enforced separation from family members, a difficult burden for many women in a culture where there is a considerable emphasis on the importance of family and specific gender roles. One respondent noted the particular difficulties face by women who experienced the death of a child, or separation from a child when one or both were considered Ebola contacts, leading to isolation from each other. Women who are faced with these situations stated anxiety related to who will care for their children if they are gone. This overlaps into stigma, as some families would not accept children, or survivors who have had contact with Ebola.

Additionally, the loss of possessions (destroyed as part of infection control procedures) and concern over lost employment coupled with worry about future survival was reported to cause considerable anxiety, for life after Ebola is almost always irrevocably changed from before. Quite a few respondents talked about the reduced economic opportunities related to not being able to return to life as it was before Ebola. Often contacts have had their personal effects burned and they have to start again, purchasing basic home items from scratch, if they are able to.

Several respondents discussed the issue of teenage pregnancy. This was a response that I had not expected, but participants mentioned this in relation to women they had come across personally. In the minds of the respondents there was a link between women not being able to

attend education due to EVD, and being pushed into having families and marriage, and being economically 'viable' to one's family. This is difficult to research further due to lack of supporting data and statistics, but remains an interesting observation.

Another strong theme mentioned in the response to question five, and one which re-occurs throughout this paper, has been cultural roles for women increasing their risk of acquiring EVD. As stated, these include activities such as caring for the sick and preparing deceased relatives for burial, once again this is well supported in literature as a means of disease transmission and is mentioned earlier in this report. Guilt over spreading the disease to other family members was noted by several respondents in conversation with women affected by EVD.

Respondents cited the loss of obstetric and maternity care as a significant issue. This was described as being associated with the non-functioning of the health system, additionally; this was also described as having a possible peripheral corresponding impact on fertility. This was a response that the author once again did not anticipate, but poses some interesting questions for survivors, both male and female. For male survivors, EVD may linger in sperm for months after the virus has ceased to be clinically visible otherwise. This has implications for relationships with others many months later. According to the literature, there have been no recorded cases at the time of writing, in which it is believed that transmission occurred sexually. However, sexual transmission of other filoviruses has certainly been proven to have occurred in a laboratory environment (Rogstad & Tunbridge, 2015; WHO, 2014; Parsons & Ahmad, 2015).

Further to this, this has implications for after care and precautionary advice given to people following discharge from an Ebola Treatment Centre. For women, there is a gap in the literature relating to Ebola and the potential direct effects on fertility, however indirectly there is considerable evidence that EVD has caused the loss of children right up to full term and as neonates, as well as indirect effects from skilled maternity care not being available to them due to general health system collapse (Jamieson, Uyeki, Callaghan, Meaney-Delman, & Rasmussen, 2015).

The responses from question five can be further analysed to understand how they fit into the wider overall context of the EVD situation within Sierra Leone, as it was at the height of the EVD

response. As such, the observations and themes from question five above can be condensed, into the four following groupings, these are as follows:

Firstly, overall systemic systems failures: The collapse of the health and education system impacted upon women in a number of ways. The traditional pathway to adulthood was suspended during the EVD crisis, children could no longer go to school. In addition, there was a total absence of healthcare in some areas, and severely reduced services in others. This resulted in the absence of care if a person was sick or a women pregnant. No obtainable statistics have been kept regarding infant mortality rates over this period, or children who entered the workforce as a result of these changes. Systems failures persisted until well into the recovery period, when the all clear was given for students to return to the education system, and enough staff could be found to allow hospitals to function again. The long term effects of Ebola on Sierra Leone is beyond the scope of this report but would warrant further research.

Secondly, individually significant impacts: On an individual level, strong themes of grief and loss are evident, in addition to stigmatisation. The author has been able to find a large amount of material concerning the efforts of NGOs and other organisations to engage with the public over behaviour change relating to stopping the spread of Ebola, but nothing to date about preventing stigmatisation, which has been a significant theme in the literature as well. For the people who suffered loss and grief, as well as stigmatisation as a result of their illness, the effects have been devastating. Mental health services in Sierra Leone are minimal to non-existent, and non-professional assistance in dealing with grief and loss must come from peer support networks or the community.

Thirdly, culturally significant impacts: A woman who has lost her family may find it impossible to remarry, especially where issues of stigmatisation may potentially be present. As stated, relationships with family and spouse are valued social connections in Sierra Leone.

Fourthly, the pre-existing gendered landscape: The pre-existing environment, which in Sierra Leone is weighted in favour of men, and can consciously or un-consciously discriminate against women. These themes will be addressed further in Chapter 6.

Observations around how Ebola may affect female survivors differently to male survivors, question six.

The final question in the survey asked respondents what they had observed about the impact of Ebola on female survivors, and whether this was different to male survivors. This question focuses on EVD survivors, and aims to explore some of the issues observed as being of concern to people during the often-lengthy convalescence period needed post Ebola. One respondent noted that female survivors back in their home communities were faced with:

> *…being at home and daily confronted with the reality of losing family, as opposed to men who have more freedom to pursue opportunities outside of the home environment.*

This answer reflects the psychosocial impacts of EVD, and includes many of the responses associated with the previous survey questions including dealing with grief and loss, as well as touching on gender roles, and even the economic situation of women within Sierra Leonean society.

Discrimination was a strong theme in many answers to question six, along with the potential stigmatization of survivors as mentioned above, as was the difficulties of rebuilding lives and livelihoods. According to respondents, for survivors, reintegration back into the community amounted to a huge challenge. Respondents describe some NGOs as having formal and informal policies of giving a one-off cash payment to survivors at the time of their discharge from an ETC. According to one respondent, their NGO gave survivors a 'survivor pack' containing oil, tarpaulins, food, blankets, and other items. Otherwise there is little information about how much actual cash was given to them or how far this payment would stretch toward being able to re-purchase essential items such as clothing and food, or transport to their home locations. This donation did not differentiate for gender.

Overall most people working in an ETC had little to do with survivors after they were discharged, unless they were employed as 'survivor nurses' to look after the children and infants of EVD confirmed parents, during their quarantine period as EVD contacts. The services of Ebola survivors have been welcomed by some NGOs such as UNICEF, and the IFRC, because orphan children or children whose parents may be sick with Ebola are considered Ebola contacts and are considered at risk of developing the disease. Consequently, they must be isolated for the recommended period of 21 days and monitored to see if they develop the illness. Survivors are considered by many to have some innate immunity to EVD, however,

there is no in depth conclusive research that has been able to prove how long or to what extent this immunity may actually last (CDC, 2015). These survivor nurses are almost exclusively women, in addition, as previously discussed, women have the cultural role of traditional caregivers, and undertake tasks such as caring for the elderly and the sick, within their families. This means they may be exposed earlier and for longer (Kupferschmidt, 2015). Additionally, some survivors came back and talked with staff about the ongoing post viral symptoms, which were described as being significant, to the point of preventing the individual from working.

Conclusion

This key chapter in the research report describes and thematically analyses information and responses from the survey. We can see from the first question that health professions particularly nursing dominate the response, although medicine had a strong showing as well. It can be seen that the average time spent on deployment in Sierra Leone was around three month's duration. The second part of the chapter analyses the observed impacts of EVD on the general community, and other key questions around how EVD affected women as opposed to men. The final question deals with survivors of EVD and, the issues they were observed to face. The next chapter is the final chapter of this report, and will summarise the research findings in relation to literature around EVD and human rights. Additionally, the last chapter will also go on to make a number of recommendations around NGO intervention, in relation to international humanitarian response.

Chapter Six: Discussion and Conclusion

Introduction

The aim of this research was to explore the ways a major disease outbreak impacts on the human rights of women In particular, this study has examined the social and economic effects and impact of Ebola Viral Disease (EVD) on women within Sierra Leone, through a human rights lens in order to better understand the possible gender issues that may occur within humanitarian interventions, more specifically in disasters and epidemics such as EVD. This chapter will bring together the literature and findings from the research in order to address these aims.

The first part of this chapter will bring together and critically analyse the themes of gender and human rights in the context of the EVD outbreak in Sierra Leone. The second part of Chapter Six will summarise the findings from this research report in relation to the literature available on these topics and, finally, this report will provide a number of recommendations based upon the findings of this paper, and answer the research questions.

Ebola through a Human Rights lens: The Right to Health

It is a basic human right to have access to the highest obtainable level of health care. The World Health Organisation recognises Ebola as an easily communicable disease, and a disease of such inherent lethality that even a single confirmed case must be treated as an outbreak (WHO, 2005). Given the seriousness of the illness, it is easy to question why the international response to the disease took as long it did to mobilise. In the early phase of the outbreak the humanitarian response to the illness was critiqued as uncoordinated, and ineffective, especially when the health systems of countries like Sierra Leone were so obviously failing to contain the spread of the illness (Bauscha, et al., 2014; Boseley, 2015). From the outset, the question must be asked, why was more not done to address the need for urgent medical assistance on the ground in the early stages? (Boseley, 2015).

The government of Sierra Leone had little choice but to ask the international community for assistance with the EVD outbreak, given the scale of the number of people affected and the speed with which the infections took hold. For this not to happen would be unethical, and

against the established mandates of organisations dedicated to supporting the notion of human rights, such as the UN milieu, and humanitarian organisations. Yet it took some months for international assistance to be available on the ground with sufficient numbers to start making a difference to the mortality figures. Ward (2008) goes on to suggest the reasons for the delay in any disease response go beyond just the logistical difficulty of establishing a health presence in remote areas. Further to this, Wilkinson & Leach, (2015, p137) state that "*a disease emerges in a remote location and spreads across a world highly connected by globalization and air travel to threaten us all – read the globally powerful North*".

The opposing view to this suggests that the slow response may be related to the historical perception of Ebola as a remote and rural disease not likely to spread very far due to the poor roads and infrastructure that people must contend with in Africa; an inherently high mortality rate also acts to limit the spread of the illness, (Semalulu, Wong, Kobinger, & Huston, 2014). However, the 2015 outbreak occurred in major population centres, which are also transport hubs with busy airports, complete with trans-border trade, and the movement of thousands of people daily, this factor was not present in early outbreaks and contributed to the spread of EVD.

What is clear is that an epidemic of the scale of the EVD outbreak presented many challenges to both the Government of Sierra Leone and the international community, however the failure to effectively address the issue of Ebola *quickly enough* has had a considerable impact upon the lives of the people of Sierra Leone, especially the women of Sierra Leone. It has highlighted human rights failings based on gender inequality, which in turn has led to further human rights failings in the Ebola response measures put in place (Foreign & Commonwealth Office, 2015). There have been repeated calls from international NGOs and foreign governments to those directly dealing with the Ebola outbreak in Sierra Leone, as well as other African states who have become inexorably dragged into the Ebola response, to respect human rights and dignity as much as possible (Foreign & Commonwealth Office, 2015).

Regarding Human Rights and EVD, the following quote by Human Rights Watch seeks to remind governments of their human rights obligations:

> *Governments in Ebola-affected countries should better protect health workers from infection, limit use of quarantines, address the gender dimensions of the outbreak, ensure*

security forces responding to the crisis respect basic rights, and facilitate independent monitoring of emergency measures and donations (Human Rights Watch, 2014).

Unfortunately, many Sierra Leoneans harbour an innate distrust of the actions of their own government (Gilpin, 2014). This coupled with fear and even denial of the existence of the illness in some communities hampered response efforts to curb the spread of the illness in West Africa (Human Rights Watch, 2014).

Ebola has then entered the socio-cultural landscape creating a huge upheaval at every level of society, and is viewed by some Sierra Leoneans as an almost divine, apocalyptic illness (Boseley, 2014). During such social upheaval, as the world has seen countless times, human rights can be consciously and unconsciously eroded. For example, as this report has discussed, in Sierra Leone even the right to movement was curtailed numerous times through road-blocks and frequent curfews. These measures invariably attract corruption as some are allowed through and others may not be, or are allowed if they pay money. Women in Sierra Leone are often economically dependent upon being able to move around from place to place, as many operate stalls and at markets, or other low paid urban work. In the words of Human Rights Watch, "t*he quarantines have not been adequately monitored, making them ineffective from a public health perspective and disproportionately impacting people unable to evade the restrictions, including the elderly, the poor, and people with chronic illness or disability"* (Human Rights Watch, 2014). At a microeconomic level, a reduction in the ability to move around due to curfew and border closure has also impacted upon other small traders as well (African Development Bank, 2014), for example, the diamond mining industry, an industry where a substantial informal sector exists in which women play a major part (Copley & Sy, 2014).

Ebola and Gender

Gender equality is at the very heart of human rights, and is a fundamental concept underpinning the United Nations Charter signed by world leaders in 1945. As such, protecting and promoting the human rights of women is a core responsibility of all states, yet many women globally continue to experience discrimination. As observations from the literature and the case study from Bangladesh inform us, this discrimination and higher levels of poverty have been shown to limit an individuals' ability to take steps to protect themselves from the EVD, or

from its associated economic impacts (UNDP, 2014; Ariyabandu & Foenseka, 2006). For example, women on average in Sierra Leone have less education, are less literate, and have less economic opportunity than men have, as well as fewer resources to mobilise to assist in mitigating against the effects of poverty. In this way they can be considered less resilient to disasters and disease outbreaks such as Ebola, than men are (Gilpin, 2014).

As such, in the case of Sierra Leone, EVD has acted as a lens, intensifying and highlighting the gender inequalities already present in the country, a view supported by Farrar & Piot (2014). When looking at gender and Ebola through a human rights lens, it is possible to see the impact from two different perspectives. The first is as described, a world in which Ebola affects women more so than men, in which they are more at risk of the illness and potentially less able to bounce back from the social effects of the disease. The second, is the bigger picture; the world in which the women of Sierra Leone live. In this world, women feature poorly in global statistics relating to human rights and gender, where literacy, health care, lack of meaningful political representation, and family violence, are all real day to day issues for women. Dealing with a major disease outbreak such as EVD is a huge proposition for any government. Having to deal with EVD at a community and an individual level is immensely challenging when the odds are already stacked against you as a woman.

Over a year and a half has passed since Ebola first began to ravage West Africa. The ripples from the outbreak and the knock on effects continue to unfold, often in unforeseen ways. More women than men have died from Ebola in Sierra Leone (Boseley, 2014; Farrar & Piot, 2014; Medecins Sans Frontieres, 2014; WHO, 2014; UNDP, 2015). This gender imbalance in mortality regarding Ebola has also been the case in neighbouring countries such as Guinea (UNDP, 2015). As demonstrated within this report, the reasons for this are complex and multi-factorial, reflecting both cultural, epidemiological, economic, biological, and social influences. Because of this the need for ongoing community education is huge, even if the EVD epidemic has subsided, both to prevent any renewed outbreak, and to ensure issues such as the stigma faced by women surviving the illness is reduced. Indeed, if basic human rights such as education, and healthcare are able to be addressed, then the impact of as epidemics such EVD may well be lessened (Bradshaw, 2013; Friel & Marmot, 2011).

A Summary of Findings; Cross-Cutting Themes from the Research and Literature

One of the key objectives of this study was to better understand the role of gender during a major disease outbreak such as EVD within Sierra Leone, in the short to medium term. As the above discussion makes clear, the pre-exisiting human rights and gender landscape in Sierra Leone had a significant impact on outcomes for women. This reseach has also highlighted a number of ways in which the EBV crisis impacted directly on women, in particular changes to cultural practices, the role of education, the impact of the health system collapse, and the ongoing issues faced by survivors.

Cultural practices

As stated in Chapter Four, other activities that may put women at risk include cultural practices such as washing and preparing the deceased for burial. A person who has died of Ebola has the highest levels of the virus in their body, and is highly contagious (CDC, 2015). Touching, washing and dressing the deceased and cultural burial rites, where the carer may have contact with blood or body fluid poses a very significant risk of transmission (Kupferschmidt, 2015, National Ebola Response Centre, 2015). This has been a cross cutting issue across most of West Africa, and is believed to have contributed to a large number of people falling ill with EVD, and a many corresponding number of deaths. A great deal of literature supports this observation (CDC, 2015; Kupferschmidt, 2015; Medecins Sans Frontieres, 2014; Piot, Muyembe, & Edwards, 2014).

Interventions around curbing the spread of EVD have therefore had to take into consideration traditional burial practices, and Safe and Dignified Burial Teams, funded by the government and various NGOs have taken over the role of removing the deceased and burying them, from community areas or from hospitals. This has necessitated a considerable amount of negotiation between NGOs, the community and the Government of Sierra Leone, as burial rites are culturally significant rituals (Bolkin, Bash-Taqi, Samai, Gerdin, & Von Schreeb, 2014). This negotiation, out of necessity, has resulted in the suspension of traditional practices for the time being. What effects this may have upon traditional roles and practices relating to burial in the future remains to be seen.

Education

The changes needed in traditional burial and other cultural practices meant considerable community education was necessary during the outbreak. However, it is worth noting the criticism some authors have levelled at the way community engagement was handled regarding Ebola education (Beeching, Fenech, & Houlihan, 2014). It has been suggested that community education was extremely prescriptive rather than involving communities in a more collaborative way to assist them in providing their own solutions (Wainberg, Kippax, Bras, & Sow, 2014).

Education methods were also not ideal, as messages regarding Ebola were placed around the community on billboards, (joining a raft of other health and political messages displayed in this fashion) but literacy levels may have determined if this massage was fully absorbed or not. Certainly in the case of the Bangladesh disaster, information about storm shelters was displayed in written form, and was shown not to have reached all people, especially women, because of this (Bern, et al., 1993). This issue has been further compounded by the total closure of schools throughout time period that EVD has been evident in Sierra Leone, although most are now open at the time of writing.

Further to this, given that women are at the forefront of the fight against Ebola both as carers, parents, and health care workers, but it would seem that education around Ebola has missed them entirely, otherwise unsafe burials would not be seen to the extent they were so far into the epidemic. In addition to this, community education teams approaching various communities faced considerable hostility and on occasion were attacked, where people have been under the misguided perception that they are connected with the spread of Ebola (De Cock & El-Sadr, 2015). This situation parallels other notable disasters where preventative education has not been optimised for women, such as cyclone preparedness in Bangladesh, mentioned elsewhere in this text. In that example, as well as the example of Ebola, there have been tragic consequences for women.

Impacts of health system collapse

On face value we know reasonably accurately how many people have died from Ebola, due to good record keeping by NGOs, and government departments, as well as lab results. However, what is harder to define is the morbidity and mortality rates among women due to not being able to access basic non-Ebola related healthcare as a result of health system collapse, or fear

of engaging with health care providers due to concern over Ebola (Carod-Artal, 2015). This figure would could also include women who were unable have a skilled birth attendant at the birth of their child.

Additionally, almost all community and hospital based health programmes have been affected in some way, for example immunisations. Some NGOs such as International Rescue Committee and the IFRC have changed their focus as a response to this situation, from directly treating EVD sufferers to supporting and rebuilding the health service itself.

Survivors

Another cross cutting theme touched upon earlier is the physical and psychological problems that are faced by survivors. Literature around EVD reports surviving Ebola can bring with it significant physical and psychological disability (UNPF, 2015; WHO, 2014). For example, a group of male and female survivors from the Kenema district of Sierra Leone were interviewed by the World Health Organization in 2014, and approximately 50% of the people interviewed who had survived Ebola described ongoing headaches, muscle pains, and vision disturbances; some people were documented as losing their vision entirely (WHO, 2014). Additionally, as stated previously, significant psychological trauma is common to all survivors, as they have invariably lost friends, and family to the illness (WHO, 2014; WHO, 2015). This was summarised by the following quote from an Ebola survivor, concerning Sierra Leone becoming Ebola free:

> *As much as we've successfully reached the supposed 42 days, I'm in a mourning state since November 2014, I lost eleven family members including my mum to Ebola. My heart is heavy and unable to recover from my grief, I contracted the virus same time last year. For me, I'm not celebrating but mourning"* (Kargbo, 2015).

Documentation of physical symptoms post EVD infection is seemingly a very under researched area of medicine, with as yet few published scientific articles on the subject, however this is a well-documented phenomenon with other viral haemorrhagic fevers (Carod-Artal, 2015)

In the case of women who have survived the disease, coming home again can pose a whole new set of problems when they face stigma in trying to fit back in to their home communities, (UNPF, 2015). Stigma appears to be a considerable issue for many, even those willing to assist in the Ebola response effort, as Kargbo notes:

> *My community would say: 'you're a woman, why did you join the burial team?' Even my comrades, my friends, became estranged from me because they said I am dealing with Ebola people. They didn't understand that I was helping*. (Kargbo, 2015).

This hostility can be even more traumatic for women when they return to their villages, having at the same time also had to adjust psychologically to the grief of losing loved ones. The loss of family can include every significant other known to the individual, from children, to husbands and parents, and in Sierra Leonean culture, a person's family may be the only significant social safety net available in times of hardship. From a human rights perspective, these issues have not been effectively dealt with at all by the government of Sierra Leone.

As recorded by research respondents, possessions too can be gone, burned as an infection prevention and control measure. Some NGOs provide for this using a grant to replace these items, and this money could be used for survival, as jobs, especially for women who are already disadvantaged, marginalised and more vulnerable both socially and economically, may be hard to come by; employers can and do shun anyone who is perceived to have had contact with Ebola (African Development Bank, 2014). At this point it is unclear what the future holds for survivors, although as this research found, some continue to record their feelings and frustrations on social media sites dedicated to survivors. There is also likely to be a continued need for survivors to support each other and, as noted in Chapter 5, the services of Ebola survivors have been welcomed by some NGOs. Indeed, some survivors have found purpose by returning to offer their services to looking after others such as orphan children who have lost their families to Ebola or been abandoned by them.

Conclusion

> *To effectively address the Ebola outbreak in West Africa, it must be viewed in terms of the connections between health, gender, politics, security, the environment, and poverty. For the people in the countries involved and those responding, it is more than the viral illness* (Downes, 2015, p2).

This research confirms that the intrinsic pre-existing inequalities in gender, (as well as poverty, and other determinants of health) have a significant part to play in the course of an outbreak or event for those people in marginal or vulnerable groups, including women. In Sierra Leone "*gender power relations constitute one of the root causes of gender inequality and are among*

the most influential of the social determinants of health" (Sen & Ostlin, 2011, p65). Women are often unable to access even basic healthcare at times normally, due to embedded gender inequalities and power relationships in Sierra Leonean society (Maclure & Denov, 2009). As such, existing inequalities in gender within a country tend to become exacerbated during a disease or emergency event where literacy and other metrics in which women feature poorly would play a part in prevention or faster recovery. This is obvious in the literature, especially in gender-disaggregated statistics (Aoláin, 2011; Ariyabandu, 2012).

During times of crisis and emergency, it can be easy for basic human rights to take a back seat; decisions made by governments can impact hugely upon the wellbeing of women (Aoláin, 2011). It can also be concluded that NGOs involved in the response to such crises must also factor in the differing effects emergency situations will have upon people depending on their gender (Ariyabandu & Foenseka, 2006, Ariyabandu M., 2012). This means implementing strategies in the field, and advocating for gender specific responses at every level where necessary. This includes advocating for, and upholding basic human rights where political actions may impinge upon them. As such it is widely recognised among NGOs and in literature, that disasters and emergencies impact upon women to a greater extent than men; this has resulted in a number of major NGOs creating gender specific guidelines around humanitarian interventions (Ariyabandu & Foenseka, 2006; Bradshaw, 2013; Gourevitch, Lake, & Stein, 2012; IFRC, 2015; UNDP, 2001).

However although there is now recognition of the need for gender specfic guidelines in humanitarian interventions, a constant factor encountered by the researcher in exploring gender, and human rights in the current Ebola outbreak has been lack of depth of available research to draw upon. It is the opinion of the author that in subsequent years more studies will become available for researchers in the field of social sciences to refer to. In the case of EVD, the lethality of the illness breeds caution among field researchers, and the speed of the onset of the Ebola outbreak added pressure to the overall response.

Every person has the right to the best possible obtainable level of healthcare; this is a basic human rights issue. In reality, however, there are many factors influencing what level of healthcare and services people are able to access. The main determinants of health in many countries are linked to "*the unfair distribution of power, money, and resources and the conditions of everyday life"* (Friel & Marmot, 2011, p1). These inequalities are particularly obvious in relation to gender. This in where a human rights lens becomes valuable in looking at

a major disease outbreak such as EVD, essentially, in Sierra Leone and in many countries around the world, more needs to be done to meet the needs of women both during outbreaks such as EVD, and in day to day life where everyday inequalities are legion.

In relation to a post-civil war society such as Sierra Leone, there is often a certain level of scepticism within the community regarding the actions of the government at the best of times. This became evident during the Ebola response, for example, community resistance to the authorities' social mobilisation campaigns; populations are suspicious not only of health systems but also of their governments, sadly often with good reason. Yet, in other parts of the country, EVD brought people together with a common purpose toward a national goal, and where social cohesiveness was able to occur the effects of EVD were lessened. This once again highlights the importance of social engagement by governments and NGOs in tackling disease outbreaks in the community, and by extension the importance of engaging with women who, it can be argued, are the key to implementing prevention measures in the home and community (Abdullah, Ibrahim, & King, 2010).

The world has become more globalised, and interlinked in every way imaginable. The current EVD outbreak has reminded the world that diseases do not respect geographic borders and will be carried by the people who cross them; modern travel and economic migration takes people to other countries routinely. This makes Ebola, and diseases like EVD, a global phenomenon. No longer can we say they are localised, exotic, 'African' diseases, but diseases capable of being taken to every corner of the globe. Ebola has forced the international community and affected governments to rethink how health systems can best be supported to withstand such crises, as well as strengthened in the long-term. However, how do vulnerable health systems become resilient ones? In addition, how can aid agencies better build trust with affected communities, so as to prevent disease transmission during future outbreaks and prevent major epidemics happening in the first place? This, coupled with the realisation that the economies of many countries such as those in West Africa are intrinsically entwined with each other makes us realise that EVD is a *global illness*, and as such must be approached with an internationally coordinated, collective, approach, which maintains and supports human rights, and the rights of women.

This report has demonstrated that women are worse off generally in many ways during outbreaks and emergencies, as much as day to day life. This has been recognised by most of the major aid organisations, so much so that there has been a significant trend to try to address

'gender' issues among major NGOs globally. This trend of gender mainstreaming is to be welcomed where it provides effective best practice policies regarding supporting the wellbeing of women and supporting human rights generally. Interventions must be tailored to meet the needs of women, because of the importance of their gender roles in society, to assist recovery from adverse occurrences such as natural disasters and disease epidemics, and the fact that it is not a level playing field to begin with.

In order to maintain human rights, we must encourage and ensure that when INGOs take on an intervention such as Ebola, they are supporting best practice, and where there are glaring human rights deficiencies, whatever the cause, that these are encouraged to be addressed; where countries fail on these matters, ways need to be found that promote, encourage, and incentivise meeting human rights obligations in regard to gender in emergency response. As stated by the International Human Rights Funders Group (IHRFG, 2014) "*many governments and donors have diverted funds to dealing with the clinical aspects of the epidemic, neglecting the many social and human rights challenges in these communities"*. This report has looked at the multi factorial reasons why EVD became a major outbreak, and how the outbreak has affected women and human rights. To understand the context of EVD, it is essential to look at the socio-cultural, economic, gendered, historical and political factors that have shaped the outbreak. These factors combined to create a situation that cost the lives of thousands of people and has influenced the lives of many more catastrophically.

It is especially important during such an occurrence, that human rights and dignity are maintained, as this will add considerable value to overall national resilience and recovery efforts after the event. The Ebola epidemic is all but gone in West Africa at the time of writing, and the full direct and indirect death toll of the illness may never be accurately known. With the advent of effective vaccinations against EVD, it is hoped that the world will never see the like again. For those who were caught in the midst of the epidemic, they have had a glimpse, maybe, of how things might have been in times past when the world faced other epidemics even more destructive than Ebola.

Recommendations

Based upon the findings from the research, this research report makes the following recommendations in regard to humanitarian emergency response, gender and human rights.

Firstly, it is recommended that any planned humanitarian action, especially international actions initiated in response to an event such as EVD, take into the account the pre-existing gendered landscape. As this report has shown, tailoring humanitarian response to better meet the needs of vulnerable groups such as women, will help to ensure they are not negatively represented in statistics in the future.

Secondly, it is recommended that in recognising and acting upon the needs of women more effectively, humanitarian actors will not only be promoting the human rights of women, but also will be providing leadership by example in their actions. This in itself sends a strong message to all, the message being human rights are universal, and that human rights are to be respected.

Thirdly, it is recommended that humanitarian actors invest further in ensuring messages of prevention and health promotion can reach the vulnerable in ways that they can understand, for example, the written word is not effective in the face of poor literacy. This may mean a continued effort toward communicating health messages in non-traditional, asymmetrical ways. It is clear that if messages regarding EVD had been able to be disseminated more rapidly, and in ways tailored to the needs of the population more effectively, then lives would have been saved in West Africa.

Appendix 1

The Survey Monkey Questionnaire

1. Please define your role in the Ebola response, Doctor, Nurse, Infection Prevention and Control, Community, or other.
2. What is your country of origin?
3. How long have you worked on the Ebola response, 0-3 months, 3-6 months, 6-9 months, longer than 9 months?
4. What do you think are some of the general challenges faced by people, or a community affected by Ebola?
5. In what ways might the effects of Ebola impact differently upon women to men, i.e. what challenges might they face that are particular to their gender?
6. What have you observed about how Ebola may affect female survivors differently to male survivors?

Appendix 2

Information sheet for participants in the Survey Monkey Questionnaire

In the past ten years, there has been a trend among humanitarian organisations toward more gender specific interventions when delivering humanitarian aid. This has been based upon research and opinion that suggests humanitarian crisis and disaster may effect women and men in different ways.

This survey questionnaire is intended to explore the observations of humanitarian health care workers who have been directly involved in the care of people suffering from Ebola. Through the opinions and observations of those humanitarian health care workers, I would like to explore in what ways has the current Ebola Viral Disease (EVD) outbreak in West Africa affected women specifically. The link to the questionnaire will be sent out to a number of people and humanitarian organisations with the hope that those who have spent time caring for the victims of EVD will be able to respond and give their opinions on this issue. The information gathered here will form part of a research report, which is itself part of a course of academic study by the author, toward a Masters of International Development, at Massey University, New Zealand.

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